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Issues - Medicaid Expansion [1]

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07/29/98 03:53:00 PM

Record Type: Record

To: Daniel C. Montoya, Todd A. Summers

cc:

Subject: Update on Medicaid Expansion in California

I just wanted to give you all a brief update on a meeting Fred Dillon (the Foundation's State Policy Director) and I attended yesterday with the California Department of Health Services (DHS) regarding Medicaid Expansion:

The meeting with DHS went very well. On our side were AIDS Healthcare Foundation, SFAF, AIDS Project Los Angeles, Project Inform, Jim Driscoll with Log Cabin Republicans and a couple of pharmaceutical reps. DHS Director Kim Belshe was there for the entire time, and was very engaged. Stan Rosenstein from Medi-Cal and Wayne Sauseda (and staff) from Office of AIDS were also there, as well as Jim Stratton (State Health Officer) and folks from the DHS legislative office.

In short, Kim agreed that the issue raised a number of important policy questions (ie. role of Medi-Cal in providing early care, definition of disability) as well as the obvious fiscal question of cost neutrality. Without saying so directly, Kim indicated that the Governor would likely veto AIDS Healthcare Foundation's bill that is now pending (introduced by Dion Aroner and Carole Migden), which would require the State of California to seek a waiver. The basis for the veto would essentially be that, because these questions had not yet been answered, it was premature. In addition, she said that Wilson would not want to commit a future Administration to such action. A number of folks, including AHF's lobbyist, are suggesting that AHF consider dropping the bill to avoid a second veto message (Wilson vetoed a similar Polanco bill last year) and as a show of good faith since the meeting ended on what all of us agree was a good note of cooperation and collaboration.

Regardless of a veto, however, Kim stated that she could and would commit this administration to working with outside groups -- including advocates, academics and foundations - to shape and complete some of the analysis that would answer the fiscal and policy questions she raised. This leg work could then be used by the new administration should it decide to pursue a waiver with HCFA.

As follow-up, the newly formed ad hoc California Medicaid Coalition is going to put together a short 3-5 page issue brief, which we will share with the state and foundations and other interested entities. The follow-up point people are Wayne Sauseda and Ceasar Portillo. The expectation is that Wayne would coordinate closely with Medi-Cal folks.

One not so positive note was that, when Kim Belshe asked the Medi-Cal

reps what their communications with HCFA have been on this issue, the Medi-Cal staff reported that HCFA "has been open to the idea if the state can achieve cost neutrality, but HCFA is skeptical that cost neutrality can be achieved." I will be following up with my contacts at HHS and HCFA to see if we can get a more positive message out.

HIV/AIDS 1115 Waiver Project

Mtg. w/ David Beier / OVP 8/15
Garnet Coleman, TX
King Hillier, TX

Summary: If Texas were to secure approval for an 1115 Medicaid Waiver to cover persons with HIV/AIDS to 200% of poverty, there would be an estimated 10,500 recipients in 1999. They would receive prescribed drug treatments and viral load testing, that in 1999 is projected to cost around \$9,800 per person. However, over a five year period, significant Medicaid cost savings are projected --- nearly \$74,000. When compared with the likely drug cost and testing outlays over five years of about \$53,000, the net savings per person would approach \$21,000. Program expenditures for drug therapies and viral load testing 1999 – 2003 are estimated to be \$578 million, of which \$218 million are local/state funds. The projected five year savings for all participants is \$230 million.

Research Highlights:

- TDH reports indicate that there were 4,887 persons with AIDS in Texas in 1996. Nearly 4,500 are estimated for 1997. This translates into about 24 persons per 100,000 population.
- No precise figures are available for people who have HIV but have yet to develop AIDS. Using projected seroprevalence rates for the U.S., one study projected that there were 650,000 to 900,000 persons infected with HIV in 1992 --- or 0.3% of U.S. residents.
- Using an overall seroprevalence rate applied to Texas population, nearly 57,000 are estimated to have HIV or HIV/AIDS.
- Assuming persons in the Texas Criminal Justice System are not eligible for the program, and a 70% participation rate, approximately 10,500 persons would be recipients in the proposed program. The participants include those not currently on Medicaid up to 200% of poverty. Based on an analysis of 1996-1997 merged data sets from the Current Population Survey, 29.3% of the overall potential pool are estimated to be not on Medicaid and at or below 200% of poverty.
- Drug therapies would include antiretrovirals (such as AZT), protease inhibitors (such as Crixivan), or some combination. Recent treatment protocols that include combination therapies, combined with viral load testing have proven effective. Research projections indicate that 70% of participants would use a triple drug therapy. An example: Retrovir, Epivir, and Norvir. Four viral load tests and four CD4 tests are assumed per recipient per year.
- Persons receiving the treatments would delay onset of disabling conditions, not enter the rolls via the SSI program --- and therefore not have Medicaid costs. Medicaid costs attributable to persons with HIV/AIDS are estimated to be over \$16,000 in 1999, an amount growing to nearly \$20,000 by 2003.
- Using a five year analysis, the program would not save money in the first 2 years of operation, but would hit break even during the third year, where by year-end there would be a positive savings. Over the five year period, nearly \$21,000 is expected in savings per person. Note that non-Medicaid benefits, such as SSI outlays of approximately \$6,000 per person per year, are not counted in the cost-benefit analysis.

Conclusion: Research indicates that implementation of an 1115 Waiver program in Texas Medicaid is a sound move.

**A new HIV benefit in the U.S. Medicaid system:
Health and federal fiscal implications**

12th World AIDS Conference
July 1, 1998

James G. Kahn*[@], Brian Haile*, Sophia W. Chang[†]

* Center for AIDS Prevention Studies, AIDS Research Institute, and
Institute for Health Policy Studies, University of California, San
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Background

- Advent of potent triple ARV therapy
- Formal treatment guidelines - ARVs recommended for very large group
- Funding crisis in AIDS Drug Assistance Program (uninsured HIV+ individuals)
- Many still have financial barriers to ARVs

Objective

- Assess the health and federal fiscal effects of expanding Medicaid to cover HIV care for those lacking financial access to HIV medications

Health effects: New AIDS diagnoses
Deaths
Years of life

Fiscal effects: Medical care spending
Income support for disabled
Budget neutrality

Methods

- **Spreadsheet model**

- HIV disease stages, clinical progression
- Federal costs: Medicaid, Medicare, AIDS Drug Assistance Program, SSDI/SSI
- 5 years, all of U.S.

- **Data inputs**

- **Clinical:**

- HIV natural history
 - Current use of ARVs
 - Clinical effects of ARV triple therapy

- **Costs:**

- costs of medical care and ARV therapy
 - enrollment in insurance, income programs

Methods (cont'd)

- **New Medicaid benefit**

Eligibility:

- CD4 < 500 or elevated viral load
- inadequate or absent medication coverage
- income < \$10,000 per year

Coverage:

- Limited: drugs and outpatient
- Full: drugs, outpatient, inpatient, etc.

assume 90% use ARV triple therapy

Initial HIV/AIDS Disease Distribution

	Number	Proportion aware of serostatus
Asymptomatic CD4 > 500	167,000	0.42
Asymptomatic CD4 < 500	167,000	0.45
Symptomatic	167,000	0.79
AIDS (1993 definition)	150,000	0.92
AIDS (1987 definition)	100,000	1.00
Total	750,000	0.70

Clinical effect of ARV triple therapy

Pre-AIDS to:

AIDS (6 viral load studies):	60% reduction
Death (1 clinical study):	70% reduction

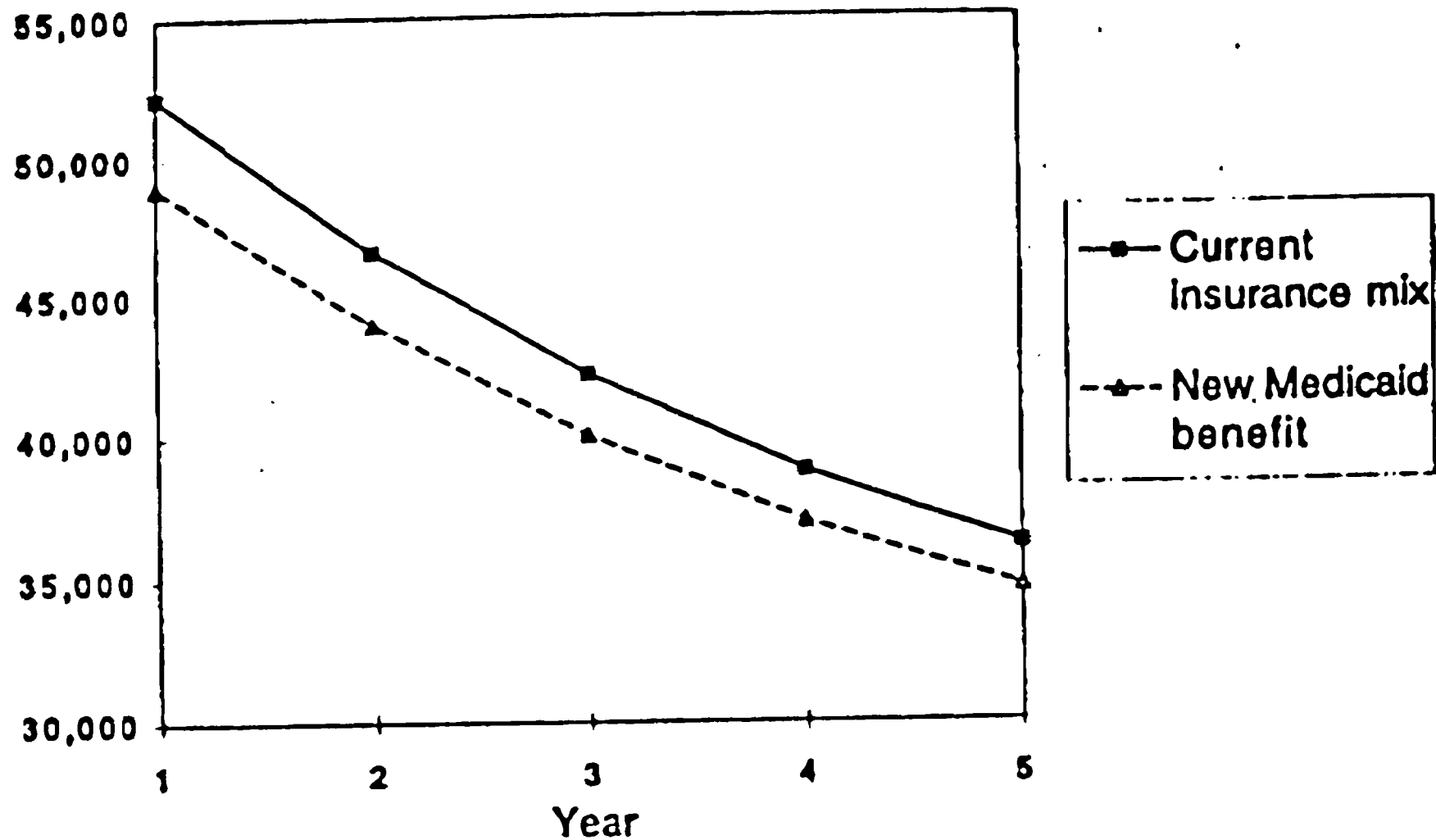
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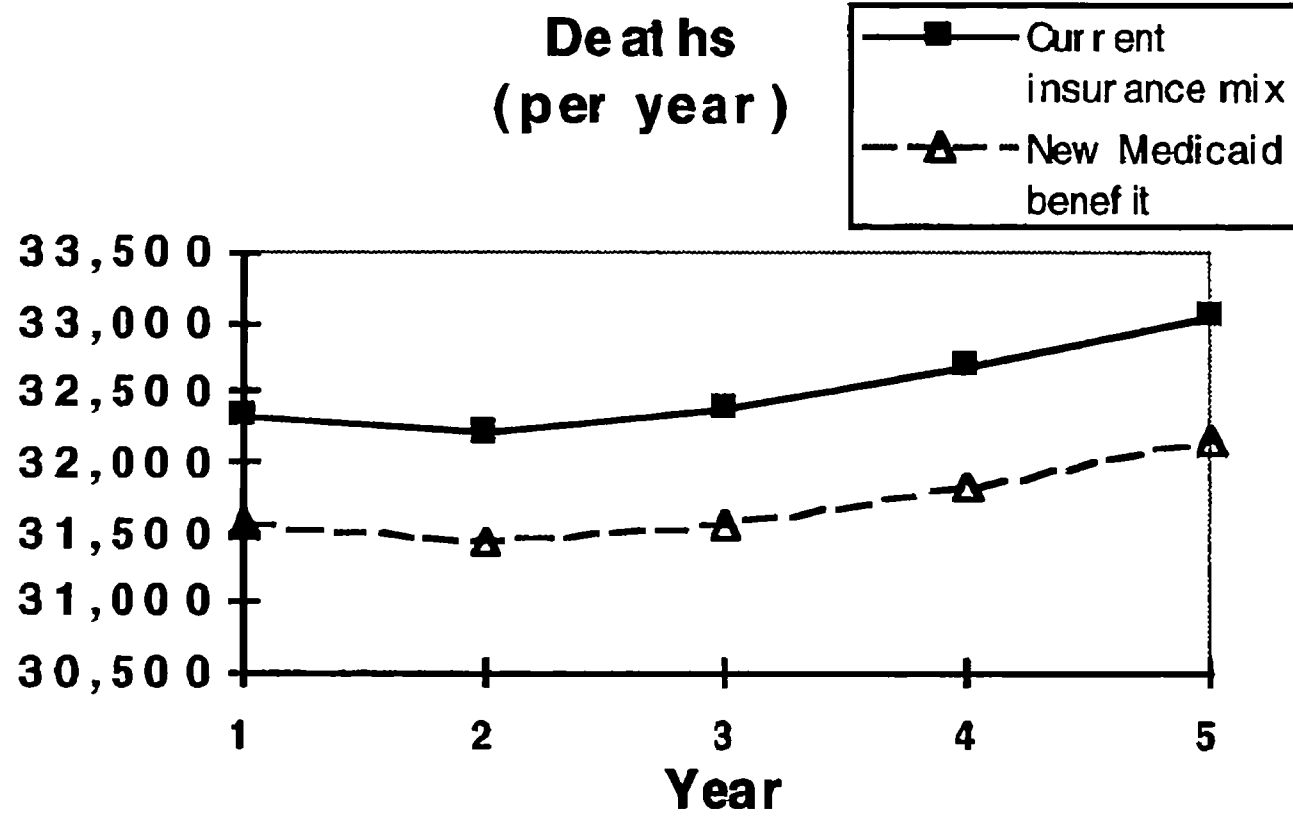
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Projected Number of Benefit Participants

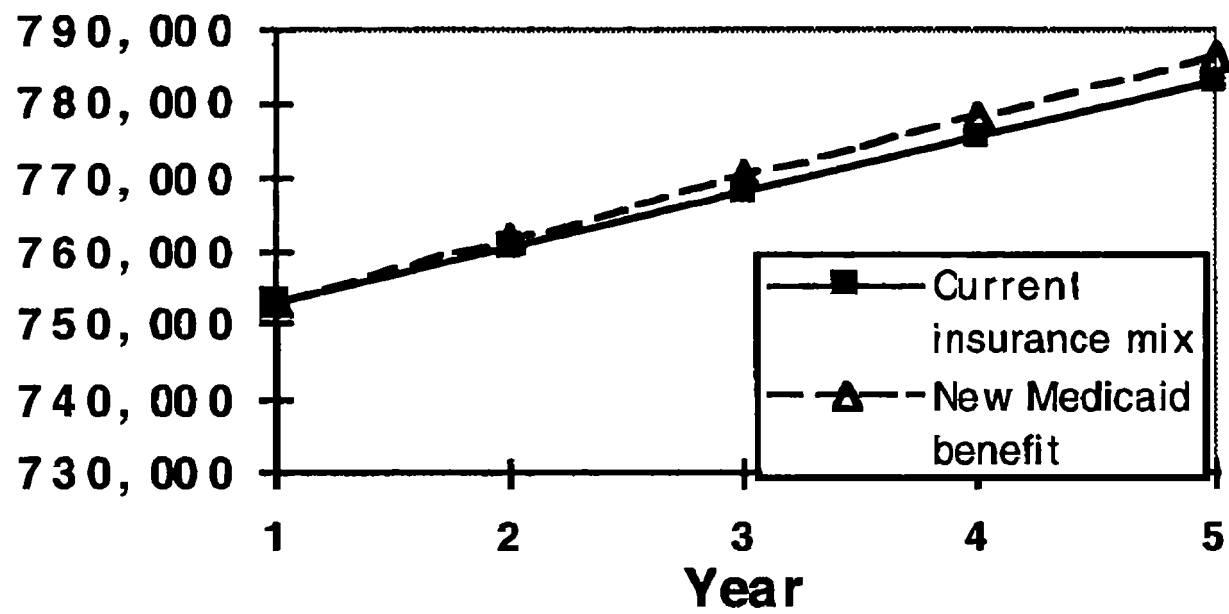
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New AIDS diagnoses (per year)





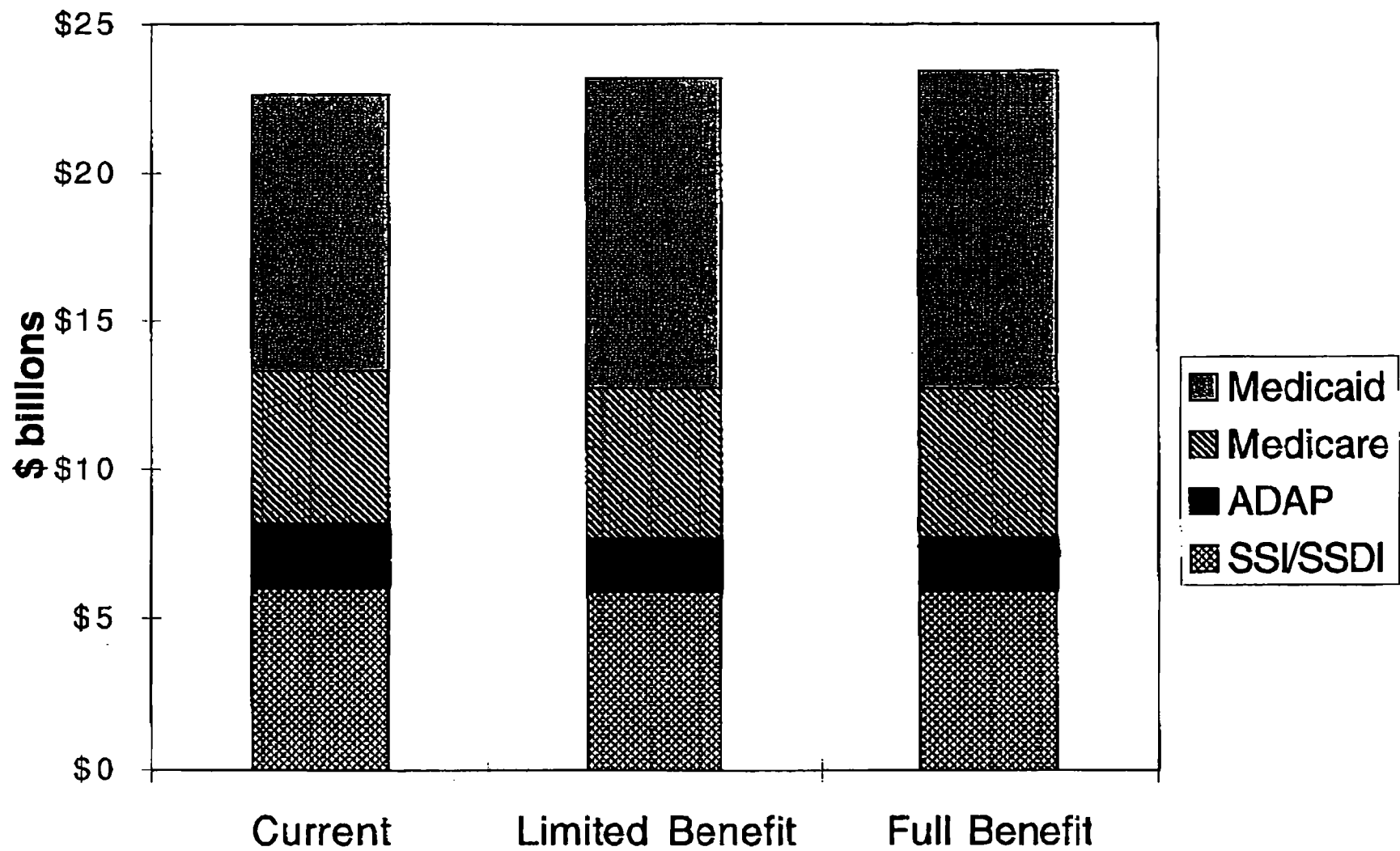
Life years (per year)



Outcomes - Health (over 5 years)

- 11,400 fewer new AIDS diagnoses
- 4,200 fewer deaths
- 9,600 more years of life

Federal Spending (5 years)



Outcomes - Federal costs (over 5 years)

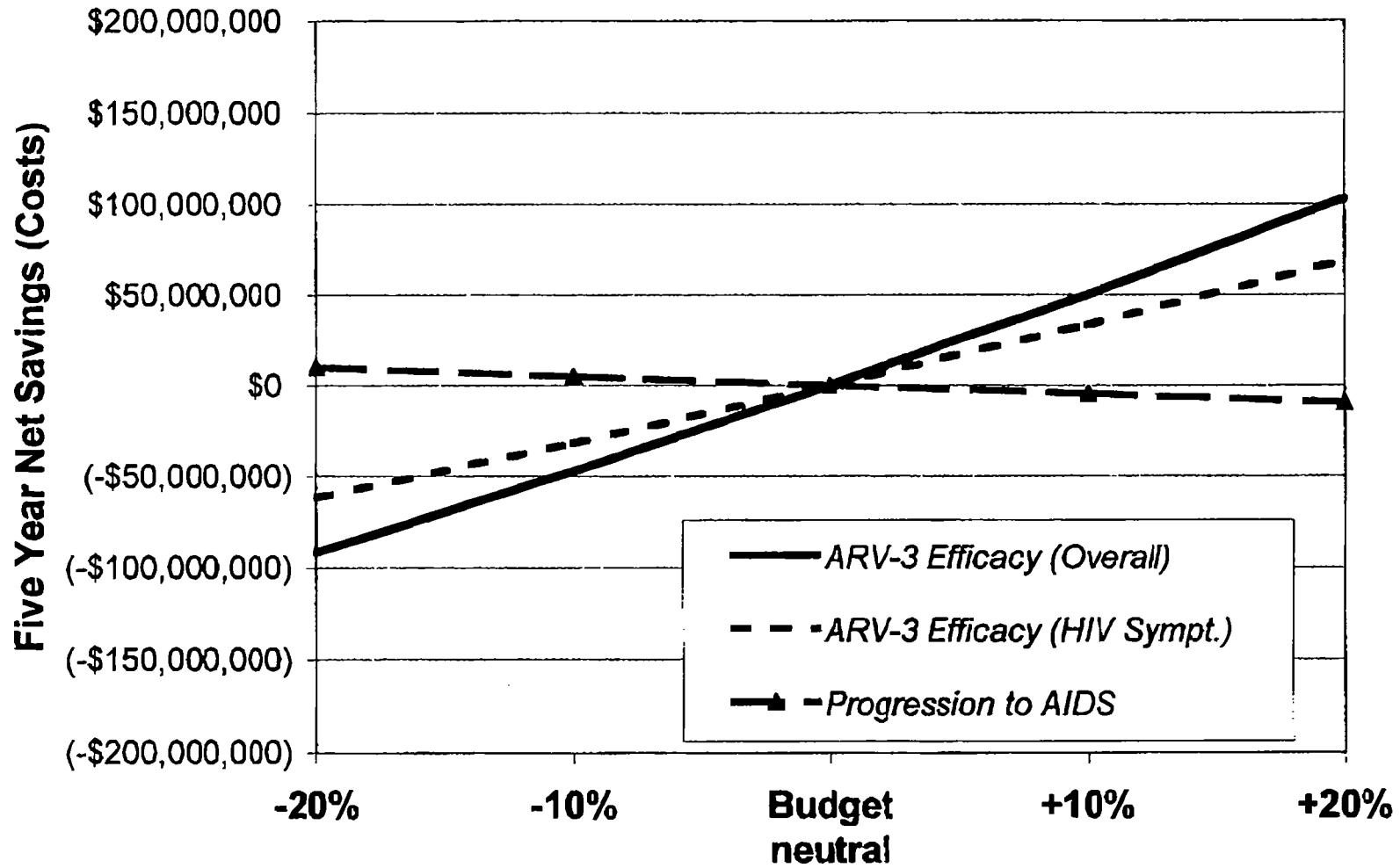
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Sensitivity Analysis: Progression to AIDS & Clinical Efficacy of ARV-3



Implications

New Medicaid benefit

- Substantial health benefits
- Limited benefit: budget neutrality feasible
- Multiple potential beneficiaries of policy
- Key part of increasing access to ARV therapy

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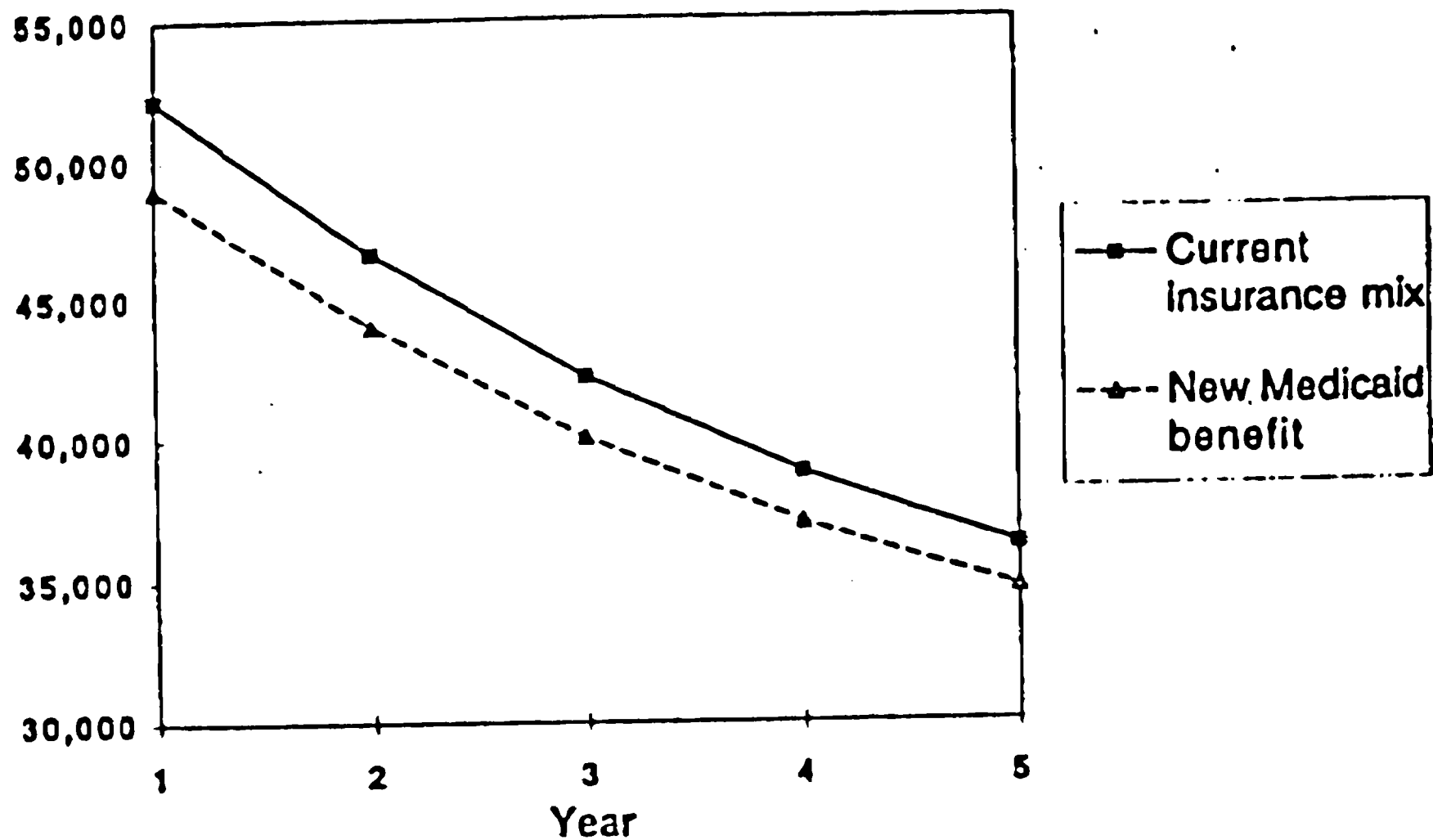
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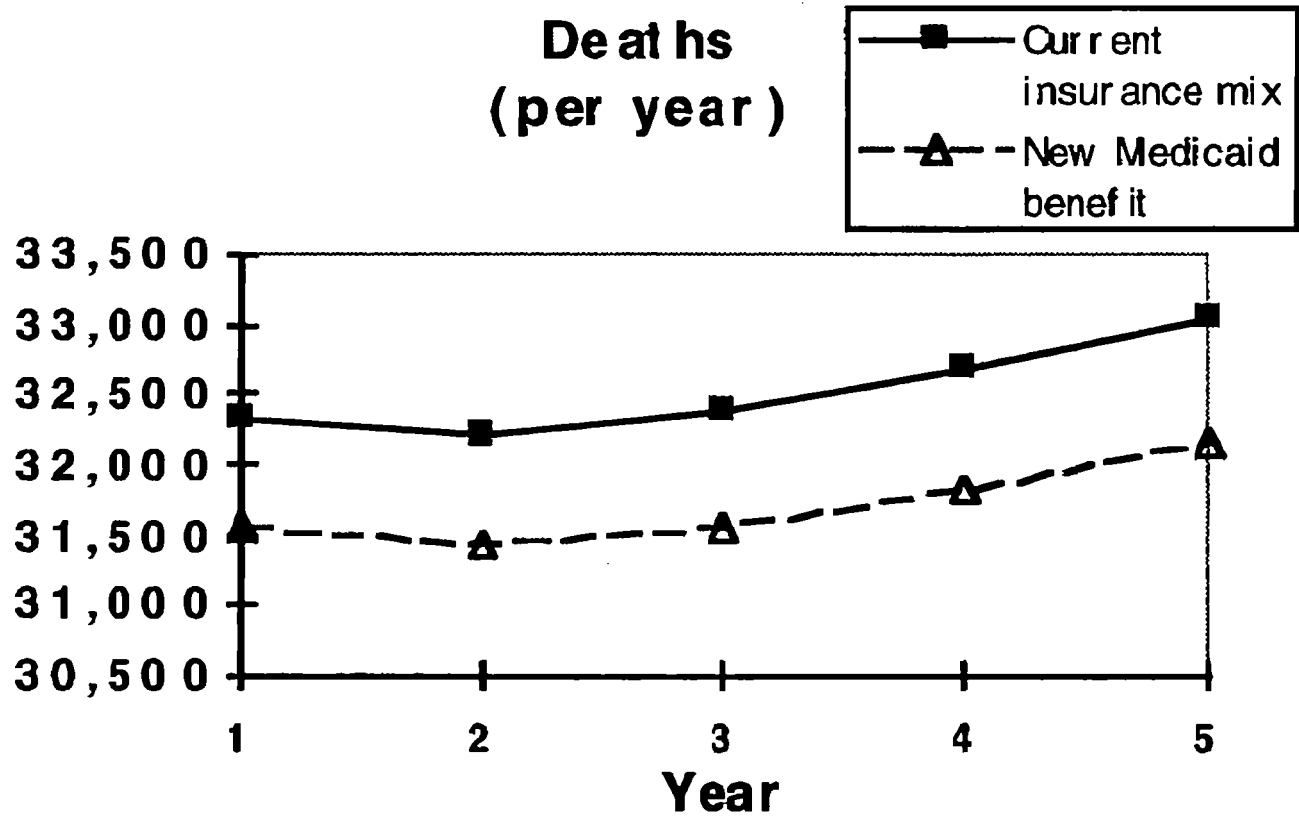
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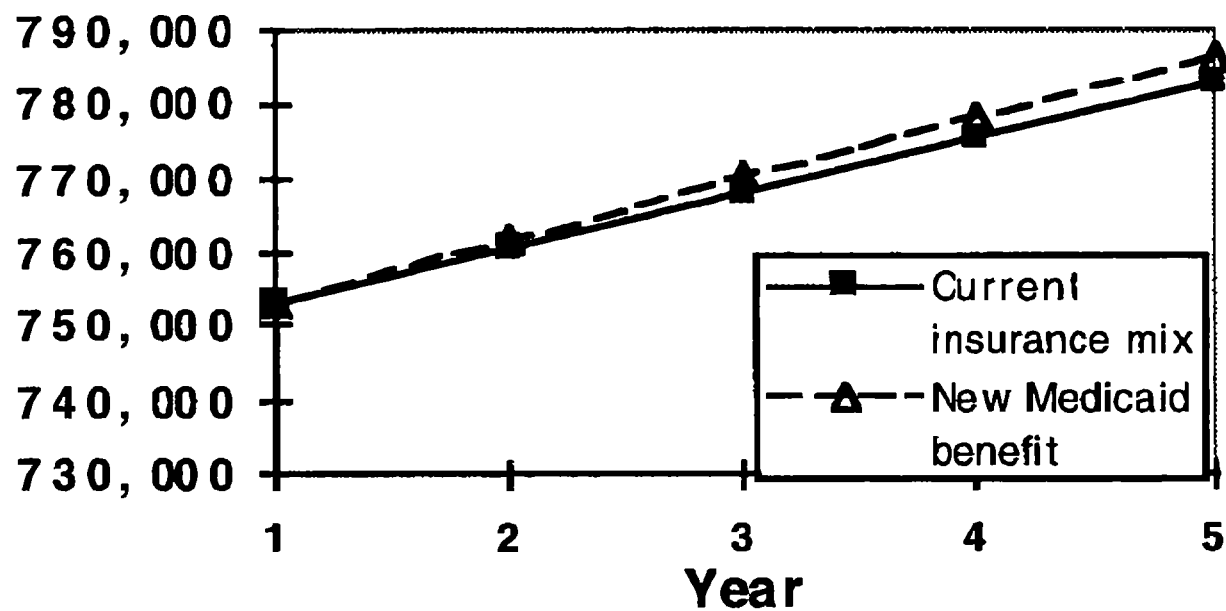
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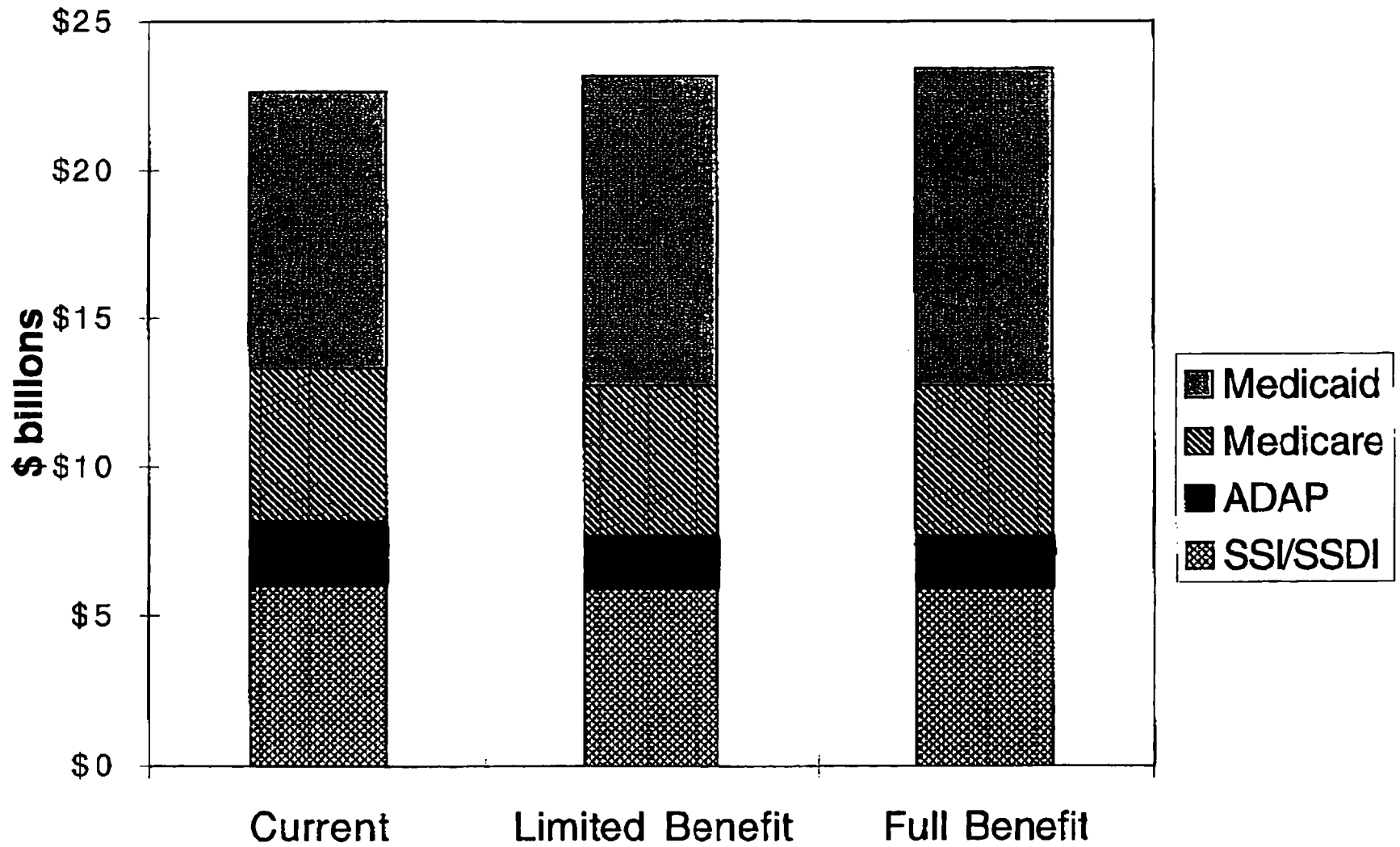
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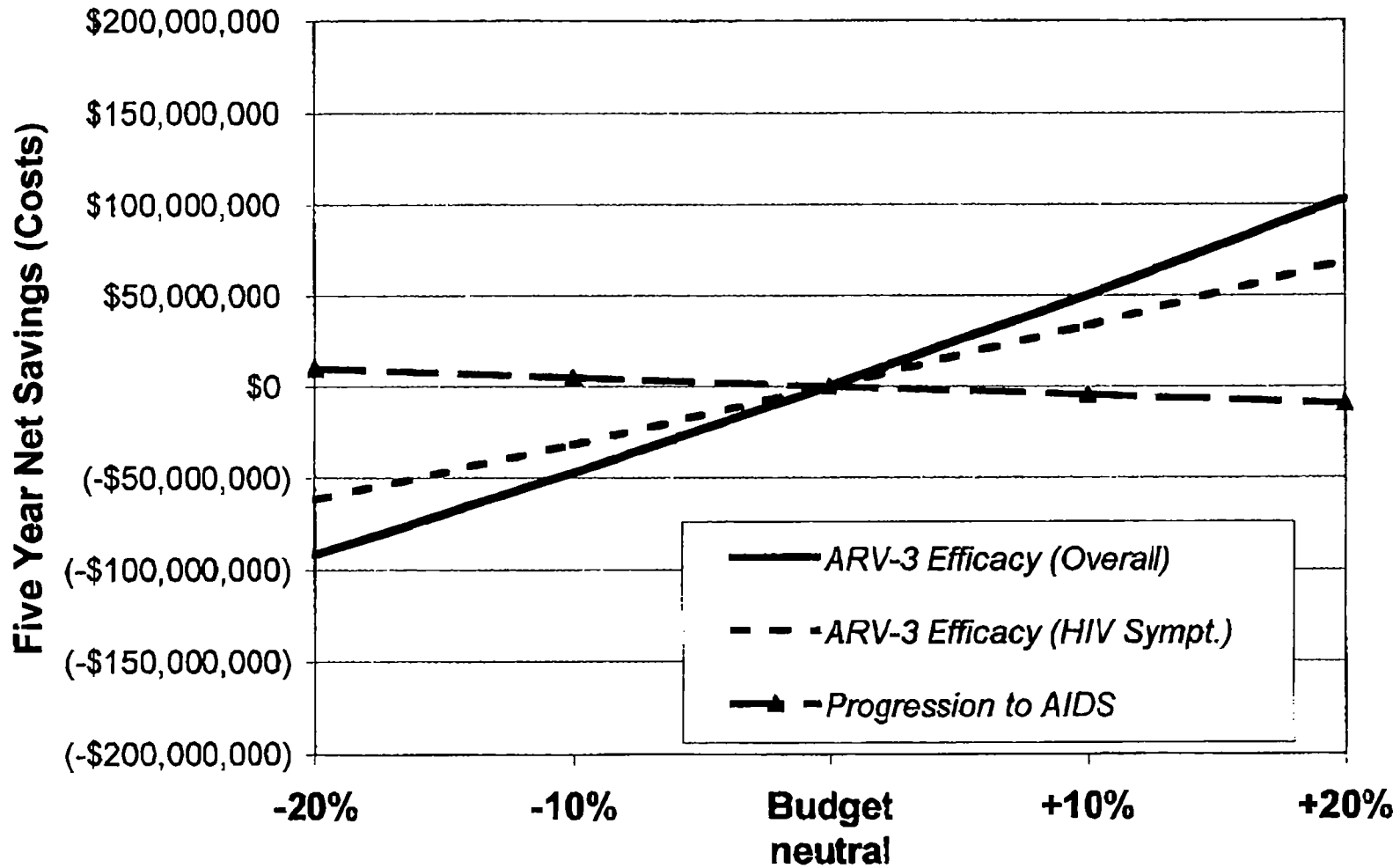
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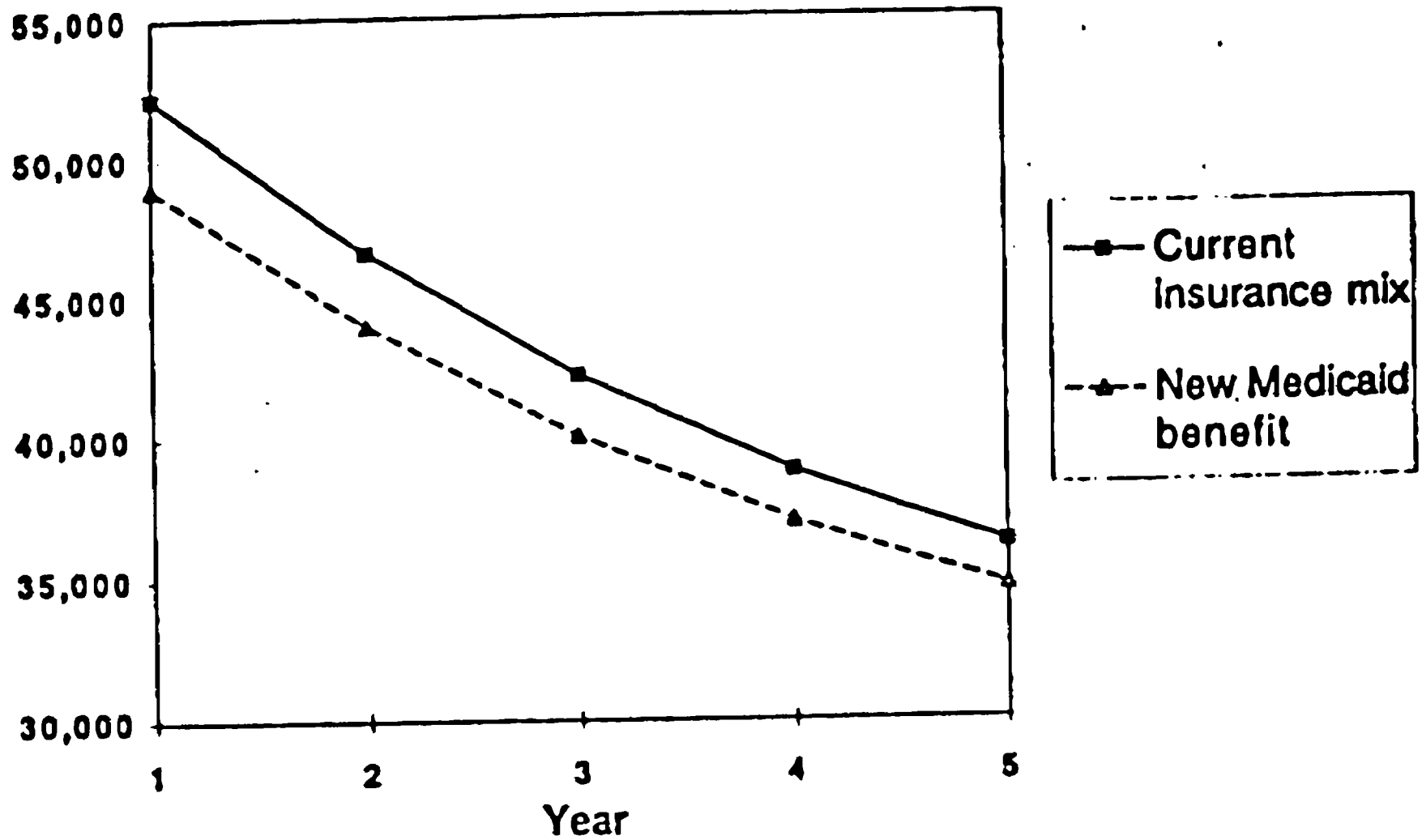
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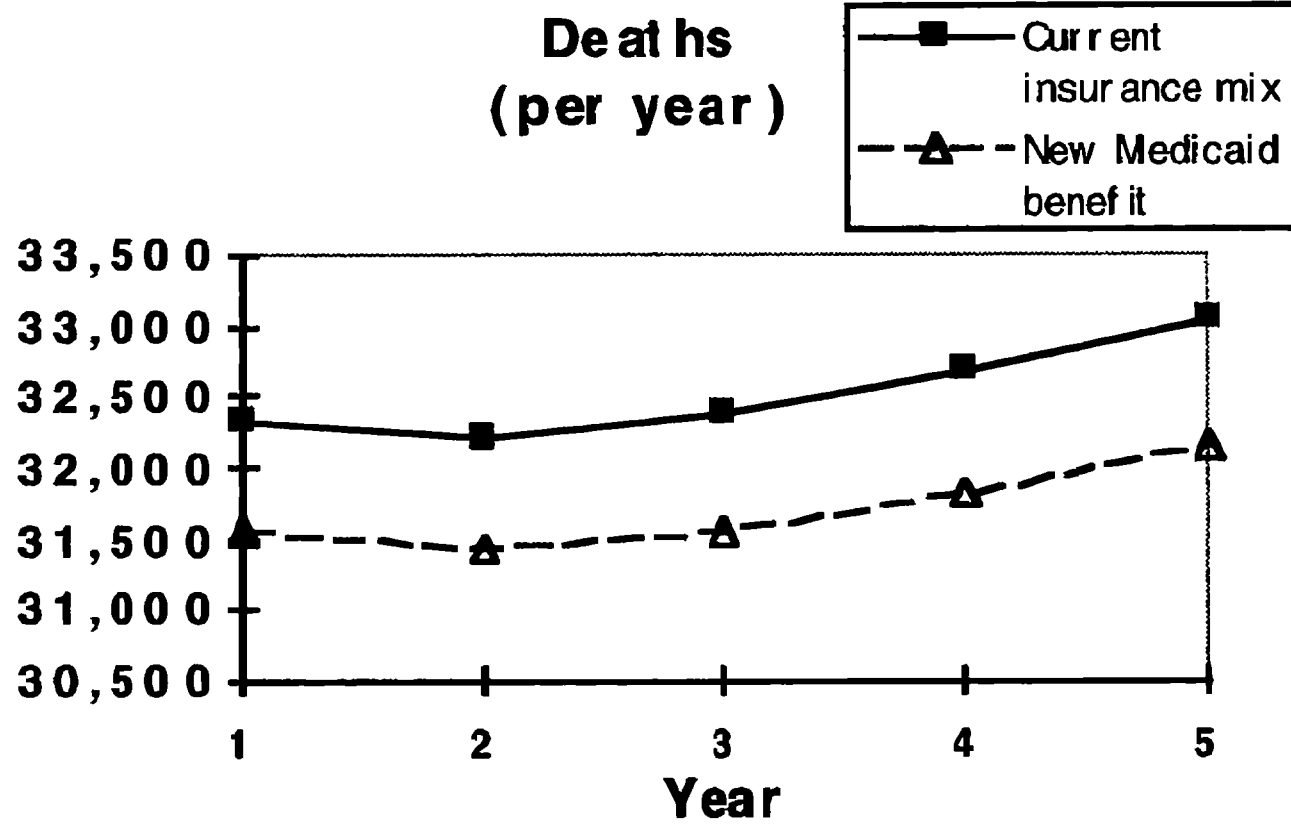
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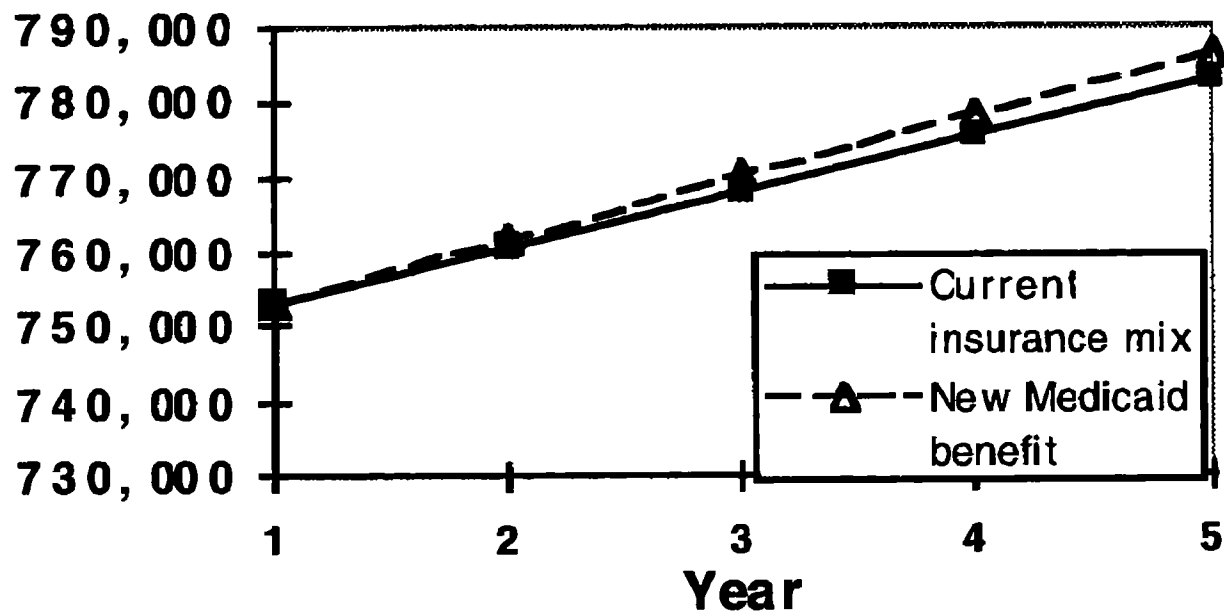
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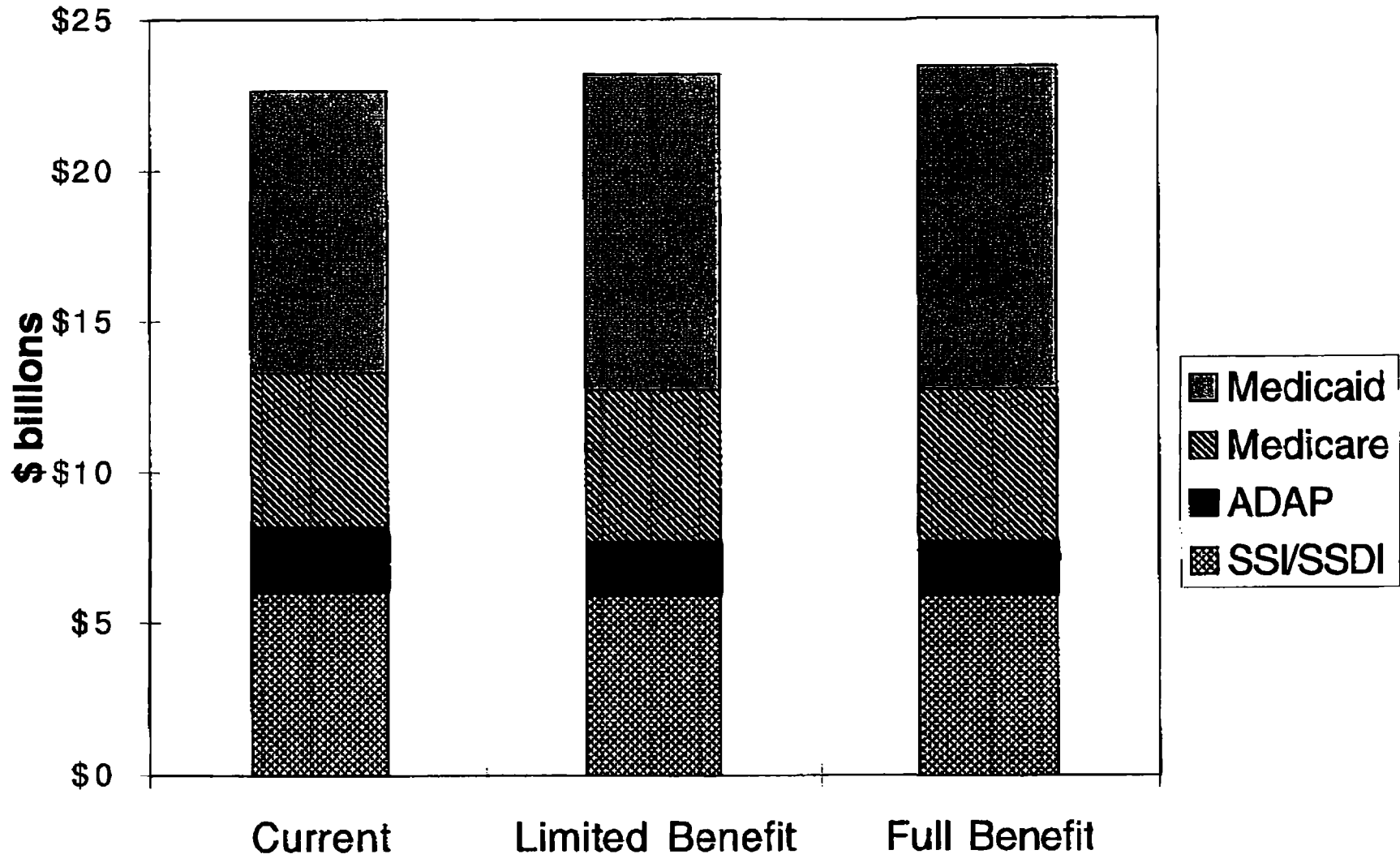
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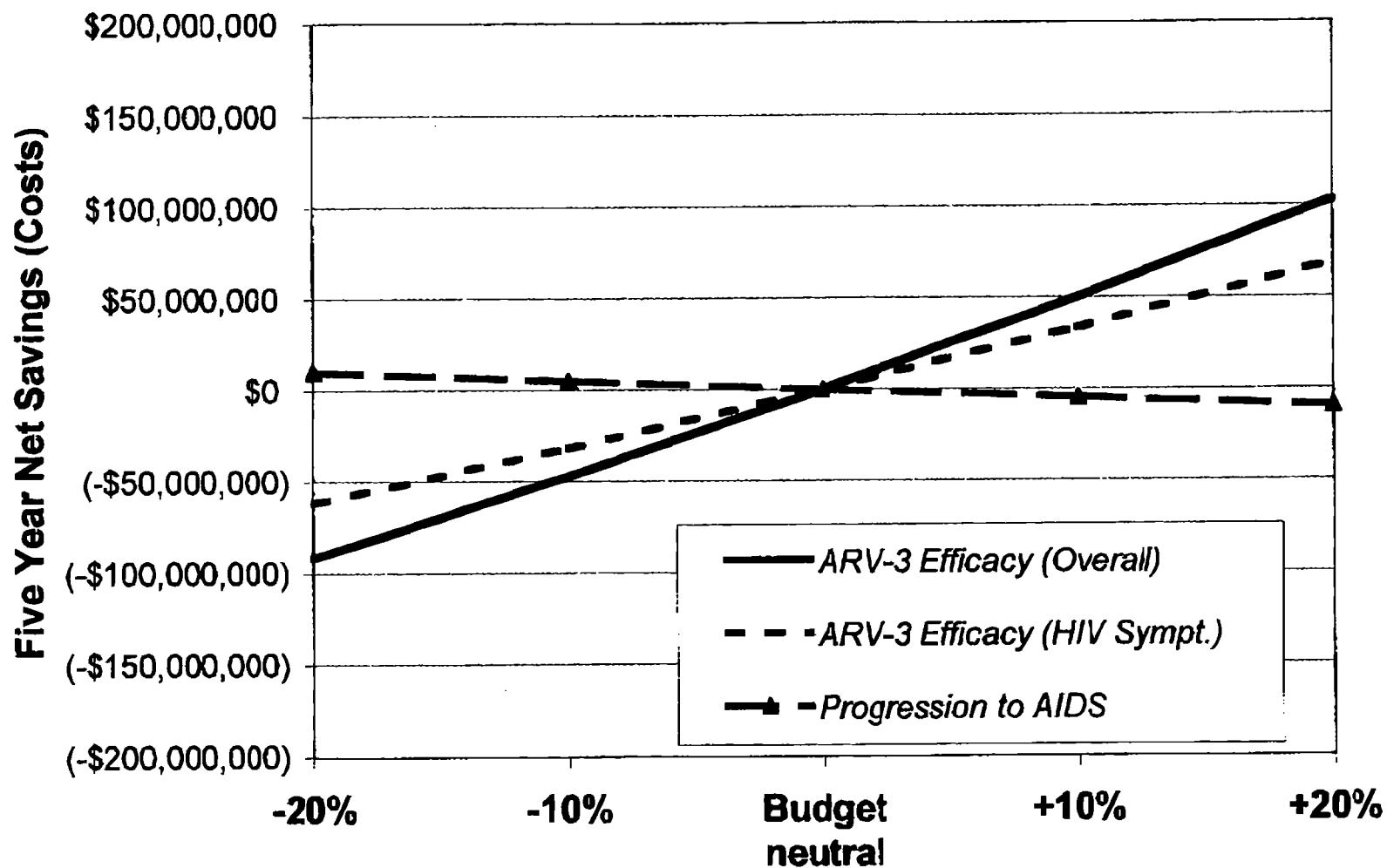
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EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

More information about this project can be obtained by contacting
Christine Lubinski, AIDS Action Council of Washington, D.C. at (202) 986-1300, or
Robert Greenwald, AIDS Action Committee of Massachusetts, at (617) 450-1257.

The duplication and distribution of this report is supported in part by a generous grant from The George Gund Foundation, Cleveland, Ohio.

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

INTRODUCTION

Recent research has shown that a long-held assumption about AIDS was wrong—there is no initial dormant phase of HIV infection. Instead, the virus attacks the body's immune system from the outset. This improved understanding of how HIV functions, along with the advent of powerful new medications, has led to new recommendations for care and treatment. Specifically, experts now advise comprehensive care and treatment, often with combination drug therapy, from the earliest stages of HIV disease.

Despite the experts' recommendations for early treatment and the existence of effective drugs, significant obstacles to accessing care and medications remain for low income people living with HIV. Existing programs cannot meet the need for comprehensive health care and preventive services. The current Medicaid requirements force most HIV positive individuals to wait until they develop full-blown AIDS to become eligible for coverage, a model which is inconsistent with clinical standards, inhumane, and costly.

EARLY INTERVENTION WORKS, SAVING LIVES AND DOLLARS

The new standard of care for people with HIV emphasizes early clinical intervention, calling for both primary care and combination drug therapy, including protease inhibitors, at earlier stages of infection. The National Institutes of Health (NIH) report that "...it has been suggested that the best opportunity to eradicate HIV infection is provided by the initiation of potent combination antiretroviral therapy during primary infection."¹ According to Dr. David Ho, director of the Aaron Diamond AIDS Research Center, mathematical models suggest that patients caught early enough and treated with combination drug therapies could be free of HIV in two to three years.²

While complete eradication of the HIV virus from the body has not yet been demonstrated, combination drug therapies have proven effective for many, driving viral loads (the amount of virus in the blood) below detectable levels, and maintaining or dramatically improving overall health. Combination therapies can slow the progression from HIV to AIDS, and can help prevent opportunistic infections (OIs). For example, researchers at NIH's National Eye Institute recently discovered that a combination of protease inhibitors and other anti-HIV drugs can prevent or delay the progression of cytomegalovirus (CMV) retinitis, a common complication of AIDS which causes blindness without proper treatment.³ Some patients in

¹ C. Carpenter, et. al., "Report of the NIH Panel to Define Principals of Therapy of HIV Infection," June, 1997.

² L. Altman, "With AIDS Advance, More Disappointment," *New York Times*, January 19, 1997.

³ NIH News Release, "Combination Drug Therapy for AIDS Found to Control Blinding

the study were able to stop standard CMV retinitis treatment, which can be cumbersome, toxic, and extremely costly (between \$50-100,000 per patient per year), without advancement of their disease.⁴

Combination drug therapies including protease inhibitors are expensive, with costs ranging from \$8,000 to \$10,000 per year. But several studies have indicated that the dollars spent “up front” on these medications are offset by later savings on hospitalizations and other expensive care and treatment for AIDS-related illnesses. A study by Dr. Peter Ruane of the Tower Infectious Disease Medical Associates in Los Angeles found that each dollar spent on combination drug therapies resulted in at least two dollars of savings on overall treatment costs, which declined 23 percent.⁵ The same study reported a 57 percent drop in the average number of days patients spent in the hospital. Data from Saint Vincent’s Hospital in New York support the conclusions of the Tower study, showing a significant decrease in inpatient care, both in terms of the number of people hospitalized and the average length of stay.⁶

The findings of the protease inhibitor studies—that early intervention and treatment can prolong health and reduce the need for more expensive treatment later—are consistent with earlier studies on the cost-effectiveness and beneficial impact of preventive treatment. Researchers at Johns Hopkins Hospital compared the outcomes of patients who received prophylactic treatment for the opportunistic infection *Pneumocystis carinii* pneumonia (PCP) with those who did not receive such treatment. The patients not taking prophylaxis accounted for all of the deaths attributed to PCP, 85 percent of the hospital days, 100 percent of the Intensive Care Unit days, and 89 percent of the inpatient charges. The study concluded that those “who developed PCP despite prophylaxis had a better outcome and used fewer resources than patients not receiving preventive therapy.”⁷ Another study examining preventive treatment for PCP found that prophylaxis resulted in longer life and a savings of \$16,503 for each patient, as compared with no prophylaxis.⁸

Comprehensive care and treatment which prevents or delays the progression from HIV infection to AIDS can both improve quality of life and save money. A survey of the costs of care for

Eye Infection,” May 20, 1997 (reporting study results published in the *Journal of the American Medical Association*, May 21, 1997).

⁴ *Id*

⁵ P. Ruane, “Dramatic Reductions in Use of Healthcare Services by Patients with HIV Result from Use of Combination Therapy with a Protease Inhibitor,” Tower Infectious Disease Medical Associates, Inc., January 23, 1997.

⁶ R. Torres, “Impact of Potent New Antiretroviral Therapies on In-Patient and Out-Patient Hospital Utilization by HIV-Infected Persons,” Saint Vincent’s Hospital and Medical Center, January 23, 1997.

⁷ J. Gallant, et. al., “The Impact of Prophylaxis on Outcome and Resource Utilization in *Pneumocystis carinii* Pneumonia,” *Chest*, April 1995: 1018-1023.

⁸ A. Castellano and M. Nettleman, “Cost and Benefit of Secondary Prophylaxis for *Pneumocystis carinii* Pneumonia,” *Journal of the American Medical Association*, August 14, 1991: 820-824.

Medicaid patients with HIV in Baltimore found that monthly costs for people with CD4+ T-cell counts under 50 (generally a sign of more advanced HIV disease) were more than twice those of people with more than 500 T-cells.⁹ Stated simply, providing care for those who are seriously ill costs more than caring for healthier people. Yet under the present Medicaid system, many living with HIV must wait for their T-cells to drop and their illness to worsen before they can receive coverage and access care.

GAPS IN HEALTH CARE COVERAGE REMAIN

The advances in overall health care and drug treatments have brought renewed health and unprecedented hope to many people living with HIV disease. For the first time in the 15 years of the AIDS epidemic, there has been a decrease in the numbers of Americans dying from AIDS. The U.S. Centers for Disease Control (CDC) reported a 13 percent decline in the number of AIDS deaths for the first six months of 1996, as compared to the same period in 1995, and attributed this decline to improved medical care, prophylaxis for OIs, and the use of combination therapies.¹⁰

In the same report, however, the CDC noted that AIDS continues to be the leading cause of death of Americans aged 25 to 44, and that the “increased prevalence of AIDS [in the U.S.] indicates the need for medical and other services for persons with HIV infection.” While the new medications make obtaining care more important than ever, challenges in expanding access to primary care and treatment remain.

Medicaid provides access to health care coverage for low income, uninsured, disabled people. Individuals who are HIV positive but have not been diagnosed with AIDS, however, are often not eligible for Medicaid, because they do not meet the program’s disability standards or other categorical eligibility requirements. To qualify for Medicaid, people must meet income requirements and the disability criteria of the federal Supplemental Security Income (SSI) program. The Social Security Administration uses the CDC’s definition of AIDS, along with evidence of functional impairments, as proof of disability.¹¹ **Despite the fact that early clinical intervention—including primary care, preventive services, and medication therapies—has been shown to improve health and delay the onset of expensive opportunistic infections, most HIV positive individuals must wait until they “get sicker” and develop AIDS before they can receive Medicaid.**

⁹ R. Moore and R. Chaisson, “Costs to Medicaid of Advancing Immunosuppression in an Urban HIV-Infected Patient Population in Maryland,” *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 1997, 14:223-231.

¹⁰ Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173. For the first nine months of 1996, AIDS deaths declined even more dramatically, by 19 percent over the same period in 1995.

¹¹ The CDC definition of AIDS for surveillance purposes is: documented CD4+ T-lymphocyte counts <200 per microliter or percent of total lymphocytes <14 percent or a variety of opportunistic infections.

This is particularly devastating because the populations in which HIV infection is increasing are the ones likely to enroll in Medicaid once their HIV infection becomes full-blown AIDS. The epidemic is growing fastest among groups which have traditionally been socioeconomically disenfranchised, including racial and ethnic minorities, injection drug users, and women. In 1996, for the first time, blacks accounted for more AIDS cases than whites (41 percent versus 38 percent).¹² Women represented 20 percent of new AIDS cases in 1996, up from seven percent in 1985. While overall AIDS deaths declined 19 percent in the first nine months of 1996, deaths among blacks decreased 10 percent and deaths among women, only seven percent.¹³

These populations are also the groups less likely to have health insurance and access to treatments, and more likely to face barriers in obtaining health care, according to a survey by the Agency for Health Care Policy and Research.¹⁴ People who are uninsured or underinsured not only lack access to expensive combination therapies, but also to basic primary care and preventive services.

Additionally, current Medicaid requirements undermine public health efforts by preventing many people with HIV from receiving care earlier in their disease. Under the present system, we are often not reaching these people to teach and reinforce behavior changes which can prevent HIV transmission. Even if people are able to obtain the new combination therapies, they may lack access to the primary care and medical case management needed to ensure that the prescribed treatment regimen is appropriate and effective, and to support them in following complex treatment plans. If patients do not strictly comply with their combination therapy regimens, they are likely to develop drug-resistant strains of HIV. The existence of such drug-resistant HIV mutations may further complicate public health efforts to combat AIDS.

Despite the existence of federal AIDS programs, such as the AIDS Drug Assistance Programs (ADAPs) and the other components of the Ryan White CARE Act, Medicaid serves as the foundation of AIDS care through its provision of both comprehensive health care and drug therapies. ADAPs provide limited prescription drug coverage for some uninsured and underinsured people with HIV and AIDS. But these programs cannot (and are not designed to) meet the need for comprehensive primary care and diagnostic services. In spite of their limited mission—to provide access to a limited formulary of proven AIDS medications—ADAPs face severe financial pressure in many states, and often cannot meet the growing demand for new combination therapies. In some states, ADAPs do not even cover protease inhibitors, and many offer a very limited formulary of antiretroviral and OI drugs. In other states, there are lotteries, long waiting lists, and increasingly restrictive eligibility criteria for ADAP participation.

While other Ryan White CARE Act programs pay for some primary care and drug

¹² Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173.

¹³ B. Seitz, "AIDS Sufferers Living Longer," ABC News.com, July 15, 1997.

¹⁴ P. Mohr, Patterns of Health Care Use Among HIV-Infected Adults: Preliminary Results," *AIDS Cost and Services Utilization Survey*, Agency for Health Care Policy and Research, September 1994: 3.

reimbursement, they are not intended to provide widespread comprehensive health care. Ryan White funding is used for a range of care and services, including food, transportation, and case management for people living with AIDS. Additionally, many ADAPs and Ryan White-funded primary care programs have eligibility criteria which exclude people in the earlier stages of HIV disease. These programs lack the financial resources to broaden their eligibility criteria to cover such individuals.

The Medicaid eligibility framework—requiring total disability to qualify for coverage—is at odds with current clinical and public health knowledge. Many low income HIV positive individuals with relatively intact immune systems are not presently eligible for Medicaid, but will eventually qualify for Medicaid after developing AIDS. Unable to afford adequate treatment early in their HIV disease, they cannot obtain the health care services necessary to manage the disease, and will be more ill when they do enroll in Medicaid. Ironically, earlier access to these medical services and treatments would enable them to preserve their health, learn how to prevent transmission of HIV to others, and avoid more costly care such as inpatient hospitalization. For humane, financial, and public health reasons, it is time to make Medicaid's eligibility requirements consistent with the clinical realities of HIV disease.

A COLLABORATIVE RESPONSE

In response to the contradictions between current Medicaid disability criteria and AIDS clinical evidence and care standards, which call for early treatment of HIV disease, representatives from the AIDS Action Council, community-based AIDS service organizations, the Health Care Financing Administration (HCFA) and the Office of Management and Budget (OMB) have begun to work collaboratively to address these issues. Response from the administration has been unequivocally supportive, culminating in an endorsement from Vice President Al Gore, who has asked HCFA to find ways in which to expand Medicaid and allow more low-income Americans with HIV to access care and therapies. Gore is quoted as saying “[Medicaid expansion] can ease suffering, it can increase hope, and it can get new drug therapies into the hands of people who need them.” As a result of these collaborations, we are all working together under HCFA's leadership to develop a plan for expanding eligibility to Medicaid for persons who are HIV positive.

AN AIDS-SPECIFIC EXPANSION

As participants in these discussions, we have recognized several reasons for an AIDS-specific expansion of Medicaid. We believe that it serves the interests of public health, scientific knowledge, and fairness to broaden Medicaid coverage to include people with HIV.

Public health: With earlier health care and treatment, as mentioned above, people living with HIV are more likely to avoid behaviors which can spread the virus, and are more likely to adhere to complex treatment plans, which can both prolong health and prevent development of drug-resistant strains of HIV. Earlier access to care can also serve as an incentive for people to learn their serostatus for the first time, and then take steps to avoid either contracting or transmitting HIV.

Scientific knowledge: Protease inhibitors and other new medications received rapid FDA approval, have not yet been in long-term use, and have been researched mainly by studying people in more advanced stages of HIV disease. There are many remaining questions about the benefits, risks, and best way to use combination therapies in people who are HIV positive, but do not have AIDS. A Medicaid expansion demonstration project which brings people with HIV into care provides the opportunity to gather data and conduct research studies designed to answer these questions.

Fairness: The current Medicaid system requires most low-income people with HIV to develop AIDS in order to gain access to health care and new combination therapies. This is in conflict with principles and guidelines recently released by the Department of Health and Human Services and the NIH, which call for earlier intervention with combination drug therapies as the standard of care for the treatment of HIV in most cases. The government should ensure that this standard of care, endorsed by its own agencies, is accessible to those who have no other way to obtain it. Our federal government has always recognized the importance of ensuring access to treatment for other communicable diseases, such as sexually transmitted diseases and tuberculosis—it is unfair and inhumane to deny such treatment to people with HIV.

PROPOSAL DESIGN

The objective of this program is to expand Medicaid eligibility to low-income individuals who have tested positive for the presence of HIV and who would otherwise be eligible for Medicaid once their health status met an AIDS-defining diagnosis. States participating in this initiative will demonstrate that the provision of earlier access to care and treatment will extend the period of time that a person who is HIV positive remains asymptomatic, defer the onset of opportunistic infection, and delay hospitalization, all of which will result in significant cost savings and life-enhancing benefits. The following section describes what we believe are the core components of this initiative.

Eligibility

Any and all individuals who meet the following criteria will be eligible under this program:

- test positive for the presence of HIV; and
- have income at or below 200 percent of the federal poverty level.

State demonstrations will coordinate resources with other private, state, and federal programs. Individuals with private insurance can apply for and become eligible for Medicaid as a “wrap-around benefit” thereby maximizing private insurance participation. State proposals will specify the state specific eligibility guidelines and coordination of other state and federal programs.

Covered Benefits

Ideally, states will provide the full benefit package (i.e., mandatory and optional Medicaid services) to individuals eligible through this program. In any case, benefit packages must be flexible to accommodate new treatment advances and changes in standards of care that become available during the course of the demonstration. Through this project, states, at a minimum, must provide:

- primary care,
- prescription drugs,
- diagnostic and laboratory services,
- mental health services, and
- substance abuse treatment services.

Options to Participate in the Demonstration Projects

Section 1115 of the Social Security Act allows the Secretary of Health and Human Services to grant waivers from the usual federal Medicaid requirements¹⁵ to states which want to create demonstration projects to test new approaches to Medicaid. These demonstration projects must be designed to promote the objectives of Medicaid,¹⁶ and must include a research and evaluation component. Generally, demonstration projects created under a Section 1115 waiver are supposed to be “budget neutral” over the life of the project, meaning that costs under the demonstration project do not exceed what costs would have been without the waiver in place. Section 1115 also authorizes matching federal funds for certain expenditures.

This initiative will be designed to provide states with the maximum flexibility possible in participating in a Medicaid expansion demonstration project. The project does not necessarily need to meet the traditional definition of “budget neutrality,” since there can be federal and/or state subsidies. Also, budget neutrality should be measured within a time frame which is appropriate for assessing the clinical impact and cost-effectiveness of the new combination therapies (e.g., over a period of five to ten years).

Options for participation include the creation of a free-standing demonstration program or new or amended 1115 waivers. New 1115 waivers could provide the vehicle to expand Medicaid eligibility and/or allow a Medicaid buy-in option for those individuals otherwise ineligible for coverage. Amending an approved or pending 1115 waiver could also be used to expand eligibility. In addition, states could increase the income standards for their Medicaid buy-in programs, allowing more persons who are HIV positive to qualify. For example, states could set the income standard at 200 percent of the federal poverty level or they could use a graduated system to make more individuals eligible.

¹⁵ As defined in Section 1902 of the Social Security Act, and other provisions incorporated through Section 1902.

¹⁶ As set out in Title XIX of the Social Security Act.

NEXT STEPS

Over the next several months, the AIDS Action Council will work with HCFA to develop and refine a solicitation process for states to successfully participate in the HIV Expanded Eligibility Demonstration Initiative. It is important for community-based AIDS service organizations to urge their state governors and Medicaid directors to advocate for this initiative with HHS and HCFA. While we expect that this initiative will offer states tremendous opportunities to provide cost-effective access and coverage to its most vulnerable populations, we also recognize the range of development and design issues that need to be resolved. Over the next several months, the AIDS Action Council will work with states and HCFA to complete the following tasks:

- Continue to work with HCFA to design a program that includes adequate incentives for state participation in this initiative.
- Build consensus among federal and state leadership, elected officials, and government staff, including representatives from Medicaid programs, Departments of Health, and Departments of HIV Services.
- Work with HCFA to develop a process that allows states to efficiently design and implement a vehicle for eligibility expansion that responds to the unique environment and situations of each state (waiver amendment or new waiver submission).
- Design a process to solicit input from consumers, AIDS service organizations, primary care and other health care providers, and health care agencies regarding program design and program effectiveness, on an ongoing basis.
- Work with HCFA to develop a methodology that allows states maximum flexibility in measuring cost effectiveness. The goal will be to have HCFA resolve methodology issues related to baseline measurements, the measurement of savings in other government programs, and evaluation time frames.
- Work with HCFA to identify and develop data bases that provide the information needed to estimate current expenditures and projected costs for the purposes of assessment and future planning. Necessary data includes the number of newly eligible individuals by state and service area (persons who are HIV positive with incomes below state defined eligibility criteria), utilization of services, and cost.

DRAFT

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

More information about this project can be obtained by contacting
Christine Lubinski, AIDS Action Council of Washington, D.C. at (202) 986-1300, or
Robert Greenwald, AIDS Action Committee of Massachusetts, at (617) 450-1257.

DRAFT

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

INTRODUCTION

Recent research has shown that a long-held assumption about AIDS was wrong—there is no initial dormant phase of HIV infection. Instead, the virus attacks the body's immune system from the outset. This improved understanding of how HIV functions, along with the advent of powerful new medications, has led to new recommendations for care and treatment. Specifically, experts now advise comprehensive care and treatment, often with combination drug therapy, from the earliest stages of HIV disease.

Despite the experts' recommendations for early treatment and the existence of effective drugs, significant obstacles to accessing care and medications remain for low income people living with HIV. Existing programs cannot meet the need for comprehensive health care and preventive services. The current Medicaid requirements force most HIV positive individuals to wait until they develop full-blown AIDS to become eligible for coverage, a model which is inconsistent with clinical standards, inhumane, and costly.

EARLY INTERVENTION WORKS, SAVING LIVES AND DOLLARS

The new standard of care for people with HIV emphasizes early clinical intervention, calling for both primary care and combination drug therapy, including protease inhibitors, at earlier stages of infection. The National Institutes of Health (NIH) report that "...it has been suggested that the best opportunity to eradicate HIV infection is provided by the initiation of potent combination antiretroviral therapy during primary infection."¹ According to Dr. David Ho, director of the Aaron Diamond AIDS Research Center, mathematical models suggest that patients caught early enough and treated with combination drug therapies could be free of HIV in two to three years.²

While complete eradication of the HIV virus from the body has not yet been demonstrated, combination drug therapies have proven effective for many, driving viral loads (the amount of virus in the blood) below detectable levels, and maintaining or dramatically improving overall health. Combination therapies can slow the progression from HIV to AIDS, and can help prevent opportunistic infections (OIs). For example, researchers at NIH's National Eye Institute recently discovered that a combination of protease inhibitors and other anti-HIV drugs can prevent or delay the progression of cytomegalovirus (CMV) retinitis, a common complication of AIDS which causes

¹ C. Carpenter, et. al., "Report of the NIH Panel to Define Principals of Therapy of HIV Infection," June, 1997.

² L. Altman, "With AIDS Advance, More Disappointment," *New York Times*, January 19, 1997.

blindness without proper treatment.³ Some patients in the study were able to stop standard CMV retinitis treatment, which can be cumbersome, toxic, and extremely costly (between \$50-100,000 per patient per year), without advancement of their disease.⁴

Combination drug therapies including protease inhibitors are expensive, with costs ranging from \$8,000 to \$10,000. But several studies have indicated that the dollars spent “up front” on these medications are offset by later savings on hospitalizations and other expensive care and treatment for AIDS-related illnesses. A study by Dr. Peter Ruane of the Tower Infectious Disease Medical Associates in Los Angeles found that each dollar spent on combination drug therapies resulted in at least two dollars of savings on overall treatment costs, which declined 23 percent.⁵ The same study reported a 57 percent drop in the average number of days patients spent in the hospital. Data from Saint Vincent’s Hospital in New York support the conclusions of the Tower study, showing a significant decrease in inpatient care, both in terms of the number of people hospitalized and the average length of stay.⁶

The findings of the protease inhibitor studies—that early intervention and treatment can prolong health and reduce the need for more expensive treatment later—are consistent with earlier studies on the cost-effectiveness and beneficial impact of preventive treatment. Researchers at Johns Hopkins Hospital compared the outcomes of patients who received prophylactic treatment for the opportunistic infection *Pneumocystis carinii* pneumonia (PCP) with those who did not receive such treatment. The patients not taking prophylaxis accounted for all of the deaths attributed to PCP, 85 percent of the hospital days, 100 percent of the Intensive Care Unit days, and 89 percent of the inpatient charges. The study concluded that those “who developed PCP despite prophylaxis had a better outcome and used fewer resources than patients not receiving preventive therapy.”⁷ Another study examining preventive treatment for PCP found that prophylaxis resulted in longer life and a savings of \$16,503 for each patient, as compared with no prophylaxis.⁸

³ NIH News Release, “Combination Drug Therapy for AIDS Found to Control Blinding Eye Infection,” May 20, 1997 (reporting study results published in the *Journal of the American Medical Association*, May 21, 1997).

⁴ *Id.*

⁵ P. Ruane, “Dramatic Reductions in Use of Healthcare Services by Patients with HIV Result from Use of Combination Therapy with a Protease Inhibitor,” Tower Infectious Disease Medical Associates, Inc., January 23, 1997.

⁶ R. Torres, “Impact of Potent New Antiretroviral Therapies on In-Patient and Out-Patient Hospital Utilization by HIV-Infected Persons,” Saint Vincent’s Hospital and Medical Center, January 23, 1997.

⁷ J. Gallant, et. al., “The Impact of Prophylaxis on Outcome and Resource Utilization in *Pneumocystis carinii* Pneumonia,” *Chest*, April 1995: 1018-1023.

⁸ A. Castellano and M. Nettleman, “Cost and Benefit of Secondary Prophylaxis for *Pneumocystis carinii* Pneumonia,” *Journal of the American Medical Association*, August 14, 1991: 820-824.

Comprehensive care and treatment which prevents or delays the progression from HIV infection to AIDS can both improve quality of life and save money. A survey of the costs of care for Medicaid patients with HIV in Baltimore found that monthly costs for people with CD4+ T-cell counts under 50 (generally a sign of more advanced HIV disease) were more than twice those of people with more than 500 T-cells.⁹ As noted above, spending money in the early stages of HIV disease for treatment with combination drug therapies can reduce more expensive interventions later. Yet under the present Medicaid system, many living with HIV must wait for their T-cells to drop and their illness to worsen before they can receive coverage and access care.

GAPS IN HEALTH CARE COVERAGE REMAIN

The advances in overall health care and drug treatments have brought renewed health and unprecedented hope to many people living with HIV disease. For the first time in the 15 years of the AIDS epidemic, there has been a decrease in the numbers of Americans dying from AIDS. The U.S. Centers for Disease Control (CDC) reported a 13 percent decline in the number of AIDS deaths for the first six months of 1996, as compared to the same period in 1995, and attributed this decline to improved medical care, prophylaxis for OIs, and the use of combination therapies.¹⁰

In the same report, however, the CDC noted that AIDS continues to be the leading cause of death of Americans aged 25 to 44, and that the “increased prevalence of AIDS [in the U.S.] indicates the need for medical and other services for persons with HIV infection.” While the new medications make obtaining care more important than ever, challenges in expanding access to primary care and treatment remain.

Medicaid provides access to health care coverage for low income, uninsured, disabled people. Individuals who are HIV positive but have not been diagnosed with AIDS, however, are often not eligible for Medicaid, because they do not meet the program’s disability standards or other categorical eligibility requirements. To qualify for Medicaid, people must meet income requirements and the disability criteria of the federal Supplemental Security Income (SSI) program. The Social Security Administration uses the CDC’s definition of AIDS, along with evidence of functional impairments, as proof of disability.¹¹ **Despite the fact that early clinical intervention—including primary care, preventive services, and medication therapies—has**

⁹ R. Moore and R. Chaisson, “Costs to Medicaid of Advancing Immunosuppression in an Urban HIV-Infected Patient Population in Maryland,” *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 1997, 14:223-231.

¹⁰ Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173.

¹¹ The CDC definition of AIDS for surveillance purposes is: documented CD4+ T-lymphocyte counts <200 per microliter or percent of total lymphocytes <14 percent or a variety of opportunistic infections.

been shown to improve health and delay the onset of expensive opportunistic infections, most HIV positive individuals must wait until they “get sicker” and develop AIDS before they can receive Medicaid.

This is particularly devastating because the populations in which HIV infection is increasing are the ones likely to enroll in Medicaid once their HIV infection becomes full-blown AIDS. The epidemic is growing fastest among groups which have traditionally been socioeconomically disenfranchised, including racial and ethnic minorities, injection drug users, and women. In 1996, for the first time, blacks accounted for more AIDS cases than whites (41 percent versus 38 percent).¹² Women represented 20 percent of new AIDS cases in 1996, up from seven percent in 1985. While overall AIDS deaths declined 13 percent in the first half of 1996, deaths among women increased by three percent.¹³

These populations are also the groups less likely to have health insurance and access to treatments, and more likely to face barriers in obtaining health care, according to a survey by the Agency for Health Care Policy and Research.¹⁴ People who are uninsured or underinsured not only lack access to expensive combination therapies, but also to basic primary care and preventive services. Without insurance, people are more likely to wait until they have serious health problems before seeking care—problems which are then more expensive to treat. At this point, people would likely become eligible for Medicaid, but it is both inefficient and inhumane to require people to progress to an advanced stage of illness when we could offer access to effective and less costly care and treatment at an earlier time in the disease.

A Medicaid expansion also promotes public health, by giving uninsured and underinsured people with HIV an opportunity and an incentive to enter care earlier. Reaching people who would not otherwise have contact with health care systems provides the chance to teach and reinforce behavior changes which can prevent HIV transmission. [Reducing viral load through the use of combination drug therapies may also reduce infectiousness, although there is not yet conclusive scientific data on this issue.] The ongoing primary care and medical case management funded through Medicaid helps support patients in following complex treatment plans. If patients do not strictly comply with their combination therapy regimens, they are likely to develop drug-resistant strains of HIV. The existence of such drug-resistant HIV mutations may further complicate public health efforts to combat AIDS.

Despite the existence of federal AIDS programs, such as the AIDS Drug Assistance Programs (ADAPs) and the other components of the Ryan White CARE Act, Medicaid serves as the

¹² Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173.

¹³ *Id.*

¹⁴ P. Mohr, Patterns of Health Care Use Among HIV-Infected Adults: Preliminary Results,” *AIDS Cost and Services Utilization Survey*, Agency for Health Care Policy and Research, September 1994: 3.

foundation of AIDS care through its provision of both comprehensive health care and drug therapies. ADAPs provide limited prescription drug coverage for some uninsured and underinsured people with HIV and AIDS. But these programs cannot (and are not designed to) meet the need for comprehensive primary care and diagnostic services. In spite of their limited mission—to provide access to a limited formulary of proven AIDS medications—ADAPs face severe financial pressure in many states, and often cannot meet the growing demand for new combination therapies. In some states, ADAPs do not even cover protease inhibitors, and many offer a very limited formulary of antiretroviral and OI drugs. In other states, there are lotteries, long waiting lists, and increasingly restrictive eligibility criteria for ADAP participation.

While other Ryan White CARE Act programs pay for some primary care and drug reimbursement, they are not intended to provide widespread comprehensive health care. Ryan White funding is used for a range of care and services, including food, transportation, and case management for people living with AIDS. Additionally, many ADAPs and Ryan White-funded primary care programs have eligibility criteria which exclude people in the earlier stages of HIV disease. These programs lack the financial resources to broaden their eligibility criteria to cover such individuals.

Even if a person with HIV were able to obtain medications through an ADAP or Ryan White program, without primary care and services like medical case management, it is impossible to monitor that person and assure that the prescribed treatment regimen is appropriate and effective. An expansion of Medicaid can provide such care and services.

Some may question whether it is appropriate to have a disease-specific expansion of Medicaid, even as a demonstration project. We believe that it serves the interests of public health, scientific knowledge, and fairness to broaden Medicaid coverage to include people with HIV.

Public health: With earlier health care and treatment, as mentioned above, people living with HIV are more likely to avoid behaviors which can spread the virus, and are more likely to adhere to complex treatment plans, which can both prolong health and prevent development of drug-resistant strains of HIV.

Scientific knowledge: Protease inhibitors and other new medications received rapid FDA approval, have not yet been in long-term use, and have been researched mainly by studying people in more advanced stages of HIV disease. There are many remaining questions about the benefits, risks, and best way to use combination therapies in people who are HIV positive, but do not have AIDS. A Medicaid expansion demonstration project which brings people with HIV into care provides the opportunity to gather data and conduct research studies designed to answer these questions.

Fairness: The current Medicaid system requires most people with HIV to develop AIDS in order to gain access to health care and new combination therapies. This is unfair and inhumane, especially when the government provides treatment for other communicable

diseases, such as sexually transmitted diseases and tuberculosis. Principles and guidelines recently released by the Department of Health and Human Services and the NIH call for earlier intervention with combination drug therapies as the standard of care for the treatment of HIV in most cases. The government should ensure that this standard of care, endorsed by its own agencies, is accessible to those who have no other way to obtain it.

The Medicaid eligibility framework—requiring total disability to qualify for coverage—is at odds with current clinical and public health knowledge. Many low income HIV positive individuals with relatively intact immune systems are not presently eligible for Medicaid, but will eventually qualify for Medicaid after developing AIDS. Unable to afford adequate treatment early in their HIV disease, they cannot obtain the range of health care services necessary to manage the disease, and will be more ill when they do enroll in Medicaid. Ironically, earlier access to these medical services and treatments would enable them to preserve their health, learn how to prevent transmission of HIV to others, and avoid more costly care such as inpatient hospitalization. For humane, financial, and public health reasons, it is time to make Medicaid's eligibility requirements consistent with the clinical realities of HIV disease.

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In response to the contradictions between current Medicaid disability criteria and AIDS clinical evidence and care standards, which call for early treatment of HIV disease, representatives from the AIDS Action Council, community-based AIDS service organizations, the Health Care Financing Administration (HCFA) and the Office of Management and Budget (OMB) have begun to work collaboratively to address these issues. Response from the administration has been unequivocally supportive, culminating in endorsements from Vice President Al Gore, who has asked HCFA to find ways in which to expand Medicaid and allow more low-income Americans with HIV to access care and therapies. Gore is quoted as saying “[Medicaid expansion] can ease suffering, it can increase hope, and it can get new drug therapies into the hands of people who need them.” As a result of these collaborations, we are all working together under HCFA's leadership to develop a plan for expanding eligibility to Medicaid for persons who are HIV positive.

PROPOSAL DESIGN

The objective of this program is to expand Medicaid eligibility to low-income individuals who have tested positive for the presence of HIV and who would be otherwise eligible for Medicaid once their health status met an AIDS-defining diagnosis. States participating in this initiative will demonstrate that the provision of earlier access to care and treatment will extend the period of time that a person who is HIV positive remains asymptomatic, defer the onset of opportunistic infection, and delay hospitalization, all of which will result in significant cost savings and life-enhancing benefits. The following section describes what we believe are the core components of this initiative.

Eligibility

Any and all individuals who meet the following criteria will be eligible under this program:

- test positive for the presence of HIV; and
- have income at or below 200 percent of the federal poverty level.

State demonstrations will coordinate resources with other private, state, and federal programs. Individuals with private insurance can apply for and become eligible for Medicaid as a “wrap around benefit” thereby maximizing private insurance participation. State proposals will specify the state specific eligibility guidelines and coordination of other state and federal programs.

Covered Benefits

Ideally, states will provide the full benefit package (i.e., mandatory and optional Medicaid services) to individuals eligible through this program. In any case, benefit packages must be flexible to accommodate new treatment advances and changes in standards of care that become available during the course of the demonstration. Through this project, states, at a minimum, must provide:

- primary care,
- prescription drugs,
- diagnostic and laboratory services,
- mental health services, and
- substance abuse treatment services.

Options to Participate in the Demonstration Projects

Section 1115 of the Social Security Act allows the Secretary of Health and Human Services to grant waivers from the usual federal Medicaid requirements¹⁵ to states which want to create demonstration projects to test new approaches to Medicaid. These demonstration projects must be designed to promote the objectives of Medicaid,¹⁶ and must include a research and evaluation component. Generally, demonstration projects created under a Section 1115 waiver are supposed to be “budget neutral” over the life of the project, meaning that costs under the demonstration project do not exceed what costs would have been without the waiver in place. Section 1115 also authorizes matching federal funds for certain expenditures.

¹⁵ As defined in Section 1902 of the Social Security Act, and other provisions incorporated through Section 1902.

¹⁶ As set out in Title XIX of the Social Security Act.

This initiative will be designed to provide states with the maximum flexibility possible in participating in a Medicaid expansion demonstration project. The project does not necessarily need to meet the traditional definition of “budget neutrality,” since there can be federal and/or state subsidies. Also, budget neutrality should be measured within a time frame which is appropriate for assessing the clinical impact and cost-effectiveness of the new combination therapies (e.g., over a period of five to ten years).

Options for participation include the creation of a free-standing demonstration program or new or amended 1115 waivers. New 1115 waivers could provide the vehicle to expand Medicaid eligibility and/or allow a Medicaid buy-in option for those individuals otherwise ineligible for coverage. Amending an approved or pending 1115 waiver could also be used to expand eligibility. In addition, states could increase the income standards for their Medicaid buy-in programs, allowing more persons who are HIV positive to qualify. For example, states could set the income standard at 200 percent of the federal poverty level or they could use a graduated system to make more individuals eligible.

NEXT STEPS

Over the next several months, the AIDS Action Council will work with HCFA to develop and refine a solicitation process for states to successfully participate in the HIV Expanded Eligibility Demonstration Initiative. It is important for community-based AIDS service organizations to urge their state governors and Medicaid directors to advocate for this initiative with HHS and HCFA. While we expect that this initiative will offer states tremendous opportunities to provide cost-effective access and coverage to its most vulnerable populations, we also recognize the range of development and design issues that need to be resolved. Over the next several months, the AIDS Action Council will work with states and HCFA to complete the following tasks:

- Continue to work with HCFA to design a program that includes adequate incentives for state participation in this initiative.
- Build consensus among federal and state leadership, elected officials, and government staff, including representatives from Medicaid programs, Departments of Health, and Departments of HIV Services.
- Work with HCFA to develop a process that allows states to efficiently design and implement a vehicle for eligibility expansion that responds to the unique environment and situations of each state (waiver amendment or new waiver submission).
- Design a process to solicit input from consumers, AIDS service organizations, primary care and other health care providers, and [health care ?] agencies regarding program design and program effectiveness, on an ongoing basis.

- Work with HCFA to develop a methodology that allows states maximum flexibility in measuring cost effectiveness. The goal will be to have HCFA resolve methodology issues related to baseline measurements, the measurement of savings in other government programs, and evaluation time frames.
- Work with HCFA to identify and develop data bases that provide the information needed to estimate current expenditures and projected costs for the purposes of assessment and future planning. Necessary data includes the number of newly eligible individuals by state and service area (persons who are HIV positive with incomes below state defined eligibility criteria), utilization of services, and cost.

Congress of the United States

House of Representatives

Washington, DC 20515

December 11, 1997

The Honorable Donna Shalala
Secretary
U.S. Department of Health and Human Services
200 Independence Ave., S.W.
Washington, DC 20201

Dear Madame Secretary:

It is our understanding that the Health Care Financing Administration (HCFA) has discontinued efforts to expand Medicaid to provide a limited drug benefit to low-income persons who are HIV-infected and do not otherwise qualify for Medicaid coverage. As advocates of establishing such a Medicaid expansion, we strongly urge you to reconsider this issue and provide this limited benefit in the President's fiscal year 1999 budget request.

As you know, the new HIV/AIDS treatment guidelines issued by your Department make clear that early treatment with newly developed drugs is effective in helping to save lives. We have strongly supported and fought for increased funding in the AIDS Drug Assistance Program, but, unfortunately, even with those increases far too many people will still not receive appropriate treatment. In addition, we remain concerned that further increases of the magnitude necessary in this discretionary program may be extremely difficult to achieve. It is essential, therefore, that we pursue all avenues, including expanding Medicaid, to ensure that every person living with HIV has access to the recommended early treatment. Failure to do so is simply unacceptable. There are too many lives at stake.

We understand the concerns that officials at HCFA apparently have raised regarding the cost of providing this new Medicaid benefit. We respectfully suggest, however, that in the context of the overall budget, such a Medicaid expansion in fact would save money because expensive hospitalization and other treatments would be reduced and people would be prevented from becoming disabled and moving into the SSI program. Therefore, in keeping with the leadership you have provided in the past, we request that an HIV drug treatment Medicaid expansion be included within the Administration's budget request for fiscal year 1999 and look forward to working with you on this matter.

Sincerely,


Nancy Pelosi


Richard A. Gephardt

Medicaid Waivers

Federal law under Title XIX of the Social Security Act requires that Medicaid recipients be permitted to choose the provider of their health care services — the hospital, clinic, or physician — as long as that provider is willing to provide services at the prevailing Medicaid rate. This “free choice of provider” provision is the legal impediment to state Medicaid authorities’ requiring Medicaid recipients to enroll in managed care plans. Such plans, of course, reduce costs primarily by restricting patients’ choice of providers. There are mechanisms under Title XIX by which Medicaid authorities can legally restrict patients’ choice of providers. These are called “waivers,” and are largely of two types: 1915(b) and 1115, named after their respective statutory sections in Title XIX.

States are allowed to submit waiver applications to the federal Medicaid authority — the Health Care Financing Administration (HCFA) — to waive some of the provisions — including the free choice of providers — that govern the federal Medicaid program. Section 1915(b) and 1115 waivers allow states to alter the traditional delivery and financing mechanisms of Medicaid and other services to eligible populations. Section 1915(b) and 1115 waivers are different from each other mainly in terms of scope and affected population:

- Section 1915(b) waivers generally are defined for certain existing eligible populations, such as mentally ill or women and children on AFDC.
- Section 1115 waivers can extend Medicaid coverage to broader categories of individuals, including many of the uninsured.
- Section 1915(b) waivers are not required to be statewide in scope — the waiver can affect some parts of the state and not others.
- Section 1115 waivers must be statewide in scope.
- Section 1115 waivers can waive any Medicaid rule or regulation, while section 1915(b) waivers are only available to waive Medicaid requirements related to freedom of choice, comparability, and statewideness.

In many cases, the waivers allow for the expansion of eligibility criteria to include currently uninsured populations. Proponents of both the section 1915(b) and 1115 waivers suggest that they afford states the opportunity to expand coverage and maintain basic levels of quality and standards. Opponents argue that they can be used to restrict beneficiary choice, reward underutilization, and hurt quality of care.

Medicaid Reform: Managed Care & AIDS

I. Section 1915(b) Waivers

Section 1915(b) waivers allow states to enroll Medicaid beneficiaries in managed care plans by waiving beneficiaries' right to choose their own providers and limiting statewideness and comparability of services requirements. The 1915(b) waivers limit the beneficiaries' free choice of provider usually through primary care case management (PCCM) or managed care. Traditional staff model managed care plans contain costs through controlling access to providers within a defined network. Under PCCM programs, a particular health care provider, usually the beneficiary's primary care physician, serves as a "gatekeeper" to authorize and monitor the dispersal of benefits and services available in the plan. Section 1915(b) waivers also authorize states to provide home and community based services to the elderly, disabled children, people with HIV/AIDS, the mentally ill, and people with mental retardation/developmental disabilities. Under section 1915(b) waivers, states must demonstrate that the waiver is cost effective and will not exclude beneficiaries from accessing medically necessary services. Because the waivers tend to be more narrowly defined, the process for granting these waivers is much simpler than the process for granting section 1115 waivers — unless HCFA explicitly denies the application or requests more information, the 1915(b) waiver is approved. Section 1915(b) waivers are very common, with most states currently operating at least one 1915(b) waiver.

II. Section 1115 Waivers

Waivers under section 1115 of the Social Security Act are broader in scope than section 1915(b) waivers and have significantly changed the delivery of and eligibility for Medicaid services. Many 1115 waivers have been used to expand Medicaid coverage to uninsured groups either by expanding eligibility or by replacing traditional fee-for-service delivery models with capitated payments to managed care plans. States request 1115 waivers in order to establish statewide research and demonstration projects that are "likely to assist in promoting the objectives" of Medicaid, Aid to Families with Dependent Children (AFDC), and other Social Security Act programs. Section 1115 waiver applications are required to have research or experimental methodology. If approved, the research findings of these demonstration projects are systematically evaluated.

In 1993, responding to pressures from governors and state Medicaid directors, the Secretary of Health and Human Services revised the review and approval process for section 1115 waivers. The process was streamlined to encourage states to utilize section 1115 and expand Medicaid coverage through research and demonstration projects. Most current 1115 waivers have some of the following goals: to increase access to health services for some currently uninsured populations, to modify income or eligibility requirements, and/or to require enrollment in prepaid managed care plans. As of February 1996, fourteen (14) section 1115 waivers have been approved, one (1) waiver has been approved provisionally, and ten (10) waiver applications are currently pending. A chart outlining the current status of Medicaid waivers is attached as Appendix I.

Medicaid Reform: Managed Care & AIDS

Waivers granted under section 1115 have used a variety of approaches to expand eligibility and decrease program costs. Under the Tennessee waiver granted in 1993, the state developed the TennCare program for Medicaid beneficiaries. The TennCare program mandatorily enrolled all Medicaid beneficiaries into managed care. This mandatory enrollment cut program cost and allowed the state to expand eligibility requirement to include many of the previously uninsured working poor. TennCare offered relatively low reimbursement rates for providers, causing many physicians to opt out of the plan and restricting enrollee access to quality care.

Arizona was the first state granted a waiver under section 1115. Granted in 1982, the Arizona waiver created the Arizona Health Care Cost Containment System (AHCCCS) to provide care for the state's Medicaid beneficiaries. AHCCCS uses a competitive bidding process to identify managed care companies to contract for Medicaid managed care populations. The program has expanded eligible categories and produced cost-savings compared to traditional fee-for service Medicaid health care delivery.

Awarded in 1993, the Oregon 1115 waiver established a Medicaid managed care program that categorized and prioritized Medicaid procedures to control program costs. The program has cut costs through controlling access to what otherwise would have been provided as "medically necessary services." The Oregon waiver has used cost savings to expand eligibility to previously uninsured individuals. The Oregon plan and its prioritization of services caused much debate when originally proposed, and won HCFA approval only after revisions to comply with the Americans with Disabilities Act (ADA). These revisions ensured that various groups of people with disabilities were not adversely affected by the priority given to certain medical services.

III. Considerations for People with HIV/AIDS in the Waiver Process

The Medicaid waiver process has been used by states to expand access to the federal Medicaid program, particularly through mandatory enrollment of Medicaid beneficiaries in managed care plans. The overall goal of moving Medicaid recipients into managed care is to increase access while controlling or reducing costs; and in fact, managed care, with its emphasis on preventative and primary care, does offer, if pursued carefully, opportunities for improved health care and expanded access for the HIV-infected population. At the same time, however, consumers, patient advocates, state legislators, and others have questioned the ability of Medicaid managed care plans to provide adequate health services for people with chronic illnesses, like people with HIV/AIDS. In many instances, the waiver review and approval process has provided an opportunity for consumers, patient advocates, and others to voice concerns about the ability of Medicaid managed care plans to serve the health care needs of particular populations. During the waiver and review process, interested parties have lobbied for increased patient access, better data collection, and tighter monitoring standards, among other things. It is important to note that advocates and other interested parties can participate in both 1915(b) and 1115 waiver application

Medicaid Reform: Managed Care & AIDS

processes at both the state and federal level by voicing concerns to HCFA, state Medicaid authorities, and other entities involved in the process. In order to participate waiver application processes, advocates can:

- Develop contacts with state Medicaid authorities;
- Request information regarding waiver applications from HCFA Regional Offices;
- Participate in public meetings on waiver applications;
- Provide written comments regarding waiver applications to HCFA and other oversight authorities; and
- Develop coalitions with consumer groups, organized labor, health provider organizations, and other HIV/AIDS advocates.

Mandatory enrollment in Medicaid managed care poses specific issues for people with HIV/AIDS. People with HIV/AIDS and other special populations may have particular problems obtaining access to appropriate health care and other services in a managed care health delivery system. One particular concern for people with HIV/AIDS and others with chronic illnesses and disabilities is that specialists, rather than the primary care "gatekeepers" of most managed care plans, may better provide the care these populations need. People with HIV/AIDS require a broad range of treatment interventions during the course of their illness, often having higher utilization rates for medical services. Capitated financing mechanisms in managed care may adversely affect those beneficiaries who are more intensive users of care — like people with HIV/AIDS. As a result, many advocates have proposed excluding "special needs populations," like people with HIV/AIDS from mandatory enrollment in managed care. The following issues have arisen in waiver application processes as particular issues concerns for people with HIV/AIDS under Medicaid managed care:

- Role of the "gatekeeper" — specifically, the extent to which a "gatekeeper" without significant HIV expertise would impose barriers to medically necessary health care services for people with HIV/AIDS;
- The ability of plans to provide and document quality of care for people with HIV/AIDS;
- Availability of prescription drug services without significant restrictions on drug formularies; and
- Exclusion of pharmaceutical costs from capitated rate structures since the high and uncertain cost of drug treatments and prophylactic therapies for people with HIV/AIDS will greatly complicate the calculation of wraparound capitated rates.

In June 1995, HCFA presented a report related to the New York State waiver application. The HCFA report raised questions related to the following: primary care provider capacity; the effects on people with HIV/AIDS and other chronically ill and disabled populations; the effects on providers who serve low-income populations; quality of care; and the effects of budget cuts on the Medicaid managed care program. The HCFA questions were very specific in terms of the needs of people with HIV/AIDS under Medicaid managed care. In November 1995, the New York State Senate and Assembly requested that HCFA review the New York State waiver application in the same thorough manner it reviewed the New York City waiver application. In particular, the request focused on plan capacity, quality, enrollment and client education, the fate of "essential community providers," and access for people with HIV/AIDS and other chronically ill and disabled populations. The New York State waiver application is currently pending.

✓✓✓ Medicaid Waiver Action

1. **Develop contacts in your state in order to gain early access to information about proposed or pending waiver applications by your state.** (States are neither required to give public notice about waiver applications nor are they required to obtain approval from state legislatures prior to seeking Medicaid waivers. This further demonstrates the need for advocates to develop contacts with state Medicaid authorities.) Potential contacts include:
 - Individuals in your state Medicaid agency;
 - Contact person with the Health Care Financing Administration (HCFA) Regional Office responsible for your state waiver;
 - Consumer advocacy organizations in your area; and
 - Health care provider organizations in your area, like a hospital association, local and state medical and nursing societies and professional associations.
2. **Obtain public documents that refer or relate to the proposed or pending waiver.** Contact the state legislative bill service to determine if state legislation related to the waiver is pending. Obtain a copy of the waiver, including the state's model health plan/provider contracts and requests for proposal.
3. **Attend public meetings about the proposal.** Encourage providers and consumers to either submit comments and/or attend meetings.
4. **Obtain information about other state waivers.** Waivers from state to state are often similar in scope, and the experiences of other states can be particularly relevant.

Medicaid Reform: Managed Care & AIDS

- Managed care programs often limit access to mental health and substance abuse treatment. With the increased co-morbid conditions associated with HIV/AIDS, plans need to provide intensive case management and mental health and substance abuse services for people with HIV/AIDS.
- Plans have been reported to discourage providers from identifying themselves as HIV/AIDS specialists, for fear that people with HIV/AIDS would be attracted to join the plan.
- Some managed care plans may require copayments or other premiums for certain services. Copayments have been particularly problematic to people with HIV/AIDS due to the number and frequency of medical services they require.
- Providers and people with HIV/AIDS often do not have access to appropriate, HIV-specific quality of care measures so that they can judge comparative performance by managed care plans in providing AIDS care.

✓✓✓ Medicaid Managed Care Action

1. If your state is seeking a waiver for the mandatory enrollment of Medicaid beneficiaries into managed care plans, you need to become involved in the process. Advocates must highlight the potential problems of enrolling people with HIV/AIDS and other chronically ill populations into the plan.
2. Advocates should demand that managed care plans demonstrate their ability to provide physicians with HIV expertise and other factors important to HIV/AIDS patient population.
3. Advocates may want to suggest a modified enrollment schedule for people with HIV/AIDS and/or the development of HIV-specific managed care plans to provide specialized care for people with HIV/AIDS.
4. Advocates must demand adequate capitation rates for managed care plans for people with HIV/AIDS, that rates must be risk-adjusted, and that all medically necessary services be covered by the plans, including prescription drugs.
5. Advocates should demand that capitation rates have adjustment mechanisms to reflect costs of new treatments and therapies, as they are developed and approved by the Food and Drug Administration (FDA).
6. Demand that managed care plans include HIV/AIDS-specific outcomes and quality data. Marketing materials for managed care plans should also include patient satisfaction data for people with HIV/AIDS.

A Comparison of the Medicaid Provisions
in the
Balanced Budget Act of 1997 (P.L. 105-33)
with Prior Law

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INTRODUCTION

A Overview

The following table compares prior Medicaid law with the Medicaid provisions contained in the Balanced Budget Act of 1997 (P.L. 105-33), signed into law by President Clinton on August 5, 1997.¹ The legislation makes significant changes in the structure of the Medicaid program in the areas of eligibility, provider qualification and reimbursement, long-term care, and managed care. In many respects, the legislation reflects many of the changes in law and program structure which have taken place under statewide Medicaid managed care demonstrations authorized under Sections 1915 and 1115 of the Social Security Act.² The Congressional Budget Office has estimated federal savings of \$13 billion over five years from reductions in Medicaid spending under the Balanced Budget Act.

Eligibility. The Balanced Budget Act adds new state eligibility options for children and disabled persons, expands premium assistance for low income Medicare beneficiaries, and restores Medicaid coverage to children and immigrants who lost SSI benefits as a result of the 1996 welfare reform legislation.

Benefits. The legislation retains Medicaid as a program that covers a defined set of benefits. It adds a new primary care case management benefit option and liberalizes eligibility requirements for Medicaid assistance under home- and community-based care waivers.

Premiums and Cost Sharing. The new law permits states to impose cost sharing on beneficiaries enrolled in managed care organizations to the same extent as is permitted in the fee-for-service program.

Provider Participation and Reimbursement. The new law makes major changes in payment rules for hospitals, nursing homes, intermediate care facilities, home health agencies, federally qualified health centers (FQHCs), and rural health clinics (RHCs). In fact, most of the reductions in federal Medicaid spending are achieved through reductions in provider payments, the most significant of which are targeted to disproportionate share hospitals. The new law also repeals the Boren Amendment and phases out cost based reimbursement for FQHCs and RHCs. The legislation also allows states to pay Medicare providers the Medicaid reimbursement rate for services provided to Qualified Medicare Beneficiaries and dual eligibles.

¹For an additional analysis detailing the new legislation and the financial assumptions on which it is based see Andy Schneider, *Overview of Medicaid Provisions in the Balanced Budget Act of 1997, P.L. 105-33* (Center on Budget and Policy Priorities, Washington D.C., August, 1997).

²For a review of Section 1115 demonstrations and their implications for Medicaid reform see Sara Rosenbaum and Julie Darnell, *Statewide Medicaid Managed Care Demonstrations under Section 1115 of the Social Security Act: A Review of the Waiver Applications, Letters of Approval and Terms and Conditions*, (Washington, D.C.: Kaiser Commission on the Future of Medicaid), 1997.

Managed Care. The Balanced Budget Act eliminates many of the provisions of prior law for which states frequently request waivers under Section 1915 and Section 1115 of the Social Security Act. Most significantly, the new law permits states to require Medicaid beneficiaries to enroll in a managed care organization without first obtaining waiver approval from HCFA. Furthermore, the new law permits the establishment of Medicaid-only plans without Secretarial approval by eliminating the pre-existing 75/25 Medicaid/private coverage composition requirement and increases to \$1 million the threshold for prior federal approval of managed care contracts. Finally, the law establishes certain new managed care consumer protections, but exempts Section 1915 and Section 1115 waiver states from its new requirements.

Long-Term Care. The new law establishes an optional program, Program of All Inclusive Care for the Elderly (PACE), for Medicare entitled Medicaid beneficiaries who are 55 years of age or older, require nursing facility-level care, reside in the PACE program service area, and meet other applicable conditions of eligibility permitted under the program.

Federal Financial Assistance. The Balanced Budget Act makes changes in the amount of federal payments to the states and the territories and to specific providers. The new law increases federal payments to D.C., Alaska, and the territories. Furthermore, it entitles 12 states with the highest number of undocumented persons to additional funding for FY 1998 through FY 2001 for emergency services furnished to otherwise eligible undocumented persons. The law places additional caps on state DSH allotments, beginning 1998, with the specific amount established per state until FY 2002; thereafter, the allotment is increased by the CPI.

B Eligibility

The legislation makes the following changes in Medicaid eligibility:

- **Restores Medicaid (and Supplemental Security Income (SSI)) to elderly and disabled legal residents who lived in the U.S. and received assistance as of August 22, 1996**, the date on which the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, which terminated such coverage, was signed into law. Additionally, the legislation permits legal residents who were in the U.S. as of August 22, 1996, to receive SSI and Medicaid if they become disabled in the future.
- **Restores Medicaid to children who were receiving SSI and Medicaid as of August 22, 1996 who lose their SSI coverage as a result of changes enacted in the welfare reform legislation**, and who continue to meet the previously applicable SSI disability criteria (which included coverage of children with functional disabilities) as well as SSI financial eligibility rules and other conditions of eligibility.

- **Creates a new state option to provide 12 months of continuous eligibility to children up to age 19.** States also have new authority to grant presumptive (i.e., temporary) Medicaid eligibility to children under 19 while their applications for Medicaid or the state's children's insurance program are pending.
- **Permits states to guarantee 6 months of Medicaid coverage to managed care enrollees.**
- **Establishes a new capped Medicare Part B block grant** (\$1.5 billion between FY 1998 and FY 2002) which entitles states (but not individuals) to financial assistance for the cost of paying Medicare Part B premiums for low income persons on a first-come, first-served basis. Eligibility for full premium assistance is limited to individuals with incomes between 120% and 135% of the federal poverty level, with partial premium assistance for individuals with incomes between 135% and 175% of the federal poverty level.
- **Creates a new state option to permit disabled SSI beneficiaries with incomes up to 250% of the federal poverty level who are not otherwise eligible for benefits to buy into Medicaid** on a sliding scale premium basis.

Companion provisions in the Act provide states with \$20.3 billion over a five-year time period beginning in FY 1998 to extend insurance coverage to children. The new State Children's Health Insurance Program (Title XXI of the Social Security Act) gives states the option of using their new funds to either extend Medicaid coverage to additional children or establish alternative insurance programs for these children. The legislation also permits states to accelerate coverage of poverty-level children under age 19 regardless of their date of birth (prior law limited mandatory coverage to children born after September 30, 1983).

C Benefits

The law retains the existing defined set of benefits but restricts assistance for Medicare beneficiaries who also qualify for Medicaid. The new law:

- **Eliminates state requirement to pay the 20 percent Medicare coinsurance for qualified Medicare beneficiaries and dual enrollees** if such payments exceed the state Medicaid program's payment schedule for similar services. Medicare providers would be prohibited from balance billing beneficiaries for the unpaid coinsurance amount.
- **Requires the Department of Health and Human Services to conduct a study and report to Congress on the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit.** The report is due one year following enactment.

D Premiums and Cost Sharing

The new law modifies the rules on cost-sharing for enrollees in managed care organizations

- **The legislation retains most prior rules on cost sharing**, but permits states to impose cost sharing on managed care organization enrollees to the same extent that it is permitted in the fee-for-service system

E Provider Participation and Reimbursement

The legislation includes major changes in payment rules for hospitals, nursing homes, intermediate care facilities and home health agencies. The law also revises the payment system for federally qualified health centers (FQHCs) and rural health clinics (RHCs) that participate in managed care. In addition, the law alters the payment methodology for disproportionate share hospitals and sets new rules for payment to hospitals that participate in managed care arrangements. The legislation

- **Repeals the Boren Amendment and related cost reimbursement provisions** relating to nursing facilities, intermediate care facilities for the mentally retarded (ICF/MR) and home health agencies
- **Revises the existing disproportionate share hospital (DSH) payment requirements and reduces DSH payments by \$10.4 billion over 5 years.** It requires states to develop a system for identification of DSH facilities and for making payment adjustments to these facilities. The law also limits DSH payments to Institutions for Mental Diseases* (IMD) and requires direct supplemental DSH payments in certain instances to qualifying disproportionate share hospitals that participate in managed care arrangements.
- **Phases out cost-based reimbursement over a 6 year period while establishing new state payment obligations to FQHCs and RHCs that contract with managed care organizations.**

*The law provides a phase down method for payments to IMDs. Early analysis suggests that the IMD payment formula will need to be revised because it was erroneously drafted and results in federal payment reductions that are significantly below the agreed-upon level

The legislation makes far-reaching changes and establishes new consumer protections under Medicaid managed care. States with Section 1115 and Section 1915 managed care demonstrations are exempted from new consumer and managed care organization provider protections (unless also required as a condition of their demonstration approval).⁴ The law

- **Permits states to condition Medicaid coverage for nearly all enrollees on mandatory enrollment in a qualified managed care entity.** This new Section 1932 option does not require federal waiver approval but operates instead through the more simple state plan amendment process. Exempted from the new state option process are children with special health care needs (including SSI children, certain institutionalized children, children receiving foster care and adoption subsidies, and children recognized as "special needs" children under state Maternal and Child Health Block Grant programs) as well as Medicaid beneficiaries also enrolled in Medicare (e.g., as dual enrollees, qualified Medicare beneficiaries (QMBs) or specified low income Medicare beneficiaries (SLMBs)). States may seek permission under Section 1915 or Section 1115 to mandate enrollment of these populations. States may also continue to use Section 1915 and Section 1115 for other populations.
- **Permits states to continue their managed care demonstration programs and exempts them from new consumer and managed care organization (MCO) protections.** States would be permitted to extend their Section 1115 demonstrations through an expedited process for up to 3 years. They could also continue to use the Section 1915 waiver statute both for the special needs children and low income Medicare beneficiaries who are exempt from the new state managed care option, as well as for other populations covered by the new option. States that continue to operate their managed care programs as demonstrations would be exempt from the new consumer and MCO protection requirements.
- **Creates two basic statutory categories of "managed care entities": primary care case managers and managed care organizations.** These entities may participate in the program if they meet applicable conditions of participation set forth in the statute and in their provider contracts. Certain federal requirements are applicable to both types of entities, while others apply only to larger "managed care organizations" which are distinguished by the fact that they are at financial risk for three or more contract services. Primary care case managers (PCCMs) (first authorized under Section 1915 enacted in 1981) may participate if they enter into either fee-for-service or risk-based "primary care case management" contracts with a state. Managed care organizations include traditional federally qualified or state licensed HMOs as well as other organizations (including Medicare Provider Sponsored Networks and other entities participating in the new Medicare+Choice program).

⁴The Secretary could alter her demonstration standards to require compliance with these new requirements as a condition of approval of new or continuing waivers. At this point no action has been taken.

- **Establishes minimum federal conditions of participation for PCCMs and revises the conditions of participation for HMOs and other managed care organizations.** The law repeals certain HMO standards (most notably, the prohibition against participation by plans with 75% or greater Medicare/Medicaid enrollment) and revises and, in some cases, expands other requirements. The law establishes new consumer protections in the areas of emergency care (requiring coverage in accordance with a "prudent layperson" standard), hospital stays for mothers and newborns, and mental health parity. The legislation also establishes new standards governing prohibitions on physician communication, managed care organization solvency, information and disclosure, and access to care.⁷ Most standards applicable to managed care organizations do not apply to PCCMs.
- **Gives auto-enrolled managed care enrollees a 90-day period to switch plans.**
- **Creates certain requirements for states that elect to mandate managed care enrollment,** including choice of plan for non-rural beneficiaries, information and disclosure to beneficiaries, use of certain intermediate sanctions in the case of plans which are substantially out of compliance with conditions of participation, anti-fraud and abuse measures, requirements applicable to contracts with managed care entities, and prior approval of all contracts valued at \$1 million or more by HCFA.
- **Creates a new right of managed care entities to notice and a hearing prior to the termination of a contract with a state Medicaid agency.** States may, but are not required to, notify enrollees that a termination proceeding is under way and offer them the choice of disenrollment.
- **Retains the right of most managed care enrollees to select the family planning provider of their choice.** The right is retained for enrollees of comprehensive service managed care organizations regardless of whether they are enrolled through Section 1915 or Section 1932 or waived as part of a Section 1115 demonstration. PCCM enrollees in Section 1915 demonstrations continue to have a free-choice-of-provider right, but the right does not appear to extend to PCCM enrollees in the Section 1932 state option arrangements that do not require Secretarial waiver approval.

⁷House provisions which would have guaranteed beneficiaries direct access to obstetrical and gynecological care as well as set forth more detailed grievance requirements for managed care organizations were dropped in conference.

G Long Term Care

The legislation creates a new long-term care option, building on the experience of the On Lok and PACE demonstration programs, which are terminated

- **The legislation creates a new state option to extend the Medicare PACE program** (Programs of All Inclusive Care for the Elderly) to Medicare entitled Medicaid beneficiaries who are 55 years of age or older, who require nursing facility-level care, and who meet other applicable conditions of eligibility permitted under the program. PACE providers would be required to furnish eligible persons with 24 hour-per-day access to all medically necessary services covered under Medicare and Medicaid without any limitation or condition on amount, duration and scope and without application of deductibles, coinsurance or other cost sharing that would otherwise be applicable under Medicaid. States have the authority to limit enrollment under PACE.

H Federal Financial Assistance

The new law makes no change to prior payment structure but reduces federal DSH payments by \$10.4 billion over five years, with upward adjustments for inflation in subsequent years. It also includes a 4-year \$100 million emergency care fund (\$25 million a year) for 12 states with high numbers of undocumented aliens. The law:

- **Reduces disproportionate share hospital (DSH) payments to states**, establishing specific annual payment levels for each state in the statute. After 2002, each state's DSH payment would be permitted to rise with the medical component of the CPI, subject to an upper limit of 12 percent of total state Medicaid expenditures.
- **Increases federal payments to the District of Columbia and the trusts and territories.** The law increases the federal medical assistance percentage (FMAP) to the District of Columbia from 50 percent to 70 percent. Federal payments to the trusts and territories are increased but continue to be subject to statutory limits.
- **Authorizes a new state entitlement grant program of \$100 million over 4 years (FY 1998 through FY 2001) for emergency services to each of the 12 States with the highest number of undocumented aliens.** Each state's allotment of total funds would be based on its share of the total undocumented aliens in the 12 eligible states. Estimates of the number of undocumented aliens would be prepared by the Immigration and Naturalization Service (INS).

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
A. OVERVIEW		
1. Summary	Eligibility. Entitles individuals who meet eligibility conditions to coverage for a range of required and optional acute and long-term care services. Benefits. Entitles individuals to coverage for a defined set of benefits. Premiums and Cost Sharing. Permits copayments for Medicaid beneficiaries in limited circumstances. Provider Participation and Reimbursement. Entitles certain providers, including hospitals, nursing homes, home health agencies, federally qualified health centers (FQHCs), and rural health clinics (RHCs), to reimbursements in accordance with cost principles under a provision commonly known as the Boren Amendment. Providers serving Medicaid beneficiaries with Medicare receive the Medicare payment rate. Managed Care. Permits states to offer voluntary managed care enrollment. Permits states to mandate enrollment via federal waivers of the freedom of choice provisions (Section 1915 or Section 1115). Permits states to implement research and demonstration programs for up to 5 years. Long-Term Care. Mandates coverage of nursing facility, home health benefits and hospital services for all beneficiaries and gives states the option to cover other benefits. Federal Financial Assistance. States are entitled to open ended federal contributions toward program costs, with upper limits on disproportionate share hospital payments. Prohibits non-emergency Medicaid coverage of otherwise eligible undocumented aliens.	Retains Medicaid as an individual entitlement with open ended federal financing. Adds new eligibility options for children and persons with disabilities, expands coverage of low income Medicare beneficiaries, and restores coverage for certain disabled children and elderly and disabled legal residents. Retains the existing defined benefit package while adding new benefit options for primary care case management, and liberalizing eligibility requirements for assistance under home and community based care. Expands state options to require cost sharing for members of managed care organizations to the same extent that it is permitted in the fee for service system. Repeals Boren Amendment cost payment requirements for hospitals, nursing facilities and home health agencies. Phases out cost reimbursement for FQHCs and RHCs. Eliminates entitlement to payment at the Medicare rate for Medicaid beneficiaries who also are enrolled in Medicare. Permits states to mandate managed care enrollment for all Medicaid beneficiaries except special needs children and Medicaid beneficiaries who receive Medicare. Allows states to continue their Section 1115 and 1915 demonstrations and to continue using the demonstration authority in lieu of the new state option. Creates a new state option to extend the Medicare PAUL program. Makes no change to prior payment structure but reduces federal DSH payments by \$10.4 billion over five years, with upward adjustments for inflation in subsequent years. Includes a 4 year \$100 million emergency care fund for 12 states with high numbers of undocumented aliens.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
B. ELIGIBILITY		
1. General approach to eligibility	Entitles eligible persons to coverage for defined benefits, with eligibility conditioned on a series of financial, categorical and general conditions of eligibility Entitles individuals who meet eligibility requirements to coverage for medical assistance items and services covered under a State's Medicaid plan when furnished by participating providers	Retains the individual entitlement to coverage for eligible individuals with open-ended financing. Adds new eligibility options for children and persons with disabilities, expands coverage of low income Medicare beneficiaries, and restores coverage for certain disabled children and elderly and disabled legal residents Permits states to condition coverage for most beneficiaries on mandatory enrollment in a managed care entity. Exempts Medicaid beneficiaries who receive Medicare and special needs children (those who receive SSI, are in foster care or adoption placements, are recognized as "special needs" children under Title V, and certain institutionalized children) from mandatory managed care enrollment
2. Poverty-level children	Mandates coverage of all poverty level children up to age 19 who meet financial conditions of eligibility and who were born after September 20, 1983, thereby phasing in coverage for children under 19 to the year 2002 States can expand coverage to children under 1902(r)(2) or Section 1115 waivers	Clarifies state option to immediately extend coverage to all poverty level children under age 19. Accompanying provisions under the State Children's Health Insurance Program provide additional federal financial participation (FIP) to states that elect to extend Medicaid eligibility to additional groups of children
3. Disabled children	Disabled children who receive SSI automatically receive Medicaid in most states. Children's disability criteria was restricted under the 1996 welfare reform law to remove functionally disabled and certain mentally ill children. Approximately 95,000 children receiving SSI (out of 170,000 cases reviewed) have had their benefits terminated	Requires states to restore Medicaid to children who lose SSI as a result of welfare reform and who would continue to qualify for SSI under pre-welfare reform SSI standards
4. Continuous coverage of children	Terminates eligibility for children who no longer meet conditions of eligibility	Permits states to guarantee 12 months continuous eligibility following a determination of eligibility up to an age specified by the state, but not exceeding 19 years of age
5. Presumptive eligibility for children	Provides states with the option to extend a period of presumptive (i.e., temporary) eligibility for prenatal care in the case of pregnant women who have applied for Medicaid and who, based on preliminary information, appear to be eligible for coverage.	Adds a state option to provide presumptive Medicaid eligibility for children under age 19 and identifies the following organizations as potentially qualified to make presumptive eligibility determinations: Head Start agencies, child care providers and WIC programs. Presumptive eligibility costs are offset against payments to states under the new State Children's Health Insurance Program

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
B. ELIGIBILITY		
6. Legal Immigrants	The 1996 welfare reform law terminated SSI for legal aliens and authorized, but did not require, states to continue Medicaid. As of Spring 1997, seven states had elected not to extend Medicaid to some or all former SSI recipients who were qualified aliens. Imposes 5 year limit on Medicaid coverage for non-emergency care only for otherwise eligible "qualified" aliens who enter the U.S. on or after August 22, 1996.	Restores SSI and Medicaid benefits to all elderly and disabled qualified aliens who received SSI and Medicaid as of August 22, 1996. Additionally permits legal residents in the U.S. as of August 22, 1996, to receive SSI if they subsequently become disabled and qualify for coverage. Extends from 5 to 7 years the time period for which eligible refugees may receive SSI and emergency Medicaid coverage. Adds Cuban and Haitian entrants to the group of legal immigrants covered by the exemptions for refugees. Exempts legal immigrants who are members of an Indian tribe from the restrictions on SSI and Medicaid eligibility.
7. Undocumented aliens	Prohibits medical assistance other than emergency coverage to undocumented aliens who would otherwise meet the eligibility requirements for the state's Medicaid program.	Authorizes a new capped state entitlement grant program of \$100 million (\$25 million per year for FY 1998 through FY 2001) for emergency services for undocumented aliens to each of the 12 States with the highest estimated number of undocumented aliens. Each state's allotment of total funds would be based on its share of the total undocumented aliens in the 12 eligible states. Estimates of the number of undocumented aliens would be prepared by the Immigration and Naturalization Service.
8. Low-income Medicare beneficiaries	Requires states to pay for the premiums, deductibles and coinsurance to Qualified Medicare Beneficiaries (QMBs) with resources at or below twice the SSI resource eligibility standard and with incomes at or below 100% of the FPL. Requires states to pay Medicare premiums for Specified Low Income Medicare Beneficiaries (SLIMBs) with family incomes at or below 120% of the FPL and resources at or below twice the SSI resource eligibility standard. Federal contributions to the QMB and SLMB program are at the state's federal medical assistance percentage rate (between 50% and 79% of total state outlays).	Creates a new \$1.5 billion, 100% federally financed state entitlement, payable out of Medicare Part B, to provide premium assistance to low income elderly and disabled beneficiaries. Specifies that individuals are not entitled to coverage. Funds are allocated to states based on the proportion of low income elderly persons residing in the state. Funds would be used to assist states to increase coverage of SLIMBs from 120% to 135% of the Federal Poverty Level (FPL) and to provide partial assistance to beneficiaries with incomes up to 175% of the FPL to offset the Part B premium rise as a result of Medicare home health coverage changes. Coverage of eligible persons would be on a first come, first served basis until funding runs out. Program ends in December 2002.

A Comparison of the Medicaid Provisions In the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
B. ELIGIBILITY		
9. Disabled workers	Mandates coverage of persons "who previously received SSI if they continue to have a disabling physical or mental impairment, continue to meet all SSI requirements other than income from earnings, do not have enough earned income to disqualify them from special SSI coverage, and would be seriously inhibited from continuing to work in the absence of Medicaid and do not have enough earnings to provide a reasonable equivalent to Medicaid "	Authorizes states to offer buy-in coverage (with the premium based on a sliding scale) to otherwise ineligible disabled workers with incomes up to 250% of the FPL who, but for excess income, would receive SSI

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
C. BENEFITS		
1. General approach to benefits	Medicaid beneficiaries are entitled to coverage for a defined set of benefits. Certain benefits are required while others are included at state option. Coverage must be sufficient in amount, duration and scope to reasonably achieve the purpose of the benefit and states may not arbitrarily discriminate in coverage based on a condition or diagnosis.	Retains the existing defined benefit structure while adding new benefit options for primary care, case management, and liberalizing eligibility requirements for assistance under home- and community-based care waivers.
2. Early and Periodic Screening, Diagnosis and Treatment (EPSDT)	Mandates coverage for beneficiaries under 21 years of periodic and as needed health exams, vision, dental and hearing care, and all federally recognized medically necessary treatment regardless of coverage for adults. Coverage levels exceed usual benefits offered by most commercial insurance plans.	Directs the Secretary to contract a study of the actuarial value of the EPSDT benefit, including the medically necessary treatment requirement. The report is due to Congress one year following enactment.
3. Primary care case management services	Primary care case management services are not an explicitly recognized Medicaid benefit. States may cover case management services at their option (case management services are required for children if medically necessary). Case management is defined as a service which assists beneficiaries to obtain necessary medical, educational, health or social services.	Adds a new primary care case management (PCCM) coverage option. PCCM benefits are defined as "case management related services (including coordinating and monitoring of health services) provided by a primary care case manager under a PCCM managed care contract. Primary care means services customarily provided by primary care practitioners (including medical, health and lab services).
4. Home- and community-based care	Limits coverage of habilitation services under Section 1915(c) home- and community-based demonstrations to individuals who otherwise require nursing home or other forms of institutional care.	Eliminates the prior institutionalization requirement for habilitation services in the case of individuals participating in home- and community-based care demonstration programs.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
D. PREMIUMS AND COST SHARING		
1. General approach to premiums and cost sharing	Authorizes the use of copayments in the case of certain beneficiaries but prohibits cost sharing for children, pregnant women (other than premiums for pregnant women with incomes > 150% of the FPL), nursing facility residents and HMO enrollees	Modifies rules on cost sharing for MCO enrollees
2. HMO copayments	Prohibits the use of copayments and cost sharing in the case of HMO enrollees	Allows cost sharing for managed care enrollees to the same extent as in the fee for service program.
3. Co-insurance requirements for dual eligibles and Qualified Medicare Beneficiaries (QMBs)	State Medicaid programs are required to pay Medicare cost sharing charges (20% coinsurance) for dual eligibles and Qualified Medicare Beneficiaries (QMBs)	Eliminates state requirement to pay 20% coinsurance for Medicare beneficiaries if payment for services under Medicare exceeds that of Medicaid
4. Payment of Medicare premiums for Specified Low-Income Medicare Beneficiaries (SLMBs)	Entitles Specified Low-Income Medicare Beneficiaries (SLMBs) with income at or below 120% of the FPL and resources at or less than twice the SSI resource eligibility standard to coverage of Medicare premiums only. Federal contributions to the SLMB program are at the state's federal medical assistance percentage rate (between 50% and 79% of total state outlays)	Establishes a total state entitlement to \$1.5 billion under Medicare Part B between January 1998 and December 2002. Funds must be used to pay Part B premiums for low income beneficiaries with family incomes between 120% and 135% of the FPL, with partial premium assistance for persons with incomes between 135% and 175% of the FPL to offset Part B premium increases resulting from Medicare home health changes. (The Part B premium is set at 25% of the program's cost, home health was transferred from Part A to Part B, thereby requiring an increase in the premium). Assistance would be on a first come, first served basis for a five-year period, with no entitlement to any individual. Federal contributions to state programs would be 100% FFP level.
5. Private health insurance premiums	Requires states to pay private health insurance premiums in the case of beneficiaries with access to private health coverage to the extent that such payments are determined to be cost effective. Individuals are required to enroll in cost effective arrangements as a condition of coverage	Revises the provision to make the purchase of private health insurance at state option along with enrollment in cost effective arrangements as a condition of coverage

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
E. PROVIDER PARTICIPATION AND REIMBURSEMENT		
1. General approach to provider reimbursement	Statute establishes certain rules on provider reimbursement with minimum payment standards for certain providers	Eliminates minimum payment standards for most classes of providers. Repeals Boren Amendment cost payment requirements for hospitals, nursing facilities, and home health agencies. Revises cost reimbursement system for federally qualified health centers (FQHCs) and rural health clinics (RHCs). Eliminates entitlement to payment at the Medicare rate for Medicare providers furnishing services to Medicaid beneficiaries also enrolled in Medicare.
2. Hospitals	State payment to hospitals must be reasonable and adequate to meet the cost of efficiently provided care as required under the Boren Amendment, subject to Medicare upper payment limits. Provisions do not apply to institutions that are participating providers in risk contracts with managed care plans.	Repeals the Boren Amendment. ⁶ Establishes a public rate setting process under which proposed rates, methodologies underlying the rates, and justifications for such rates, are published and subject to public review and comment. Requires Secretary of HHS to study the effects of state rate setting methods on access and quality. Retains Medicare upper payment limit provisions.
3. Disproportionate Share Hospitals (DSH hospitals)	Requires states to make additional payments to hospitals (known as disproportionate share hospitals (DSH hospitals)) that serve a disproportionate number of low income and Medicaid patients. States must make DSH payments to DSH hospitals that have Medicaid utilization rates more than one standard deviation above the average Medicaid utilization rate for participating hospitals in the state or a low-income utilization rate greater than 25 percent. States may also treat as a DSH hospital any hospital with Medicaid inpatient utilization greater than 1% (including state mental hospitals).	Reduces federal DSH payments to states by \$10.4 billion from FY 1998 to 2002, with actual payment amounts per state set forth in statute for each fiscal year between FY 1998 and FY 2002. After 2002, DSH payments for each state would rise by an amount equal to the medical care component of the Consumer Price Index (CPI) for urban consumers, with aggregate DSH payments capped at 12% of a state's total Medicaid expenditures. Prohibits states from folding DSH payments into HMO payments and requires separate and direct payment to DSH facilities. Exempts current payment arrangements.
4. Nursing facilities	State payment to nursing facilities must be reasonable and adequate to meet the cost of efficiently provided care as required under the Boren Amendment. Medicare upper payment limits apply. Provisions do not apply under HCFA regulations to institutions that are participating providers in risk-based managed care plans.	Repeals the Boren Amendment. Establishes a public rate setting process under which proposed rates, methodologies underlying the rates, and justifications for such rates are published and subject to public review and comment. Requires Secretary of HHS to study the effects of state rate setting methods on access and quality.

⁶The statute is unclear regarding whether the repeal of the Boren requirements is retroactive.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
E. PROVIDER PARTICIPATION AND REIMBURSEMENT		
5. Managed care entities	Requires that Medicaid payment to a contractor under a risk contract for a defined scope of services be actuarially sound Payment may not exceed the cost to the agency of providing similar services on a fee-for-service basis (known as upper payment limits)	No change to prior law No change to prior law
6. Federally qualified health centers (FQHCs) and rural health clinics (RHCs)	Federally qualified health center (FQHC) and rural health clinic (RHC) services are mandatory. FQHCs and RHCs receive cost-based reimbursement. Special rules apply to FQHCs and RHCs that participate in risk-based managed care systems that permit them to elect cost-based reimbursement.	Phases out reasonable cost payment as follows: 100% in FY 1998 and 1999, 95% in FY 2000, 90% in FY 2001, 85% in FY 2002, and 70% in FY 2003. Repeals requirement on October 1, 2003. Additionally, limits the definition of FQHCs and RHCs to exclude entities that are provider-owned. Prohibits managed care organizations from discriminating against clinics in establishment of payments. Establishes new payment system for FQHCs and RHCs that contract with managed care organizations that requires state agencies to pay FQHCs and RHCs the difference between the amount received from managed care organizations and the amount they are owed under applicable cost principles.
7. Obstetric and pediatric providers	Requires states to submit data on obstetric and pediatric payment levels to demonstrate that payments are sufficient to enlist adequate numbers of providers.	Eliminates obstetric and pediatric payment rate requirements.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
F. MANAGED CARE		
1. General approach to managed care	Authorizes states to offer enrollment as a beneficiary option in qualified managed care entities. Entities that meet the requirements of Section 1903(m) (HMOs and HIOs) are the only entities formally recognized in statute. Additionally the Secretary permits states to mandate enrollment through Section 1915 or Section 1115 freedom-of-choice waivers. States may offer enrollment in HMOs and HIOs or with primary care case managers (PCCMs) who may be paid on a fee-for-service or risk basis. As of 1996 virtually all states mandated managed care enrollment for at least some Medicaid beneficiaries; one third of all beneficiaries were enrolled in managed care. Federal statute establishes conditions of participation for HMOs and HIOs covered by Section 1903(m). States may seek waiver of these conditions under Section 1115 demonstrations.	Permits states to mandate managed care enrollment as a condition of coverage and without either Section 1915 or 1115 waivers for all Medicaid beneficiaries except beneficiaries who are either: (1) receive Medicare, Indians and children with special health care needs (i.e., children on SSD, children with special health care needs under the Title V MCH block grant, or certain institutionalized children). Indians may be required to enroll under certain circumstances. Creates two new groups of "managed care entities" under the statute: "managed care organizations," which are managed care companies at risk for both hospital and physician care and which must meet the conditions under Section 1903(m), and primary care case managers, which do not offer comprehensive care and which may be paid on a fee-for-service or risk basis. States may continue to seek Section 1915 and Section 1115 waivers in order to mandate enrollment for special needs children and Medicare/Medicaid beneficiaries. States may also seek Section 1115 waivers for other aspects of their managed care programs (e.g., waiver of new conditions of participation). Expands categories of managed care organizations covered by Section 1903(m). Relaxes certain existing conditions of participation for managed care organizations covered by Section 1903(m) while adding other conditions of participation in the areas of access, solvency, fraud and abuse, quality assurance, protections against patient billing, information and disclosure and marketing.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
F. MANAGED CARE		
2. Continuation of Section 1915 and 1115 waivers	Under authority granted by Section 1115 of the Social Security Act, the Secretary may allow states to implement research and demonstration programs for a period of up to five years. In the case of Arizona, however, the waiver has been renewed several times since its implementation in 1983. As of September 1997, 26 states had requested, been approved to operate, or actually were operating statewide mandatory Medicaid managed care demonstrations under Section 1115. Under the authority granted under Section 1915 states may waive the freedom of choice provision in order to require enrollment in managed care arrangements. States may implement Section 1915 waivers for up to 2 years, with renewals available thereafter. As of 1997, 40 states were operating 1915(b) waivers.	Allows states to continue their Section 1115 and 1915 demonstrations and to continue using the demonstration authority in lieu of the new state option. States operating under Section 1115 or 1915 are exempt from the new consumer and managed care organization protections until the protections are included as waiver conditions. Establishes an expedited Section 1115 renewal process, with 3 year renewals available. Allows states to continue to mandate managed care enrollment as part of a Section 1915 demonstration as opposed to the new option, which is subject to new federal requirements.
3. Mandatory enrollment as a condition of coverage	States have the option to offer managed care enrollment to any group of beneficiaries on a voluntary basis. Enrollment may be mandatory only if states receive federal waivers and the federal government approves in advance the design of the managed care program with respect to access and quality.	Creates a new state option to mandate managed care enrollment as a condition of eligibility for medical assistance for all beneficiaries except individuals eligible for Medicare, Indians, and special needs children. State mandates would be implemented as state plan amendments and without advance federal approval except for contracts valued at \$1 million or more, adjusted for inflation.
4. Enrollment composition of Medicaid-qualified managed care organizations	Managed care organizations operating on a full-risk basis (i.e., at risk for three or more services) may have a public (i.e., Medicaid/Medicare) enrollment of no more than 75% of total enrollees, commonly referred to as the "75/25" rule. (This provision is frequently waived under Section 1115 demonstration programs.)	Eliminates the "75/25" rule.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
F. MANAGED CARE		
5. Default enrollment	Mandatory managed care demonstrations all include provisions to "default enroll" into a plan individuals who do not select a plan. HCFA conditions of participation set certain maximum standards for the size of the default population. States with large default rates must permit beneficiaries additional time to choose a plan.	Requires state default enrollment systems to consider maintaining existing provider individual relationships or relationships with traditional Medicaid providers. If maintaining such relationships is not possible, states must provide for the equitable distribution of default enrollees among qualified managed care entities, consistent with their enrollment capacity.
6. Guaranteed enrollment	States may guarantee 6 month enrollment in federally qualified HMOs without waivers. States conducting Section 1115 demonstrations may elect to guarantee enrollment for a minimum period of time for enrollees with any managed care entity.	Permits states to guarantee 6 months enrollment in any qualified managed care entity, not just federally qualified HMOs.
7. Disenrollment	Permits beneficiaries to disenroll without cause in the case of voluntary HMO enrollment after 30 days membership. This provision is commonly waived in Section 1115 demonstration programs, with no cause disenrollment rights restricted.	Provides states the option to restrict no cause disenrollment to the first 90 days in an enrollment period which may last up to 12 months. Permits disenrollment for cause at any time (cause is not defined).

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
F. MANAGED CARE		
8. Conditions of participation for PCCMs	The statute establishes no conditions of participation for partial risk plans or primary care case management (PCCM) providers. HCFA regulations and guidelines establish general access conditions.	Adds a limited set of conditions of participation for primary care case management (Entities that are not governed by broader Section 1903(m) standards are subject to those applicable comprehensive MCOs.) PCCM contracts must: • Provide for reasonable and adequate hours of operation including 24 hour availability of "information, referral and treatment" with respect to medical emergencies. • Limit enrollment to individuals living sufficiently near the PCCM delivery site(s) to be able to reach the site within a reasonable time "using available and affordable modes of transportation." • Provide for arrangements with sufficient physicians and other health professionals "to ensure that services under the contract can be furnished to enrollees promptly and without compromise to [sic] quality of care." • Prohibit discrimination on the basis of health status in enrollment, disenrollment and re-enrollment. • Provide for compliance with a "prudent layperson" emergency care coverage standard and the post stabilization standard. Compliance with a "prudent layperson" emergency care coverage standard requires PCCMs to provide coverage for emergency services "without regard to prior authorization or the emergency care provider's contractual relationship with the MCO or the PCCM." Defines emergency medical condition as "a medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that a prudent layperson who possesses an average knowledge of health and medicine could reasonably expect the absence of immediate medical attention to result in serious impairment to bodily function or serious dysfunction of any bodily organ or part." Compliance includes compliance with post stabilization requirements applicable to managed care organizations participating in Medicare + Choice. • Specify which benefits the PCCM is responsible for under the contract and which remain the direct responsibility of the state. • Prohibit use of marketing materials that contain false or materially misleading information. Obtain prior approval of marketing materials from the state. Prohibit direct, door-to-door and cold call marketing, selective service area marketing, and tie-ins. • Require the provision of information on request, including information on participating providers, enrollee rights and responsibilities, covered services, grievance and appeals procedures, and comparative information showing benefits and cost sharing, service area, and quality and performance to the extent available.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
F. MANAGED CARE		
9. Conditions of participation for MCOs	Federal law establishes a series of conditions of participation for full risk managed care organizations participating in Medicaid	Adds amendments to the conditions of participation for managed care organizations. Entities that are not governed by broader Section 1903(m) standards are subject to those applicable comprehensive MCOs. Requires managed care organizations to • Comply with a "prudent layperson" emergency care coverage standard which requires MCOs and PCCMs to provide coverage for emergency services "without regard to prior authorization or the emergency care provider's contractual relationship with the MCO or the PCCM." Define emergency medical condition as "a medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that a prudent layperson who possesses an average knowledge of health and medicine could reasonably expect the absence of immediate medical attention to result in serious impairment to bodily function or serious dysfunction of a bodily organ or part." Compliance includes compliance with post stabilization requirements applicable to managed care organizations participating in Medicare+Choice. • Specify all managed care benefits in the contract for which the MCO is responsible and which remain the direct responsibility of the state. • Not discriminate against individual providers based on their licensure or certification under law. • Comply with the Mothers and Newborns Protection Act (the 48-hour hospital stay rule) and the Mental Health Parity Act. • Agree to external review of all contract obligations by an independent entity unless the plan is accredited or (at state election) participates in the Medicare+Choice. • Include increased solvency protections to (in order to be licensed) require licensure by the state as an HMO or lawful risk bearing entity unless the managed care organization has solvency guaranteed by the state, is a public entity, or is not at risk for hospital care. • Prohibit use of marketing materials that contain false or materially misleading information. Obtain prior approval of marketing materials to obtain prior approval from the state. Prohibit direct, door-to-door and cold call marketing, selective service area marketing, and tie ins. • Not place restrictions on provider/patient communications. • Maintain an internal grievance procedure for enrollees and providers to challenge the denial of coverage or payment. Retain fair hearing requirements. • Protect enrollees against liability for payment in the event of an MCO's insolvency.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
F. MANAGED CARE		
9. Conditions of participation for MCOs <i>(continued)</i>		• Provide information on request regarding participating providers, enrollee rights and responsibilities, information on covered services, grievance and appeals procedures, and comparative information showing benefits and cost sharing, service area, and quality and performance to the extent available • Demonstrate that the managed care organization "has the capacity to serve the expected enrollment in the service area" including assurances that the organization "offers an appropriate range of services and access to preventive and primary care services for the population expected to be enrolled in such service area and maintains a sufficient number, and geographic distribution of providers of services " • Apply balance billing limitation requirements to any entity subcontracting with the MCO
10. Prior approval of contracts with managed care organizations	HCFA must pre-approve MCO contracts valued at \$100,000 or greater	Raises pre-approval threshold from \$100,000 to \$1 million, indexed for inflation
11. Plan protections	States impose a variety of sanctions against managed care entities under their contracts ranging from financial penalties and freezing enrollment to contract termination.	Requires states to build into their managed care organization contracts intermediate sanction for certain types of misconduct. Sanctions include financial penalties, beneficiary disenrollment options, receivership, freezing enrollment and withholding payments. Sanctionable offenses include "substantial" failure to provide medically necessary items and services, charging excess amounts for care, and discrimination on the basis of health status or need for health services. Prohibits states from terminating contracts with managed care entities without notice and hearing that meets due process standards. At their option states may, but need not, notify beneficiaries and permit them to disenroll from an entity that is in contract termination proceedings.
12. Payments to Disproportionate Share Hospitals	Prior law is silent about how DSH hospitals should be paid when they treat managed care patients	Prohibits folding DSH payments into HMO premiums. Requires that a DSH payment adjustment for services furnished by a hospital for individuals entitled to benefits and enrolled in a managed care plan or PCCM be made directly to the hospital and not as part of the capitation amount

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
F. MANAGED CARE		
13. Quality assurance	Federal statute requires that HMOs maintain internal quality assurance processes and requires an independent external review of contractor performance. There are no similar provisions for PCCMs and partial risk plans Requires states to have quality assurance systems for Section 1903(m) entities	Permits waiver of external review procedures in the case of Section 1903(m) managed care organizations that participate in Medicare+Choice. Does not require external quality assurance reviews of PCCMs Requires states to develop and implement a quality assessment and improvement strategy (consistent with standards established by the Secretary and in consultation with the states) that includes (1) "[s]tandards for access to care so that covered services are available within reasonable time frames and in a manner that ensures continuity of care and adequate primary care and specialized services capacity," (2) examination of other quality of care measures, and (3) procedures for monitoring and evaluating the quality and appropriateness of care and services to enrollees, including submitting quality assurance data meeting requirements for entities with Medicare contracts or other requirements approved by the Secretary, and periodic assessment of quality assurance measures
14. Enrollment of Indians	No special rules in the statute regarding treatment of Medicaid eligible Native Americans. HCFA may condition approvals of state waiver requests on compliance with certain provisions regarding access to health services by Indians	Requires Indians to enroll with a managed care entity only if it is one of the following (and is participating under a state's managed care program): the Indian Health Service, an Indian health program operated by an Indian tribe or tribal organization, an urban Indian health program operated by an urban Indian organization
15. Treatment of family planning services	Patients have free choice of family planning providers for covered family planning services even if enrolled in managed care. States may obtain waivers of the family planning freedom-of-choice provisions under Section 1115	Retains free choice of provider rule except for persons enrolled in new Section 1932 state option PCCM program. Enrollees in MCOs retain freedom of choice unless waived as part of Section 1115 demonstration

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
G. LONG-TERM CARE		
1. Long-term care services	Mandates coverage of nursing facility, home health benefits and hospital services for all beneficiaries (including frail elderly), and gives states the option to cover a broad range of other long-term care benefits. Authorizes the Secretary to waive otherwise applicable limitations on benefits, statewideness and eligibility in order to permit states to cover home and community-based services for individuals at risk for nursing home care.	Establishes a new optional "Program of All Inclusive Care For the Elderly (PACE)" authorizing coverage of integrated acute and long-term care services. PACE program benefit consists of all items and services covered under Medicare and Medicaid without limitation or condition related to amount, duration and scope (within PACE specified protocol for benefits) and without copayment and coinsurance. Enrollment is voluntary, states may limit number of enrollees. Services furnished through certified PACE program providers who are paid on a prospective capitated basis, who comply with a PACE protocol, and meet conditions of participation. PACE program eligible persons are individuals ages 55 years and older, who require nursing facility-level care, reside in the PACE program service area, meet other applicable eligibility conditions, and whose health status meets PACE protocols. Health status eligibility must be evaluated annually unless there is no reasonable expectation of improvement. Secretary may waive aspects of PACE protocols to permit adaptation of PACE to needs of particular organizations. Secretary is required to carry out for-profit PACE provider demonstrations. [Note: Corresponding provisions also added to Medicare.]

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
H. FEDERAL FINANCIAL ASSISTANCE		
1. General Approach	States are entitled to open ended federal contributions toward program costs, with upper limits on disproportionate share hospital payments. Prohibits non-emergency Medicaid coverage of otherwise eligible undocumented aliens.	No change to prior payment structure but reduces federal DSH payments by \$10.4 billion over five years, with upward adjustments for inflation in subsequent years. Includes a 4 year \$100 million emergency care fund for states with high numbers of undocumented aliens.
2. Disproportionate share hospital (DSH) payments	Federal payments toward states' disproportionate share hospital program are capped at an aggregate level per state as well as at a facility level. For FY 1994, the total federal DSH allocation was \$18.5 billion.	Reduces the federal DSH allocation by \$10.4 billion over 5 years. State DSH allocations are specified by statute from FY 98 through 2002, with upward adjustment beginning in FY 2003. The percentage increase in the medical care component of the consumer price index for urban consumers, up to an aggregate ceiling of 12 percent of total state Medicaid program outlays.
3. Disproportionate share hospital payments for institutions for mental diseases (IMDs)	States may cover Medicaid services furnished in an institution for mental diseases (IMD) only in rare circumstances. An IMD is a hospital, nursing facility, or other institution of more than 16 beds which is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases. IMDs include state and private psychiatric hospitals and large board and care homes. Services in IMDs are covered only for beneficiaries under age 21 and ages 65 and older, effectively excluding coverage for persons between the ages of 21 and 64 (except for those residing in an IMD with 16 or fewer beds). DSH payment rules do not prohibit DSH payments to IMDs or establish upper limits. A number of states made high DSH payments to state mental institutions to support their activities.	Curbs use of DSH for children in mental institutions. Freezes federal DSH payments to IMDs and other mental health facilities at the DSH spending level for 1995. No state will receive more than the 1995 level. Furthermore, beginning in FY 2001, phases down the payment amount as follows: 50% in FY 2001, 40% in FY 2002, and 33% in FY 2003 and each succeeding fiscal year.
4. Federal Medicaid assistance percentage (FMAP)	The Federal government contributes between 50% and 80% of every state dollar spent on medical assistance for eligible persons, this amount is known as the federal medical assistance percentage (FMAP) and is based on a state's per capita income relative to the national average. Federal financial assistance for the District of Columbia is 50%. Federal payments to the territories is 50%, subject to statutory limits.	Increases the FMAP for the District of Columbia from 50 percent to 70 percent, beginning FY 1998, and for Alaska from 50 percent to 59.8 percent for FY 1998, FY 1999, and FY 2000. Increases federal payments to Puerto Rico, Virgin Islands, Guam, the Northern Mariana Islands, and American Samoa for FY 1998. In subsequent years the rate will reflect the percentage increase in the medical care component of the CPI.

A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 with Prior Law

ISSUE	PRIOR LAW	BALANCED BUDGET ACT OF 1997 (P.L. 105-33)
H. FEDERAL FINANCIAL ASSISTANCE		
5. Federal financial assistance for care of aliens	Federal financial participation is available for Medicaid coverage for emergency services only for undocumented persons who otherwise would meet the eligibility requirements for the state Medicaid program.	Authorizes a new state entitlement grant program of \$100 million (\$25 million per year) for 1998 through FY 2001 for emergency services to each of the 12 states with the highest number of undocumented aliens. Each state's allotment of total funds would be based on its share of the total undocumented aliens in the 12 eligible states. Estimates of the number of undocumented aliens would be prepared by the Immigration and Naturalization Service.

DRAFT

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

More information about this project can be obtained by contacting
Christine Lubinski, AIDS Action Council of Washington, D.C. at (202) 986-1300, or
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DRAFT

**PHOTOCOPY
PRESERVATION**

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

INTRODUCTION

Recent research has shown that a long-held assumption about AIDS was wrong—there is no initial dormant phase of HIV infection. Instead, the virus attacks the body's immune system from the outset. This improved understanding of how HIV functions, along with the advent of powerful new medications, has led to new recommendations for care and treatment. Specifically, experts now advise comprehensive care and treatment, often with combination drug therapy, from the earliest stages of HIV disease.

Despite the experts' recommendations for early treatment and the existence of effective drugs, significant obstacles to accessing care and medications remain for low income people living with HIV. Existing programs cannot meet the need for comprehensive health care and preventive services. The current Medicaid requirements force most HIV positive individuals to wait until they develop full-blown AIDS to become eligible for coverage, a model which is inconsistent with clinical standards, inhumane, and costly.

EARLY INTERVENTION WORKS, SAVING LIVES AND DOLLARS

The new standard of care for people with HIV emphasizes early clinical intervention, calling for both primary care and combination drug therapy, including protease inhibitors, at earlier stages of infection. The National Institutes of Health (NIH) report that "...it has been suggested that the best opportunity to eradicate HIV infection is provided by the initiation of potent combination antiretroviral therapy during primary infection."¹ According to Dr. David Ho, director of the Aaron Diamond AIDS Research Center, mathematical models suggest that patients caught early enough and treated with combination drug therapies could be free of HIV in two to three years.²

While complete eradication of the HIV virus from the body has not yet been demonstrated, combination drug therapies have proven effective for many, driving viral loads (the amount of virus in the blood) below detectable levels, and maintaining or dramatically improving overall health. Combination therapies can slow the progression from HIV to AIDS, and can help prevent opportunistic infections (OIs). For example, researchers at NIH's National Eye Institute recently discovered that a combination of protease inhibitors and other anti-HIV drugs can prevent or delay the progression of cytomegalovirus (CMV) retinitis, a common complication of AIDS which causes

¹ C. Carpenter, et al., "Report of the NIH Panel to Define Principals of Therapy of HIV Infection," June, 1997.

² L. Altman, "With AIDS Advance, More Disappointment," *New York Times*, January 19, 1997.

blindness without proper treatment.³ Some patients in the study were able to stop standard CMV retinitis treatment, which can be cumbersome, toxic, and extremely costly (between \$50-100,000 per patient per year), without advancement of their disease.⁴

Combination drug therapies including protease inhibitors are expensive, with costs ranging from \$8,000 to \$10,000. But several studies have indicated that the dollars spent “up front” on these medications are offset by later savings on hospitalizations and other expensive care and treatment for AIDS-related illnesses. A study by Dr. Peter Ruane of the Tower Infectious Disease Medical Associates in Los Angeles found that each dollar spent on combination drug therapies resulted in at least two dollars of savings on overall treatment costs, which declined 23 percent.⁵ The same study reported a 57 percent drop in the average number of days patients spent in the hospital. Data from Saint Vincent’s Hospital in New York support the conclusions of the Tower study, showing a significant decrease in inpatient care, both in terms of the number of people hospitalized and the average length of stay.⁶

The findings of the protease inhibitor studies—that early intervention and treatment can prolong health and reduce the need for more expensive treatment later—are consistent with earlier studies on the cost-effectiveness and beneficial impact of preventive treatment. Researchers at Johns Hopkins Hospital compared the outcomes of patients who received prophylactic treatment for the opportunistic infection *Pneumocystis carinii* pneumonia (PCP) with those who did not receive such treatment. The patients not taking prophylaxis accounted for all of the deaths attributed to PCP, 85 percent of the hospital days, 100 percent of the Intensive Care Unit days, and 89 percent of the inpatient charges. The study concluded that those “who developed PCP despite prophylaxis had a better outcome and used fewer resources than patients not receiving preventive therapy.”⁷ Another study examining preventive treatment for PCP found that prophylaxis resulted in longer life and a savings of \$16,503 for each patient, as compared with no prophylaxis.⁸

³ NIH News Release, “Combination Drug Therapy for AIDS Found to Control Blinding Eye Infection,” May 20, 1997 (reporting study results published in the *Journal of the American Medical Association*, May 21, 1997).

⁴ *Id.*

⁵ P. Ruane, “Dramatic Reductions in Use of Healthcare Services by Patients with HIV Result from Use of Combination Therapy with a Protease Inhibitor,” Tower Infectious Disease Medical Associates, Inc., January 23, 1997.

⁶ R. Torres, “Impact of Potent New Antiretroviral Therapies on In-Patient and Out-Patient Hospital Utilization by HIV-Infected Persons,” Saint Vincent’s Hospital and Medical Center, January 23, 1997.

⁷ J. Gallant, et. al., “The Impact of Prophylaxis on Outcome and Resource Utilization in *Pneumocystis carinii* Pneumonia,” *Chest*, April 1995: 1018-1023.

⁸ A. Castellano and M. Nettleman, “Cost and Benefit of Secondary Prophylaxis for *Pneumocystis carinii* Pneumonia,” *Journal of the American Medical Association*, August 14, 1991: 820-824.

Comprehensive care and treatment which prevents or delays the progression from HIV infection to AIDS can both improve quality of life and save money. A survey of the costs of care for Medicaid patients with HIV in Baltimore found that monthly costs for people with CD4+ T-cell counts under 50 (generally a sign of more advanced HIV disease) were more than twice those of people with more than 500 T-cells.⁹ As noted above, spending money in the early stages of HIV disease for treatment with combination drug therapies can reduce more expensive interventions later. Yet under the present Medicaid system, many living with HIV must wait for their T-cells to drop and their illness to worsen before they can receive coverage and access care.

GAPS IN HEALTH CARE COVERAGE REMAIN

The advances in overall health care and drug treatments have brought renewed health and unprecedented hope to many people living with HIV disease. For the first time in the 15 years of the AIDS epidemic, there has been a decrease in the numbers of Americans dying from AIDS. The U.S. Centers for Disease Control (CDC) reported a 13 percent decline in the number of AIDS deaths for the first six months of 1996, as compared to the same period in 1995, and attributed this decline to improved medical care, prophylaxis for OIs, and the use of combination therapies.¹⁰

In the same report, however, the CDC noted that AIDS continues to be the leading cause of death of Americans aged 25 to 44, and that the “increased prevalence of AIDS [in the U.S.] indicates the need for medical and other services for persons with HIV infection.” While the new medications make obtaining care more important than ever, challenges in expanding access to primary care and treatment remain.

Medicaid provides access to health care coverage for low income, uninsured, disabled people. Individuals who are HIV positive but have not been diagnosed with AIDS, however, are often not eligible for Medicaid, because they do not meet the program’s disability standards or other categorical eligibility requirements. To qualify for Medicaid, people must meet income requirements and the disability criteria of the federal Supplemental Security Income (SSI) program. The Social Security Administration uses the CDC’s definition of AIDS, along with evidence of functional impairments, as proof of disability.¹¹ **Despite the fact that early clinical intervention—including primary care, preventive services, and medication therapies—has**

⁹ R. Moore and R. Chaisson, “Costs to Medicaid of Advancing Immunosuppression in an Urban HIV-Infected Patient Population in Maryland,” *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 1997, 14:223-231.

¹⁰ Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173.

¹¹ The CDC definition of AIDS for surveillance purposes is: documented CD4+ T-lymphocyte counts <200 per microliter or percent of total lymphocytes <14 percent or a variety of opportunistic infections.

been shown to improve health and delay the onset of expensive opportunistic infections, most HIV positive individuals must wait until they “get sicker” and develop AIDS before they can receive Medicaid.

This is particularly devastating because the populations in which HIV infection is increasing are the ones likely to enroll in Medicaid once their HIV infection becomes full-blown AIDS. The epidemic is growing fastest among groups which have traditionally been socioeconomically disenfranchised, including racial and ethnic minorities, injection drug users, and women. In 1996, for the first time, blacks accounted for more AIDS cases than whites (41 percent versus 38 percent).¹² Women represented 20 percent of new AIDS cases in 1996, up from seven percent in 1985. While overall AIDS deaths declined 13 percent in the first half of 1996, deaths among women increased by three percent.¹³

These populations are also the groups less likely to have health insurance and access to treatments, and more likely to face barriers in obtaining health care, according to a survey by the Agency for Health Care Policy and Research.¹⁴ People who are uninsured or underinsured not only lack access to expensive combination therapies, but also to basic primary care and preventive services. Without insurance, people are more likely to wait until they have serious health problems before seeking care—problems which are then more expensive to treat. At this point, people would likely become eligible for Medicaid, but it is both inefficient and inhumane to require people to progress to an advanced stage of illness when we could offer access to effective and less costly care and treatment at an earlier time in the disease.

A Medicaid expansion also promotes public health, by giving uninsured and underinsured people with HIV an opportunity and an incentive to enter care earlier. Reaching people who would not otherwise have contact with health care systems provides the chance to teach and reinforce behavior changes which can prevent HIV transmission. [Reducing viral load through the use of combination drug therapies may also reduce infectiousness, although there is not yet conclusive scientific data on this issue.] The ongoing primary care and medical case management funded through Medicaid helps support patients in following complex treatment plans. If patients do not strictly comply with their combination therapy regimens, they are likely to develop drug-resistant strains of HIV. The existence of such drug-resistant HIV mutations may further complicate public health efforts to combat AIDS.

Despite the existence of federal AIDS programs, such as the AIDS Drug Assistance Programs (ADAPs) and the other components of the Ryan White CARE Act, Medicaid serves as the

¹² Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173.

¹³ *Id.*

¹⁴ P. Mohr, Patterns of Health Care Use Among HIV-Infected Adults: Preliminary Results,” *AIDS Cost and Services Utilization Survey*, Agency for Health Care Policy and Research, September 1994: 3.

foundation of AIDS care through its provision of both comprehensive health care and drug therapies. ADAPs provide limited prescription drug coverage for some uninsured and underinsured people with HIV and AIDS. But these programs cannot (and are not designed to) meet the need for comprehensive primary care and diagnostic services. In spite of their limited mission—to provide access to a limited formulary of proven AIDS medications—ADAPs face severe financial pressure in many states, and often cannot meet the growing demand for new combination therapies. In some states, ADAPs do not even cover protease inhibitors, and many offer a very limited formulary of antiretroviral and OI drugs. In other states, there are lotteries, long waiting lists, and increasingly restrictive eligibility criteria for ADAP participation.

While other Ryan White CARE Act programs pay for some primary care and drug reimbursement, they are not intended to provide widespread comprehensive health care. Ryan White funding is used for a range of care and services, including food, transportation, and case management for people living with AIDS. Additionally, many ADAPs and Ryan White-funded primary care programs have eligibility criteria which exclude people in the earlier stages of HIV disease. These programs lack the financial resources to broaden their eligibility criteria to cover such individuals.

Even if a person with HIV were able to obtain medications through an ADAP or Ryan White program, without primary care and services like medical case management, it is impossible to monitor that person and assure that the prescribed treatment regimen is appropriate and effective. An expansion of Medicaid can provide such care and services.

Some may question whether it is appropriate to have a disease-specific expansion of Medicaid, even as a demonstration project. We believe that it serves the interests of public health, scientific knowledge, and fairness to broaden Medicaid coverage to include people with HIV.

Public health: With earlier health care and treatment, as mentioned above, people living with HIV are more likely to avoid behaviors which can spread the virus, and are more likely to adhere to complex treatment plans, which can both prolong health and prevent development of drug-resistant strains of HIV.

Scientific knowledge: Protease inhibitors and other new medications received rapid FDA approval, have not yet been in long-term use, and have been researched mainly by studying people in more advanced stages of HIV disease. There are many remaining questions about the benefits, risks, and best way to use combination therapies in people who are HIV positive, but do not have AIDS. A Medicaid expansion demonstration project which brings people with HIV into care provides the opportunity to gather data and conduct research studies designed to answer these questions.

Fairness: The current Medicaid system requires most people with HIV to develop AIDS in order to gain access to health care and new combination therapies. This is unfair and inhumane, especially when the government provides treatment for other communicable

diseases, such as sexually transmitted diseases and tuberculosis. Principles and guidelines recently released by the Department of Health and Human Services and the NIH call for earlier intervention with combination drug therapies as the standard of care for the treatment of HIV in most cases. The government should ensure that this standard of care, endorsed by its own agencies, is accessible to those who have no other way to obtain it.

The Medicaid eligibility framework—requiring total disability to qualify for coverage—is at odds with current clinical and public health knowledge. Many low income HIV positive individuals with relatively intact immune systems are not presently eligible for Medicaid, but will eventually qualify for Medicaid after developing AIDS. Unable to afford adequate treatment early in their HIV disease, they cannot obtain the range of health care services necessary to manage the disease, and will be more ill when they do enroll in Medicaid. Ironically, earlier access to these medical services and treatments would enable them to preserve their health, learn how to prevent transmission of HIV to others, and avoid more costly care such as inpatient hospitalization. For humane, financial, and public health reasons, it is time to make Medicaid's eligibility requirements consistent with the clinical realities of HIV disease.

A COLLABORATIVE RESPONSE

In response to the contradictions between current Medicaid disability criteria and AIDS clinical evidence and care standards, which call for early treatment of HIV disease, representatives from the AIDS Action Council, community-based AIDS service organizations, the Health Care Financing Administration (HCFA) and the Office of Management and Budget (OMB) have begun to work collaboratively to address these issues. Response from the administration has been unequivocally supportive, culminating in endorsements from Vice President Al Gore, who has asked HCFA to find ways in which to expand Medicaid and allow more low-income Americans with HIV to access care and therapies. Gore is quoted as saying “[Medicaid expansion] can ease suffering, it can increase hope, and it can get new drug therapies into the hands of people who need them.” As a result of these collaborations, we are all working together under HCFA's leadership to develop a plan for expanding eligibility to Medicaid for persons who are HIV positive.

PROPOSAL DESIGN

The objective of this program is to expand Medicaid eligibility to low-income individuals who have tested positive for the presence of HIV and who would be otherwise eligible for Medicaid once their health status met an AIDS-defining diagnosis. States participating in this initiative will demonstrate that the provision of earlier access to care and treatment will extend the period of time that a person who is HIV positive remains asymptomatic, defer the onset of opportunistic infection, and delay hospitalization, all of which will result in significant cost savings and life-enhancing benefits. The following section describes what we believe are the core components of this initiative.

Eligibility

Any and all individuals who meet the following criteria will be eligible under this program:

- test positive for the presence of HIV; and
- have income at or below 200 percent of the federal poverty level.

State demonstrations will coordinate resources with other private, state, and federal programs. Individuals with private insurance can apply for and become eligible for Medicaid as a “wrap around benefit” thereby maximizing private insurance participation. State proposals will specify the state specific eligibility guidelines and coordination of other state and federal programs.

Covered Benefits

Ideally, states will provide the full benefit package (i.e., mandatory and optional Medicaid services) to individuals eligible through this program. In any case, benefit packages must be flexible to accommodate new treatment advances and changes in standards of care that become available during the course of the demonstration. Through this project, states, at a minimum, must provide:

- primary care,
- prescription drugs,
- diagnostic and laboratory services,
- mental health services, and
- substance abuse treatment services.

Options to Participate in the Demonstration Projects

Section 1115 of the Social Security Act allows the Secretary of Health and Human Services to grant waivers from the usual federal Medicaid requirements¹⁵ to states which want to create demonstration projects to test new approaches to Medicaid. These demonstration projects must be designed to promote the objectives of Medicaid,¹⁶ and must include a research and evaluation component. Generally, demonstration projects created under a Section 1115 waiver are supposed to be “budget neutral” over the life of the project, meaning that costs under the demonstration project do not exceed what costs would have been without the waiver in place. Section 1115 also authorizes matching federal funds for certain expenditures.

¹⁵ As defined in Section 1902 of the Social Security Act, and other provisions incorporated through Section 1902.

¹⁶ As set out in Title XIX of the Social Security Act.

This initiative will be designed to provide states with the maximum flexibility possible in participating in a Medicaid expansion demonstration project. The project does not necessarily need to meet the traditional definition of “budget neutrality,” since there can be federal and/or state subsidies. Also, budget neutrality should be measured within a time frame which is appropriate for assessing the clinical impact and cost-effectiveness of the new combination therapies (e.g., over a period of five to ten years).

Options for participation include the creation of a free-standing demonstration program or new or amended 1115 waivers. New 1115 waivers could provide the vehicle to expand Medicaid eligibility and/or allow a Medicaid buy-in option for those individuals otherwise ineligible for coverage. Amending an approved or pending 1115 waiver could also be used to expand eligibility. In addition, states could increase the income standards for their Medicaid buy-in programs, allowing more persons who are HIV positive to qualify. For example, states could set the income standard at 200 percent of the federal poverty level or they could use a graduated system to make more individuals eligible.

NEXT STEPS

Over the next several months, the AIDS Action Council will work with HCFA to develop and refine a solicitation process for states to successfully participate in the HIV Expanded Eligibility Demonstration Initiative. It is important for community-based AIDS service organizations to urge their state governors and Medicaid directors to advocate for this initiative with HHS and HCFA. While we expect that this initiative will offer states tremendous opportunities to provide cost-effective access and coverage to its most vulnerable populations, we also recognize the range of development and design issues that need to be resolved. Over the next several months, the AIDS Action Council will work with states and HCFA to complete the following tasks:

- Continue to work with HCFA to design a program that includes adequate incentives for state participation in this initiative.
- Build consensus among federal and state leadership, elected officials, and government staff, including representatives from Medicaid programs, Departments of Health, and Departments of HIV Services.
- Work with HCFA to develop a process that allows states to efficiently design and implement a vehicle for eligibility expansion that responds to the unique environment and situations of each state (waiver amendment or new waiver submission).
- Design a process to solicit input from consumers, AIDS service organizations, primary care and other health care providers, and [health care ?] agencies regarding program design and program effectiveness, on an ongoing basis.

- Work with HCFA to develop a methodology that allows states maximum flexibility in measuring cost effectiveness. The goal will be to have HCFA resolve methodology issues related to baseline measurements, the measurement of savings in other government programs, and evaluation time frames.
- Work with HCFA to identify and develop data bases that provide the information needed to estimate current expenditures and projected costs for the purposes of assessment and future planning. Necessary data includes the number of newly eligible individuals by state and service area (persons who are HIV positive with incomes below state defined eligibility criteria), utilization of services, and cost.

Partial Glossary of Managed Care, Medicaid and Medicare Terms

209(b) State	A state which takes advantage of a law that allows them to have more restrictive eligibility standard than those created by the Supplemental Security Income (SSI) program
1115 Waiver	Special permission granted to states under the Social Security Act, which allows them to waive any provision of the Medicaid law for a demonstration Medicaid program. Waivers are usually granted for research purposes, to test a program improvement or investigate an issue of interest to HCFA. Most projects run for a limited period, no more than 3 or 4 years, and are usually not renewable.
1915(b) waivers	Allows states to enroll Medicaid beneficiaries in a managed care plan by waiving the participant's right to choose their own providers. Also called freedom-of-choice waiver.
2176 waiver	Also known as 1915(c) and 1915(d) waivers. Medicaid law contains waiver authority allowing states to offer community-based long-term care services to persons who would otherwise require nursing home care or other forms of institutional care. Under this waiver, States provide a broad range of home and community-based services to elderly, mentally retarded, and other disabled and chronically ill persons. States must apply to the federal department of Health and Human Services (HHS) for each service
Activities of daily living (ADLs)	A set of basic tasks –dressing, bathing, toileting, eating and mobility – used to measure an individual's level of functional impairment.
Adjusted average per capita cost (AAPCC)	The basis of payment for Medicare risk HMOs, the AAPCC is a yearly projection of program spending in fee-for-service Medicare (traditional Medicare). Medicare pays risk HMOs 95% of the AAPCC for each enrolled Medicare beneficiary, with adjustments for factors such as geographic cost differences (by county), age, sex, and disability status.
Ambulatory Care	Health Care that does not require a hospital admission for the patient – also known as outpatient care, commonly provided in a doctor's office, clinic, or health center.
Approved charge	The amount Medicare approves for payment to a physician. Typically Medicare pays 80% of the cost, the beneficiary 20%, for most services.
Assignment	A Medicare process in which a beneficiary agrees to have Medicare's share of the cost of a service paid directly (assigned) to a doctor or other provider, and the provider agrees to accept the Medicare approved charge as payment in full. Typically, Medicare pays 80%, the beneficiary, 20%.
Balance billing	In Medicare and private fee-for-service health insurance, the practice of a care provider billing patients in excess of the amount approved by the health plan. Under Medicare, the excess amount cannot be more than 15% over the approved charge.
Beneficiary	A person who is eligible for or receiving benefits under an insurance policy or plan. The term is commonly used in Medicaid and Medicare.
Benefits or Benefit Package	The health care services covered by a health plan or health insurance company, under the terms of its member contract. Terms of the contract outline copayments, deductibles, limitations on the amount or length of coverage, and conditions such as having care delivered through the health plan and authorized in advance.
Boren Amendment	Part of the Medicaid law which provides that the state payment rates for hospitals and nursing facilities must be reasonable and adequate to meet the costs incurred by efficiently and economically operated facilities to provide care and services meeting state and federal standards

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INFORMATION, INSPIRATION, AND ADVOCACY FOR PEOPLE LIVING WITH HIV/AIDS

COBRA	A federal law known as the Consolidated Omnibus Budget Reconciliation Act of 1986 that requires employers with 20 or more employees to offer continued health care coverage of terminated employees and their eligible dependents. An employee can be eligible for between 18 and 29 months of coverage. The employee is responsible for the insurance premium.
Capitation	A method of paying for medical services and health care on a per-person rather than a per-procedure basis. For example, an HMO might pay a doctor the same set fee whether he or she sees a patient once or twenty times during a month.
Case Management	A program or method that health plans and insurers use to coordinate the care of patients who have complex or expensive medical needs to ensure appropriate and cost effective care.
Carrier	Private organization, usually an insurance company that has a contract with the Health Care Financing Administration to process claims under Part B (the doctor insurance) of Medicare.
Categorically needy	Medicaid eligibility based on defined indicators of financial need by families with children and pregnant women, and to persons who are aged, blind, or disabled. Persons not falling into these categories cannot qualify, no matter how low their income. Medicaid defines over 50 population groups as potentially eligible, including those who must be covered and those who the state has the option to cover. The scope of covered services that states must provide to the categorically needy is much broader than the minimum scope of services for other groups receiving Medicaid benefits.
Claim	The documentation of a medical service that was provided to a covered patient by a doctor, hospital, laboratory, diagnostic service or other medical professional. The provider or the patient files the claim with the insurer to request payment for the service.
Clinician	A term for many types of medical professionals who care for patients including doctors, nurses, physicians' assistants, therapists, etc.
Co-insurance Co-payment	The portion of the bill for a medical service that must be paid by the patient (co-insurance is usually a percentage, co-payments are a flat amount, e.g., \$5.00 per office visit).
Community Rating	A means of setting monthly health plan or insurance premium rates by estimating the cost of providing health care to the entire membership and dividing by the estimated number of members each month. Each grouping within the membership pays the same rate. "Community rating by class" starts with the community rating and adjusts it up or down based on a given group's demographic (age and sex) makeup. "Adjusted community rating" starts with community rates and, using past use of medical services, adjusts up or down estimating what the cost of providing health care for that group might be in the upcoming year. "Experience rating" is a rate based on the actual cost of providing care to that specific group.
Deductible	Typically found in fee-for-service arrangement. The amount that the patient must pay toward the cost of the covered services they receive before the insurance plan begins paying for benefits.
Deeming	In Medicaid, considering income or resources which are available to an individual not receiving assistance as available to an individual receiving assistance.
Disproportionate share hospital (DSH)	Hospitals that receive an additional payment under Medicare or Medicaid if they serve a relatively large volume of low-income patients.
Dual eligible	A Medicare beneficiary who also receives the full range of Medicaid benefits in his or her state
Employer contribution	The amount of money an employer pays toward the health benefit plans of its employees.

Enrollment Area	The geographical area within which a health plan member must reside in order to be eligible for coverage. Most HMOs place a limit on the length of time members can live outside the enrollment area each year and still be covered unless they are students.
Federally Qualified	An HMO that has met a set of federal standards. All HMOs are subject to federal and state regulations whether they are qualified or not.
Fee-for-Service	The method used by traditional health insurers; the medical provider charges a fee for each service, and the insurer pays all or a portion of that fee.
Formulary	A list of prescription drugs and their recommended doses, which have been selected by a health plan, insurer or group of doctors on the basis of cost and effectiveness, for a given condition. Formulary drugs may be only recommended or they may be the only drugs reimbursed.
Freedom of choice	A principle of Medicaid which allows a recipient the freedom to choose providers. Can be waived
Gatekeeper	A term used to describe one role of a primary care doctor in an HMO or other managed care network that requires its members to have all of their care provided, arranged, or authorized by the members' primary care doctors, except in the case of life-threatening emergencies.
Health Care Financing Administration (HCFA)	A federal agency within the Department of Health and Human Services that operates Medicare and, together with the states, Medicaid.
Health Screening	A mechanism used by some insurers to determine whether applicants are likely to create high medical costs. It is used to determine preexisting medical conditions and to determine applicants who may be at risk due to factors such as a past history of drug abuse.
Health Maintenance Organization (HMO)	An entity that is both the insurer and provider of care, giving most of the necessary care for a prepaid (capitated) fee. HMOs often place an emphasis on prevention and careful assessment of medical necessity. Services are provided through a system of affiliated providers.
Home Health Care	Care rendered in a patient's residence by employees of a home health agency or other approved provider.
Hospice	A public or private organization primarily engaged in providing pain relief, symptom management and supportive services to terminally ill people. Medicare beneficiaries may elect to receive hospice care instead of standard Medicare benefits for terminal illnesses.
Inpatient	Medical care that requires the patient to occupy a bed in a hospital. Not all hospital care is inpatient care; a patient can also receive "outpatient" care in a hospital's emergency room or ambulatory care center.
Long term care	Ongoing health and social services provided for individuals who need assistance on a continuing basis because of physical/mental disability. Services can be provided in an institution, the home or community, and include informal services provided by family/friends and formal services provided.
Managed care	Any system of payment or delivery arrangement where the health plan attempts to control or coordinate use of health services by its enrolled members in order to contain spending, improve quality or both. Arrangements often involve a defined delivery system of providers with some form of contract with the plan to furnish services to those enrolled.
Medicare	Federal health insurance program for persons age 65 and older, and some severely disabled persons under age 65. It consists of Part A, hospital insurance and Part B, supplementary medical insurance.
Medigap policy	An insurance policy that must be privately purchased that supplements Medicare coverage and meets specified requirements set by federal statute and the National Association of Insurance Commissioners.

Network/Participating Providers	Used to describe the doctors, clinics, health center, medical group practices, hospitals, and other providers that an HMO, PPO, or other managed care network plan has selected and contracted with to care for its members.
Open Enrollment	A period during which health plans or insurers accept new applicants for membership. Employers typically hold these once a year.
out-of-pocket Costs	The portion of the cost of health care and medical services that a person with health care coverage is responsible for paying.
Preexisting Condition	An illness or medical condition that an individual has before applying to a health plan or insurer for coverage. Some plans turn down people with certain preexisting conditions.
Primary Care	Preventive health care and routine medical care that is typically provided by a doctor trained in internal medicine, pediatrics, or family practice, or by a nurse, nurse practitioner, or physician's assistant, in a doctor's office, clinic, or health center. HMO members are encouraged or required to choose a primary care provider who must provide, arrange or authorize their care.
Provider	A term used to describe all types of health care professionals and facilities.
Qualified Medicare beneficiaries	Medicare Part A eligible individuals with income at or below the federal poverty level and who do not have resources exceeding twice the level allowed by SSI (\$4000 per individual). State Medicaid agencies must pay Medicare premiums, deductibles and coinsurance for such individuals
Reasonable and Customary Charges or Fees	An amount determined by an insurance company or HMO to be the appropriate amount to pay for a particular medical service. Insurers will often pay no more than reasonable and customary charges for services provided to their members.
Referral	A formal process by which a patient is authorized to receive care from a medical specialist or a hospital. HMOs usually require a referral from a primary care provider in order for specialty care to be covered.
Risk	An insurance term related to financial responsibility for medical care. A "high-risk" individual is someone who has a high likelihood of having a serious illness. "At risk" or "risk bearing" means being financially responsible for the care of patients. For example, when an HMO pays a provider a set or "capitated" rate, the provider is at risk for any care that costs more than they are paid. "Risk adjustment" means paying a health plan an extra amount if its members are, on average, sicker and more expensive to care for.
Self-Referral	The ability for an HMO patient to refer himself or herself, under certain circumstances, for specialty medical care, without receiving a formal referral or prior authorization from the patient's HMO or primary care doctor.
Self-Insured	An arrangement whereby employers pay directly for the health care services their employees need, rather than paying premiums to an insurance company or health plan for coverage. Some self-insured plans contract with HMOs or other managed care networks to provide all or most of their employees health care.
Skilled nursing facility	An institution that offers nursing services similar to those given in a hospital, to aid recuperation of those who are seriously ill.
Skimming	A practice by which insurers or health plans try to avoid enrolling people whose medical care may be very expensive, including people who are elderly or who have a history of illness.
Social Security Disability Insurance (SSDI)	The portion of Social Security that pays monthly benefits to disabled workers under age 65 and their dependents. SSDI recipients (but not their dependents) automatically become eligible for Medicare after a two-year waiting period. SSDI payments are based on your contributions made while you were working.
Spenddown	Individuals in 209 (b) states or those eligible under the medically needy program who must make payments on medical bills until their income, minus expenses for medical care, falls to or below the income level set by the state to qualify for Medicaid.

Supplemental Security Income (SSI)	A federal income support program for low-income disabled, aged and blind persons. Eligibility does not depend on previous work or contributions to a trust fund, and usually carries with it automatic eligibility for Medicaid.
Supplementary medical insurance	Part B of Medicare; it covers the costs of physicians' services, outpatient laboratory and X-ray tests, durable medical equipment, outpatient hospital care and certain other services. This is a voluntary program that has a monthly premium.
Utilization	The amount of medical services used by a given population, usually measured over a specific period of time or as an average related to the number of people in the population.
Waiting period	A period after the effective date of enrollment during which a new member of a health insurance plan is not covered for a preexisting medical condition

This glossary was compiled largely from two sources: "Medicaid Reform: Managed Care & AIDS, AIDS Action Council and The HMO Health Care Companion, Alan G. Raymond, 1994, Harper-Collins Publishers, Inc.

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COMMENTS:

VP's April 9 remarks - HCFA part on
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**Remarks of Vice President Al Gore
AIDS Action
7th Annual National Leadership Awards
Washington, DC
April 9, 1997**

[Acknowledgments from advance]

Thank you for this wonderful award. And thank you for honoring all that Tipper Gore, my partner, has done to raise awareness of AIDS, to heal those who hurt, and to work to end this epidemic. Whether reading names at the quilt, or placing panels on the fence of our home at the Naval Observatory, or participating in all those AIDS walks, Tipper has been an inspiration. Thank you for letting me bask in her reflected glory.

I'm humbled by this award, because I am humbled by all of you.

Tonight-- in this theater -- are the heroes of the crusade against AIDS. All of you are on the front lines; that's where any battle is always toughest. But each day you return -- delivering knowledgeable, consistent, and compassionate health care. Your organizations bring meals on wheels . . . organize buddy systems so nobody will ever fall out of the community's sight . . . deliver the care people with AIDS need to get better, and to maintain highest level of function.

So tonight I want to do more than thank you for presenting Tipper and me this award. I want to thank you for the work you do every day of your lives. From the bottom of my heart, thank you for your energy, your commitment, and your tireless devotion to a cause larger than any single one of us.

And, of course, thank you for keeping our feet to the fire. If all citizens used their vocal chords and their e-mail and the fax machines as skillfully as the AIDS community, this country would have made a lot more progress on a lot more problems. I appreciate your input and ideas. And I pledge to you that my door -- and that Tipper's door -- is always open.

The AIDS virus is too sinister and too wily to succumb to any single opponent. We've got to work together. This must be a partnership. A partnership of those living with HIV, the community of care givers and care providers, AIDS activists, local and national AIDS organizations, and the federal government -- especially the White House. If I may paraphrase the First Lady, it takes a village to end an epidemic.

And I want you to know that the President and I -- along with Tipper, the First Lady, and the entire administration -- are committed to strengthening this partnership. We're committed to working together to get people better -- and in the end, to find a cure for this dread disease. Let me tell you some of the things we're doing to supplement the extraordinary efforts you are making on the front lines.

For starters, earlier this week, the President appointed a new director of the Office of National AIDS Policy, Sandy Thurman. Many of you know her. As the President said, she speaks the truth unvarnished. And that's exactly what we need.

Her presence gives the AIDS community a powerful, effective, and credible voice at the center of the debate. I could not be more excited about having someone of her caliber at the table, making decisions. This was a great choice. She will do a great job.

Sandy's energy and drive will take us to the next level. Her willingness to tell it like it is will help all of us -- together -- write the next chapter in beating this epidemic. And her work will be laid upon the foundation of slow and steady progress we have built these last four years. We've boosted investments in AIDS research, prevention, and services by 60 percent. Ryan White funding has increased 158 percent. We've speeded up the FDA approval process -- leading to the approval of eight new AIDS drugs and 19 drugs for AIDS-related conditions.

And I'm delighted to announce this evening that we will soon be taking steps to bring those cutting-edge drugs to more people -- by expanding Medicaid drug coverage. Specifically, I've asked the Health Care Financing Administration and the Office of National AIDS Policy to look into the possibility of moving Medicaid eligibility closer to the sero-conversion point by doing a pilot project, what HCFA calls a demonstration. At the moment, people with HIV must wait until their T-cells reach extremely low levels or they develop opportunistic infections, resulting in a diagnosis of full-blown AIDS before they're eligible for Medicaid. That makes some of these new drugs prohibitively expensive for people who need them.

We think this should change. Our view is that getting these drugs to people earlier won't cost more in the long run. It may even save money. It will certainly save lives. I've asked HCFA to report back to me in 30 days. I don't want to raise any false hopes. But this can be a very important step. It can ease suffering, renew hope, and help ensure that good people aren't priced out of life-saving medicine.

It's more urgent than ever, too, because progress on new drugs the past few years has been nothing short of remarkable. Already the FDA has approved four protease inhibitors, and they are saving lives. There is new research being done to develop new types of inhibitors. And scientists are working to develop and bring to market immuno-potentiators, drugs that boost immune systems.

As some of you may know, about a year ago, I brought representatives of the major pharmaceutical companies and leading government researchers to my office to begin mapping a strategy for finding and developing more AIDS therapeutics, microbicides, and ultimately, a vaccine. This partnership has led to the establishment of the Forum for Collaborative HIV Research, an unprecedented partnership between drug companies, the government, advocates and insurance companies to optimize the use of the new drug therapies. I am so proud that this collaboration has been so successful and I pledge to keep working to build these partnerships.

Of all the times during this epidemic, this moment is the most optimistic. People who thought they were certain to die, are now living healthy lives. Deaths from AIDS are dropping for the first time ever. The estimated number of new infections has slowed. Education and prevention efforts are expanding. And for the first time, we can see -- maybe not immediately, but sometime within our view -- our ultimate goals: a cure and a vaccine. Let there be no mistake about that. Until they're achieved, those will remain our highest goals: a cure for those who are sick and a vaccine so nobody will have to suffer this disease again. But at long last, we have good reason for optimism.

However, this recent burst of good news doesn't mean the epidemic is over. Far from it. We've got a long way to go before we beat this monster.

For instance, we've got to make sure pediatricians have the information they need to prescribe these new medicines to children with HIV.

And something else is equally clear: the emergence of new drugs doesn't mean we can short-change care-givers; it doesn't mean we can compromise the work of the people serving people with AIDS. It wasn't until 1991 that the federal government even invested any money in care for people with AIDS. That was well after the epidemic had begun, well after good people had passed away.

We cannot turn our back on the people who have shouldered so much of the burden of this disease. And even though budgets are tight, and Congress is not exactly welcoming, you have my word that this Administration will fight for the people doing the front line work all of you undertake every single day. If we don't give a damn about care, how can we expect anyone to care about giving a damn?

And while this is a time of optimism, we face other adversaries besides tight budgets, a tough Congress, and a mean virus. We face the adversary of racism. We cannot turn our eyes from the devastation this epidemic has unleashed in communities of color. The AIDS virus doesn't discriminate. Neither should we. This isn't a white disease or a black disease. It's a human disease. And that's how we've got to address it.

We face the adversary of homophobia. Let me say it plain: there is no room in American medicine or American life for discriminating against people because of their sexual orientation. Gays and lesbians are part of the American family, and to try to exclude them or punish them for who they are is just plain wrong. We will not stand for it. We will not stand for homophobia. We will not stand for racism. We will not stand for discrimination in any form.

And finally, we face a quieter foe, the adversary of indifference -- a lack of concern bred in part by the latest good news and by the sense among many that this is someone else's illness. This is perhaps the gravest threat, because it is so difficult to identify.

And here the work you do is also so critical. You have seen the face of this disease, and that sight has meant you **cannot** be indifferent. But you must continue to educate and inspire others -- to shake them from their natural inclination to look the other way.

We cannot be indifferent -- in part because AIDS itself is indifferent. It is indifferent to wealth or gender or sexual orientation or race or just about anything else. AIDS revels in its indifference, and is happy to live wherever it can find a home. AIDS lives in our offices. It lives in our schools. It lives on our block.

Tipper and I know that. A few years ago, when we lived in Arlington, Virginia, Jim Nichols, our neighbor a few doors down, died of AIDS. We watched him go, comforted him in his final days. AIDS lived on our block. We cannot be indifferent.

Last year, as Tipper mentioned, when she and I visited the AIDS quilt on the mall -- all 11 city blocks of it -- we read Jim's name and the names of many others who had touched our lives and had perished from this disease. It was unforgettable. There on the Washington Mall, between all those other monuments, was this quilted monument of grief -- thousands upon thousands of names of people who did not have to die . . . unimaginable human possibility unrealized. They lived on America's block. We cannot be indifferent.

But that quilt and those panels also embodied hope. The hope that comes from remembering. The hope that comes from the notion that our lives, all of our lives, are somehow stitched together. The hope that comes from the knowledge that once we're touched by AIDS, we cannot be indifferent ever again.

Thank you for all you're doing to eradicate indifference. Thank you for your part in this partnership. Together, we will end this epidemic. And until we do, we will never, ever stop fighting.

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· "Gore Statement on Expanding HIV/AIDS Drug Therapies"
U.S. Newswire (12/09/97)

Vice President Al Gore said Tuesday that he was "extremely disappointed" that the Health Care Financing Administration and the Office of National AIDS Policy could not find a way to provide earlier Medicaid coverage for HIV-infected people. Gore stressed that he would continue to search for a solution, noting that "this Administration understands the urgency of finding innovative ways to ensure that all people with HIV benefit from the promise of new and effective treatments."

Office of National AIDS Policy

Executive Office of the President

Release Date: December 7, 1997



Statement of Sandra Thurman Director, White House Office of National AIDS Policy on Presidential Advisory Council Report

For more than a decade we have relied on those on the front lines to sound the alarms -- and remind all of us of the urgency of this epidemic. This longstanding tradition has served people living with HIV and AIDS and all Americans well. And it is for this reason that the President appointed an advisory committee made up of those actively engaged at the community level in our nation's battle against AIDS. The overarching message of this report is loud and clear -- this epidemic is not over and we all have much more work to do.

Last week, on World AIDS Day, everyone stopped to acknowledge the tragedy of AIDS. But for those on the front lines of this epidemic -- every day is world AIDS day. And it is out of this sense of urgency and frustration that the Council puts forward its recommendations. I certainly understand their anxiety, and I share their desire to continue the progress that this Administration has made.

However, reports that this Administration has abandoned its desire to expand Medicaid access to life-saving therapies could not be further from the truth. This Administration certainly understands the urgency of ensuring that all people with HIV benefit from the promise of new and effective treatments. The fact that our initial attempt to expand Medicaid has turned out to be more difficult than anticipated in no way lessens the Administration's resolve to seek a workable means of extending life-prolonging therapies to all those in need.

The Clinton Administration has a strong track record of addressing the needs of people living with HIV and AIDS:

- The President worked vigorously to save the Medicaid program, which is the largest single payor for AIDS services and treatment in the country -- in 1997, federal Medicaid expenditures for people living with HIV/AIDS totaled \$1.8 billion, including nearly \$500 million for AIDS drugs.
- The President established the HIV Vaccine Initiative, with the goal of finding a vaccine against HIV within 10 years.
- The President has pushed for increases in the Ryan White CARE Act, including a 450% increase in the State AIDS Drug Assistance Program since 1996.
- This Administration has supported the research that resulted in the new treatments that are saving so many lives, with funding for AIDS research at NIH increasing 50% since the start of this Administration.

There is no absence of will to meet this challenge; there is, however, a different sense of what can be accomplished in an often polarized political environment in which ideology can overwhelm science. The struggle to get the best quality of care and the best medications to all HIV-positive Americans is a very difficult fight and one I know that the President is committed to winning.

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Talking Points

- The Clinton Administration remains strongly committed to insuring that people living with HIV and AIDS have access to the medical treatments they need.
- The experts at HCFA are finding it difficult to make this expansion cost neutral, which is the test that we must meet to change benefits without Congressional action
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