Making Fair Decisions About Financing Care for Persons with AIDS

WILLIAM L. ROPER, MD
WILLIAM WINKENWERDER, MD

Dr. Roper is Administrator of the Health Care Financing Administration and Dr. Winkenwerder is Special Assistant to the Administrator. John Kostas, Office of Communications, made substantive contributions to the paper.

Tearsheet requests to Mr. Kostas, Office of Communications, Health Care Financing Administration, Rm. 305H, Hubert Humphrey Bldg., 200 Independence Ave. SW, Washington, DC 20201.

Synopsis

An estimated 40 percent of the nation's 55,000 persons with acquired immunodeficiency syndrome (AIDS) have received care under the Medicaid Program, which is administered by the Health Care Financing Administration (HCFA) and funded jointly by the Federal Government and the States. In fiscal year 1988, Medicaid will spend between $700 and $750 million for AIDS care and treatment. Medicaid spending on AIDS is likely to reach $2.4 billion by fiscal year 1992, an estimate that does not include costs of treatment with zidovudine (AZT).

Four policy principles are proposed for meeting this new cost burden in a way that is fair, responsive, efficient, and in harmony with our current joint public-private system of health care financing.

The four guidelines are to (a) treat AIDS as any other serious disease, without the creation of a disease-specific entitlement program; (b) bring AIDS treatment financing into the mainstream of the health care financing system, making it a shared responsibility and promoting initiatives such as high-risk insurance pools: (c) give States the flexibility to meet local needs, including Medicaid home care and community-based care services waivers; (d) encourage health care professionals to meet their obligation to care for AIDS patients.

AN ESTIMATED 40 PERCENT of the nation's 55,000 persons with acquired immunodeficiency syndrome (AIDS) have received care under the Medicaid Program, which is administered by the Health Care Financing Administration (HCFA) and funded jointly by the Federal Government (55 percent) and the States (45 percent). Although the 40 percent figure is a national average, the proportion of AIDS patients served by Medicaid is much higher in some areas of the United States, such as New York and New Jersey, where it may reach 65 to 70 percent.

Most AIDS patients become eligible for Medicaid by meeting the disability requirement under the Supplemental Security Income (SSI) Program, which provides benefits to disabled persons with low incomes and few or no assets. Patients with AIDS not qualifying for SSI may still receive Medicaid as "medically needy" persons in 1 of the 36 States that have such programs, or by qualifying for Aid to Families with Dependent Children (AFDC).

In fiscal year 1988, Medicaid will spend between $700 and $750 million for AIDS care and treatment, including the costs of zidovudine (AZT). This sum is about 25 percent of the current overall medical costs for AIDS. By contrast, Medicare pays for less than 1 percent of the total cost. AIDS patients are eligible for Medicare only if they are 65 years of age or older or they survive a 24-month waiting period after becoming disabled and receiving Social Security disability benefits, neither circumstance being very likely.

Future Costs of AIDS

HCFA now estimates that Medicaid spending on AIDS is likely to reach $2.4 billion by fiscal year 1992. This figure does not include the costs of providing AZT, which is estimated to be $120 million in 1988 and obviously would be far higher by 1992.

Those figures, while considerable, could be conservative. Future costs are difficult to predict and depend largely on emerging therapies, changing survival rates, and future epidemiologic trends, especially the spread of AIDS among intravenous drug abusers. Some studies now raise the question

of whether the numbers of inner city minorities and children being infected are far greater than was first anticipated.

Even so, a healthy perspective is important in ascertaining the true financial impact of AIDS care. Under current projections, AIDS spending will still be only 3 percent of the Medicaid budget by fiscal year 1992. Under a gradually worsening scenario, that proportion would steadily increase during the decade of the 90s, but would remain a relative fraction of Medicaid costs, reaching perhaps 6 percent. Because AIDS is disproportionate in its impact on the Medicaid Program, overall AIDS medical care spending will have somewhat less impact on total national health expenditures.

Despite improved therapies, AIDS will certainly continue to be a devastating illness for those who contract it, prompting not only continued research and public education efforts, but soul-searching questions about public policy and individual behavior as well. AIDS will also continue to pose significant problems in terms of financial and human resources for particular areas of the country. But despite these difficulties, there is simply no evidence that the cost of AIDS care will cause our health care system to collapse.

Allaying the fears of doomsayers, however, is not a sufficient response to the challenge of financing the care of AIDS victims. This challenge must be addressed directly, and it should be taken up by both sectors of our health care system, public and private.

Before the passage of the Medicare and Medicaid Programs in 1965, the Federal Government spent very little on health care. Today, just two decades later, it commits nearly 10 cents of every dollar it spends to assure access to quality care for its citizens. The lion's share of these expenditures is dispensed through the Medicare and Medicaid Programs, whose combined outlays exceeded $126 billion in 1987. This sort of investment commits the nation's taxpayers to a serious role in funding the medical care of AIDS patients.

Although government's role in health care has grown, patients themselves and their private health insurers still pay about 60 percent of all health care costs. The private sector, therefore, is still a major pillar in our current health care system. The question, then, should be not so much whether the Federal Government will pay for AIDS care: it will pay for the care of all those who qualify for Federal programs, as defined by the Congress and the American people. The more important question rather is how we can all share this new cost burden in a way that is fair, responsive, efficient, and in harmony with our current private-public system of health care financing.

Proposed Policy Guidelines

We would like to propose four principles to help assure that goal:

1. Treat AIDS as any other serious disease. Legislation was introduced in Congress in 1987 to eliminate the 24-month disability waiting period needed to qualify for Medicare coverage, solely for persons with AIDS. HCFA estimates this could cost Medicare an additional $2.1 to $8.3 billion over the next 5 years. If this waiting period were eliminated for all disabled persons, the estimated additional cost would be $35 billion to $42 billion over the next 5 years.

HCFA opposes this legislation because it treats AIDS differently from other devastating illnesses and because it advances a disease-specific view of Medicare. Our view is that persons with AIDS should be treated like all who have terminal illnesses or are disabled, that is, with a similar 24-month waiting period after disability has been determined. If changes are made to shorten the waiting period, they should apply equally to all persons.

Medicine, like justice, should be blind to discriminatory factors in treating AIDS victims. Decisions must be based on the general nature of the illness or disability, rather than on the specific characteristics of any given disease. Yet the restraint imposed by an equal treatment standard has other implications as well.

It would be an unwise precedent to single out AIDS from the many other diseases which medical science has yet to overcome. As a matter of equity, HCFA believes that payment for AIDS should not be through any disease-specific entitlement program. The victims of many other chronic, crippling, or fatal diseases, together with their families, their physicians, and their well-wishers would like to have a special program established for them. Clearly, however, the establishment of a disease-specific program for any single group would create intolerable political pressures and divide the medical community into special interest groups at the expense of the general welfare.

2. Make AIDS care and treatment a shared responsibility. Rather than establishing separate payment methods to fund AIDS treatment, we should

instead bring AIDS into the mainstream of the health care financing system. HCFA believes that AIDS financing must be a responsibility shared between the public and private sectors and that all parties must contribute—individuals, private insurers, local communities, States, and the Federal Government.

In the private sector, the responsibility must be shouldered not only by group insurers, but also by those offering individual coverage, self-insured employers, charities, churches, and private foundations. A shared commitment is the greatest incentive we have to broaden support for AIDS treatment and research. One avenue that must be pursued is the provision of private insurance to those with high-risk conditions (not simply AIDS, but other diseases as well) who are medically uninsurable. Several States have already explored the development of high-risk pools that are supported through a combination of private and public sector funds.

Within government, financial support is needed at all levels, including local communities, State governments, and the Federal Government. HCFA is working closely with the Assistant Secretary for Health, the Surgeon General, the Social Security Administration, and others to ensure maximum coordination on AIDS issues. We also have a HCFA-wide working group that meets regularly to analyze and make recommendations about issues, policies, and new information. In addition, AIDS coordinators have been designated in all 10 HCFA regional offices to deal with issues on the local level.

3. Give States the flexibility to meet local needs. Services to Medicaid recipients, including persons with AIDS, now vary from State to State. Coverage is required for certain services, such as inpatient and outpatient hospital care and physician services. In addition, States may provide prescribed drugs, intermediate care, hospice care, case-management, and private duty nursing. Currently, only five States do not cover treatment with AZT, although one of these, Florida, does have a considerable number of AIDS patients.

Several States have begun to address the need for providing cost-effective care for Medicaid-eligible AIDS patients. It is important that States be encouraged to do so in a way that meets local needs within local resources. The makeup of the AIDS population varies considerably in different communities, based on such epidemiologic factors as the incidence of intravenous drug abuse, and such marked variations have a serious impact on the methods that different States must adopt for delivering and financing care for AIDS victims.

To provide the States with maximum flexibility, HCFA has already approved Medicaid home and community-based care services waivers for patients with AIDS in New Jersey, New Mexico, Ohio, and Hawaii. North Carolina and Illinois have indicated they are serving AIDS patients under waivers targeted to disabled populations, and several States have added case-management services targeted to AIDS patients. Applications for waivers from several other States are under review.

The significance of local control can be more clearly drawn by citing another public policy debate. Lawmakers in the State of Oregon recently weighed whether the State should use its limited resources to pay for organ transplants for about 30 persons or whether services should be provided for 1,500 poor pregnant women in need of prenatal care.

The State ultimately decided to provide prenatal care and to limit certain transplant operations. Regardless of how one views this decision, Oregon should be commended for directly addressing a very complicated and emotional issue. Our society must make difficult decisions on how to allocate finite resources, and States must be a part of this process. Simply because a problem is tough does not necessarily mean it is a Federal problem. In fact, governments at the State and local levels are often better equipped to make certain difficult choices.

4. Meet our obligation as health care professionals to care for AIDS patients. Care must never be denied to a person who has contracted AIDS or human immunovirus (HIV) infection. Broad access to care can be ensured only if all health facilities and all medical professionals stand ready to provide care. It is important that leaders in the medical and health professions speak out to their constituents about this issue, as have Surgeon General Dr. C. Everett Koop and the American Medical Association.

These, then, are the four principles that HCFA believes are important as guidelines in formulating an equitable policy for financing the care and treatment of those with AIDS or illnesses related to the HIV virus. From such general guidelines can come more specific approaches within both the private and public sectors that build on the strengths of our current health care system. These principles are offered not only to meet the pressing

public health problem of AIDS, but to do so in a way that fairly recognizes the many competing priorities in health care and the host of public and private resources that can be mobilized to meet the challenge that lies ahead. We in HCFA look forward to meeting our responsibilities and to working together with all others who are committed to an equitable response to AIDS.