



### Equitable Financing of AIDS and Other HIV-Related Health Care: Summary of an Invitational Meeting (1988)

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**EQUITABLE FINANCING OF AIDS AND OTHER HIV-RELATED HEALTH CARE**  
" **Summary of an Invitational Meeting**

**INSTITUTE OF MEDICINE**

**Division of Health Care Services**

**1988**

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This meeting summary was prepared by the staff of the Institute of Medicine's Division of Health Care Services, directed by Karl D. Yordy. Major themes are reported to provide highlights of the conference discussions; however, they do not represent policy statements by the Institute of Medicine.

The Institute of Medicine was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of appropriate professions in the examination of policy matters pertaining to the health of the public. In this, the Institute acts under both the Academy's 1863 Congressional charter responsibility to be an advisor to the federal government, and its own initiative in identifying issues of medical care, research and education.

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## **EQUITABLE FINANCING OF AIDS AND OTHER HIV-RELATED HEALTH CARE**

### **MEETING SUMMARY**

The rapid growth of AIDS cases represents not only human tragedy but a substantial added financial burden on a health care system in which rising expenditures are already a concern. The financing of care for those infected with the human immunodeficiency virus (HIV) raises public policy questions of great urgency.

What is an appropriate standard of care for those infected, and how much will it cost to provide it?

What is a fair distribution of the cost? What shares would be borne by patients and their families out-of-pocket, by private and public third-party payers, by state and local governments, by health care providers in the form of uncompensated care, and by private charity?

How can a fair distribution be achieved? What policies will foster an orderly division of responsibilities among payers and providers, private and public, so the needs of patients infected with HIV can be met without jeopardizing the welfare of others in the system?

Should such policies include special treatment of HIV patients on the grounds of special needs, or does special treatment constitute unfair discrimination against other equally deserving groups?

On February 10 and 11, 1988, at the request of the Health Care Financing Administration, a meeting was convened by the Institute of Medicine. The purpose was to bring together people from the private and public sectors to explore HIV-related financing issues informally. It was hoped that such discussion would increase

understanding and facilitate future collaboration in coping with this complex social problem.

Because the meeting was intended to be exploratory, no set of options or program of action was expected to result. However, the meeting's sponsors consider it worthwhile to issue a summary of the "sense of the meeting," committing to writing the areas of agreement and disagreement that emerged in the discussion.

### **HIV Financing in Perspective**

Meeting participants agreed on the need to place the financing of HIV-related care in the context of total expenditures on personal health care. However, the information with which to do this is limited.

Widespread HIV infection is so relatively new that its full natural history is not yet known. Surveillance data tracks only cases that meet official definition of AIDS; there is no firm data on the number and distribution of people who have other HIV-related conditions or who are seropositive (carry antibodies to HIV) but asymptomatic. Most information on the cost of care covers AIDS only and is based on studies that are small and geographically specific. These studies usually emphasize hospital costs, providing little or no information on out-of-hospital care and medications, and suffer from measurement problems even for the types of care included. Cost estimates do not include the value of the many hours of patient care provided by volunteers--care that would otherwise have to be provided by paid health care workers.

It was agreed that the early estimate of the lifetime cost per AIDS case (\$147,000) was too high. Current lifetime costs per case were believed to be in the range of \$60,000; for 1991, a reasonable range was \$80,000 to \$90,000, with the caveat that there is an

enormous margin for error in these figures. Estimates of costs as a percentage of total personal health care expenditures based on CDC epidemiological projections yield relatively small figures, about 0.3 percent in 1987, rising to 1.4 percent in 1991. But again, this includes only AIDS cases, not other HIV-related morbidity, and there is an enormous margin of error.

Meeting participants emphasized that a national average figure understates the impact of the epidemic, because the geographic concentration of cases has created very difficult adjustment problems in high incidence areas. Also, there are less quantifiable social costs of care: the cost of overcoming the reluctance of providers to care for HIV patients; the stress that dealing with a terminal, infectious disease places on providers who do accept the burden; the disproportionate impact of HIV infection on minorities; and the cost of finding ways to reach and handle difficult patients such as intravenous drug users.

Better information about the incidence and prevalence of HIV-related conditions and the cost of treatment was deemed essential. There was discussion of efforts by entities such as the National Center for Health Services Research, the Health Care Financing Administration, the Centers for Disease Control, philanthropic foundations, and private insurance organizations to develop more information. Private insurance representatives emphasized the difficulties in using claims data to ascertain cost of care, because they are collected for payment purposes, not for epidemiologic or cost-of-disease studies. Claims data may also be inaccurate in reporting AIDS diagnosis. Participants agreed that coordination of data collection efforts would be desirable. It was suggested that agreement be reached on a minimum set of cost data and that collection of such data be linked to trials of new drugs and of alternative service delivery arrangements. Those projects must collect utilization information anyway, and might provide a more

cost-effective approach to data collection than mounting separate cost studies.

### **The Role of Private Insurance**

American health care financing is based on private group health insurance for the employed and public sector coverage for the elderly and certain categories of the disabled and the poor, supplemented by a variety of other public and private payment mechanisms. However, gaps in the system leave an estimated 37 million Americans with no public or private insurance, and millions more with inadequate coverage for a serious illness such as AIDS. Moreover, there is concern that insurers will respond to the AIDS epidemic by looking for ways to reduce their exposure to risk: for example, by requiring blood tests of prospective subscribers and rejecting those who are seropositive, or by changing marketing strategies or withdrawing altogether from markets in high incidence areas, or by restructuring benefit packages to exclude or limit services for AIDS patients.

At this time, employees of large firms are the most likely to have adequate coverage of out-of-hospital care, prescription drugs, personal service care, and counseling--all benefits that are especially important to AIDS patients. Employees of smaller firms and people outside the labor force who maintain private insurance coverage usually face stricter limits on coverage and consequent higher out-of-pocket costs. These increase the likelihood that patients will exhaust their resources and require public assistance, and may also encourage the substitution of more expensive covered services for uncovered ones.

Even comprehensive employment-related coverage may be inadequate security for a person who becomes too sick to work. Traditionally, loss of employment often meant loss of group insurance at a time when a worker would find it difficult to afford or qualify medically for

an individual policy. Recent legislation guarantees workers who leave their jobs the opportunity to continue insurance at lower group rates for at least 18 months, but some workers may still have difficulty affording the premiums.

Meeting participants agreed that, as with costs, too little quantitative information is available about existing patterns of private insurance financing for HIV-related costs and the responses of insurers to these costs. However, the consensus of the meeting was that AIDS insurance claims have not been high enough thus far to trigger widespread concern or major changes in employment-related group health insurance plans for larger firms. The overall trend is for group plans to treat HIV-related illness as they do other serious health conditions. Subscribers are accepted for coverage without any special health assessment and services are provided as for other diseases. If anything, AIDS may be reinforcing a trend toward use of individualized case management for the seriously ill, with modification of standard coverage rules possible when it is in the interest of both patient and insurer (for example, to pay for home health care as a substitute for inpatient hospital care).

AIDS has had a more severe impact on the market for individual and small group policies. Some insurers have altered benefits, changed marketing strategies, or withdrawn from the individually underwritten market altogether. A particularly controversial issue has been the use of indicators of HIV risk status to exclude high risk persons from the common pool. In this market, health risk has traditionally been assessed on an individual basis. Companies argue that because insurance is about sharing risk, and not about funding actual or highly probable expenses, they should be able to use information about HIV risk status just as they use other health risk information to decide whether to insure and at what premium. To do otherwise would be unfair to other policyholders and would expose the insurer to the risk of bearing a disproportionate share of AIDS



expenditures. Critics argue that private health insurance is not just another commodity and that avoidance of all potential risks undermines the foundations of the private health insurance system. They contend that private insurance firms are part of a system whose goal is fulfillment of a societal obligation to guarantee Americans access to adequate health care, whatever their financial resources and whatever role their own behavior played in their illness. Screening for AIDS--or other health risks--undermines this system, the critics say.

States have taken various positions on the screening issue; some regulate the use of HIV tests, others are considering such regulation, and some states have passed legislation but rescinded it.

Efforts to avoid HIV-related risks were seen as relatively infrequent in group insurance, and thus not affecting the majority of the privately insured. But some participants were concerned about the instances that do occur, on the grounds that they will become more common in the future as claims rise. They were also concerned that employers, especially those who self-insure, would have an incentive to screen out seropositive job applicants to control future fringe benefit costs (an action that would raise legal issues of employment discrimination that have not yet been resolved). There was considerable discussion of the effect of the Federal Employment and Retirement Income Security Act (ERISA) in limiting the ability of states to regulate the behavior of self-insuring employers, who now constitute more than 50 percent of the health insurance market.

Participants recognized that even if there is no erosion in coverage for those at risk for HIV-related disease, there are many who already lack access to adequate private coverage. The HIV epidemic has brought new urgency to the long-standing problem of securing access to health care for the uninsured.

State-sponsored risk pools for high risk individuals were discussed as funding mechanisms for AIDS patients. Such pools offer basic insurance to people who are otherwise uninsurable, spreading the cost over all insurers, with or without state subsidization. So far, enrollment in pools has been limited by their low availability, high premium costs, and lack of sufficiently broad sources of financing. ERISA limits a state's ability to require participation in such pools by employers who self-insure. Participants discussed the possibility of modifying ERISA to facilitate the development of risk pools. Methods of financing risk pools that are compatible with existing law, such as broad-based state taxes, were also discussed.

### **The Role of Medicaid**

As a major source of care for the low-income uninsured, Medicaid plays a significant role in financing HIV-related care. Although information is limited, the consensus is that Medicaid's share of expenditure is increasing.

At the meeting, there was a consensus that the AIDS epidemic has highlighted, once again, long-standing and well-known problems in the structure of Medicaid. These problems include eligibility, service coverage, payment rates, and the impact of rising costs on state budgets.

To qualify for Medicaid, a person must meet both categorical and financial requirements. The income and asset limits vary across states but are low enough so that the applicant must be impoverished. Certain services must be covered by all states, while other services are optional. As a result, service coverage also varies across states. In many states Medicaid coverage of home and community-based care, supportive social services, counseling, and personal service care is limited, making it difficult to finance appropriate care for AIDS patients. However, states can apply for

special waivers (Section 2176 Home and Community-Based Waiver) and design HIV-specific programs if they believe that program alterations could provide more appropriate care at the same or lower cost. New Jersey, New Mexico, North Carolina, Illinois, Ohio, and Hawaii have such programs and other states, including California, are in the process of introducing them. Furthermore, there are other options under Medicaid, such as hospice care, case management programs, incentive payments for heavy-use patients that could be implemented to better serve persons with AIDS.

Providers have long complained that Medicaid does not pay the full cost of care. This situation may be more serious for HIV patients if they are more expensive to treat. Inadequate payment results in restricted access to services for patients and a higher burden in uncompensated care for providers. This has been of particular importance to public hospitals and inner-city teaching hospitals, which bear a disproportionate share of the burden of care for the poor.

Variations across states in program eligibility, service coverage, and payment levels raise equity issues for beneficiaries and providers. On the other hand, even with greater federal matching rates, poor states do not have the resources to provide the coverage that wealthier states may be able to afford. Moreover, the geographic distribution of those unable to provide for their own health needs is far from even.

Those infected by HIV are especially concentrated geographically. The impact on the Medicaid program in the states of highest incidence has been severe, creating dilemmas of resource allocation between the needs of those with HIV infection and the needs of the traditional Medicaid clients. Some discussants questioned whether Medicaid was an appropriate vehicle for financing HIV-related care, given the uneven incidence of the disease and their belief that many

patients had migrated to high incidence areas in search of a particular life-style before becoming infected, or in search of quality health care after being diagnosed. The concentration of incidence is clear, the extent of net migration at the current time or in the future is not clear. There is some recent evidence of migration of people at high risk or already infected with HIV from high incidence to low incidence areas.

### **The Role of Medicare**

So far, Medicare plays a small role in financing HIV-related care, because of the incidence of infection is very low in the elderly, and patients who are too sick to work rarely live out the waiting period for qualification on disability grounds.<sup>1/</sup> This situation could change if new treatments such as AZT prolong life or if an increasing prevalence of disease occurs among those near or over 65 years of age.

It could also change if the waiting period is eliminated for AIDS patients or for all the permanently disabled. Meeting participants discussed the fact that Medicare is a national program and would therefore have certain advantages over Medicaid in spreading the burden of the disease on a broader basis and achieving similar treatment of AIDS patients wherever they are. On the other hand, eliminating the waiting period only for AIDS patients would be expensive and would raise serious questions of fairness to those suffering from other disabling conditions; the costs of eliminating the waiting period for all the permanently disabled would be very high indeed.

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<sup>1/</sup> Five months of eligibility are required for disability income and 24 additional months for Medicare eligibility.

Moreover, Medicare emphasizes medical care for acute episodes of illness and requires out-of-pocket payments; thus it would still leave many of the costs of HIV-related care uncovered.

### **The Role of State and Local Government and Private Charitable and Voluntary Organizations**

The existing financing system leaves a considerable role for state and local governments in assisting those with no other resources. Public hospitals, especially, depend on local government financing and in high incidence areas have been hard hit by the cost of care for indigent AIDS patients. Meeting participants discussed the great strain that HIV is putting on state and local governments, certain private hospitals, and charitable and volunteer organizations in areas of high incidence.

### **Conclusions**

There was agreement that people with HIV-related conditions should be able to receive appropriate care and that somehow the financing should be available to make this possible.

There was agreement that "appropriate" care does not mean "unlimited," and that it is important to encourage the development of a cost-effective standard of care, using case management as a tool and emphasizing out-of-hospital care.

There was agreement that radical restructuring of the health care financing system as a whole, or even of individual parts of it such as Medicaid and Medicare, is unlikely to be feasible in the immediate future, therefore, it is necessary to look for methods of adapting the existing system in incremental ways to meet the AIDS challenge.

There was agreement that the financing of care for HIV-related

conditions is a responsibility to be shared by the public and private sector.

In discussing the division of responsibility, participants distinguished between people in the work force, with reasonable financial resources, and those out of the work force and/or with extremely limited resources (for example, most intravenous drug abusers). For the first group, most meeting participants considered it worthwhile to explore possibilities for increasing the availability of affordable coverage and maintaining private coverage throughout the duration of illness. The range of possibilities discussed included public subsidies for private insurance premiums, mandated employer-provided coverage, risk pools, and changes in public programs that would allow them to function as "stop-loss" or "catastrophic" coverage for the privately insured.

State-sponsored risk pools received the most attention. High premium cost, ERISA regulations, and the incentives for employers to cease providing benefits and consumers to wait until they are at high risk to purchase insurance were recognized as major obstacles to be overcome in the development of risk pools as a solution to the problems of the high risk uninsured.

Meeting participants agreed that the care of those out of the work force is almost inevitably a public responsibility. For this group, the challenge is to explore possibilities for financing needed care without straining existing public programs too far. Possibilities discussed included increased use of Medicaid waivers, other options such as hospice care and case management programs, elimination of the Medicare waiting period, and special "impact grants" to state Medicaid programs or directly to state and local governments in areas of high incidence. Public support for volunteer and other private efforts was seen as important.

**There was agreement that, although there is a special stigma attached to HIV-related illness, the physical suffering and financial burdens are not unique; they are experienced by many of those who suffer from other serious health conditions. Therefore, fairness across diseases is an important consideration in the development of policies for the financing of HIV-related care.**

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