# Financing Health Care for Persons with HIV Disease:

## Policy Options

Technical Report Prepared for the

## National Commission on AIDS

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# FINANCING HEALTH CARE FOR PERSONS WITH HIV DISEASE: POLICY OPTIONS

The gaps in the United States health care financing system have become increasingly evident with the Human Immunodeficiency Virus (HIV) epidemic. Treatment of HIV disease is costly from the earliest stages and often proves to be an unbearable expense even to those fortunate enough to have health care insurance. The disease is disproportionately represented among poor and minority groups, who are at greater risk of being among this nation's uninsured. High treatment costs cause the uninsured to suffer unnecessarily as they delay seeking care, and threatens to render those uninsured or underinsured who do seek care destitute. It is creating an intolerable financial burden on many health care providers who are attempting to respond to the need for care, even to those who are unable to pay.

Unfortunately, these health care financing problems are not unique to the HIV disease epidemic. Individuals without adequate health insurance face similar problems in seeking treatment regardless of their particular health condition.

While the primary solution to this problem is the enactment of universal health insurance, it is unrealistic to assume that this will ensure timely relief. More modest steps must be taken during the interim to close the gaps in health care financing for those with HIV disease and others who are chronically ill and experience catastrophically expensive health care.

To assist with the policy debate over health care financing, this report provides a summary of the current health care financing system and highlights gaps in the provision of health care financing as experienced by individuals with HIV disease. It sets forth a number of options with the objective of extending current health care financing coverage to more people and improving the benefits provided. These options may be implemented solely for the HIV disease population, or they may be implemented incrementally for all persons with serious chronic illnesses requiring expensive recurring care. The report embraces the concept of comprehensive reform of the U.S. health care system and the implementation of shorter-term expansions of public programs as quickly as possible.

## I. The Economics of HIV Disease

### A. Population in Need

The Centers for Disease Control (CDC) has monitored the HIV epidemic since 1981 and CDC figures on new incident cases, estimated prevalence of all living cases, projected future cases, and HIV morbidity and mortality have become standard sources of information. Accordingly, in this report we will use CDC's figures and estimates wherever applicable. These figures, it must be noted, remain approximations. For example, the CDC estimates that the reported figures on AIDS mortality represent between 70 to 90 percent of the true number of deaths (CDC, 1991b). Adjustments for underreporting use an assumption of 85 percent reporting of total AIDS cases as a standard (CDC, 1990a).

Over one million Americans are currently HIV-infected, but the HIV disease has not yet advanced to a clinical diagnosis of

AIDS. An additional estimated 111,000 to 122,000 persons were living with AIDS during 1990 (see Table 1) (CDC, 1990a). (This report uses the term HIV disease to refer to both those who are HIV-positive but do not yet have a clinical diagnosis of AIDS, as well as those with AIDS. It uses the term AIDS only when it is referring to those with advanced HIV disease who meet the CDC definition of AIDS. As this report is written, CDC is changing the clinical definition of AIDS to include persons with CD4s below 200 cu/mm3 counts below 200; numbers included are based on the old definition.)

New cases are also being steadily reported. As shown in Table 1, new AIDS cases diagnosed in 1990 are estimated to be 52,000 to 57,000, with adjustment for underreporting. The net effect of new cases less deaths among persons with AIDS yields a steadily increasing prevalence of the disease. This number will grow to between 127,000 and 153,000 by the end of 1991, and to between 151,000 and 225,000 by the end of 1993 (see Table 1).

CDC reports approximately 100,000 diagnosed deaths from AIDS as of October 1990 (see Table 2). CDC estimates that AIDS deaths are underreported by 10 to 30 percent. Nearly a third of all AIDS deaths (31,196) were reported in 1990, making AIDS the second leading cause of death for American men aged 25 to 44 years in that year. Current estimates of the average life expectancy of persons with AIDS after diagnosis is 15 months (Hellinger, 1990b). However, new advances in treatment and the growing number of pediatric cases with a longer life expectancy make estimates of the number of persons with AIDS requiring health care services during a year extremely difficult to estimate accurately.

The total number of Americans infected with HIV is even more problematic. Seroprevalence studies have never been done on a national basis. CDC estimates that approximately one million individuals are currently HIV infected. However, estimates range from a low of 700,000 to a high of 1.5 million (CDC, 1990a). These estimates are affected by the incidence of new cases. CDC estimates that at least 80,000 new infections per year occur in adults, and 1,500 to 2,000 new infections per year occur among newborns (CDC, 1990a). More recent work by Brookmeyer suggests that the infection rate has slowed to 60,000 to 67,000 annually (Brookmeyer, 1991).

CDC's HIV prevalence estimates are derived from methods of extrapolation and of back calculation (CDC, 1990a and Gail and Brookmeyer, 1988). The latter has also provided fairly accurate short term projections of new AIDS cases. Projections of AIDS cases to 1993 are based on observed AIDS incidence and an estimation of incubation time (from HIV infection to clinical AIDS). These estimates have been adjusted for unreported cases. More problematic, however, is the effect of early intervention on the incubation time to clinical AIDS. Thus, projections beyond 1990 may be less accurate than earlier estimates.

Long term follow-up suggests that nearly all of these infected individuals will eventually progress to AIDS, despite current anti-retroviral therapy. However, findings from the San Francisco Cohort study suggest that about 11 percent of persons infected with HIV are healthy 10 or more years later (Rutherford et al., 1991). The median incubation period from HIV infection to AIDS has steadily increased and is now estimated at 11 years, with a range of 6 months to 24 years (Gail and Brookmeyer, 1988).

HIV infection remains highly correlated with certain high risk behaviors and subpopulations, but the relative risks within those populations have changed considerably in the last four years. From 1981 to 1986 approximately 17 percent of cases were intravenous drug users (IVDUs), while 65 percent were homosexual/bisexual men (CDC, 1990a). Other cases include heterosexual transmission, blood transmission, and perinatal transmission. By 1990 these percentages were 25 percent IVDUs and 67 percent homosexual/bisexual men (including 5 percent homosexual/bisexual men who are also IVDUs) (CDC, 1991c). This shift toward a higher fraction who are IVDUs is projected to continue (see Table 3). By 1993, CDC projects that homosexual/bisexual men will account for 54 percent of all AIDS cases while IVDUs will represent 28 percent of cases. Rates of new infection continue to rise with the exception of homosexual/bisexual men, where new infection rates have apparently slowed since 1987.

Since both IVDUs and homosexual/bisexual men tend to live in specific urban centers, the distribution of AIDS cases is markedly uneven across the U.S. Five states (New York, California, New Jersey, Florida and Texas) account for 64 percent of all known cases as of March 1991 (CDC, 1991a). Major cities, especially New York, San Francisco, Los Angeles, Newark, and Miami, account for large percentages of cases in these states. The burden of AIDS cases is thus highly unevenly distributed.

### B. Current Estimates of the Cost of Caring for Persons with HIV Disease

In estimating the cost of HIV disease, it is useful to make separate cost estimates for those with AIDS and for those with HIV infection, but without a clinical diagnosis of AIDS. Both the health care needs and the numbers of persons affected are substantially different for the two subpopulations. At a minimum an individual with HIV infection would need three ambulatory visits a year and laboratory tests. New drugs are also proving effective in delaying the onset of AIDS. As the disease progressed to AIDS the individual would need at least six ambulatory visits, on average one to two hospital inpatient stays, laboratory work and prescription drugs. Eventually, the person may also need long term care and home care. The types of services that will be needed by a person with HIV infection or AIDS will change as new discoveries yield information on effective treatment for pediatric AIDS cases as well as adults and as life expectancy increases. This is likely to increase the need for housing, home care, other long term care, and chronic care (Green, 1990).

### 1. The Health Care Costs of AIDS

The latest estimates of the costs of AIDS are from Hellinger, and were presented at the International Conference on AIDS in Florence in June, 1991 (Hellinger, 1991). Hellinger estimated that it cost $32,000 a year to treat a person with AIDS in 1990. Of the total, $24,000 was for inpatient hospital services, $4,000 for prescription drugs, and $4,000 for other services, mostly outpatient. For the purpose of this analysis, Hellinger's 1990 estimates were increased by 10 percent to adjust for inflation and obtain the 1991 estimated cost of AIDS of $35,200. Since an estimated 85,000 are living with AIDS in mid-1991, this yields an estimated total cost of care for persons with AIDS of $3 billion.

These estimates are much lower than even Hellinger's previous estimates. The costs of medical treatment of AIDS have been decreasing due to prescription drugs such as zidovudine (AZT) and aerosol pentamidine, which reduce hospitalizations. Last year, Hellinger estimated that the yearly medical care costs were $51,200 in 1989 dollars (Hellinger 1990a). Previously, his estimates were $60,000 a year in 1988 dollars (Hellinger, 1990b).

Hay et al. estimated that the lifetime medical care costs of AIDS was $60,000 in 1987 but would decrease to $35,000 (in 1987 dollars) in 1991 (Hay, Osmond and Jacobson, 1988). They based this prediction on an outpatient-oriented approach to the treatment of patients in the San Francisco area, and assumed that the nation's health care system would soon adopt such "cost-saving" methods of treatment.

A few other estimates are widely quoted. The Coolfont report from the Public Health Service (PHS) reported a total AIDS care cost between $8 and $16 billion dollars in 1991 (PHS, 1986). The cost for treating a patient with AIDS was $48,000 (1991 dollars) for the low range estimate and for the higher range the treatment cost was doubled. Hellinger's earlier article using a lifetime medical care cost of $60,000 dollars (1988 dollars) yielded a total AIDS care cost estimate of $6.0 billion for persons diagnosed in 1991 (Hellinger, 1988b). Using more recent estimates of the cost per person and number of cases, he currently estimates a 1991 cost of $5.8 billion (in 1990 dollars) (Hellinger, 1991).

Scitovsky and Rice estimated the total AIDS medical care cost to be $8.5 billion in 1991 (in 1991 dollars) (Scitovsky and Rice, 1987). Their estimate differs from Hellinger's, as they used prevalence based data and included the cost of treating persons with AIDS diagnosed during previous years who received patient care during that year, while Hellinger used incidence based data. Scitovsky and Rice also estimated that there would be 172,800 AIDS care cases in 1991 at a $50,000 yearly cost of care (Scitovsky and Rice, 1987).

The widely varying estimates included in the literature and the rapidity with which estimates are changed suggest considerable caution in using any given cost estimate. Further, cost estimates used in this report may need to be revised at a later date to reflect the changing nature and recommended treatment of HIV disease. They may need to be adjusted for pediatric cases, which may have a 20 percent higher cost of care per year (Parrott, 1991). An adjustment should also be made for the increasing population of intravenous drug users (IVDUs) who are becoming HIV positive. The IVDU sub-group tends to be much sicker and have a higher cost of care per year due to other social and economic problems and a generally poor medical condition, as opposed to the homosexual/bisexual cohort who often tend to have stronger support services, and outpatient treatable diseases (e.g., Kaposi's sarcoma) (Kelly, Ball and Turner, 1989). In addition, many of the current cost estimates are based on the San Francisco data base, which has a strong social support system, and "cost-saving" strategies for AIDS intervention. Also, the fact that AIDS patients are living longer with AZT should be taken into account. Moore and Scitovsky have both conducted studies which indicate that individuals with AIDS who have received zidovudine have a longer survival time. The Scitovsky study showed these individuals lived an average of 7.4 months longer (Scitovsky et al., 1990). A Maryland study found that the median survival was 19 months longer with the use of AZT (Moore et al, 1991). Most important, the total cost figures should be based on prevalence-based data, not incidence-based data.

## 2. The Health Care Costs of HIV Infection

The cost of treating HIV positive individuals using current treatment methods can be estimated from an Arno study which showed a mid-range estimate for monitoring HIV seropositivity of $528, and annual treatment costs of $5,094 (including drug costs of $2,700) (Arno, 1990). Arno estimates there are 800,000 seropositive individuals all of whom would benefit from early intervention to assure appropriate testing, counseling, and monitoring. Approximately 60 percent of the seropositive population are indicated for treatment, those with CD4+ counts of less than 500 (CDC, 1990a). In the first stages of a national early intervention program, a demand model estimates that 23 percent of this population would use early intervention treatments leading to a total cost of $1.2 billion during the first year (Arno, 1990). This cost could be expected to increase over time as a much greater proportion of HIV positive individuals needing treatment get into the program (e.g. 60 percent). However, these cost figures could be significantly decreased if drug prices were to fall or if a cap were placed on drug prices. For the purpose of this analysis, Arno's estimates were increased by 10 percent, to adjust for inflation. This gave an average cost of $2,754 for the monitoring and treatment of individuals with HIV infection for 1991.

## II. Health Financing for Persons With HIV Disease: The Current System

The major sources of financing for persons with HIV disease include private health insurance coverage, Medicare and Medicaid. The military and Veterans Administration are also sources of publicly-financed health care -- but will not be addressed in this report. These public and private insurance programs are available to individuals meeting a variety of eligibility criteria.

For those without insurance or ready access to care from the Veterans Administration, military health system, or other restricted sources, the cost of drug treatment or health services can pose a serious financial burden. Such persons must often self-finance their own care. Other sources of financing for uninsured persons with HIV disease include targeted funding from public or private agencies and charity or reduced cost care from selected providers. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act provides limited federal funding for health care services. State and local governmental agencies as well as nonprofit organizations also provide assistance in some communities. Public hospitals and teaching hospitals are often a provider of last resort -- willing to provide care to those in need even when payment is not possible.

### A. Health Insurance Coverage: An Overview

While firm estimates of insurance coverage are not available, the most recent estimates indicate that Medicaid covers 40 percent of individuals with AIDS, Medicare 2 percent, private health insurance about 29 percent, and the remaining 29 percent are uninsured (estimates based on HCFA, 1990 and Andrulis et al., 1989). The absence of nationally representative surveys of persons with AIDS with information on insurance coverage, income, and employment status, however, makes such estimates tentative.

These estimates are roughly consistent with the 1987 US Hospital AIDS study which showed that 44 percent of inpatient hospital admissions were paid by Medicaid, 29 percent were paid by private insurance, 2 percent were paid by Medicare, 2 percent were prisoners and the remaining 23 percent were self-pay or other. However, this study did not include a representative sample of hospitals and may be misleading (Andrulis et al., 1989).

Compared with earlier studies, it appears that Medicaid's share of the financial burden is growing, while that of private insurance is declining. A report by The National Center for Health Statistics showed that publicly funded inpatient care for AIDS increased from 25 to 41 percent, while privately funded inpatient care decreased from 49 to 43 percent between 1984 and 1987 (Green and Arno, 1990). Other studies have indicated that private health insurance covered 40 to 60 percent of total AIDS related costs, while Medicaid covered 20 to 30 percent and Medicare covered 1 to 3 percent (Merlis, 1990).

It is unclear if these figures indicate a shift in insurance financing or a change in the composition of the AIDS population. The increase in Medicaid coverage may represent an increase in the number of low income individuals with AIDS. The decline in private health insurance coverage may be explained by barriers set up to prevent individuals at high risk for HIV disease from obtaining private insurance coverage and by the high premium cost which many, who have contracted the disease, cannot maintain after the loss of employment.

## B. Private Insurance

Persons with AIDS who do have private health insurance would typically qualify for it as part of employer-provided coverage. Most large firms provide health insurance to their workers, and for the most part all employees are eligible for coverage regardless of health condition.

Employer-based coverage is less available to persons with AIDS employed in smaller firms. Although 90 percent of firms with 25 to 49 employees have a health plan, only 54 percent of firms with 5 to 9 employees and 26 percent of firms with fewer than 5 employees have a health plan (HIAA, 1989). Even those firms with health plans may not cover all employees, especially part-time employees. Many small firms do not offer health insurance to any workers. Further, insurance companies implement a variety of underwriting practices that restrict coverage to persons with significant health problems or health risks employed by smaller firms. Employees in a given firm may be excluded from coverage, pre-existing conditions may be permanently excluded from coverage, and premiums may be excessive for any small group viewed as a significant health risk.

The Health Insurance Association of America (HIAA) reports that the average monthly premium for a conventional employer health plan (non-HMO) was $119 for an individual and $271 for a family in 1989 (Gabel et al., 1990). Under such a plan, the employee may be expected to contribute toward the cost, paying on average $200 annually toward the premium, a $200 deductible and up to $1,000 for cost sharing, for single coverage in 1989. The amount varies by the employer offering the coverage and the health care benefits being provided.

The heavy financial burden of providing health insurance for employees with HIV disease has become a serious concern for employers providing coverage under group plans. In companies where the premium is based on experience rating or a group's past medical claims, the prevalence of HIV disease can result in significantly higher premiums.

Workers in small firms who are not HIV-positive but who are perceived by insurance companies to be at high risk may also be unable to obtain insurance coverage. Insurance companies may "redline" certain types of companies, such as the performing arts, beauty shops, florists and health professionals, and refuse to write coverage at any premium because they believe employees of such organizations are more likely to be at risk (IHPP, 1990).

Most larger companies self-insure, rather than purchase insurance from a private health insurance company. Companies that self-insure are exempt state mandated requirements for coverage of specific services and services provided by specific providers. A few of these companies have been known to reduce health insurance costs by denying employees coverage for HIV disease, or by setting maximum ceilings on benefits for care of persons with HIV disease.

Costly private health insurance practices can undermine the continued health coverage of persons with HIV disease and may lead to employment discrimination as employers become anxious about the high health care benefit costs associated with employees with HIV disease. Without private health insurance, the only recourse for coverage may be Medicaid. Even if the individual could continue working, he or she may decide not to work in order to gain and retain Medicaid coverage (Green and Arno, 1990).

Even if persons with HIV disease are covered under an employer health insurance plan, this coverage may be lost when the individual is unable to continue working. Under the Consolidated Omnibus Reconciliation Act of 1985 (COBRA), employers with 20 or more employees are required to continue any employee who leaves employment and dependents under the group plan, if the employee pays the full group premium plus 2 percent. For those who leave their job because of disability or illness and receive Social Security Disability Insurance payments, this coverage can be continued for 29 months, provided that the individual pay 150% of the premium after the eighteenth month. However, some persons with AIDS may be unable to afford the full COBRA premium which can be as high as $2,000 to $2,500 for single coverage annually, and as a result they may drop their coverage. In response to persons with AIDS losing private insurance coverage with employment, eight states (California, Colorado, Connecticut, Maryland, Michigan, Minnesota, Texas, and Wisconsin) and the District of Columbia have taken steps to cover these premiums with state funds, although most are pilot programs for low-income persons (IHPP, 1991).

An even less adequate alternative to private group insurance is individual coverage. Individually-purchased health insurance accounts for about 10 percent of all insurance coverage for the general population (HIAA, 1990). It is rarely an option for individuals who already have AIDS or are HIV positive. As with any other chronic medical condition, the insurance industry is alert to the heavy cost implications of treating individuals with HIV disease. Insurance companies, particularly those offering individual coverage, have responded with stringent underwriting practices. The insurance underwriters will set the price of the premium or refuse coverage based on a medical history or physical examination and the potential medical costs to be accrued. An individual with an AIDS diagnosis is automatically defined as being "uninsurable" and this definition has been extended by some companies to include all stages in the progression of the disease. Twenty-two of the 74 Blue Cross and Blue Shield Plans have open enrollment programs that accept applicants with HIV disease but may require more cost sharing and often are more expensive for young adults than other individual policies (Consumer Reports, 1990).

Even individuals who are not HIV positive may find themselves falling in a category that insurance companies refuse to cover including marital status, place of residence, and occupation. This approach to refusing coverage may result in screening out individuals who are not at high risk of developing the disease (Merlis, 1990).

Even if a person with HIV disease were to obtain individual insurance, pre-existing condition clauses are used by insurance companies to exclude or delay coverage for any condition existing at the time insurance begins. Waiting periods range from six months to two years for any conditions requiring treatment or showing symptoms in the last one to two years or anytime in the past (Consumer Reports, 1990). Therefore, most persons with HIV disease could be excluded completely. Blue Cross and Blue Shield Plans often credit continuous enrollment under any other Blue Cross or Blue Shield contract towards the waiting period.

### C. Medicaid

Medicaid is currently the most important source of financing for HIV disease (HCFA, 1990). It is estimated in 1990 that it covered 40 percent of the persons with AIDS, including 90 percent of children with AIDS (HCFA, 1990 and IHPP, 1990). These figures may be expected to increase with an increasing incidence of the disease in Hispanic and black populations, who are more likely to be low income than whites (Green and Arno, 1990).

Although Medicaid is the most important source of financing for individuals with HIV disease, it still falls short of meeting the needs of even low income persons. Many poor individuals are not eligible, including those who do not meet the stringent low-income and asset criteria and those with HIV disease who are not clinically diagnosed as "disabled." The requirement of a clinical diagnosis of AIDS is particularly limiting to coverage of persons in the early stages of HIV disease. These individuals are not eligible for Medicaid coverage of early intervention treatments even if they are destitute. This makes it extremely difficult for low-income persons to receive early testing, counseling, monitoring, and treatment essential to prevent serious illnesses from developing.

Medicaid spent an estimated $1.3 billion on HIV-related health care benefits in fiscal year 1990: $670 million in Federal funds and $630 million in State funds. This represents two percent of total Medicaid expenditures (HCFA, 1990). These combined expenditures are expected to increase to just under $3 billion by 1993 (HCFA, 1990).

Medicaid is a federal-state program, which varies widely, by state, both in the eligibility criteria for individual coverage and the types of benefits provided. The variation in the eligibility criteria is evident in a 1987 hospital survey which showed that in the Northeast, 54 percent of AIDS patients were Medicaid eligible at the time of admission, while in the South only 18 percent were Medicaid eligible (Andrulis, et al, 1989). This variation arises because states have a degree of autonomy in determining, within federal guidelines, the eligibility requirements and the benefits to be covered. All states, however, are, required to provide Medicaid to persons receiving cash assistance under Aid to Families with Dependent Children (AFDC), and most states also cover all persons receiving assistance under the Supplemental Security Income (SSI) program (HCFA, 1988).

The fiscal pressures on states to restrict Medicaid funding have made both the number of individuals and the types of benefits covered issues of immediate concern. The Medicaid program is designed to provide medical care coverage to low-income women and children and low-income elderly, blind, or disabled people rather than to individuals with a specific disease such as HIV disease. This has meant that individuals with HIV disease must generally meet both the low income eligibility criteria and other categorical requirements such as disability.

Women and children with AIDS meeting state-established AFDC income and asset requirements, would be covered by Medicaid under AFDC. The majority of Medicaid recipients with HIV disease, however, receive coverage under SSI. With a clinical diagnosis of AIDS, they are considered "presumptively disabled" and contingent upon the individual meeting income and asset tests, they would qualify for Medicaid under this category. The general income limits for individuals applying for SSI are up to $5,124 in unearned income, or 77% of the federal poverty level and up to $10,777 in earned income, or 163% of the poverty level for an individual (SSA, 1991). States can supplement the SSI payments which would also increase the income limits. The general assets limits are $2,000 in cash or other liquid assets, one personal residence, and a car. Thirty-six states have accelerated eligibility procedures for individuals qualifying for SSI, while there are stricter financial criteria in the remainder (IHPP, 1990).

States may optionally provide Medicaid coverage through the medically needy program. Under this program Medicaid coverage may be extended to individuals who cannot finance burdensome medical expenses, even though their incomes and resources may be above the limits allowed for AFDC or SSI eligibility. This coverage would generally be extended to individuals with HIV disease whose medical care costs have caused their income net of medical expenses to fall below the income eligibility level (i.e. they qualify by "spending down" to coverage). Thirty-five states and the District of Columbia cover medically needy persons (HCFA, 1990). Of the fifteen states with the highest number of AIDS cases, 12 have medically needy programs for the aged, blind, disabled, families, pregnant women and certain children. Texas and Georgia only cover pregnant women and children in their medically needy programs. Ohio does not have a medically needy program per se, but does have a "spend-down" program for SSI recipients. Medically needy income levels vary by state and can be lower than the state SSI levels. Fifteen states provide prescription drugs to their categorically needy recipients but not to the medically needy, and four states do not provide hospice services to the medically needy (HCFA, 1990).

There is also another state option to extend full Medicaid coverage to Medicare disabled persons with income levels up to 100 percent of poverty. Thirteen states have chosen this option. Out of the fifteen states with the highest number of AIDS cases, New Jersey, Florida, Pennsylvania, Michigan, and Massachusetts allow Medicare disabled poor to obtain Medicaid.

The extent of medical care services covered by Medicaid under the categorical and medically needy programs varies by state, both in the types and quantity of services provided. The minimum benefits package that States are required to provide to all Medicaid beneficiaries must include hospital inpatient and outpatient services, physician services, skilled nursing facility care, laboratory and x-ray services, health screening and follow-up services for children and supplies, and rural health clinic services (HCFA, 1990). Although states are required to provide these services, they may limit the services provided, for example, by only covering a set number of inpatient days or physicians visits, requiring a copayment for a service or setting a cap on the total service cost covered (HCFA, 1988). Some of these limits can be exceeded if the services are medically necessary.

Medicaid services optionally provided by the states include clinic services, prescription drugs, miscellaneous diagnostic services, skilled nursing, intermediate care and home health care for individuals under twenty-one, personal care, case management and hospice care (HCFA, 1990). The most frequently offered optional services include prescribed drugs, optometrists' services, clinic services, and intermediate care facility services, while the least frequently offered included hospice and case management services (HCFA, 1990).

Coverage of expensive prescription drugs is particularly important for individuals with HIV disease, because they are key to prophylactic treatments which delay the progression of the disease. States have the option of covering prescription drugs. All provide minimum coverage for zidovudine (AZT), ganciclovir, acyclovir, septra/bactrim, alpha interferon and aerosolized pentamidine for AIDS patients (HCFA, 1990) although most prohibit coverage of experimental drugs. However, variation by state in the provision of prescription drugs include limits on the quantity, cost and number of refills (IHPP, 1990), and some states do not cover drugs such as fluconazole, erythropoietin and sulfdoxine/ pyrethamine (IHPP, 1990).

State Medicaid programs may also extend Medicaid coverage, specifically to Medicaid recipients with HIV disease, by applying for the federal section 2176 waivers to provide home and community-based long-term care services. These waivers are approved for a three year period and are only approved if states can show that the benefit will not add to program costs (HCFA, 1990). Ten states (California, Florida, Hawaii, Missouri, New Jersey, New Mexico, Pennsylvania, Ohio, South Carolina, and Washington) have received AIDS home and community-based waivers in order to provide home and community-based services such as case management, foster care, private duty nursing, and personal care. Two states (Illinois and North Carolina) provide home and community-based services to broader groups of disabled persons, including persons with AIDS.

Two additional Medicaid concerns, apart from the patchwork of benefits being provided to a select group with HIV disease, are low provider reimbursement rates and disproportionate financial burdens on specific state Medicaid programs. The low reimbursement rates are partially responsible for the practice of referring Medicaid patients with AIDS to public and teaching hospitals (Merlis, 1990). This has put a serious financial burden on hospitals in areas with a high prevalence of HIV disease such as California and New York. Low physician reimbursement rates may lead to reduced participation of office-based physicians in the provision of care to AIDS patients, which may in turn be reflected in the quality of primary care provided to individuals with HIV disease (Green and Arno, 1990). It should be noted, however, that many office-based physicians may be reluctant to treat persons with HIV disease regardless of insurance status. Emergency rooms and hospital outpatient departments often serve as a usual source of primary care (Green and Arno, 1990). Reliance on hospitals as a source of primary care is also a function of the undersupply of primary care physicians in inner-city areas with a geographical concentration of HIV disease patients.

The financial burden of providing HIV disease health care benefits under Medicaid is becoming much more significant in States where there are more people with the disease, such as New York or California. It has been estimated that approximately one-third of all AIDS cases are in New York City, San Francisco and Los Angeles (Green and Arno, 1990). In New York and California it has been estimated that payments for AIDS consumed 5 to 6 percent of total Medicaid expenditures in FY 1990 (Merlis, 1990). In addition to a disproportionate financial burden on specific state Medicaid programs, there is also concern for the burden on inner-city public health systems (Green and Arno, 1990).

Under provisions of OBRA 1990, Medicaid is funding two demonstrations for HIV-positive persons with an authorization of $30 million. The objective of the demonstrations is to compare costs of treating HIV-positive persons at an early stage contrasted with those treated at a later stage. A broad range of services beyond the standard Medicaid benefit package will be available to 200 participants meeting state income and asset requirements for Medicaid.

## D. Medicare

Medicare finances a relatively small portion of AIDS health care benefits totaling an estimated $110 million in federal funds in FY 1990 or one to two percent of the direct AIDS-related medical care costs (HCFA, 1990). It is estimated that 2,100 persons with AIDS were Medicare recipients in FY 1990, increasing to 3,100 in FY 1991 (HCFA, 1990).

The small number of persons with AIDS covered under the Medicare program is explained by the eligibility criteria. Individuals must be either 65 years or age or over, disabled, or have end stage renal disease, and additionally have a work history that entitles them to social security cash benefits or payments from the railroad retirement system.

The majority of persons with AIDS become eligible for Medicare when they can no longer work, when they have the required employment history and they meet the standards to qualify them for Social Security Disability Insurance (SSDI). Eligibility for SSDI is determined by work experience under Social Security covered employment. In general, a person must work for 20 quarters of the last 40 quarters (10 years). For the disabled under age 31, half the quarters elapsed after age 21 are required with a minimum of six quarters. A person working at the minimum wage for the last eight years would be eligible to receive $457 in monthly SSDI benefits if disabled in 1991. To receive monthly SSDI benefits above poverty, a person would have had to earn an average of about $11,000.

Access to Medicare disability coverage is further limited by a 29 month waiting period requirement. A disabled person must wait for five months before disability cash benefits begin and then must wait an additional 24 months to be entitled to Medicare. The original purpose of this waiting period was to ensure that only persons with severe and long term disabilities would be eligible and thereby protect the Medicare trust funds (Bye and Riley, 1989).

Once an individual is eligible, Medicare will cover inpatient hospital care, some inpatient skilled nursing facility care, home health care and hospice care under Hospital Insurance (Part A). Individuals have the option of purchasing Supplementary Medical Insurance (Part B), by paying the premium. Under Supplementary Medical Insurance the individual will be covered for physician services, outpatient hospital services, durable medical equipment and other medical services and supplies. Both Part A and Part B have deductibles which must be exceeded before benefits begin, and Part B has a coinsurance of 20 percent of Medicare's allowable charge for covered physicians' services. The financing of the deductibles, coinsurance, and premiums for Medicare part A and part B can prove to be a serious financial burden for individuals with AIDS.

In addition to the problem of financing the premium and cost sharing for the coverage of services provided under Medicare, the individual will also have to finance services not covered such as prescription drugs, dental care, eyeglasses and a variety of long-term care services which tend to be needed by individuals with AIDS in the latter stages of the disease. For example, Medicare only covers a limited number of skilled nursing facility days.

Certain low income Medicare beneficiaries may be eligible for state Medicaid coverage of the premiums and cost-sharing. Under recent legislation states must cover all Medicare beneficiaries with incomes below the federal poverty level under Medicaid and pick up the Medicare premium and cost-sharing. On a phased-in basis, states will be required to pay the Medicare premiums for such beneficiaries up to 120 percent of the federal poverty level. States have the option, but are not required, to extend to these poor disabled beneficiaries the full Medicaid benefits such as prescription drugs that are not covered by Medicare.

## E. <u>Other Health Financing Sources</u>

While private health insurance, Medicaid, and Medicare are the most important sources of financing care for persons with HIV disease, they leave about 25 to 30 percent without any health insurance. Limitations on benefits can lead to inadequate coverage even for those with some health insurance. For those who are uninsured or have inadequate health insurance, some public support is available through limited programs.

The most important categorical funding program for services to persons with HIV disease is the federal Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. The

Ryan White Act provides emergency relief to cities and states experiencing a burden of AIDS cases. The annual authorization level is $875 million, although appropriated funds have fallen far short of the full authorization amount.

Specifically, the funds under the Ryan White Act go for: (1) grants to cities for health and support services; (2) grants to states for comprehensive care programs including care consortia, home and community-based services, buy-in COBRA extension of private insurance coverage, and treatment to prolong life or prevent deterioration; (3) grants to states for health care clinics for early intervention services; and (4) demonstration grants for pediatric AIDS programs.

State and local government agencies also provide limited funding for the care of persons with HIV disease. In FY 1989, state-only non-Medicaid funds contributed $65 million for the patient care of individuals with HIV disease (IHPP, 1989). This is a dramatic increase from the $25 million contributed in FY 1988 -- but still relatively small. In FY 1989, 26 percent of this state-only funding was spent directly on inpatient care, with 14 percent being spent on outpatient care and just over 11 percent being spent on AZT and case management services. Comparisons between states of the distribution of funding for direct patient care indicate substantial variation (IHPP, 1989).

Some states have taken steps to extend private insurance to persons with HIV disease under COBRA (IHPP, 1990). Eight states and the District of Columbia have some form of premium paying program. Under these programs the states pay health insurance premiums for individuals with HIV disease who have been forced to leave employment for health reasons. The states participating include California, Colorado, Connecticut, the District of Columbia, Maryland, Michigan, Minnesota, Texas and Wisconsin (IHPP, 1990). Some of these programs are in the preliminary stages of being developed and they vary in the way they have been implemented. In California, under a pilot program for example, the state will pay the private insurance premium for Medi-Cal eligible AIDS patients (IHPP, 1990). They estimate expected savings at $20,000 per person per year. In Texas, a combination of hospital districts, counties and the state Medicaid agency have been authorized to pay the private insurance premiums for eligible patients (incomes below 200% of poverty) diagnosed with a terminal or chronic condition. This would include persons with HIV disease (IHPP, 1990).

## III. Additional Health Care Financing Considerations

### A. Delays and Barriers to Early Intervention and Treatment

### 1. Access to Testing

While inadequate insurance coverage may delay or prevent individuals with HIV disease from obtaining essential medical care, further delays in care can result when these individuals do not have ready access to early HIV testing or cannot bear the cost of early drug therapy. The evidence that early testing and treatment are not reaching the majority of persons with HIV disease is reflected by the fact that the most common presentation of HIV disease still remains pneumocystis carinii pneumonia (PCP), an essentially preventable illness (Arno, 1990).

Limited HIV testing can lead to major delays in early diagnosis and treatment. Delays in undergoing HIV testing occur in several ways: when individuals have limited access to testing; when individuals choose not to undergo timely testing because they believe that their test results will not be treated in a confidential manner; or when the test results may lead to discrimination in employment, insurance, and health care. Presently, there are no effective federal restrictions in these areas, leaving the regulation of these issues to the discretion of the states. In the absence of consistent legal safeguards against the use of HIV test results and possible discrimination, testing will remain a critical issue affecting the early diagnosis and treatment of HIV disease.

Persons with HIV disease may also delay seeking early care when testing is not accompanied by adequate pre- and post-test counseling by trained personnel. Such counseling is essential if patients are to make informed decisions regarding their diagnosis and any subsequent therapy. However, at this time there are not adequate numbers of properly trained individuals, especially individuals trained to meet the counseling needs of the populations experiencing a rise in new cases of HIV disease: women, children, and IVDUs.

Improving access to early intervention will also facilitate broader prevention efforts if proper risk-reduction counseling is included as part of testing efforts. This would lead to a reduction in the number of new cases and ultimately reduce the overall cost of care related to HIV infection.

2. Access to Drug Treatments

As Arno has pointed out, the major cost (about 90 percent of the total) in early intervention is prescription drugs (Arno, 1991). While Medicaid pays for most prescription drug costs, Medicare does not. And for the uninsured, these drug costs, estimated at approximately $5,000 per patient per year, are likely to be prohibitive. Many private insurers also limit prescription drug payments. As early intervention prolongs the "pre-AIDS" period, these drug costs can be expected to mount for individuals and for other payers.

While a large proportion of the estimated cost of AIDS care is for prescription drugs, the majority of costs associated with early intervention in HIV disease, is due to these costs (Arno et al, 1988). An estimation of early intervention costs for New Jersey's state program found that $9,673 of $10,491 per person per year, or 92 percent of the total costs, were due to prescription drugs, principally AZT (Retrovir) and aerosolized pentamidine (Hummel et al., 1990). HCFA estimates that at least 80 percent of the prescription drug costs in the U.S. are paid by patients directly out-of-pocket, and this percentage is thought to be higher for the HIV disease population (HCFA, 1990). Much of this cost is, as Arno has noted, artificial. This cost is principally due to patent protection and provisions of the

Federal Orphan Drug Act of 1983 (P.L. 101-239) (Arno, et al, 1989).

The Orphan Drug Act was originally intended to protect pharmaceutical manufacturers from losses incurred in the development of drugs for rare diseases. The law allows the manufacturer of such a drug an exclusive marketing license for seven years, offers a variety of research support grants, and a series of tax credits and tax deductions which have been estimated to reduce losses on clinical trials by as much as 70 percent (Merlis, 1990). Burroughs Wellcome, the maker of AZT, has marketed its drug under the monopoly granted by the Orphan Drug Act in 1985 and a 17 year patent granted by the U.S. patent office in 1988. The cost of AZT in 1987 was $10,000 per year. Burroughs Wellcome later agreed to successive price reductions partly as a result of pressure from AIDS activists. Since 1989 lower doses of the drug have been used, and lower dose regimens have been approved for early intervention, making the annual cost of AZT between $2,200 to $2,800 (Chase, 1991).

Aerosolized pentamidine is now considered a standard PCP prophylaxis for patients with AIDS and for persons with HIV disease who have CD4s below 200 cu/mm3. After the maker of pentamidine was granted a monopoly under the Orphan Drug Act in 1987, the price of a 300 mg vial of pentamidine rose from $24.95 to $99.45, a 400 percent increase over the next two years (Arno, et al, 1989). Pentamidine is given monthly for PCP prophylaxis, and with equipment charges for the nebulizer this amounts to a cost of approximately $3,000 per patient per year.

The CDC estimates that approximately 60 percent of persons with HIV disease who are pre-AIDS (between 480,000 and 720,000 persons) would currently benefit from treatment with one or both of these drugs. In addition, the majority of persons currently living with AIDS require therapy with both drugs, or with another antiviral agent -- an addition of a least 50,000 persons in 1991.

### 3. Delays and Barriers for Special Populations

Intravenous drug users and their partners, which include the overwhelming majority of women with HIV disease, are confronted with special barriers to early intervention. Both populations are the most likely of all to be uninsured, and although they may qualify for Medicaid, typically they are not enrolled. Frequently, they also are victims of a long-standing enmity between themselves and the medical community (Hansen, 1985). Consequently they are unlikely to seek medical care, and if they do, they are unlikely to be able to afford it.

IVDUs are most likely to receive HIV testing if the test site has staff sensitive to the needs of this population, is convenient regarding location and hours of operation, will ensure confidentiality of test results, and can provide follow up referral and care (Vlahov et al., 1991).

Women with HIV disease also face unique barriers to early intervention and treatment. First, women with HIV disease are typically poorer than all other HIV-infected groups. Second, as the primary care givers in the home, many women with HIV disease provide care for their family members before seeking care for themselves. As a result they often present initially with advanced HIV disease. Poor minority women are more likely to experience discrimination by health care providers. Delays in receiving treatment may be indicated in one study showing that women have a shorter life expectancy after a diagnosis with AIDS when compared to men (Rothenberg et al., 1987). Finally, the CDC criteria for defining AIDS is based on criteria related to males; infections and medical conditions peculiar to women which may be associated with HIV disease are currently not well understood and therefore not part of the criteria used to diagnose AIDS. Consequently, early intervention and therapy for women with AIDS is further delayed.

Because of their need for frequent blood product transfusions, hemophiliacs are at special risk for HIV disease. Of the roughly 20,000 hemophiliacs in this country, approximately 50 percent have HIV disease. Of those infected, 1,617 have developed AIDS, and 1,092 have died as a result of their HIV disease (Brownstein, 1991).

Although recent technological advancements now make it possible to obtain relatively safe blood products through a process of viral inactivation, this advancement has brought with it massive price increases for such treatment. In 1987, for example, the cost of providing clotting factor therapy to meet the ordinary needs of one person with severe classical hemophilia (which represents roughly 85 persons of all persons with hemophilia) was approximately $10,000 per year. However, today that same therapy, after blood product deactivation, regularly costs from $60,000 to $100,000 per year. In some cases, complications may drive the cost to as much as $300,000 or more. This places an enormous economic burden on these patients to be able to pay for their care, in addition to their medical needs related to HIV.

Finally, hemophiliacs with HIV disease face other barriers to primary care. The current system of regional comprehensive hemophilia diagnostic and treatment centers has been extremely successful in providing comprehensive care for individuals with various forms of hemophilia. However, as these individuals become burdened with a second chronic disease, HIV disease, they require additional and more frequent care. Thus, patients who were seen at these treatment centers only once or twice a year, now are seen 4-12 times per year depending upon the stage of their HIV disease. In addition, as spouses and sexual partners become HIV infected, they also seek testing, counseling, and treatment at these centers which have a limited capacity for additional services (Brownstein, 1991).

### B. Provider Centered Barriers

Physicians, and health care providers in general, are charged with providing care without discrimination on the basis of diagnosis. And yet, provider reluctance to treat patients with HIV disease may be a significant barrier to early intervention and care in HIV disease. Levin has found that physician attitudes toward care are affected by HIV serostatus, with significant differences in the use of aggressive management, even in asymptomatic HIV disease patients (Levin, 1990).

This reluctance to treat may be even more marked in the case of IVDU patients, a group with historically poor relations with the medical community. A study in Maryland found that IVDU status and minority status were strongly negatively correlated with access to early intervention, specifically AZT and pentamidine (Hidalgo, 1990). Early intervention is essentially outpatient primary care, and the lack of physicians engaged in primary care in the urban areas where the vast majority of IVDUs live may further compound this problem.

## C. Financial Burden on Providers

### 1. Hospitals

Public and teaching hospitals, partly due to their location in inner cities, frequently serve as the primary source of care for many uninsured, as well as insured AIDS patients. Both uninsured patients, and patients insured through Medicaid, are less likely to receive preventive health care services. Consequently, their site of care is frequently the hospital emergency room.

The lack of preventive care for AIDS patients is also evident in that it is believed that the most common presenting symptom for AIDS patients is PCP. In fact, the number one cause of an HIV-related admission in the New York City area in 1988 was

PCP. Of the 14,233 admissions for HIV-related problems that year, 2,969 (20.9 percent) were for PCP. More importantly, these patients utilized 1.6 times more hospital days for their PCP infection than did patients with any other HIV-related admission (Codman, 1991).

The financing of health care for many persons with HIV disease contributes to their inability to obtain timely preventive care and other health care services as well. For example, the financing of health care for hospitalized AIDS patients appears to be steadily shifting away from reimbursement through private insurance plans and moving more toward reimbursement through Medicaid. This shift in payer distribution has occurred among white as well as black and Hispanic populations (Green and Arno, 1990). In New York City, 58.5 percent of all HIV-related hospital admissions in 1988 reported Medicaid as their primary payor (Codman, 1991).

This shift in source of payment places a significant economic burden on institutions which care for patients with HIV disease. States such as New York, New Jersey, Maryland, and Massachusetts have state rate-setting systems that reduce or eliminate substantial differences between Medicaid payment rates and that of private insurers for inpatient care. However, in the majority of the other states Medicaid reimbursement for hospital care of AIDS patients may be substantially lower than the rates paid by private insurers. Consequently, the number of hospitals and clinics willing to provide medical care to individuals with HIV disease is limited.

One study sampling both private and public hospitals in 1987 found that a small percentage of hospitals (less than five percent) provided care for the majority of all AIDS admissions; 20 percent of all hospitals provided care for 77 percent of AIDS admissions (Andrulis et al., 1989). These findings were based on a very small sample of U.S. hospitals and are not representative of all hospitals.

Public and teaching hospitals, especially those in inner city locations, and their emergency rooms, may bear a disproportionate share of care for AIDS patients. In the Andrulis survey, 54 percent (9917) of AIDS patients were admitted into public hospitals, while the remaining 46 percent (8459) were admitted into private hospitals. This correlates closely with the distribution of AIDS cases which are likely to reside near public and teaching hospitals.

The Andrulis survey also suggests that public hospitals may provide a large portion of the outpatient care for AIDS patients. In the sample of hospitals, 82 percent of all outpatient visits by AIDS patients for treatment in 1987 were made at public hospitals. Importantly, 57 percent of those outpatient visits at public hospitals were made by patients categorized as "self pay" (Andrulis et al., 1989).

### 2. Migrant/Community Health Centers and Clinics

The nearly 500 Migrant/Community Health Centers (M/CHCs) and their related 1,500 clinics around the country provide a variety of medical services for over 6 million patients each year. Since these centers have been located in high poverty and high need areas, the population served is disproportionately uninsured. Although roughly 11 percent of all Americans are uninsured, 49 percent of all patients seen at M/CHCs are uninsured; another 38 percent are insured under Medicaid. Treating such a high proportion of uninsured and underinsured patients places a burden on these centers -- especially when budgetary cutbacks limit direct public funding.

Although many centers are providing education, prevention, and counseling services to persons with HIV disease, many others are not providing such essential services, or are just beginning to do so. There is no well-established, integrated system linking these and other clinics to a variety of other services necessary to provide comprehensive care for these patients as the disease progresses and their needs change. For example, many centers are not actively involved with local AIDS care networks and cannot draw upon the additional services available from other providers, thus the range of support services available may not be adequate to meet their needs. Community-based organizations (CBOs) serving persons with HIV disease have been founded specifically to provide care for this population. Volunteers have helped expand the range of services available in such CBOs, but they are not equipped to meet the needs of the new HIV disease populations requiring care such as families, women, and children.

Finally, funding cutbacks at the federal, state and local government level threaten to jeopardize the ability of community health centers and community-based organizations to meet the growing need for care of the HIV disease population.

### 3. Primary Care Providers and Medicaid

The adequacy of reimbursement under Medicaid can also be an important factor in the availability of primary care to persons with HIV disease. Medicaid reimbursement rates for physician office visits and services are substantially lower than for visits financed through private insurance. In 1988, all but five states reimbursed for comprehensive office visits at a rate substantially below the prevailing Medicare charge (PPRC, 1991). On average Medicaid pays physicians at 64 percent of the Medicare rate -- although there is wide variation from state to state and service to service. With a nearly eight-fold difference in the rate of reimbursement between Medicaid and private insurance in some states, there is little incentive for physicians to provide care to AIDS patients. Not only does Medicaid typically reimburse at lower rates, but some states place artificial limits on the number of covered visits (for an AIDS patient the need for primary care visits will increase over the course of the disease). Medicaid reimburses for very few adult preventive services (AIDS patients need access to a wide range of preventive services).

All of these factors discourage many physicians from accepting new AIDS patients if they present initially with coverage only through Medicaid. Other physicians will care for patients receiving Medicaid, but usually only if they initially presented with private insurance coverage.

## D. Inefficiency in Current Care Patterns

The question of whether the current health financing system contributes to inefficient patterns of care is not clearly resolved by current research. However, there are a few indications that there are more efficient care patterns than those currently used.

A study from Texas showed that Medicaid spends more per AIDS case than does private insurance, but the number of hospital days per admission is less (the authors felt that this may indicate that Medicaid patients may not be receiving optimum care) (Begley and Hintz, 1990). In addition, state Medicaid programs are growing rapidly because of federally-mandated expansions of coverage to low-income pregnant women and children. Some states are diverting funds to Medicaid from other programs, e.g. sexually-transmitted disease (STD) programs with the resultant alarming increase in incidence rates of STDs (Rowe and Ryan, 1988). In fact, new cases of syphilis are at their highest level since 1949.

Currently, it is difficult to forecast if there is any added cost-savings to using AZT or other early intervention programs. AZT and aerosolized pentamidine generally prevent or delay some of the more serious infections associated with AIDS. This should increase the interval between hospitalizations, and shorten the length of hospitalization. A recent study based on 14 patients indicates that the average costs for treating hospitalized AIDS patients were significantly lower for patients' using AZT (Scitovsky et al., 1990). However, these savings were derived during the first six months of the investigation. Indeed, the last six months of the study did not yield significant savings as the lower early costs of AZT therapy eventually ends, and the costs begin to rise substantially towards the terminal phase of the disease. Schulman et al. also found evidence of savings from early intervention (Schulman et al., 1991).

It should be noted that increased survivability of persons on AZT increases the lifetime cost of treatment. However, the gain in life expectancy is valuable in human terms. Lengthened life expectancy also confers economic benefits from the greater length of time that persons with HIV disease are able to remain productive members of the work force, thus, reducing the indirect costs of the disease. In fact, a recent study showed that the average annual earnings of male AIDS patients (in Texas) was only 11 percent below the national average (Yelin et al., 1991). Another factor which needs to be taken into consideration is that there may be a slight cost-saving component to using AZT in terms of direct costs, as Scitovsky et al. (1990) used a "high estimate" of the cost of AZT, and in fact the dosage has recently been reduced by 50 percent since the time of their study.

Outpatient management of AIDS cases has proven to be successful in early studies. The most important example of this is the San Francisco area which in one study showed a lowered treatment cost per AIDS patient once outpatient regimens had begun (Hiatt et al., 1990). Another reason that the San Francisco cohort may have lowered AIDS care costs is that many medical care providers in that area have vast experience in treating AIDS leading to greater efficiency.

## IV. Policy Options and Recommendations for Improving Health Financing for Persons with HIV Disease

The policy options set forth in this report provide a selection of incremental steps which could be acted upon immediately to improve health care financing for persons with AIDS/HIV and other chronic illnesses. In developing these policy options, the primary objective has been to keep them consistent with longer term comprehensive reform and a policy of universal health insurance which would ensure access to health care for all Americans. Additionally emphasis has been placed on options which:

- Encourage greater access to health care, especially through early intervention and outpatient primary care;
- Provide financing for a sufficiently broad range of health care benefits to avoid distortions and inefficiencies in patterns of patient care;
- Assure provider participation by setting payment rates at adequate rates, while avoiding

unseemly profits and open-ended escalating health care costs;

- Promote equity and fairness by giving the greatest assistance to those most in need -- the poor and those with catastrophically expensive illnesses.

The options do not emphasize an employer-based health insurance approach because it would not be successful in meeting the immediate needs of persons with HIV disease. Many affected persons, desperately needing care at the current time, are outside the workforce or are unable to continue working once the disease progresses to an advanced stage. Their needs are expensive and private insurers have been reluctant to shoulder a greater portion of the financing burden. Regulatory attempts to force this burden on employers and insurers in the absence of more comprehensive reforms are likely to be circumvented.

The policy options which follow include expanding current financing programs such as Medicaid, Medicare, and private health insurance, direct funding to providers of services, and regulatory efforts to lower the cost of drug treatments. While the focus of the discussion is on the specific impact and cost of covering persons with HIV disease, it is assumed that any policy action taken would apply to all similarly situated persons suffering from other types of health conditions. Such coverage might be phased in over time, beginning with high priority groups such as pregnant women, children, and those with costly or terminal illnesses. Where available cost estimates are presented for phasing in coverage for persons with HIV disease and for extending the policy option to the entire disabled population. It should also be noted that all estimates of costs and impacts are preliminary and tentative. The absence of systematic data on the HIV disease population, including income, insurance coverage, employment status, and health care utilization and expenditure patterns is a serious barrier to reliable estimates. See Appendix A, prepared by Actuarial Research Corporation, for a description of the data sources and assumptions used in the cost estimates.

## A. Universal Health Insurance

Option 1: Provide universal health care coverage for all persons living in the United States to ensure access to quality health care services.

### 1. Impact

This option would extend health insurance coverage to an estimated 34 million uninsured Americans and improve the adequacy of health care benefits for tens of millions more. Most importantly, a system of universal health insurance coverage would guarantee continuity of health insurance coverage -- so that no one would have to fear losing health insurance coverage if they changed jobs, were unable to work, or incurred a serious medical illness. Guaranteed universal coverage would remove the discrimination against coverage for persons with HIV disease.

Universal continuous coverage can most simply to accomplished in a single public plan covering the entire population. Legislative universal health insurance plans which would rely on a single public plan include proposals by Congressman Marty Russo (D.-Ill.) and Congressman Tom Downey (D.-N.Y.), Senator Robert Kerrey (D.-Neb.). Another public plan approach is to extend the current Medicare program to the entire population. Congressman Pete Stark (D.-Cal.) and Congressman Sam Gibbons (D.-Fla.) have Medicare for all proposals.

Universal health coverage can also be achieved through a combination of private health insurance coverage provided through employers and a public plan to cover everyone not covered under such a plan. One mixed private-public plan is called employer "play or pay" which would required employers to either provide health insurance to workers and dependents or pay a payroll tax to a public plan to provide such coverage. Legislative proposals along this line include those introduced by Senator George Mitchell (D.-Me.), Senator Edward M. Kennedy (D.-Mass.), Senator Jay Rockefeller (D.-W.Va.), and Senator Donald Riegel (D.-Mich). Employer "pay or play" plans that also incorporate all-payer provider payment cost controls include proposals by Congressman Henry Waxman (D.-Cal.) and Senator Jay Rockefeller (D.-W. Va.) and Congressman Dan Rostenkowski (D.-Ill.). Plans that retain a major role for private health insurance typically reform the provision of coverage to small firms, eliminating many of the underwriting practices that currently discriminate against persons with HIV disease.

All of these proposals include a benefit package that includes hospital and physician services and limited preventive services. However, most of these plans do not include prescription drugs which are essential for care of persons with HIV disease. Nor do they provide long-term care, such as home health care and skilled nursing facility care. It is important that any universal health insurance plan be expanded to include at least those prescription drugs that are needed in the care of persons with HIV disease.

### 2. Cost

The cost of universal health insurance varies by plan. Plans that require employers to provide health insurance coverage to workers and dependents have the least impact on federal budgetary outlays -- typically around $25 billion in federal budget outlays to provide universal health insurance for health care, and another $40 billion for long-term care. Comprehensive public plans that provide a single plan covering the entire population and replacing employer-provided private health insurance would add $225 to $300 billion to the federal budget.

Cost to the health system would be considerably less, however, since some federal costs would replace current spending by state governments and individuals. Estimated new health spending would be $12 billion to $35 billion, depending on the benefit structure, or less than 5 percent of total health expenditures.

## B. Medicaid

Option 2: Expand Medicaid to cover all low-income people with HIV disease. Increase Medicaid payment rates for physicians, health centers, hospitals, and other health care providers to a level sufficient to ensure adequate participation.

### 1. Impact

Most persons with HIV disease who currently qualify for Medicaid do so under the disability eligibility category. People who have tested HIV positive but have not advanced to a diagnosis of AIDS do not qualify, even if they meet the low-income eligibility requirements. This restriction renders poor people with HIV disease who do not have a clinical diagnosis of AIDs virtually ineligible for the early intervention treatments and services that can delay progression of HIV disease, prevent opportunistic infections, and limit numerous (and expensive) hospital visits.

This option would increase the number of persons covered by Medicaid in two ways. Eliminating the disability requirement would lead to coverage of low-income persons in early stages of HIV disease, rather than postponing coverage until they have a clinical diagnosis of AIDS.

In addition this option raises the income eligibility level for coverage. Currently, an individual must actually be, or in some states be at risk of becoming, extremely poor to meet the income eligibility requirements for Medicaid. Many people with HIV disease are not impoverished but nevertheless do not have the health insurance or independent means to pay for the health care treatments and services they need. Therefore, either they are forced to rely on the already overburdened public hospital system for expensive inpatient care or they must spend themselves into poverty to qualify for Medicaid. Once impoverished and eligible for Medicaid, they become dependent on many other welfare programs for such basic needs as food, clothing, and shelter.

Eliminating the disability requirement for people with HIV disease and raising the current income eligibility to 100 percent of the federal poverty level would expand Medicaid coverage to include an estimated additional 6,800 persons with incomes below poverty with AIDS and 63,700 with incomes below poverty with HIV infection.

The option would include permitting anyone with an income between 100 percent and 200 percent of poverty to be covered by Medicaid by paying a premium that varies on a sliding scale with income. It is expected that 13,600 individuals with AIDS with incomes between 100% and 200% of poverty and 15,544 individuals with HIV infection with incomes between 100% and 200% would pay an income based premium to purchase Medicaid. Individuals with an income of 200% of poverty would pay a full premium of $1068 (U.S. average for adult males), and individuals with an income of 150% would pay a premium of $532. Although the full premium of $1068 would appear to be high, it is significantly lower than premiums for private individual or group insurance.

This recommendation would be particularly beneficial to Medicaid eligible individuals who are HIV positive, but who do not have a clinical diagnosis of AIDS. By extending coverage to HIV positive persons, this option would address their urgent need for expensive early intervention treatments, including counseling to prevent the spread of the disease and drugs to both delay the progression of the disease and to improve patient functioning. Currently, Medicaid and Medicare do not provide for early intervention because they are generally only available to individuals with a clinical diagnosis of AIDS.

In general, individuals, meeting the Medicaid eligibility criteria under this recommendation, would have improved access to a comprehensive package of health benefits. This package would include hospital inpatient and outpatient services, physician services, skilled nursing facility care, laboratory and x-ray services, and health screening and follow-up services and supplies.

This option would also address the current low Medicaid provider reimbursement rates. Medicaid's substandard provider payment rates limit the availability of ambulatory care to persons with HIV disease. It contributes to inappropriate substitution and use of emergency rooms and outpatient departments as a regular source of care (Green and Arno, 1990 and IHPP, 1990). Medicaid payment rates for physicians should be raised at least to the new Medicare physician fee schedule to be implemented in January 1992, rather than averaging only 64 percent of Medicare rates as is presently the case (PPRC, 1991).

To expand primary care to Medicaid beneficiaries with HIV disease, all community health centers and community-based organizations receiving Ryan White funding should be entitled to Federally Qualified Health Centers (FQHCs) status. As a FQHC, these providers would be eligible for reimbursement at 100 percent of reasonable cost under Medicaid. This should increase the availability of primary care in areas with large concentrations of persons in need of care.

Low reimbursement rates to hospitals may contribute to an inequitable distribution of patients with HIV disease. States should ensure that payment rates are adequate to cover cost of caring for persons with AIDS/HIV in an efficient manner.

### 2. Cost

The estimated Medicaid cost of this option is $610 million in FY 1991, split $311 million to the federal government and $299 million to state governments. This option would represent less than a one percent increase in total Medicaid expenditures. However, costs can be expected to increase in future years with increases in life expectancy and the prevalence of AIDS/HIV among low income IVDUs.

Variations on this option could reduce or increase this basic cost. If coverage were limited to those with incomes below the poverty level, the overall estimated Medicaid cost of this option would be $345 million in FY1991, split between the federal government ($176 million) and state governments ($169 million).

If the income requirement were raised to 185 percent of the federal poverty level, with applicable asset tests, Medicaid would cover 91,000 people with HIV infection and 21,000 people with AIDS. The total cost for Medicaid would be $660 million, and would be split between the federal government ($337 million) and state governments ($323 million).

If the income requirement were raised to 200 percent of the federal poverty and the asset test for eligibility were eliminated, Medicaid would cover 103,200 more people with HIV infection and 22,100 with AIDs. The total cost to Medicaid would be $727 million, and would be split between the federal government ($371 million) and state governments ($356 million).

### 3. Equitable Treatment of non-HIV Disease Disabled Populations

This option could also be extended to all low income individuals with similarly chronic diagnoses, such as cancer. Those with serious, expensive chronic health conditions requiring recurring care should be the top priority for Medicaid expansion. There are an estimated 16 million uninsured persons and 5 million persons with non-group insurance with incomes below the federal poverty level (Census Bureau, 1990). If all poor persons without group insurance were to be covered under Medicaid, rather than just poor persons with HIV disease, the estimated cost would be more than $25 billion in 1991.

Another approach, which would be more limited but preserve equitable treatment would be to expand SSI and Medicaid to cover all poor disabled persons. There are about 680,000 disabled persons (estimated as 20 percent of the current SSI population) with incomes below the poverty level, who are not on Medicaid. If all of them were to be covered under Medicaid, the estimated cost would be about $4.1 billion assuming a cost of $6,000 per person. Currently, the state SSI eligibility levels are at least 77 percent of poverty levels for a single individual with unearned income (more with state supplements) and at least 163 percent of poverty levels for those with earned incomes. States have the option of covering the disabled with incomes up to 100 percent of the poverty level.

<u>Option 3</u>: Provide all states with the option of expanding Medicaid coverage, with federally matched state funding, to all individuals with HIV infection or AIDS with incomes below the federal poverty level and meeting the SSI asset test.

1. <u>Impact</u>

This option differs from Option 2 in that it would make expanded coverage optional to the states, rather than mandatory. Its impact, therefore, hinges on the number of states which are likely to seek federal matching for care for low-income persons with HIV disease if such an option were available.

It is expected that this option would be attractive to states with a disproportionate share of individuals with HIV disease. It would relieve some of the states' financial burden experienced when they use state-only funds to provide care to persons with HIV disease. This could be particularly beneficial at a time when many states are being forced to restrict their Medicaid programs in response to alarming budget deficits.

It is assumed that New York and California, the two states with the largest HIV disease populations, would choose to follow through with this option. Together they have 43 percent of the total HIV disease population, so they would receive a considerable amount of federal funding in the form of matched funding. It is estimated that 25,231 individuals with HIV disease in New York and California would be newly enrolled in Medicaid in 1991. An estimated 1,000 individuals in New York with full blown AIDS would be enrolled in Medicaid (persons with AIDS in California already receive Medicaid coverage through their liberal SSI program). The majority of persons newly covered with HIV disease would have been previously uninsured.

State Medicaid programs currently have the option of enrolling all disabled persons with incomes below a level up to 100 percent of the poverty level. However, only 13 states altogether and only five of the 15 states, characterized as having the largest AIDS populations, had chosen this option by the end of 1990. New York and California have not. California does, however, have one of the most liberal SSI programs with an income limit exceeding 100 percent of the poverty level so that all the persons with a clinical diagnosis of AIDS and a low income would qualify for SSI and Medicaid on the basis of disability. However, the eligibility requirement of a clinical diagnosis of AIDS, in both New York and California and the rest of the U.S., is very restrictive for individuals, with HIV disease but without full blown AIDS. It is a problem for many because it often delays an individual from qualifying for SSI and Medicaid until later stages in the progression of the disease.

This option therefore would be particularly beneficial to individuals with HIV disease by addressing their need for early intervention services.

While this option would increase the number with Medicaid coverage in New York and California, low provider reimbursement rates under Medicaid could again significantly limit the availability of care to persons with HIV disease. In New York there are not enough physicians available to provide care to individuals with AIDS/HIV on Medicaid. California's Medicaid physician fees were 54 percent of Medicare prevailing charges in 1988. These low reimbursement rates and limited availability of Medicaid providers may lead individuals with HIV disease to utilize emergency rooms and outpatient departments inappropriately as a regular source of primary care.

Although this recommendation would extend Medicaid coverage to many individuals in the states accepting this proposal, it would also leave many near-poor and other low-income persons without coverage. It would probably not extend coverage in states such as Illinois where there are an estimated 2,600 individuals with AIDS and 34,800 other individuals with HIV disease. In order to become eligible for Medicaid these individuals would have to "spend down" below the required medically needy levels.

California and New York both provide comprehensive health care benefits to all Medicaid recipients whether or not they are categorically needy receiving cash payments. In California and New York, individuals would receive prescription drugs under this option. If the state has limits on prescription drugs under Medicaid, it is expected that coverage would be granted on the grounds that the prescription drug could be determined "medically necessary."

2. Cost

The estimated Medicaid cost of this option is $139 million in 1991, half paid by the federal government and half by the states. Of the total cost, $109 million is for the care of persons with HIV infection while $30 million is for the care of persons with AIDS. This option would increase total Medicaid expenditures by 0.1 percent. The 1991 average Medicaid reimbursements per person would be $2,588 for HIV treatment in California and New York, $28,160 for AIDS treatment in New York, $2,199 for non-HIV related medical treatment in New York and $1,301 for non-HIV related medical treatment in California. Forty percent of the HIV population will receive monitoring and counseling at a cost of $418 per person while the other sixty percent have CD4+ cell levels below 500 and would receive medical treatment that is estimated to be $4,034 per person.

Again as in the Medicaid recommendation, these cost estimates can be expected to increase in future years with the increases in prevalence of HIV disease. Further, cases in the future may be more costly with increases in life expectancy and the number of IVDU's. In addition, the percentage of full-blown AIDS cases who would be eligible for Medicaid under the current guidelines will probably rise (0.5-1 percent a year) due to the projected epidemic in IVDUs.

3. <u>Equitable Treatment of non-HIV Disease Disabled Populations</u>

Again, as in the first Medicaid option, this option could be extended to all low income individuals with similarly chronic diagnoses, such as cancer.

<u>Option 4</u>: Mandate Medicaid to pay COBRA health insurance premiums for low-income persons with HIV disease who have left their jobs and cannot afford to pay the health insurance premium.

1. <u>Impact</u>

This option is an extension of the current COBRA 1985 provisions. Medicaid funds would be used to continue private insurance coverage provided by an employer for up to 29 months, by paying the premiums for individuals with HIV disease who have left employment. If the coverage had been allowed to lapse, the current legislation would be amended to permit Medicaid to reinstate employer-based coverage. The option assumes that individuals would qualify for Medicare on the basis of disability at the end of the 29 month coverage period.

This option would extend employer sponsored insurance to an estimated 2,030 persons with AIDS and 7,959 persons with HIV infection by mandating Medicaid to pay the premium. Of the 2,030 persons with AIDS receiving coverage under this option, 1,624 would have previously been eligible for Medicaid. (It is assumed that the low-income population cannot afford the COBRA premiums and would apply for Medicaid).

This option has the advantage of buying beneficiaries into private coverage which is generally much more attractive, compared to Medicare or Medicaid, in terms of provider reimbursement rates. In addition, a comprehensive package of benefits is provided through many employer sponsored group plans, which would include the early intervention treatments. A drawback to this option would occur when the employer based plan had taken provisions to exclude the coverage of HIV disease health care benefits.

The more generous reimbursement rates would be attractive to providers and persons with HIV disease, who would not be required to change their source of care, as they would if covered under Medicaid and their physicians and/or hospital did not participate in Medicaid. This option might take some of the burden of providing care to individuals with HIV disease away from the teaching and public hospital and also from those physicians accepting Medicaid assignment.

Disadvantages to this option are that it only applies to people who have left employment with companies with 20 or more employees that currently provide health insurance to workers and dependents. As a result, it affects a comparatively small number of individuals. The cost of employer coverage could be expected to increase under this option. Smaller firms providing health insurance are likely to be hardest hit and may well drop coverage altogether, rather than continue to be responsible for coverage of persons with HIV disease following termination of employment. It might also increase discriminatory barriers to employment for persons with HIV disease.

Currently, as discussed earlier, Medicaid law provides all states with the option of paying COBRA premiums in this manner. A total of eight states and the District of Columbia have taken preliminary steps to implement this type of a policy. In particular, the experiences of Texas and Washington could be monitored and used as models for a nationally mandated Medicaid premium paying program.

### 2. Savings

This option results in a net cost savings to Medicaid as a result of shifting costs from the Medicaid program to employers through continuing coverage under employer sponsored insurance plans. Overall FY 1991 savings to Medicaid would be $4 million for both the HIV positive and AIDS populations. Of this, $28 million is saved for the AIDS population, while the net cost is $24 million for the HIV positive population.

### 3. Equitable Treatment of non-HIV Disease Disabled Populations

This option could be extended to individuals suffering from other similar chronic conditions, such as cancer. A further equity issue, however, is that it assists those who previously had employer-provided health insurance but does not assist similarly situated persons without such coverage. This option would, therefore, be less likely to cover women, children, Hispanics and blacks, who have higher rates of unemployment or part-time employment where insurance is not offered.

This option could be extended to the entire poor SSDI disabled population. HCFA's Office of the Actuary (1991) estimated that 805,000 SSDI beneficiaries would be in the Medicare waiting period in 1991. It would cost about $150 million for Medicaid to purchase COBRA premiums and $100 million to pay for the deductibles and coinsurance for the SSDI beneficiaries with incomes below the poverty levels.

## C. Medicare

Option 5: Permit Social Security Disability Insurance (SSDI) beneficiaries with AIDS to purchase Medicare during the two year waiting period. Require Medicaid to purchase Medicare coverage for poor SSDI beneficiaries.

### 1. Impact

This option would allow an estimated 10,506 SSDI beneficiaries with AIDS to purchase Medicare coverage, of whom an estimated 4,860 would be bought in by Medicaid and 5,646 would purchase Medicare on their own. Once eligible for SSDI, the individual would immediately be allowed to purchase Medicare coverage without having to wait the 24 month waiting period. The annual cost to the beneficiary would be $3,559, the full actuarial cost, for Medicare Part A, Hospital Insurance and Part B, Supplemental Medical Insurance premiums. In addition, beneficiaries would be liable for Medicare cost-sharing and non-covered services such as prescription drugs. The cost to beneficiaries is, therefore, estimated at $9,600 annually. Individuals with incomes above the federal poverty level would be expected to make these payments. It is estimated that 35 percent of the SSDI beneficiaries would take advantage of this option.

There are significant gaps and cost-sharing in the coverage provided by Medicare, which would put a heavy financial burden on many individuals purchasing Medicare under this option. Specifically, the out-of pocket costs for Hospital Insurance include a deductible of $628 per spell of illness. There are also out-of-pocket costs for Supplementary Medical Insurance, the coverage for physician and related services, which include a premium of $359 per year, a deductible of $100 per year and coinsurance of 20 percent of the allowable Medicare charge (figures are effective as of January 1, 1991) (U.S. Congress, Green Book, 1991).

Under Medicare Part A individuals would be covered for inpatient hospital care, some inpatient skilled nursing facility care, home health care and hospice care, while under Part B they would be covered for physician services, outpatient hospital services, durable medical equipment and other medical services and supplies. However, individuals would not be covered for prescription drugs, dental care, eyeglasses and a variety of long term care services. The lack of prescription drug coverage would be particularly significant for some individuals because the average annual cost of prescription drugs is $4,400 per year for a person with AIDS (Hellinger, 1991).

Despite these limitations in benefits, Medicare coverage will be attractive to many SSDI beneficiaries. Many are uninsured and unable to obtain private health insurance coverage. Without Medicare they will be quickly driven into poverty or risk doing without needed care.

A further benefit of this option is that the reimbursement rates are higher than under Medicaid, which would act as an incentive for physicians to provide ambulatory care to individuals with HIV disease.

Currently, an employer discontinues COBRA for persons eligible for Medicare. COBRA laws will need to be amended under this option to require employers to continue offering COBRA insurance for those persons with AIDS for 29 months. COBRA premiums at an average of $1,862 (Gabel, et al, 1990) are lower than the Medicare premiums of $3,559. Also, most of the employer health plans cover prescription drugs, which Medicare does not. Therefore, it is likely to be more attractive to those who have the option of COBRA coverage to retain such coverage, rather than purchasing Medicare.

2. <u>Cost</u>

The cost of this option to the Medicare program is $220 million, over and above payments paid by beneficiaries through premiums, deductibles, and co-insurance. This net cost to Medicare occurs because the premium is based on the average cost of Medicare coverage for all beneficiaries. The actual cost for SSDI persons with AIDS is expected to exceed this average cost, resulting in a net subsidy.

There is a net savings to Medicaid of $78 million. This is a result of Medicaid being used to purchase Medicare premiums for those individuals eligible for Medicaid. Medicaid would continue to be used for paying coinsurance, deductibles and for items not covered by Medicare, such as drugs for those individuals with incomes below 100% of poverty. Of the $78 million savings, approximately $40 million would be federal dollars, and $38 million state dollars.

3. <u>Equitable Treatment of non-HIV Disease Disabled Populations</u>

This option could be extended to other SSDI beneficiaries. Since all SSDI beneficiaries are seriously disabled, they should be permitted the option of purchasing Medicare by paying the full actuarial cost of coverage during the two year waiting period. This would extend coverage to an estimated 355,000 persons at an annual cost to Medicare of $1.2 billion and to Medicaid of $900 million, to cover those with incomes below poverty level.

<u>Option 6</u>: Allow all individuals with AIDS to purchase Medicare. For individuals with incomes below the federal poverty level

Medicaid would pay the Medicare premiums, deductibles and coinsurance.

1. Impact

This option is broader than Option 6 in that it would permit any individual with AIDS, not just those with a work history who qualify for SSDI, to purchase Medicare. Under this option a significant portion of the AIDS population would receive Medicare coverage. Currently only 3,100 persons with AIDS are estimated to have Medicare (HCFA, 1990). A total of 52,071 persons would be enrolled in 1991, of which 40,800 would be persons bought in by Medicaid and 11,271 would purchase Medicare on their own. Of the persons bought in by Medicaid, 34,000 would have had prior Medicaid coverage.

Once diagnosed with AIDS, the individual would immediately be allowed to purchase Medicare coverage without having to wait 29 months, which is currently the practice for individuals eligible for SSDI wanting to gain Medicare coverage. The annual cost to the beneficiary would be $3,559, the full actuarial cost, for Medicare Part A and Part B premiums. In addition, beneficiaries would be liable for Medicare cost-sharing and non-covered services. Including the purchase of prescription drugs of $4,400 which are not covered by Medicare, the cost to beneficiaries is therefore estimated at $9,600 annually. For those individuals without supplemental Medicaid financing this could prove to be a heavy financial burden. Individuals would receive the same Medicare coverage as discussed in option 5.

Again as discussed under option 5, an added benefit of this option is that provider reimbursement rates are higher than under Medicaid, which would act as an incentive for physicians to treat individuals with AIDS or HIV infection. Individuals previously having Medicaid coverage would have increased access to care as a result.

2. Cost

Under this option, Medicaid would save a total of $497 million and Medicare would spend an additional $1.1 billion. The Federal government would share in 51 percent of the Medicaid savings, or $253 million. The savings to Medicaid occur because many poor disabled persons with HIV disease who are currently covered by Medicaid would now be covered by Medicare. Medicaid would pay the Medicare premium, but this premium should be substantially less than the actual cost of care currently provided by Medicaid.

3. Equitable Treatment of non-HIV Disease Disabled Populations

This option could be extended to all disabled persons. There are currently about 2.9 million disabled persons who do not receive SSDI payments or receive SSDI payments but are in the 24 month waiting period for Medicare. The costs of extending this option to all of these disabled persons would be $11.1 billion for Medicaid and $4.8 billion for Medicare.

Option 7: Eliminate the current two-year waiting period for SSDI beneficiaries with AIDS to receive Medicare. Medicaid supplements Medicare coverage for poor SSDI beneficiaries.

1. Impact

This option differs from Option 5 in that it automatically extends Medicare coverage to all SSDI beneficiaries, without requiring them to pay the full actuarial premium of $3,559. Instead beneficiaries would be charged a much more modest Part B annual premium of $359.

Under this option an estimated 26,999 individuals with AIDS qualifying for SSDI benefits would immediately be covered by Medicare, without having to wait the two-year waiting period. This option focuses on a population with a clinical diagnosis of AIDS, rather than all individuals with HIV disease. Individuals are automatically enrolled in Part A without a premium. They would have the option of purchasing Part B for only $29.90 a month ($359 annual) which is a fourth of the actuarial value. This is a significant benefit and all persons with AIDS can be expected to purchase Part B coverage.

Individuals with incomes above the federal poverty level would be expected to contribute to the coinsurance and deductible for Medicare Part A and the premium, coinsurance and deductible for Part B. However, for individuals with incomes below the federal poverty level Medicaid financing would be available to cover the coinsurance, deductibles and premium. Of the estimated 26,999 SSDI beneficiaries, who would be eligible, 4,860 would be poor and would qualify for Medicaid assistance. Of these 4,860, 3,888 would have already been on Medicaid and would continue to receive all Medicaid services.

In addition, individuals could elect to continue their employer sponsored insurance coverage to supplement Medicare benefits. The employer plan would serve as a secondary payer, covering premiums, deductibles, coinsurance, and other non-covered Medicare expenses. COBRA would have to be amended to accommodate this option.

Individuals would be eligible for the benefits covered under Medicare as described in options 5 and 6. This means that they would not be covered for prescription drugs, dental care, eyeglasses and a variety of long term care services unless they had supplemental coverage. Again as in options 5 and 6, the lack of prescription drug coverage could be particularly significant for some individuals because the average annual cost of prescription drugs is $4,400 per year for persons with AIDS. Also as discussed earlier an added benefit of this option is that the reimbursement rates are higher than under Medicare, which would act as an incentive for physicians to treat individuals with AIDS or HIV infection.

Employers also would benefit from this option. Currently, individuals may continue their coverage under employer sponsored insurance plans for 29 months. Under this option, the employer plans would become secondary payers, reducing the financial risk assumed under these plans. Medicare would cover more of the costs not covered by the employer sponsored insurance plans.

### 2. Cost

By eliminating the Medicare waiting period, the cost to the Medicare program would be $658 million in FY 1991 dollars to cover persons with AIDS. The net savings to Medicaid would be $127 million since Medicare coverage would replace some existing Medicaid coverage for the poor disabled. Of this, the federal Medicaid program would save $65 million, with states saving $62 million.

### 3. Equitable Treatment of non-HIV Disease Disabled Populations

This option could be extended to all SSDI beneficiaries. The estimated cost of eliminating the two-year waiting period for all SSDI beneficiaries is $6.1 billion in calendar year 1991 (HCFA, 1991).

## D. Private Health Insurance

Option 8: Reform of employer provided group health insurance benefits to prohibit: setting higher premiums for persons believed to be at risk for AIDS; limiting benefits on the basis of HIV disease diagnosis; establishing waiting periods for coverage or pre-existing condition under employer-provided groups health benefits; or refusing to issue or renew coverage on grounds of risk for HIV disease.

### 1. Impact

This option affects primarily smaller firms with fewer than 25 employees. Only 20 percent of firms with more than 100 employees have a waiting period for pre-existing conditions and less than one percent do not cover pre-existing conditions (BLS, 1990). With some exceptions, larger firms do not exclude employees with HIV disease from their health plans or try to limit their benefits. Charges for medical treatment for a person with AIDS is estimated to be $35,200 per year and medical treatment for persons with HIV infection is estimated to be $5,603 in 1991. For smaller firms, covering even one or two employees with AIDS would increase the average cost of the health plan substantially. To avoid major premium increases, therefore, the reforms would not permit premiums to vary on the basis of HIV disease risk or experience.

If premiums could not increase for actual medical claims due to HIV disease, these claims would have to be spread among all small group insurers. Unless the increased claims could be subsidized by other markets of the insurers, small group rates would have to increase, leading some firms to drop their insurance. If insurers did not spread the cost over all small groups nationwide but increase premiums more in certain cities or industries, more firms would drop their insurance.

This option could have undesirable side effects. Firms are not required to offer coverage to their workers and any increase in premiums may cause them to drop coverage or reduce benefits. Furthermore, insurance companies are likely to attempt to subvert the regulations by selective marketing practices that discourage firms at risk from purchasing coverage.

### 2. Cost

There is no direct federal cost involved in this option. However, if there are significant numbers of employees who become uninsured, uncompensated care would grow and Medicaid and other public programs would have more beneficiaries.

### 3. Equitable Treatment of non-HIV Disease Disabled Populations

There are other disabled persons with medical conditions which are likely to be excluded by small group insurers. If all disabled employees had to be included in health plans, premiums would have to increase significantly, leading many firms to drop their insurance plans.

## E. Increase in Provider Funding

Option 9: Increase appropriations to the full authorized level under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990.

### 1. Impact

The legislation authorizes $275 million in emergency relief aid for high prevalence cities and states (Titles I, II), $275 million for preventive and primary care (Title III), and another $325 million for HIV counseling, testing, drug intervention and pediatric AIDS research (Title IV). However, the Budget Reconciliation Act of 1990 cut funding substantially, appropriating only $221 million out of the authorized $875 million. Money was released for relief to cities and states first, with the next release of funds ($46 million) in the Spring of 1991 to be directed at preventive services under Title III.

This relief, at least at sufficient funding levels, will provide needed economic assistance to areas of high AIDS prevalence. Initial relief to assist hospitals in providing outpatient care will greatly reduce the economic burden they face in providing care to a large number of AIDS patients. It will provide economic support to institutions currently offering a variety of special services including those services which utilize an interdisciplinary team of subspecialists.

However, a critical portion of the law is Title III which funds preventive care for persons with AIDS through categorical grants to outpatient clinics and formula grants for HIV testing and counseling. That preventive services are not reaching AIDS patients and many of those infected with HIV is reflected in the fact that many of these patients initially present with a variety of preventable illnesses such as PCP.

Title III will help fund essential preventive services for some portion of the AIDS population. Of the two grant processes, the most important are the categorical grants. These provide financial support for primary care and preventive services at migrant/community health centers and community clinics. These primary care settings are most likely to undergo funding cuts, if they occur at the state level. On the other hand, formula grants provide funding for testing and counseling, issues with greater political support at the state level and therefore issues which are less likely to undergo significant budget cuts. Thus the categorical grants are central to insuring that preventive services be delivered.

Areas of greater AIDS prevalence are also more likely to be areas with large numbers of uninsured and indigent individuals who lack the necessary support system for providing evolving care with AIDS and who may have a variety of other pressing medical and social problems. Thus, it is important that the Title III grant process assure that grantees demonstrate that they are part of a larger, more comprehensive care system capable of directly providing a range of services along a continuum of disease so characteristic of HIV disease, or are capable of effectively referring patients for additional services in other care settings. With more aggressive preventive care through interrelated sources of care--from mental health, counseling, and clinical services--many costly hospital admissions can be avoided.

This option does not provide funding for direct inpatient care (although inpatient case management is permitted) and therefore hospitals with large numbers of AIDS admissions will still suffer economic hardship. However, relief directed at outpatient care should enable these institutions to shift some funding back to finance inpatient care.

Since this option brings an infusion of funds into currently economically deprived institutions and uses hospitals, clinics, community based organizations, and M/CHCs already serving high prevalence communities, its implementation could occur quickly and reach populations in need faster than those that rely on indirect incentives to serve these populations.

Additional incentives for providers working in M/CHC and community-based organizations giving primary care services to AIDS/HIV patients can be obtained through qualifying the center or clinic as a Federally Qualified Health Center (FQHC). Centers which qualify as FQHCs may then receive reimbursement under Medicaid at 100 percent of reasonable charges. Such an enhanced reimbursement package will serve as a better incentive to help retain physicians at these centers. This is particularly attractive because the centers may qualify essentially by providing primary care to the general public. In addition, current legislation is pending before Congress which would amend the law to allow Ryan White grantees which did not provide non-HIV primary care to qualify as FQHCs. This amendment would further broaden access to care for many HIV disease patients.

### 2. Cost

Full funding of the CARE Act would increase federal budgetary outlays by $654 million annually. However, the amount of money needed to provide adequate economic relief to hospitals and other providers serving a disproportionate share of HIV disease care to patients is not directly calculable for lack of comprehensive data.

One low estimate of the level of relief for hospitals may be developed by blending outpatient hospital utilization patterns of uninsured AIDS patients (Andrulis et al., 1987) with estimates of hospital costs for outpatient care of AIDS patients (Hellinger 1988a). Using this approach, 57 percent (19,185) of outpatient visits in 1987 in a small sample (70 hospitals) of public/teaching hospitals and 17 percent (1,214) of outpatient visits in private hospitals were classified as "self pay" (Andrulis et al., 1987). Hellinger estimates that annualized outpatient care for AIDS patients was $4,400 in 1991. To provide relief for costs due to outpatient care for the uninsured in this small sample (70 hospitals) would then approach $84.4 million for public/teaching hospitals and an additional $5.3 million for private hospitals, or a total of $89.8 million. After adjusting for inflation this would total $144.6 million (1992 dollars). Thus the actual amount needed to provide relief to the full number of hospitals providing the greatest share of care for AIDS patients would be substantially greater than this figure, which reflects the costs to only 70 of the country's over 6000 hospitals.

Regarding Migrant/Community Health Centers, the National Association of Community Health Centers has estimated that the cost of providing care for all patients known to have HIV infection, AIDS related complex or AIDS was $1.3 billion in 1989. Although the insurance status of these individuals is not known, approximately 49 percent of all patients visiting these centers are reported to be uninsured (NACHC, 1991). The amount of relief to finance preventive services and primary care would total at least $824.9 million (1992 dollars). This does not reflect the amount of relief that would be necessary to assist other community clinics and primary care entities.

Thus the funds necessary to achieve the goals of the CARE Act would exceed $1 billion. Bringing funding up to current authorization levels would cost $654 million annually.

## F. Drugs

Option 10: The federal government should undertake through the Department of Health and Human Services a consolidated purchase and distribution of drugs used in the prevention and treatment of HIV disease.

### 1. Impact

This option would enable the federal government to negotiate reduced costs for HIV disease drugs by offering pharmaceutical manufacturers volume sales. This could be done through a federal agency, such as the CDC, or through the Medicaid program. There are a number of precedents for this type of approach. This type of purchasing policy could be modelled after the federal purchase of childhood vaccines. The federal government, through CDC, buys childhood vaccines through a mechanism of negotiated, open-ended contracts with large guaranteed minimum purchases. CDC offers this consolidated purchase option to the states on a voluntary basis. All fifty states have opted to be a part of the program. By purchasing in bulk the cost of a complete vaccination series is reduced by approximately 40 percent per child over the private sector cost (CDC, 1991). Table 4 compares the 1991 CDC cost in dollars per dose of four standard pediatric vaccines to the private sector cost. It is important to note that MMR and OPV are currently produced under monopoly protection, and yet they still provide significant price savings through this program.

The consolidated purchase of vaccine was initiated by CDC in 1962 as a public health measure to improve the vaccine coverage of American children. Consolidated purchase of HIV drugs, and in particular those agents used in early intervention, would also have important public health implications. Early intervention has been shown to reduce hospitalizations and to help prevent life threatening infections, such as PCP (Arno, 1990). Lack of access to early intervention, because of the inability to pay for medication, remains a significant barrier to care for the uninsured. They would be expected to benefit considerably from this program.

Under the federally-funded AIDS Drug Assistance Program (ADAP) some state governments have taken steps to provide financing for costly AIDS drugs. Maryland, for example, has initiated the Maryland AIDS Drugs Assistance Program (MADAP), which supplies three drugs (AZT, pentamidine and alpha-interferon) to state residents who cannot afford them and who are either awaiting Medicaid coverage or do not qualify for it because of incomes above indigence in the state. MADAP benefits the uninsured population in Maryland whose incomes are above poverty level and allows recipients to continue working while they are able. Presently, this program pays the full manufacturer retail price for the three agents and works with local pharmacies. With passage of the Ryan White Act, ADAP was replaced with funding principally through Title II of the Ryan White Act.

Medicaid programs in the states which pay for prescription drugs currently pay the full retail price for HIV drugs. With consolidated purchase, state Medicaid programs could supply Medicaid recipients with their medications at a negotiated reduced rate. Drug distribution could be done at STD clinics, state or municipal public clinics, and Maternal and Child Health clinics. Since 40 percent of AIDS patients, and 90 percent of children with AIDS, are currently covered through the Medicaid programs (HCFA, 1990), the federal government and state governments could both be expected to save considerable sums on drug costs for Medicaid recipients.

A consolidated purchase and distribution approach does not reform the Orphan Drug Act or alter the incentives provided under this Act for research on drugs for rare diseases with small markets. While some anti-retroviral agents, such as AZT, dideoxyinosine, and dideoxycytidine, are likely to have large markets many AIDS related infections, such as cryptosporidiosis, mycobacterium avium-intracellular, remain relatively rare. Without the incentives of the Orphan Drug Act, research on these and other rare diseases may be curtailed. This problem was recognized by the Presidential Commission on the HIV Epidemic in their report to the President in 1988.

In terms of feasibility this approach has two strengths. First, there are considerable precedents, such as the federal vaccine program, and the parasitic diseases program, for consolidated purchase. Second, the ADAP program has increased access to AIDS drugs to uninsured populations which otherwise would not receive them, suggesting that consolidated purchase could actually increase sales of AIDS drugs. Thus, the pharmaceutical manufacturers may be more willing to support this type of program than one which would approach cost containment by price ceilings or reform of the Orphan Drug Act.

2. Cost

Administrative cost would depend on the structure of a consolidated purchase program. Savings on consolidated purchase would be dependent upon negotiations with the manufacturers. Evidence from the consolidated purchase of vaccines suggests that savings could be considerable.

3. Equitable Treatment of non-HIV Disease Disabled Populations

This option is HIV disease specific and would have only indirect effects on other prescription drug buyers. The principle behind this option, however, could be generalized for other populations.

Option 11: Reform of the Orphan Drug Act with a sales and/or a profit cap.

1. Impact

Although the stated purpose of the Orphan Drug Act of 1983 was to encourage research and development of drugs with limited financial expectations, the protection offered by the Orphan Drug Act has allowed some orphan drugs to become markedly profitable. Frequently cited examples of drugs granted orphan status which have subsequently generated considerable sales and profits include AZT, aerosolized pentamidine, recombinant human growth hormone, and recombinant erthopoeiten (EPO) (Theone, 1991). AZT and aerosolized pentamidine are used in AIDS, EPO, while principally a drug for End Stage Renal Disease patients, is also used to treat HIV-related anemia. Of these drugs only pentamidine (with 1990 sales estimated at $480 million) would be affected by reform of the orphan drug law since the others are protected by patent law beyond the seven year exclusivity of orphan status (Asbury, 1991). Reform of the Orphan Drug Act, however, might affect other drugs still under research, as well as orphan drugs used in other diseases.

Reform of the Orphan Drug Act through a sales or profits cap limit has a number if implications. It would deny orphan status once a drug had proven to be profitable, thereby, retaining orphan status for unprofitable drugs and returning the use of the law to its original intent. Further, by preserving orphan status until a drug achieved profitability, manufacturers would still be protected through the research and development phases of a new drug for a rare disease, thus research incentives would not be lost. For a previously approved drug granted orphan status for a new indication, as was the case with pentamidine, the loss of orphan status once profitability was established would mean the loss of exclusivity for that drug and for that indication. Market forces would then be expected to lower costs. This approach has the advantage over a population limit for orphan drugs in that it is based on a demonstrable endpoint (profits or sales), whereas population targets are likely to be based on figures (such as the number of HIV infected individuals) subject to considerable debate. A sales cap of $150 million has been suggested by the National Organization of Rare Diseases (NORD).

2. <u>Cost</u>

This option could result in considerable savings for all payers of AIDS and HIV drugs. Savings on pentamidine alone could amount to $900 per patient per year. There would be minimal administrative cost.

3. <u>Equitable Treatment of non-HIV Disease Disabled Populations</u>

This option would not be HIV disease specific and would be expected to benefit any patient group requiring an expensive orphan drug whose price was affected by the amendment. An example would be End Stage Renal Disease patients requiring EPO.

<u>Option 12</u>: Place a price ceiling on drugs used in the treatment of HIV disease.

1. <u>Impact</u>

A price ceiling on HIV drugs could amount to substantial savings for all buyers of these agents. Reasonably set prices might be expected to influence patients to seek early intervention, might increase the number of private insurers willing to insure HIV infected individuals, and could allow

Federal monies allocated for HIV disease care to be used in other HIV-related services. Since many drugs are used both in early intervention and in treatment of AIDS, this option could reduce the cost of treatment throughout the spectrum of HIV disease.

Prices could be set by mandate, after negotiation with manufacturers. These ceilings would initially limit profit margins, but might also encourage efficiency. Such price ceilings would have to be negotiated for each drug, or class of drugs, and the process could potentially be complex. However, incentives to develop drugs for the less common opportunistic infections associated with HIV disease may be lost.

### 2. Cost

The cost of this option would depend on the price ceiling levels set and would be borne by the manufacturers.

### 3. Equitable Treatment of non-HIV Disease Disabled Populations

These price ceilings would be HIV-specific and would have only indirect effects on other prescription drug buyers.

## VI. Summary and Conclusions

The nation urgently needs to address the health care problems of all Americans by supporting universal health insurance. Without this action, the ranks of the uninsured and the underinsured will continue to grow. Action is particularly urgent in the case of persons with HIV disease. They face serious financial barriers to care without comprehensive health insurance. Opportunities for HIV disease education, prevention, counselling, and early intervention will continue to be missed, and acutely ill individuals with HIV disease or other illnesses will increasingly turn to already overburdened public and quasi-public hospitals, requiring expensive care that would have been unnecessary had they been able to afford simple primary care.

While the primary solution to this problem is the enactment of universal health insurance, it is unrealistic to assume that this will ensure timely relief. More modest steps must be taken during the interim to close the gaps in health care financing for those with HIV disease and others who are chronically ill and experience catastrophically expensive health care. These steps should build on existing programs such as Medicare, Medicaid, and the Ryan White Act, which already provide limited assistance. Such steps are within our economic and administrative capability and should be a top priority for policy attention.

With the exception of universal health insurance, all of the policy options set forth deal with only a part of the failure of the U.S. health system to assure adequate protection for the cost of health care to all Americans. Even as applied to persons with HIV disease, they fall far short of meeting the complete needs for coverage of health and long-term care services. However, they are essential stop-gap measures which show promise of providing at least some immediate assistance to an extremely vulnerable population group.

## A. Universal Health Insurance

Dissatisfaction with incremental and piecemeal approaches to addressing gaps in the current U.S. health financing system have led to serious proposals for fundamental reform. The Bipartisan Commission on Comprehensive Health Care, called the Pepper Commission, has issued a major report calling for a mixed public-private approach to health financing. This Commission, chaired by Senator Jay Rockefeller (D.-W.Va.) and including many health leaders in the Congress, has focused greater attention on the need for universal health insurance coverage. Since the release of the Pepper Commission report in the Spring of 1990, a number of major universal health insurance legislative proposals have been introduced in the Congress. Senator Jay Rockefeller (D.-W.Va.) and Congressman Henry Waxman (D.-Cal.) have introduced legislation along the lines of the Pepper Commission recommendations. This includes requiring that all large employers (more than 100 employees) cover employees and dependents under a private health insurance plan or contribute to their coverage under a public program (Pepper, 1990). Small firms would be given strong incentives to provide coverage under private health insurance or a public plan. Remaining uninsured individuals would be covered under a public plan by paying a premium (zero for those below poverty, and subsidized between 100 and 200 percent of poverty).

Critics of the Pepper Commission have suggested alternatives. Congressman Pete Stark (D.-Cal) has proposed legislation that would cover all Americans under the Medicare program. Congressman Marty Russo (D.-Ill) and Congressman Tom Downey (D.-N.Y.) have proposed legislation that would enact a comprehensive health insurance plan modelled on the Canadian system. Senator Robert Kerrey (D.-Neb.) has introduced a comprehensive single plan that would be administered by state governments.

Mixed public-private universal health insurance plans that are closer in concept to the Pepper Commission recommendations include that introduced by Senator George Mitchell (D.-Me) and other Democratic Senators. This plan would cover all Americans under a combination of employer-provided private health insurance or a federal-state public program. Congressman Dan Rostenkowski (D.-Ill.) has a plan which would cover all Americans under either a public program similar to Medicare or employer-provided private health insurance. His plan would establish prospective targets for spending under the plan linked to growth in the gross national product.

The taxes to finance expanded coverage are unpopular with many people. Another alternative is to reform the provision of private health insurance without expanding public coverage. This approach is supported by the Health Insurance Association of America (HIAA), and is reflected in a bill introduced by Congressman Rod Chandler (R.-Wash.) and Congresswoman Nancy Johnston (R.-Conn.). This plan includes reform of the sale of private health insurance with federal regulation of underwriting practices. Insurers would be required to offer coverage to all small firms. No individual could be excluded for health reasons. Limits would be set on exclusions for pre-existing conditions.

Bounds would be set on the extent to which premiums could vary with the risk of the group. In addition, HIAA supports expansion of Medicaid to cover all poor persons.

While reform of the sale of private health insurance has merit, few believe that simply eliminating the worst abuses of underwriting in the small group market for health insurance will truly make health insurance affordable and available to all those in need of coverage. Robert Reischauer, Director, Congressional Budget Office, has estimated that it might actually reduce coverage rather than increase it (Reischauer, 1991).

Given the lengthy and ongoing public debate that is likely to be required to achieve resolution on comprehensive reform, an incremental approach that would build on current programs offers at least the hope of some near-term relief in assuring access to needed care for those in dire need of assistance. Without some assistance, many hospitals and other health care providers serving persons with HIV disease are likely to experience severe financial pressures. The policy options set forth in this paper provide a wide array of alternatives for filling the gaps in current sources of financing health care for persons with HIV disease. Each has advantages and disadvantages, but all offer some form of assistance dealing with a badly neglected problem.

## B. Medicaid Expansion

The options to expand Medicaid have a relatively modest budgetary impact and would provide some additional assistance to poor persons with HIV disease. They build on the legislative changes enacted by Congress from 1984 to 1990 to expand Medicaid to additional groups of needy individuals. The benefits are reasonably comprehensive, including coverage for many drugs needed in the treatment of HIV disease.

Their primary disadvantages include: the fiscal pressures on states that lead governors and other state officials to oppose additional federal mandated eligibility groups; their exclusion of the majority of uninsured persons with HIV disease; and the low provider payment rates that lead to low participation in the program.

## C. Medicare Expansion

The Medicare options focus on a population with a clinical diagnosis of AIDS, rather than the full HIV disease population. They require considerable patient cost-sharing, but also protect low income individuals with Medicaid supplemental coverage. The higher provider reimbursement rates under Medicare may act as an incentive to providers to provide care to individuals with HIV disease.

It should also be noted, however, that the Medicare benefit package is not ideally suited for the care of persons with HIV disease. It excludes prescription drugs, and covers only very limited long-term care benefits - hence, cost-sharing may prove prohibitively expensive to those without Medicaid supplemental coverage.

Additionally, these options may come under opposition from those who wish to protect Medicare funding for the elderly and also by those who would prefer options extending care to all chronically ill individuals and not just those with HIV disease.

### D. Private Health Insurance Reform

Reform of the market for private health insurance should eliminate some of the underwriting practices that make health insurance difficult for persons with HIV disease to obtain, but would make health insurance more expensive. It could be accomplished without any cost to the federal budget. However, even with such reforms many individuals and small firms are unlikely to find private health insurance affordable. This option, therefore, would leave many uninsured persons with HIV disease without coverage, and could lead to small firms dropping coverage for all employees.

### E. Increase in Provider Funding

Expansion of funding for major providers serving persons with HIV disease is another approach. This could be accomplished through expanded funding of the Ryan White Act. Its benefits would be immediately available and provide fiscal relief to overburdened public and teaching hospitals now caring for a majority of the HIV disease population. Its primary disadvantage is that funding would only be available in some geographic locations, funding would not necessarily be adequate to meet all the care needs of the target population, and it still would require persons to seek "charity" care. Early intervention and treatment is particularly likely to suffer.

## F. Drugs and HIV Vaccine

The consolidated purchase of drugs for HIV disease treatment would significantly reduce the cost of HIV drugs and improve access to early intervention treatments for the uninsured and the underinsured. This is a relatively inexpensive and immediate measure, which would benefit many suffering in the early stages of HIV disease and provide for their need of drug treatments to slow the progression of the disease.

Reform of the Orphan Drug Act to make widely used drugs available to persons with HIV disease at a more competitive price is an attractive option. Its primary disadvantage is the deterrent effect it might have on the research and development efforts of pharmaceutical companies.

## G. Conclusion

There can be no question that a comprehensive approach to assuring universal health insurance coverage would deal the most effectively with the need for financial access to health care services for persons with HIV disease. The primary disadvantage of such an approach is its federal budgetary cost, and depending on the specific approach its cost to small business. Politically, however, this recommendation seems furthest from immediate implementation. Action must therefore be taken to begin implementing an incremental approach, which would provide for the immediate needs of those suffering from HIV disease. Serious consideration should also be given to expanding the options of this report to a greater population, not just those with HIV disease, who are also chronically ill and facing financial hardship from medical expenses.

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TABLE 1

PROJECTED NUMBERS* OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) CASES, DEATHS AND LIVING PERSONS WITH AIDS, UNITED STATES, JANUARY 1989-DECEMBER 1993

| Year | New cases[+] | AIDS cases Alive | Deaths |
|---|---|---|---|
| 1989 | 44,000-50,000 | 92,000-98,000 | 31,000-34,000 |
| 1990 | 52,000-57,000 | 111,000 -122,000 | 37,000-42,000 |
| 1991 | 56,000-71,000 | 127,000-153,000 | 43,000-52,000 |
| 1992 | 58,000-85,000 | 139,000-188,000 | 49,000-64,000 |
| 1993 | 61,000-98,000 | 151,000-225,000 | 53,000-76,000 |
| Cumulative total through 1993[¶] | 390,000-480,000 | - | 285,000-340,000 |

*Projections are adjusted for unreported diagnoses of AIDS by adding 18% to projections obtained from reported cases (corresponding to 85% of all diagnosed cases being reported: 1/0.85 = 1.18) and rounded to the nearest 1,000.

[+] Number of cases diagnosed in that year.

[§] This number differs from the number *101,000) published in the MMWR (1990;39:110-2,117-9) because of a transcription error.

[¶] Rounded to the nearest 5,000. Includes an estimated 120,000 AIDS cases diagnosed through 1988, 48,000 persons alive with AIDS at the end of 1988, and 72,000 deaths among patients diagnosed as having AIDS through 1988.

Source: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, 1990. "HIV Prevalence Estimates and AIDS Case Projections for the United States: Report Based upon a Workshop," Morbidity and Mortality Weekly Report, November 30; 39(RR-16):1-31.

## TABLE 2

## AIDS CASES, CASE-FATALITY RATES, AND DEATHS BY HALF-YEAR AND AGE GROUP, THROUGH OCTOBER 1990, UNITED STATES

| | Adults/Adolescents | | | Children<13 years old | | |
|---|---|---|---|---|---|---|
| Half-year of diagnosis | Cases diagnosed during interval | Case-fatality rate | Deaths occurring during interval | Cases diagnosed during interval | Case-fatality rate | Deaths occurring during interval |
| Before 1981 | 78 | 82.1 | 30 | 6 | 66.7 | 1 |
| 1981 Jan-June | 92 | 93.5 | 38 | 8 | 62.5 | 2 |
| July-Dec | 199 | 91.0 | 85 | 6 | 100.0 | 6 |
| 1982 Jan-June | 394 | 90.6 | 152 | 14 | 78.6 | 9 |
| July-Dec | 685 | 88.6 | 282 | 15 | 80.0 | 5 |
| 1983 Jan-June | 1,261 | 92.1 | 515 | 32 | 93.8 | 13 |
| July-Dec | 1,631 | 91.4 | 917 | 42 | 78.6 | 16 |
| 1984 Jan-June | 2,543 | 89.0 | 1,374 | 49 | 83.7 | 25 |
| July-Dec | 3,334 | 89.8 | 1,917 | 62 | 72.6 | 24 |
| 1985 Jan-June | 4,815 | 88.7 | 2,741 | 94 | 73.4 | 44 |
| July-Dec | 6,187 | 87.0 | 3,730 | 126 | 74.6 | 68 |
| 1986 Jan-June | 8,119 | 85.2 | 4,900 | 132 | 72.0 | 64 |
| July-Dec | 9,760 | 82.3 | 6,231 | 177 | 67.2 | 84 |
| 1987 Jan-June | 12,544 | 81.4 | 7,245 | 219 | 61.6 | 112 |
| July-Dec | 13,947 | 74.5 | 7,611 | 245 | 58.4 | 157 |
| 1988 Jan-June | 15,719 | 66.9 | 8,815 | 238 | 49.2 | 129 |
| July-Dec | 16,003 | 59.9 | 9,999 | 314 | 44.9 | 150 |
| 1989 Jan-June | 17,523 | 49.0 | 11,146 | 309 | 41.7 | 155 |
| July-Dec | 16,839 | 39.4 | 12,280 | 283 | 36.7 | 158 |
| 1990 Jan-June | 15,558 | 25.6 | 10,637 | 242 | 21.5 | 128 |
| July-Oct | 5,000 | 13.1 | 3,565 | 73 | 19.2 | 47 |
| Total* | 152,231 | 62.0 | 94,375 | 2,686 | 52.0 | 1,399 |

*Death totals include 165 adults/adolescents and 2 children known to have died, but whose dates of death are unknown.

Source: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control. "Surveillance Report," Morbidity and Mortality Weekly Report, November 1990.

TABLE 3

## PROJECTED NUMBERS OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) CASES, BY RISK-BEHAVIOR GROUP*, UNITED STATES, 1989-1993

| | Homosexual/bisexual men | | Heterosexual male and female | | | |
|---|---|---|---|---|---|---|
| Year | Not intravenous drug users | Intravenous drug users | Intravenous drug users | Heterosexual transmission | Perinatal transmission | TOTAL |
| 1990 | 26,000-28,000 | 2,600-2,800 | 11,000 | 2,600-2,900 | 1,000-1,100 | 43,200-45,800 |
| 1990 | 29,000-31,000 | 2,700-3,000 | 13,000-14,000 | 3,700-4,000 | 1,300-1,500 | 49,700-53,500 |
| 1991 | 30,000-38,000 | 2,600-3,400 | 14,000-18,000 | 4,800-6,100 | 1,600-2,200 | 53,000-67,700 |
| 1992 | 30,000-44,000 | 2,500-3,600 | 16,000-23,000 | 6,100-8,800 | 2,100-3,100 | 56,700-82,500 |
| 1993 | 30,000-48,000 | 2,400-3,800 | 17,000-27,000 | 7,600-12,200 | 2,600-4,100 | 59,600-95,100 |
| Cumulative total through 1993+ | 219,000-262,000 | 21,000-25,000 | 95,000-118,000 | 29,000-38,000 | 11,000-14,000 | 262,200-344,600 |

*Projections are adjusted for unreported diagnoses of AIDS by adding 18% to projections obtained from reported cases (corresponding to 85% of all diagnosed cases being reported: 1/0.85 = 1.18) and rounded (to the nearest 1,000 for the first and third groups, and to the nearest 100 for the other three groups).

+Rounded to the nearest 1,000. Includes the following number of cases estimated to have been diagnosed through 1988: 74,000 among homosexual and bisexual mem who are not intravenous drug users (IVDUs); 8,600 among homosexual and bisexual men who are IVDUs; 25,000 among heterosexual male and female IVDUs; 4,200 attributed to heterosexual transmission, and 1,900 attributed to perinatal transmission.

Source: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, 1990. "HIV Prevalence Estimates and AIDS Case Projections for the United States: Report Based upon a Workshop," Morbidity and Mortality Weekly Report, November 30; 39(RR-16):1-31.

## TABLE 4

### Vaccine Costs in 1991 Dollars

| | Vaccine | CDC cost ($) | Private costs($) |
|---|---|---|---|
| | DPT | 6.91 | 10.95 |
| | OPV | 2.00 | 9.45 |
| | MMR | 15.33 | 22.29 |
| | HIB | 5.16 | 14.50 |
| TOTAL | | 40.31 | 86.44 |

Source: Horn, 1991.

# APPENDIX 1

# Assumptions and Data Sources for Cost Estimates of Options

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# APPENDIX I

## Assumptions and Data Sources for Cost Estimates of Options

<u>Option 2</u>: Mandate Medicaid coverage for all persons with HIV infection or AIDS with incomes below the federal poverty level meeting the SSI asset test. Allow those with incomes between 100% and 200% of the poverty level to purchase Medicaid on a sliding premium basis

A. Number of persons affected

1. HIV population with incomes below poverty

The CDC estimated that in July 1991, there would be approximately 1,160,000 persons with HIV infection (CDC 1990a). According to the 1989 Current Population Survey 19% of single males aged 25-44 had incomes below the federal poverty level (Census 1989). IVDUs accounted for 32% of persons with AIDS (CDC 1990a). If it is assumed that half of the IVDUs have incomes below the poverty level, and 19% of the other 68% of the HIV population also have low income, the weighted average is 29% with low income.

The number of new Medicaid eligibles should exclude those with employer sponsored insurance, already on Medicaid, who will continue to purchase individual insurance, or who cannot pass the SSI assets test. Only 7% of single males aged 25-44 with incomes less than the poverty level had employer sponsored insurance and 17% of those without employer sponsored insurance were already on Medicaid (CPS 1989). A higher percentage, 46% of women aged 19-44, were already on Medicaid (CPS 1987). Weighting these Medicaid rates by the male and female distributions of 90%

and 10% from the CDC gives an estimate of 249,656 who are potentially eligible for Medicaid.

The CPS asks for annual income but there are many persons with income below the poverty level part of the year. Thorpe and Siegel (1989) estimated that an additional 26% would be poor part of the year. About 16% of those without employer sponsored insurance or public insurance purchased their own individual policies (CPS 1989). It is assumed that half of the 16% will continue to purchase their own policies since private insurance allows access to more providers. There is little information about the distribution of financial assets among young adults. It is assumed that 90% of individuals with income below the poverty level would pass the assets test. It is estimated that half the HIV population does not know they are HIV positive and only half of those who know will apply for Medicaid. A total of 25% of those eligible would be added to Medicaid.

2. HIV population with incomes between 100% and 200% of poverty

According to the 1990 CPS, 16% of single males aged 25-44 had incomes between 100% and 200% of poverty, 67% of whom did not have employer sponsored insurance. Only 25% would apply for Medicaid if it were free. It is assumed that half of these persons would buy Medicaid for premiums based on a sliding scale from $0 to $1068 per person, averaging $500 per person.

3. Persons with AIDS with incomes below poverty

CDC estimated the number of persons alive with AIDS and those who died during 1990 and 1991. The number of persons alive at the end of 1990 and 1991 is estimated by subtracting those who died from those alive during the year. The number of persons with AIDS alive in July 1991 (85,000) is estimated as the average of the persons alive at the end of 1990 and the end of 1991.

Of the 85,000 persons with AIDS in July 1991, it is estimated that 40% are already on Medicaid (HCFA 1990). The 1991 average payment levels for SSI and state supplementation payment are 77% of the poverty level, counting those states with higher than 100% of poverty level as 100% (Social Security Administration 1991). According to the 1989 CPS, 16% of single males had income within 16% of the poverty level. Therefore, the difference between the income limit and 100% of the poverty level can be used to estimate the percentage of persons in that income band. SSI allows $20 in monthly income not to be counted, so the average SSI/SSP income limit is 80% and 20% is the estimate of the percentage of persons with incomes between 80% and 100% of poverty. The 20% is applied to those persons already on Medicaid. It is assumed that all of the 20% can pass an assets test. Even if a person with AIDS had assets above the $2000 level for countable resources, medical treatment and living expenses would soon reduce his or her assets.

4. Persons with AIDS with incomes between 100% and 200% of poverty

According to the 1990 CPS, 16% of single males aged 25-44 had incomes between 100% and 200% of poverty. This 16% is multiplied by 1.25 for a total of 20% because persons with AIDS are more likely to have quit work. It is assumed that 80% of these persons with AIDS would buy Medicaid at an average premium of $500 per person. Many of those buying Medicaid would have been previously uninsured but persons purchasing individual insurance or COBRA may also buy Medicaid because the Medicaid premiums are lower and Medicaid has little or no cost sharing.

### B. Costs of medical treatment

#### 1. Costs of HIV treatment

The CDC estimated that 60% of the HIV population have CD4+ cell levels below 500 (CDC 1990a). This is the group that could benefit from medical treatment, at a cost of $5603 in charges per person per year (Arno 1990 estimate of $5094). Arno recommends that the other 40% be monitored and counseled (at charges of $581 per person). Most of the charges (90%) for persons with HIV infection are for pharmaceuticals which are assumed to be paid at average wholesale prices by Medicaid, which are 80% of charges (Hellinger 1990b). On average Medicaid paid 64% of Medicare prevailing charges for physician visits in 1988 (PPRC Annual report 1991). It is also assumed that Medicare fees are about 75% of charges. Altogether, Medicaid would pay about 75% of charges for treatment and counseling for HIV infection. Medicaid costs for medical treatment not related to HIV infection is $1068 per person, based on FY 1989 Medicaid expenditures for the AFDC-type adults not receiving cash assistance (HCFA 2082 data for FY 1989). HCFA uses 51% as the Federal share for AIDS treatment (HCFA 1990). Federal shares range from 50% to 80% but the matching share is 50% in many of the states with the largest HIV populations.

#### 2. Costs of AIDS

The most recent estimate of medical treatment for AIDS was $32,000 in charges per year in 1990 (Hellinger 1991). Projected at 10% per year, this would be $35,200 in 1991. Medicaid is assumed to pay 58% of charges

(HCFA 1990).

C. Equitable Treatment for all persons with incomes below the poverty level

According to the March 1990 CPS, there were an estimated 16 million uninsured and 5 million persons with non-group insurance with incomes below the federal poverty level. If all poor persons without group insurance were to be covered under Medicaid it would cost at least $25 billion in 1991 (based on Medicaid costs of $1068 for single males). This is a rough estimate because not all who are eligible would choose to enroll and the costs may be higher or lower depending on their health needs.

To enroll just the disabled persons with incomes below poverty would cost about $4.1 billion. There were 3.4 million disabled persons receiving SSI payments in September 1990 (Social Security Bulletin March 1991), almost all of whom are enrolled in Medicaid. Another 680,000 (estimated as 20% of 3.4 million) have income above SSI/SSP levels but below the poverty level. It is assumed that these disabled persons have $6000 in medical costs.

<u>Option 3</u>: Provide all states with the option of expanding Medicaid coverage, with federally matched state funding, to all individuals with HIV infection and AIDS with incomes below the federal poverty level and meeting the SSI asset test.

A. Number of Persons affected

1. HIV Population

It is assumed that New York and California would choose the option to enroll persons with HIV infection and AIDS onto Medicaid. These are the two states with the largest HIV and AIDS populations and they would be able to receive federal matching funds to help for state-only programs.

State distributions of persons with HIV disease are taken from CDC (1991b). The Medicaid programs in New York and California are more generous than average so the percentage eligible for Medicaid reported in the CPS nationwide was increased by 20%. Otherwise, the same assumptions are used as under Option 2.

### 2. AIDS Population

Persons with AIDS are presumed disabled so if their income is low enough they can receive SSI and thus be eligible for Medicaid. In California, all of the persons with AIDS with incomes below the poverty level are already eligible for Medicaid because of its generous state SSI supplements. According to a hospital survey (Andrulis 1989), 54% of AIDS inpatient admissions in the Northeast were covered by Medicaid in 1987. This percentage is used for New York. New York's state SSI income limit is 90% of the poverty level. Raising the income limits for persons with AIDS from 90% to 100% of the poverty level would increase the New York AIDS population covered Medicaid by 10%.

## B. Medicaid Costs

### 1. Costs for persons with HIV infection

Medicaid enrollees would also have health expenses not related to HIV paid by Medicaid. The FY 1989 HCFA 2082 reports collect data from each state on expenditures. For FY 1989, New York spent $1817 per person on AFDC-type adults not receiving cash assistance and California spent $1075. These figures, inflated to 1991, were used to estimate the non-HIV related costs per person. The 1988 Medicaid fees as a percentage of Medicare fees came from the 1991 Physician Payment Review Commission Annual Report. On average, New York and California reimbursed 43% of Medicare prevailing charges for physician visits in 1988 (about 64% nationwide).

Option 4: Mandate Medicaid to pay health insurance premiums and maintain or restore insurance through the workplace for a minimum of 29 months, for persons with HIV infection or AIDS who have left employment with incomes below the federal poverty level.

A. Number of persons affected

1. Persons with HIV infection

Persons who have left employment in a firm with more than 20 employees are eligible to purchase continuing health benefits. The 1989 CPS estimates that 89% of single males were employed. According to the 1989 CPS only 55% of single males were employed by firms with more than 20 employees and also have health insurance through their employment. The Yelin study (1991) estimates that about 10% of persons with HIV quit working.

Medicaid would pay the COBRA premiums for persons with incomes below poverty level. Persons who quit their jobs have reduced incomes but are likely to be eligible for SSDI payments. Workers may also be covered by long term disability insurance. The Bureau of Labor Statistics conducts a survey of medium and large firms every two years which showed that in 1989, 45% of workers were covered by long term disability which pay on average 50% to 60% of previous earnings (BLS 1990). In most cases, long term disability insurance continues until normal retirement age.

In the estimates for COBRA and Medicare coverage, these monthly insurance payments were used to estimate the population with income less than poverty levels. According to the 1989 Social Security Bulletin Annual Supplement, 33% of male SSDI beneficiaries received monthly SSDI payments which were below the poverty level. If 45% of these workers also receive disability insurance payments, then 18% would have combined SSDI and private disability income less than poverty level. It is assumed that other income from wages, investments, etc. is not significant for this group. It is assumed that 90% of those with low income can pass the assets test.

### 2. Persons with AIDS

Persons with AIDS were divided into those diagnosed with AIDS in 1991 and those diagnosed earlier. As for persons with HIV infection, 77% of the persons with AIDS are estimated to have been in the labor force. Yelin et al (1991) estimates that about 25% quit work by the middle of the first year and 50% quit work after the first year. The 1989 CPS estimates that 55% of working males would have been eligible for COBRA. As discussed in the section on persons with HIV infection, 18% are assumed to have incomes below poverty level.

## B. Costs

HIAA conducts an annual study of employer sponsored health insurance (Gabel et al 1990). Premiums for single persons for 1989 were $119 per month. With a 12% annual inflation and adding 2% administrative fee, premiums would be $1827 for 1991. The average deductible was $200 per person and average maximum cost sharing was $1000. If Medicaid pays the COBRA premiums and the cost sharing for low income persons, total costs would be $3027 per person, or a total of $24 million.

Some of these persons would have been on Medicaid but now most of their costs will be paid by their employers' health plan instead of Medicaid. Most of the low income population would be eligible for Medicaid through SSI or the state medically needy programs. It is estimated that 80% of these low income persons would have been on Medicaid.

C. Equitable treatment for all SSDI beneficiaries without Medicare

HCFA estimated that 805,000 SSDI beneficiaries are in the two year Medicare waiting period (HCFA 1991). According to 1989 data on SSDI beneficiaries, 45% receive SSDI payments which are less than the poverty level. BLS estimates that 55% of medium and large firms do not have long term disability insurance. Using these two figures gives an estimate that 25% of the SSDI population has income less than the poverty level. It is assumed that 40% of the SSDI beneficiaries are eligible for COBRA.

<u>Option 5</u>: Permit Social Security Disability Insurance (SSDI) beneficiaries to purchase Medicare during the two year waiting period

A. Number of persons affected

1. Persons with AIDS with incomes below poverty level

Federal legislation requires state Medicaid programs to pay for Medicare premiums, deductibles and coinsurance of aged and disabled Medicare beneficiaries with low income. By January 1, 1991 states had to pay for cost sharing of Medicare beneficiaries with income less than poverty level and assets less than twice the level allowed by SSI.

The Social Security actuaries estimated that 30,099 persons with

AIDS would be SSDI beneficiaries in July 1991 (Social Security 1990). HCFA estimates that 3100 of these persons are on Medicare in 1991 (HCFA Actuaries 1990).

Medicaid would save money (compared to current law) under this buy-in program because it is estimated that 80% of those bought in are already on Medicaid because they could meet the income and assets limits. Instead of paying for all of the Medicaid services, Medicaid would pay for only drugs which are not covered by Medicare and the Medicare cost sharing.

3. Persons with incomes above 100% of poverty level

Using 1989 CPS data, it is estimated that 49% of single males with incomes above the poverty level would have been eligible for COBRA or bought their own insurance. Since the Medicare premiums are so expensive and Medicare does not cover prescription drugs as most private plans do, it is assumed that anyone with private insurance would not purchase Medicare. It is also assumed that half of those without private insurance would purchase Medicare. But it is estimated that 60% of these persons would have qualified for Medicaid after six months of medical expenses.

B. Cost to Medicaid and Medicare

This option would make Medicare secondary to COBRA and other employer sponsored insurance so that employers could not discontinue insurance coverage to SSDI beneficiaries. Medicare Part A premiums for 1991 are $177 per month for those who do not receive Part A without a premium. Part B premiums which are $29.90 per month are multiplied by four because beneficiaries only pay one-fourth of the costs. Medicare deductibles are $628 for inpatient hospital and $100 for Part B medical services. Cost sharing is 20% of Part B services. Total charges for AIDS treatment are

$35,200, of which $4400 is for prescription drugs not covered by Medicare (Hellinger 1991). According to a hospital survey, inpatient hospital costs were about 80% of charges (Andrulis 1989). Medicare is assumed to pay costs, and therefore 80% of charges for inpatient hospital services. Since inpatient hospital costs are most of the costs for AIDS treatment, 80% of charges is used as the Medicare reimbursement. Total charges for non-AIDS medical treatment are $1,473 (80% of $1068 (Medicaid reimbursement) divided by 58% (percentage of charges that Medicaid pays)).

C. Equitable treatment for all SSDI beneficiaries

Data from the SSDI were used to calculate the costs of extending Medicare to all the SSDI at a premium of $3559 and other costsharing. An estimated 25% of the 805,000 SSDI beneficiaries in the waiting period for Medicare have incomes below the poverty and 40% of them are eligible for COBRA (See Option 4C). Premiums, deductibles ($100 for Part B and $628 for estimated 30% needing Part A), and coinsurance on Part B (about half the expenses) total $4650 per person. For the 75% with higher income, 1989 CPS data shows that 51% don't have private insurance. It is assumed that half the persons without private insurance will purchase Medicare.

<u>Option 6</u>: Allow all individuals with AIDS to purchase Medicare. For individuals with incomes below the federal poverty Medicaid would pay for the premiums, deductibles and coinsurance.

A. AIDS population

Medicaid would buy in the 40% of the AIDS population who are on Medicaid plus 20%. This is the group with incomes less than the poverty level.

The Yelin study (1991) showed that 25% of persons diagnosed with AIDS quit working during the first year and 50% during the second year. Firms with 20 or more employees are required to offer COBRA continuation insurance. The percentage of employees working in the larger firms with COBRA is 55%. Using the Yelin data and the 1989 CPS data, it is estimated that 51% of the AIDS population does not have private insurance. It is assumed that half of those without private insurance will choose to purchase Medicare.

Many of the persons with AIDS who purchase Medicare would have incurred enough medical expenses to qualify for Medicaid. It is assumed that 60% of them would have been on Medicaid after six months.

B. Costs to Medicaid and Medicare

The assumptions are the same as for Option 5.

Option 7: Eliminate the current two-year waiting period for SSDI beneficiaries with AIDS to receive Medicare

A. Persons affected

As in Option 2, 18% of those SSDI beneficiaries with AIDS but without Medicare currently would be bought in by Medicaid. The rest of the SSDI beneficiaries would automatically be enrolled in Medicare for Part A and could receive Part B services after paying the Part B premium. Since Part B premiums are so inexpensive, it is assumed that everyone will enroll. COBRA and other employer-sponsored insurance would be required to offer insurance to supplement Medicare for cost-sharing and services such as prescription drugs not covered by Medicare.

### B. Costs to Medicaid and Medicare

Part B premiums for 1991 are $29.90 per month, or $359 per year. Medicaid would pay for the premiums, deductibles, and coinsurance for the low income SSDI beneficiaries. But it is estimated that 80% of the persons bought in would have been on Medicaid.

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## Policy Options
## Estimates of Population Affected and Medical Costs

II. Mandating Medicaid for all persons with HIV or AIDs with incomes less than the poverty level
those with incomes 100% to 200% of poverty can buy Medicaid (Assets test applies, HIV+ presumed disabled)

| | Population or Costs | | Data Source and Assumption |
|---|---|---|---|
| A. 1991 HIV population | 1160000 | | MMWR Nov 30, 1990 CDC estimate for 7/91 |
| 1. HIV population with incomes < poverty | 336400 | 0.29 | 1989 Current Pop Survey (CPS)<br>Never Married Males 25-44 19%<br>32% IVDU and assume half are poor |
| a. Men HIV+ | 302760 | 0.90 | CDC estimate, MMWR Nov 30, 1990 |
| b. Women HIV+ | 33640 | 0.10 | CDC estimate, MMWR Nov 30, 1990 |
| 2. Already eligible for Medicaid | 66943 | | |
| a. Men already on Medicaid | 51469 | 0.17 | 1989 CPS low income single males 25-44 |
| b. Women already on Medicaid | 15474 | 0.46 | 1987 CPS low income women 19-44 |
| 3. Not on Medicaid | 269457 | | 1. minus 2. |
| a. Adding persons poor part of the year | 339516 | 1.26 | Thorpe and Siegel 1989 |
| b. With employer-sponsored insurance (ESI) | -23766 | 0.07 | 1989 CPS low income single males 25-44 |
| c. Some continue to buy individual insurance | -27161 | Half of .16 | 1989 CPS low income single males 25-44 |
| d. Some don't pass assets test | -33952 | 0.10 | |
| 4. Potentially eligible for Medicaid | 254637 | | |
| 5. Persons who seek treatment and apply for Medicaid | 63659 | 0.25 | 1/2 know HIV+, 1/2 of them treated |
| 6. Medicaid costs for HIV treatment ($1000's) | $175,317 | $2,754 | 60% @ $5603 for treatment<br>40% @ $581 monitoring and counseling<br>75% of charges, mostly drugs |
| 7. Medicaid costs for non-HIV treatmeant | $67,988 | $1,068 | Based in HCFA FY 1989 AFDC-type adults non-cash |
| 8. Total Medicaid costs ($1000's) | $243,305 | | 6. + 7. |

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## Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumption |
|---|---|---|---|
| II B. HIV population 100% to 200% of poverty | 185600 | 0.16 | 1990 CPS never married males 25-44 |
| 1. Those without employer-sponsored insurance | 124352 | 0.67 | 1990 CPS never married males 25-44 100% to 200% of poverty |
| 2. Those who know they have HIV infection | 31088 | 0.25 | |
| 3. Those who buy Medicaid | 15544 | 0.5 | |
| 4. Medicaid costs for HIV treatment ($1000's) | $42,808 | $2,754 | See A.6 |
| 5. Medicaid costs for non-HIV treatment | $16,601 | $1,068 | |
| 6. Premiums paid by those buying in | $7,772 | $500 | |
| 7. Net costs to Medicaid | $51,637 | | 3. + 4. - 5. |
| C. AIDS population with incomes < poverty | | | |
| 1991 AIDS population | 85000 | | Estimated from MMWR Nov 1990 for 7/91 |
| 1. Already on Medicaid | 34000 | 0.40 | HCFA Medicaid Actuaries |
| 2. New on Medicaid | 6800 | 0.20 | Raising average income limits from 80% to 100% of poverty |
| 3. Medicaid costs for AIDS treatment ($1000's) | $138,829 | $20,416 | 58% of $35,200 (HCFA 1990,Hellinger 1991) |
| 4. Medicaid costs for non-AIDS treatment | $7,262 | $1,068 | Based on FY 1989 Medicaid costs |
| 5. Would have been paid by Medicaid | $43,827 | 0.60 | 60% would have qualified for Medicaid after six months |
| 6. Costs to Medicaid ($1000's) | $102,264 | | |
| D. AIDS population 100% to 200% of poverty | | | |
| 1991 AIDS population | 85000 | | |
| 1. Incomes between 100% to 200% of poverty Without employer-sponsored insurance | 17000 | 0.20 | |
| 2. Those who buy Medicaid | 13600 | 0.80 | |
| 3. Medicaid costs for AIDS treatment ($1000's) | $277,658 | $20,416 | 58% of $35,200 (HCFA 1990,Hellinger 1991) |
| 4. Medicaid costs for non-AIDS treatment | $14,525 | $1,068 | Based on FY 1989 Medicaid costs |
| 5. Premiums paid by those buying in | $6,800 | $500 | |
| 6. Would have been paid by Medicaid | $85,615 | 0.60 | Would have qualified for Medicaid after six months |
| 7. Net Costs to Medicaid | $213,368 | | 3. + 4. + 5. - 6. |

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## Recommended Policy Options
## Estimates of Population Affected and Medical Costs

III. States have option to extend Medicaid for all persons with HIV or AIDs with incomes less than the poverty level meeting the SSI assets test

| | Population or Costs | | Data Source and Assumptions |
|---|---|---|---|
| A. 1991 HIV population in California and New York | 481400 | | MMWR Nov 30, 1990 CDC estimate for 7/91 and CDC state distribution of AIDS cases |
| 1. Low income HIV population | 139606 | 0.29 | 1989 Current Pop Survey (CPS)<br>Never Married Males 25-44 19%<br>32% IVDU and assume half are poor |
| a. Men HIV+ | 125645 | 0.90 | CDC estimate, MMWR Nov 30, 1990 |
| b. Women HIV+ | 13961 | 0.10 | CDC estimate, MMWR Nov 30, 1990 |
| 2. Already eligible for Medicaid | 32808 | | |
| a. Men already on Medicaid | 25129 | 0.20 | 1989 CPS low income single males 25-44<br>Add 20% |
| b. Women already on Medicaid | 7679 | 0.55 | 1987 CPS low income women 19-44<br>Add 20% |
| 3. Not on Medicaid | 106798 | | 1. minus 2. |
| a. Adding persons poor part of the year | 134565 | 1.26 | Thorpe and Siegel 1989 |
| b. Subtracting those with employer-sponsored insurance | -9420 | 0.07 | 1989 CPS low income single males 19-44 |
| c. Some continue to buy individual insurance | -10765 | Half of .16 | 1989 CPS low income single males 19-44 |
| d. Some don't pass assets test | -13457 | 0.10 | |
| e. Eligible for Medicaid under this option | 100923 | | |
| 4. Persons who seek treatment and apply for Medicaid | 25231 | 0.25 | 1/2 know HIV+, 1/2 of them treated |
| 5. Medicaid costs for HIV treatment ($1000's) | $65,298 | $2,588 | 60% @ $5603 for treatment<br>40% @ $581 monitoring and counseling<br>72% of charges, mostly drugs |
| 6. Medicaid costs for non-HIV treatment ($1000's) | $44,154 | $1,750 | Based on FY 1989 Medicaid costs NY, CA non-cash AFDC adults |
| 7. Total Medicaid costs ($1000's) | $109,452 | | |

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## Recommended Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumptions |
|---|---|---|---|
| B. 1991 AIDs population in New York | 18615 | | MMWR Nov 30, 1990 CDC estimate for 7/91 and CDC state distribution of AIDS cases |
| 1. Already on Medicaid | 10052 | 0.54 | Andrulis 1989 for the Northeast |
| 2. New on Medicaid | 1005 | 0.10 | Raising income limits in NY from 90% to 100% of poverty |
| 3. Charges for AIDS treatment ($1000's) | $35,376 | $35,200 | Based on Hellinger 1990 |
| 4. Medicaid costs of non-AIDS treatment | $2,209 | $2,198 | Based on FY 1989 NY Medicaid |
| 5. Costs to Medicaid ($1000's) | $30,510 | | Estimate of NY Medicaid payment 80% of charges, mostly inpatient |
| IV. Medicaid pays COBRA premiums for persons with incomes less than poverty level (Assets test applies, HIV+ presumed disabled, COBRA can be reinstated if lapsed) | | | |
| A. 1991 HIV population | 1160000 | | MMWR Nov 30, 1990 estimate for July 1991 |
| 1. Employed with HIV | 893200 | 0.77 | 1989 CPS single males 25-44, .89<br>32% IVDU and assume half employed |
| 2. Employed in firms 20+ and with group insurance | 491260 | 0.55 | 1989 CPS single males 25-44 |
| 3. Those in 2. who will quit working with COBRA | 49126 | 0.10 | Estimate from Yelin's graph |
| 4. Those in 3. with incomes below poverty | 8843 | 0.18 | 1989 Social Security Annual Supplement<br>1988 males SSDI payments <poverty, 33%<br>Bureau of Labor Stat 1990, 55% of employees don't have long term disability |
| 5. Those who pass assets test for Medicaid | 7959 | 0.90 | |
| 6. Medicaid pays for COBRA | $24,092 | | |
| a. COBRA premiums ($1000's) | $14,541 | $1,827 | 1989 HIAA Survey projected to 1991 at 102% of premium for first 18 months |
| b. Deductibles and coinsurance | $9,551 | $1,200 | |

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## Recommended Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumptions |
|---|---|---|---|
| B. 1991 AIDS population | 85000 | | |
| 1. Persons diagnosed in 1991 with AIDS | 63500 | | MMWR Nov 30, 1990 |
| a. In labor force during 1991 | 48895 | 0.77 | 1989 CPS single males 25-44, 89%<br>33% IVDU and assume 50% employed |
| b. Quit work in first year after diagnosis | 12224 | 0.25 | Estimate from Yelin's graph |
| c. Potential COBRA, those who quit work for firm 20+ with ESI | 6723 | 0.55 | 1989 CPS single males 25-44 |
| d. Of those in c, with incomes below poverty | 1210 | 0.18 | 1989 Social Security Annual Supplement<br>1988 males SSDI payments <poverty, 33%<br>Bureau of Labor Stat 1990, 55% of employees don't have long term disability |
| e. Medicaid pays for COBRA | $3,663 | | |
| 1. COBRA premiums ($1000's) | $2,211 | $1,827 | 1989 HIAA Survey, 102% |
| 2. Deductibles and coinsurance | $1,452 | $1,200 | |
| 2. AIDs population diagnosed before 1991 | 21500 | | MMWR Nov 30, 1990 |
| a. In labor force before diagnosis | 16555 | 0.77 | 1989 CPS single males 19-44, 89%<br>33% IVDU and assume half employed |
| b. Quit working after first year after diag | 8278 | 0.50 | Estimate from Yelin's graph |
| c. Potential COBRA, those who quit work for firm 20+ with ESI | 4553 | 0.55 | 1989 CPS single males 25-44 |
| d. Of those in c, with incomes below poverty | 820 | 0.18 | 1989 Social Security Annual Supplement<br>1988 males SSDI payments <poverty, 33%<br>Bureau of Labor Stat 1990, 55% of employees don't have long term disability |
| e. Medicaid pays for COBRA | $2,833 | | |
| 1. COBRA Premiums ($1000's) | $1,849 | $2,255 | 1989 HIAA Survey projected to 1991<br>at 102% of premium for first 18 months<br>at 150% for 19th thru 29th month |
| 2. Deductibles and coinsurance | $984 | $1,200 | |
| 3. Savings to Medicaid | | | |
| a. Would have been on Medicaid | 1624 | 0.80 | 80% of those who are poor |
| b. Costs of services now paid by COBRA ($1000's) | $34,890 | $21,484 | $1068 + 58% of $35,200 |
| c. Savings to Medicaid ($1000's) | $28,394 | | 3b. minus 2e. minus 1e. |

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## Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumption |
|---|---|---|---|
| V. SSDI beneficiaries able to purchase Medicare during 2 year waiting period<br>Medicaid pays costsharing for those with incomes below poverty level<br>(COBRA and ESI is primary to Medicare) | | | |
| A. SSDI beneficiaries with AIDS | 30099 | | Feb 1990 estimate from Social Security for July 1991 |
| 1. Some already on Medicare | 3100 | | HCFA Medicare Actuaries 1990 |
| B. Medicaid pays for low-income SSDI | | | |
| 1. Those with income below poverty | 4860 | 0.18 | 1989 Social Security Annual Supplement<br>1988 males SSDI payments <poverty, 33%<br>Bureau of Labor Stat 1990, 55% of employees don't have Long term disability |
| 2. Medicaid buys SSDI beneficiaries into Medicare | $25,112 | | |
| a. Medicare Premiums ($1000's) | $17,297 | $3,559 | 1991 Premiums for Part A and Part B |
| b. Medicare deductibles and coinsurance ($1000's | $7,815 | $1,608 | $728 deductibles, 20% coinsurance |
| 3. Savings to Medicaid | | | |
| a. Already on Medicaid | 3888 | 0.80 | |
| b. Costs of services now paid by Medicare ($1000 | $73,608 | $18,932 | $1068 + 58% of $30,800 |
| c. Savings to Medicaid ($1000's) | $48,496 | | 3.b - 2 |
| 4. Costs to Medicare | $101,797 | | |
| a. Costs for AIDS treatment ($1000's) | $119,750 | $24,640 | 80% of $30,800 |
| b. Costs for non-AIDS treatment ($1000's) | $7,159 | $1,473 | 80% of $1068/.58 (Medicaid costs) |
| c. Premiums, deductibles, coinsurance ($1000's) | ($25,112) | | |
| C. Those purchasing Medicare on their own | | | |
| 1. Not on Medicare or bought in by Medicaid | 22139 | | |
| 2. Those eligible for COBRA or purchasing their own insurance | 10848 | 0.49 | 1989 CPS single males 25-44, non-poor<br>Since Medicare premium is so high, assume no one with private ins will buy |
| 3. Potential New SSDI on Medicare | 11291 | | 1. minus 2. |

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## Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumption |
|---|---|---|---|
| 4. Those purchasing Medicare | 5646 | 0.50 | Half will purchase Medicare |
| a. Premiums paid by beneficiaries ($1000's) | $20,094 | $3,559 | 1991 Premiums for Part A and Part B |
| b. Deductibles and Coinsurance paid by beneficiaries ($1000's) | $9,079 | $1,608 | $728 deductibles, 20% coinsurance |
| 5. Savings to Medicaid | | | |
| a. Would have been on Medicaid | 3388 | 0.60 | Would have qualified as medically needy after six months |
| b. Costs of services now paid by Medicare Savings to Medicaid ($1000's) | $30,262 | $8,932 | Six months of 58% of $30,800 |
| 6. Costs to Medicare ($1000's) | $118,261 | | |
| a. Costs of AIDS treatment ($1000's) | $139,117 | $24,640 | 80% of $30,800 |
| b. Costs of non-HIV treatment ($1000's) | $8,317 | $1,473 | 80% of $1068/.58 (Medicaid costs) |
| c. Premiums, deductibles, coinsurance ($1000's) | ($29,173) | | |
| D. Total Savings to Medicaid | $78,758 | | B.3c + C.5.b |
| E. Total Costs to Medicare | $220,058 | | B.4 + C.6 |

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## Recommended Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumptions |
|---|---|---|---|
| VI. Allow all persons with AIDS to purchase Medicare Part A and B Medicaid buys in persons with incomes less than the poverty level | | | |
| A. 1991 AIDs population with incomes below poverty | | | |
| 1. Bought in by Medicaid | 40800 | | MMWR Nov 30, 1990 |
| a. Already on Medicaid | 34000 | 0.40 | HCFA Medicaid Actuaries<br>40% of 85,000 |
| b. Not on Medicaid but with incomes < poverty | 6800 | 0.20 | Raising average income limits from 80% of poverty to 100% |
| 2. Charges for non-AIDS medical ($1000's) | $75,128 | $1,841 | Based on FY 1989 Medicaid ($1068/.58) |
| 3. Charges for AIDS treatment | $1,256,640 | $30,800 | Hellinger 1991, without drugs |
| 4. Medicaid savings | $432,874 | | |
| a. Cost of purchasing Medicare | $210,814 | $5,167 | Premiums of $3559, coinsurance<br>Deductibles of $728 |
| b. Cost of Medicaid eligibles now paid by Medicare | $643,688 | $18,932 | 58% of 2. and 3. for those in 1.a |
| 5. Medicare costs | $854,600 | $20,946 | (80% of 2 + 3) - 4a |
| B. 1991 AIDs population with incomes above poverty | | | |
| 1. 1991 AIDS population with incomes > poverty | 44200 | | |
| a. Those without employer-sponsored insurance or other insurance | 22542 | 0.51 | 1989 CPS single males, non-poor |
| b. Those who will purchase Medicare | 11271 | 0.50 | |
| 2. Charges for non-AIDS treatment ($1000's) | $20,754 | $1,841 | Based on FY 1989 Medicaid ($1068/.58) |
| 3. Charges for AIDS treatment | $347,147 | $30,800 | Hellinger 1991, without drugs |
| 4. Costs to beneficiaries | $58,237 | $5,167 | Premiums of $3559, coinsurance<br>Deductibles of $728 |
| 5. Medicare costs | $236,084 | $20,946 | (80% of 2 + 3) - 4 |
| 6. Would have been on Medicaid | 6763 | 0.60 | 60% of B.1b after six months |
| 7. Cost of services now paid by Medicare Savings to Medicaid | $64,019 | $9,466 | Six months of (1068 + 58% of $30,800) |

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## Recommended Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumptions |
|---|---|---|---|
| D. Total Savings to Medicaid | $496,893 | | A.4 + B.7 |
| E. Net Costs to Medicare | $1,090,684 | | A.5 + B.5 |
| VII. Eliminate 24 month waiting period for SSDI beneficiaries to get Medicare (COBRA or ESI becomes secondary payer to Medicare) | | | |
| A. SSDI beneficiaries with AIDS | 30099 | | Feb 1990 estimate from Social Security for 1991 |
| 1. Some already on Medicare | 3100 | | HCFA Medicare Actuaries, Feb 1990 |
| B. Medicaid pays for low-income SSDI | | | |
| 1. Low income SSDI beneficiaries | 4860 | 0.18 | Social Security 1989 Bulletin, Annual Sup 1988 males SSDI payments <poverty, 33% Bureau of Labor Stat 1990, 55% of employees don't have long term disability |
| 2. Medicaid buys SSDI beneficiaries into Medicare | $11,129 | | |
| a. Medicare Premiums ($1000's) | $1,745 | $359 | 1991 Premium for Part B |
| b. Deductibles and Coinsurance ($1000's) | $9,385 | $1,931 | $728 deductibles, 20% coin |
| 3. Savings to Medicaid | | | |
| a. Poor already on Medicaid | 3888 | 0.8 | |
| b. Costs for services now paid by Medicare | $73,608 | $18,932 | $1068 + 58% of $30800 |
| c. Savings to Medicaid | $62,478 | | 3.b - 2. |
| 4. Medicare Costs ($1000's) | $115,780 | | |
| a. Costs of AIDS treatment ($1000's) | $119,750 | $24,640 | 80% of $30800 |
| b. Costs of non-AIDS treatment ($1000's) | $7,159 | $1,473 | 80% of $1068/.58 (Medicaid costs) |
| c. Premiums, deductibles, coinsurance ($1000's) | ($11,129) | | |
| C. Those purchasing Medicare on their own | | | |
| 1. Not on Medicare or bought in by Medicaid | 22139 | | |
| 2. Premiums paid by beneficiaries ($1000's) or employers | $7,943 | $359 | 1991 Premiums for Part B |

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# Recommended Policy Options
## Estimates of Population Affected and Medical Costs

| | Population or Costs | | Data Source and Assumptions |
|---|---|---|---|
| 3. Medicare deductibles and coinsurance paid by beneficiaries or employers ($1000's) | $35,600 | $1,608 | $728 deductibles 20% coinsurance |
| 4. Savings to Medicaid | | | |
| a. Would have been on Medicaid | 6775 | | 49% have insurance<br>Of the rest, 60% would have qualified for Medicaid after six months |
| b. Costs of services now paid by Medicare Savings to Medicaid ($1000's) | $64,132 | $9,466 | Six months of (1068 + 58% of $30800) |
| 5. Costs to Medicare ($1000's) | $542,516 | | |
| a. Costs for AIDS treatment ($1000's) | $545,505 | $24,640 | 80% of ($75,000-drugs) |
| b. Costs for non-AIDS treatment ($1000's) | $32,611 | $1,473 | 80% of $1068/.58 (Medicaid costs) |
| c. Premiums, deductibles, coinsurance ($1000's) | ($35,600) | | |
| D. Total Savings to Medicaid | $126,610 | | B.3c + C.4b |
| E. Total Costs to Medicare ($1000's) | $658,296 | | E.3. and D.5 |