Medicaid and the HIV/AIDS Epidemic in the United States

T. Randolph Graydon

This article explores the impact on Medicaid costs of new AIDS treatments and other technology advances. Available data on total projected Medicaid expenditures and actual expenditures for antiretroviral drugs are presented. The article further addresses Medicaid State agencies' efforts to assure that Medicaid-eligible persons with AIDS receive quality care, and reviews recent studies on utilization of services among persons with HIV disease.

INTRODUCTION

Since the beginning of the acquired immunodeficiency syndrome (AIDS) epidemic in the early 1980s through December 1999, 733,374 cases of AIDS have been reported to the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 1999). Providing for the care for persons living with AIDS presents a remarkable burden to both public and private insurers. Holtgrave and Pinkerton, 1997 estimated that lifetime costs for treatment per patient after the advent of protease inhibitors ranged from $71,143 to $424,763 with the difference primarily based on access to care and whether the real costs were discounted.

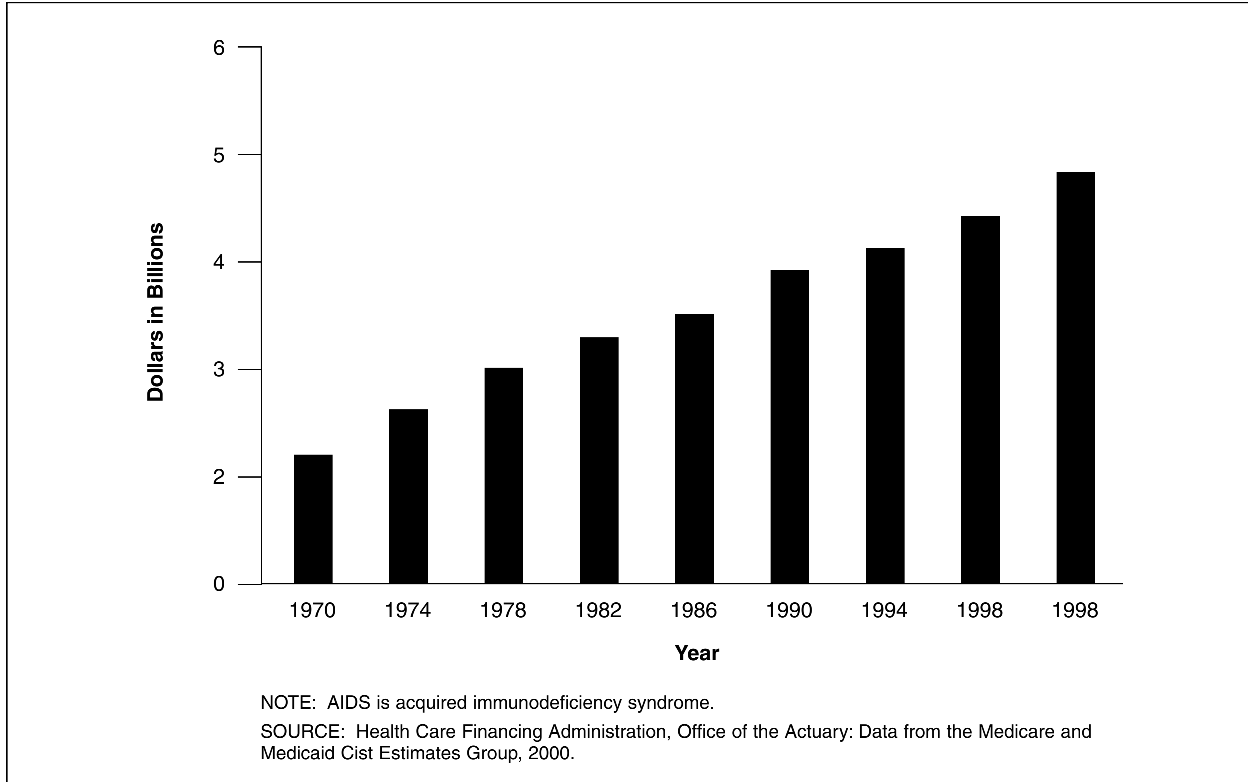
The author is with the Center for Medicaid and State Operations, Health Care Financing Administration (HCFA). The views expressed in this article are those of the author and do not necessarily reflect the views of HCFA.

HCFA'S ROLE IN FINANCING CARE

The Medicaid program is the largest payer in the United States for medical services provided to persons living with AIDS. HCFA estimates that Medicaid pays for the care of 50 percent of all persons living in the United States with AIDS and for 90 percent of the children living with AIDS. (Health Care Financing Administration, 2000a) Medicaid pays for medical and remedial services for individuals with low incomes who are either members of families with children, over the age of 65, disabled, or blind. Other optional categories of eligible persons may be covered at a State's choice (*Federal Register*, 1999). Most persons with AIDS are eligible for Medicaid because their disease has progressed to the point that they meet the Social Security Administration's definition of disability, e.g., the person is no longer able to participate in gainful activity due complications of the disease. Gainful activity is defined as being able to earn at least $700 per month.

HCFA's estimates indicate that the Medicaid program was paying for the care of 5,300 persons living with AIDS in 1986 (Health Care Financing Administration, 1990). Federal and State Medicaid expenditures were estimated in the same document to be $220 million dollars for Federal fiscal year (FFY) 1986. Today, HCFA estimates that the Medicaid program will pay for the services provided to 114,000 persons living

Figure 1
Projected Total State and Federal Medicaid AIDS Costs



NOTE: AIDS is acquired immunodeficiency syndrome.

SOURCE: Health Care Financing Administration, Office of the Actuary: Data from the Medicare and Medicaid Cist Estimates Group, 2000.

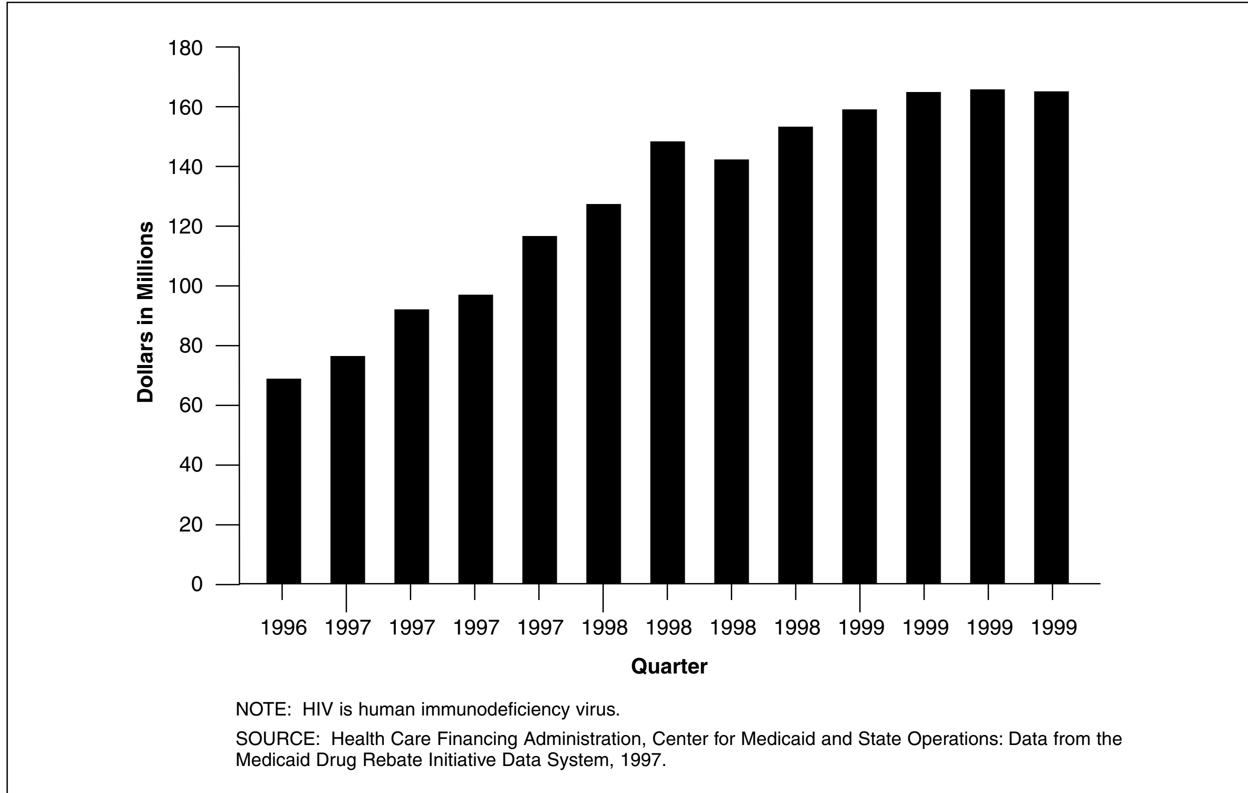
with AIDS in FFY 2000 at a cost of $4.1 billion (Health Care Financing Administration, 1997). Therefore, between 1986 and 2000, the number of persons living with AIDS who are Medicaid beneficiaries has increased by about 215 percent; Medicaid expenditures have increased over 1,860 percent.

HCFA's Office of the Actuary predicts continued growth in Medicaid expenditures for persons living with AIDS. Figure 1 shows the steady increase in the total amount of projected Federal and State Medicaid expenditures for persons living with AIDS between FFY 1994 and 2002 (Health Care Financing Administration, 1997). The remarkable difference in growth in case load to growth in expenditures can be attributed partly to the advances in treatment and monitoring of human immunodeficiency virus (HIV) disease, most significantly, the Food and Drug Administration's (FDA) approval of the first of a then new class of drugs to treat HIV, protease inhibitors (PIs). The FDA approved the first protease inhibitor, Invirase, in December 1995. Since that time, a total of seven protease inhibitors have been approved along with three drugs in a new class of drugs called non-nucleoside reverse transcriptase inhibitors (NNRTI), which are sometimes used in combination with protease inhibitors or in place of them (Department of Health and Human Services/Henry J. Kaiser Family Foundation, 2000b).

Medicaid Coverage of Prescription Drugs

Although coverage of prescription drugs is not required, all States and the District of Columbia currently cover prescription drugs

Figure 2
Medicaid Expenditures for HIV Antiretrovirol Drugs



NOTE: HIV is human immunodeficiency virus.

SOURCE: Health Care Financing Administration, Center for Medicaid and State Operations: Data from the Medicaid Drug Rebate Initiative Data System, 1997.

under their Medicaid programs. However, some States do limit the number of prescription drugs that may be filled in a month and/or the number of refills permitted.

HCFA gave clear direction to State Medicaid agencies in a letter dated June 19, 1996, that States which elect to cover prescription drugs are required to cover all the FDA-approved PIs, and other FDA-approved drugs. Most combination antiretroviral regimens cost between $12,000 and $15,000 per patient per year, however, with many patients being placed on regimens of four and five drugs, the cost can grow significantly. Figure 2 shows the increase in Medicaid expenditures for HIV antiretroviral drugs from the last quarter of FY 1996 (July, August, and September) and the last quarter of FY 1999 (Health Care Financing Administration, 2000b).

QUALITY OF CARE PROVIDED MEDICAID BENEFICIARIES

States have made efforts to improve the quality of care for Medicaid beneficiaries with AIDS by widely distributing treatment guidelines provided by HCFA, and encouraging providers to take advantage of treatment resources provided on the internet. Some States have been aggressive in developing Medicaid waivers that provide services essential to the improvement of the care and quality of life for persons with AIDS. Currently 16 States have home and community-based services waivers that provide services specifically to persons with AIDS; these services are necessary to avoid or minimize costly hospital or nursing facility stays. Services provided may include case management, homemaker

services, home health care services, adult day health care, basic living skills and vocational training, and respite care.

Despite States' efforts to improve the quality of care and the broad package of services that are available to Medicaid beneficiaries with AIDS, early studies indicated that the quality of care being provided to Medicaid beneficiaries is less than optimal. The HIV Cost and Services Utilization Study, a national sample representative of the adult HIV-infected population receiving regular medical care in the 48 contiguous States from early 1996 to early 1998, found disparities between the quality of care provided to Medicaid beneficiaries and persons having other types of insurance coverage. The study measured quality using six measures: (1) fewer than two office or outpatient visits in 6 months, (2) emergency department visit without an associated hospitalization in 6 months, (3) hospitalization in 6 months, (4) did not receive PI or NNRTI therapy by December 31, 1996 if recommendations for treatment were met, (5) never received antiretroviral treatment, and (6) did not receive prophylaxis in the last 6 months for pneumocystis carinii, a type of pneumonia to which persons with AIDS are susceptible, if CD4 count was less than 200. (CD4 count is a measure of the health of the immune system. Mean levels in healthy individuals are usually between 800-1050.) Data gathered for the base line of the study showed that Medicaid beneficiaries faired worse on all six measures than did persons with private insurance, and worse on four of the measures than Medicare beneficiaries. Not surprisingly, Medicare beneficiaries had more emergency department visits and more hospitalizations. Overall, the only group that received poorer care than Medicaid beneficiaries were those without any insurance.

However, States' efforts to improve quality are showing results. Encouragingly in the followup interviews conducted in 1998, Medicaid showed improvement in the quality of care provided as measured in all six of the indicators of quality of care. Most notable was the increase in the use of PIs and NNRTIs which rose from 53 percent to 81 percent (Shapiro et al., 1999).

CHANGING DEMOGRAPHICS OF HIV DISEASE

Over time, the demographic characteristics of the HIV epidemic have changed, as has the natural history of HIV infection among persons receiving appropriate treatment. HIV/AIDS in the developed world has been transformed from a rapidly fatal infection diagnosed at a late stage of the disease to a chronic progressive illness that affords many years of productive life under complex treatment regimens (Department of Health and Human Services, 2000a). With this change in the natural history of the disease, the categorical nature of the Medicaid program has rendered many persons receiving proper treatment unable to qualify for Medicaid because they don't meet the definition of disability. The majority of these individuals who are uninsured receive their care through the Ryan White CARE Act programs which base eligibility on HIV positive status. As persons with HIV disease live longer, the demands on Ryan White funding have increased.

Medicaid's Response to the Changing Demographics

To address the issue of the Medicaid program not being able to serve persons with chronic manageable diseases, a number of actions have taken place at both the Federal and State levels.

- The State of Maine has submitted and gained HCFA approval for a demonstration waiver that permits Medicaid coverage to be extended to persons with HIV disease prior to becoming disabled. The theory of the demonstration is that early treatment will delay the onset of AIDS and thus offset the cost of the early treatment making the demonstration budget neutral to the Medicaid program. A number of other States are also pursuing similar waiver authority. Early treatment of HIV disease is currently recommended by the DHHS/Kaiser Family Foundation sponsored Panel on Clinical Practices for Treatment of HIV Disease (Department of Health and Human Services, 2000b).
- In addition, Under the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999, the Congress has provided grant money for HCFA to award States to evaluate the impact of early interventions in HIV and other diseases. At the time of this writing, one State has been approved for a grant to provide coverage for persons with HIV disease that do not meet the Social Security Administrations' definition of disability. HCFA plans to issue a second request for proposals prior to the end of calendar year 2000. TWWIIA has also increased the income levels States may elect to allow persons with disabilities to return to work without losing their Medicaid coverage.

HCFA'S MATERNAL HIV CONSUMER INFORMATION PROJECT

Finally, the Medicaid program has also played a strong role in preventing mother-to-child transmission of HIV disease. After the National Institutes of Health's Clinical trial 076 established that mother-to-child transmission of HIV could be reduced by 75 percent using a regimen of zidovudine (commonly called AZT), HCFA launched a pilot project in four States to inform women of child-bearing age of the importance of pregnant women being tested for HIV. The campaign is known as the Maternal HIV Consumer Information Program. It also stresses that Medicaid pays for HIV counseling and testing for Medicaid-eligible pregnant women. The project brings together the Medicaid Agency, the State Health Department, and other relevant community resources. HCFA provides informational brochures about prevention of mother-to-child HIV transmission as well as a video at no charge for the State's campaign. As of August 2000, HCFA had met its National Performance Review Goal to have a consumer information campaign on mother-to-child HIV transmission in all 50 States and Puerto Rico. All States do not use the HCFA materials, but all States do have a campaign in place. HCFA now offers campaign print materials in 14 different languages, and has in production a new video in Spanish and English with accompanying educational materials for physicians and their patients.

CONCLUSION

The Medicaid program is the largest payer of health care services for persons living with AIDS in the United States. Although questions have been raised about the quality of care being provided to Medicaid beneficiaries with HIV disease, more recent studies reflect a significant improvement in quality of care as measured by the indicators used in the study. State Medicaid agencies are working with HCFA to continue the trend in improving care to persons with HIV disease. HCFA will continue to work with States and other Federal agencies to improve the delivery of services to persons with HIV disease in the most effective manner. HCFA is also

working with States to implement new programs designed to address the chronic care needs of persons with AIDS who are benefiting from new, more effective treatment regimens.

HCFA has a particular interest in prevention of childhood AIDS, as the payer of care for 90 percent of the children with AIDS. With the majority of childhood AIDS due to mother-to-child HIV transmission, HCFA is taking a leadership role in prevention of childhood AIDS by establishing and promoting its Maternal HIV Consumer Information Program.

ACKNOWLEDGMENTS

The author is grateful for the assistance of numerous HCFA staff including: Kay Alexander for compiling the drug expenditure data for Figure 2, John Klemm and Wayne Ferguson for providing expenditure and enrollment projections, and Jeremy Silanskis for providing graphic support.

REFERENCES

Centers for Disease Control and Prevention: *HIV/AIDS Surveillance Report: U.S. HIV and AIDS Cases Reported Through December 1999.* Year-end Edition Vol. 11 No. 2. Centers for Disease Control and Prevention. Atlanta, GA. 1999.

Department of Health and Human Services, Office of the Secretary, Office of HIV Policy: *Strategic Framework for Enhancing the DHHS Response to HIV/AIDS in the United States.* In clearance for distribution. Washington, DC. September 2000a.

Department of Health and Human Services/ Henry J. Kaiser Family Foundation: *Clinical Practices for the Treatment of HIV Infection: Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents.* Washington DC. January 2000b.

Health Care Financing Administration, Office of the Actuary: *Projected Federal Medicare and Medicaid AIDS Costs FY 1994 - FY 2002.* Baltimore, MD. January 31, 1997.

Health Care Financing Administration, Office of the Actuary: *Estimated Medicaid and Medicare Cost of AIDS and Numbers of Covered Individuals FY 86 – FY 93.* Baltimore, MD. February 8, 1990.

Health Care Financing Administration, Center for Medicaid and State Operations: *FACT SHEET, Medicaid and Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) Infection.* Health Care Financing Administration, Baltimore, MD. April 2000a.

Health Care Financing Administration, Center for Medicaid and State Operations: Medicaid Drug Rebate Initiative Data Base. Health Care Financing Administration. Baltimore, MD. August 2000b.

Holtgrave, D.R., and Pinkerton, S.D.: Updates of Cost of Illness and Quality of Life Estimates for Use in Economic Evaluations of HIV Prevention Program. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 16 (1) 54-62. January 1997.

Federal Register: Grants to States for Medical Assistance Programs. *Federal Register* 42(430) to End, 196-212. October 1, 1999.

Shapiro, M.F., Morton, S.C., and McCaffrey, D.F., et. al.: Variations in the Care of HIV-Infected Adults in the United States. *Journal of the American Medical Society.* 281(24)2305-2315, June 23/30, 1999.

Reprint Requests: T. Randolph Graydon, Health Care Financing Administration, S2-14-26, 7500 Security Boulevard, Baltimore, MD 21244-1850. E-mail: rgraydon@hcfa.gov