AIDS Action council

VIA COURIER

February 1, 1996

Office of the First Lady
Attn: Ms. Jennifer Klein
Senior Policy Analyst
New Executive Office
1725 17th Street, N.W.
Washington, DC 20505

Ms. Klein,

Mark Barnes, our executive director, asked me to put together for your review a packet of the numerous "Medicaid and AIDS" op-eds, editorials, and letters to the editor that we have been successful in placing in publications nationwide. I am also including with this packet some of the outstanding newspaper articles on "Medicaid and AIDS" for which AIDS Action staff have been used as sources.

I hope that this packet of information is useful to you. If you should have any further questions about our press strategy around Medicaid "reform," or if I may be of any assistance to you, please feel free to call me at (202) 986-1300, Ext. 3042.

Sincerely,

José M. Zuniga
Deputy Director for Public Affairs

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Encl.

Medicaid Patients in Danger

By DAVID CURTIS

Proposals to dismantle the Medicaid program (sometimes called "the other M program," to distinguish it from Medicare) may be taken in Congress as early as next Tuesday.

That would be almost certain to have a bad effect on health care access for more than 80,000 Vermont Medicaid residents. They include children, the blind and disabled, the elderly, and people living with HIV disease.

Commentary

Under the proposal, Vermont would also face somewhere between a 10 and 20 percent cut in its Medicaid funds, as Congress attempts to slash $182 billion from this vital health care program over the next seven years.

Although much as been said about the fight being waged around Medicare, the Congressional assault against "the other M program" (Medicaid) has been lost amid the clatter.

Medicaid is the federal "safety net" program that finances health care for more than 36.1 poor and medically needed Americans. Established in 1956, Medicaid has provided this country's medically needy with a guarantee that as long as they meet federal eligibility requirements, they are entitled to quality medical care they could not otherwise afford.

And 30 years later, Medicaid finances the health care of one in 10 Americans, including more than 46 percent of adults living with HIV-AIDS and 90 percent of children living with HIV-AIDS. Because the HIV disease is such an impoverishing disease, people with AIDS rely almost exclusively on Medicaid for outpatient services, hospitalization and nursing home care, diagnostic and laboratory services, life-saving prescription drugs, and home health care. That has been documented by the Henry Kaiser Family Foundation's study in 1993, entitled "Medicaid Expenditures and Beneficiaries."

At present, federal guidelines place requirements on states for coverage of specific groups of people and benefits. States that meet these requirements receive matching federal payments based on the state's per-capita income. The federal share now ranges from 50 to 80 percent of Medicaid expenditures.

Under the Medicaid proposals up for a vote in Congress next week — similar in both the House of Representatives and the Senate — the federal government would send 50 individual block grant checks to the states, no strings attached.

The proposals call for abolishing all federal provisions and requirements now in place to make sure that medically needy Americans do not fall through the cracks in this country's health care system. The proposals also would allow the states to decide how and on what (disease or group of people) to spend already scarce Medicaid funds.

It bears repeating:

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1. Removal of the specific protections now afforded by the law will place at risk the health care of more than 80,000 Vermont residents now on Medicaid.

2. That number includes children, the blind and disabled, the elderly, and people living with HIV disease.

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Look at the percentages based on the figures of the House Commerce Committee and the Senate Finance Committee, both reporting as late as Sept. 18.

The proposed cuts in funding would also mean between a 10 percent and 20 percent cut in funding for Vermont over the next seven years.

Is that what you want?

—

David Curtis of Burlington is a member of the board of the AIDS Action Council and also a member of the board of Vermont CARES.

The Sonoma County
Independent
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EDITORIAL

Rx for Disaster

THE REPUBLICAN-CONTROLLED House of Representatives recently voted to take a huge bite out of Medicare—$270 billion over seven years—seriously impairing the popular health care program already used by 37 million seniors. The sweeping GOP move is the pivotal point of a Republican tax reform effort to cut taxes by $245 billion and balance the budget by 2002.

And to think that just a year ago, Congress still was haggling over the possibility of universal health care. Now that seems like a pipe dream.

While the controversial overhaul of the Medicare system drew the spotlight last week, advocates for the disabled and for people living with HIV/AIDS held their breath and prepared for another round of expected cuts in the federal budget reconciliation bill being heard Friday, Oct. 27, in Congress.

This time the target is the Medicaid program.

Under that proposal, California faces a 14 to 20 percent cut in Medicaid funding to the state's 4.8 million poor and medically needy.

Ironically, the assault on Medicaid comes on the eve of the program's 30th anniversary. Created in 1956, Medicaid carries the guarantee that, as long as the medically needy can meet federal eligibility standards, they are entitled to quality health care that they otherwise could not afford.

Today, Medicaid finances the medical expenses of one in 10 Americans, including more than 46 percent of adults living with HIV/AIDS and 90 percent of the children infected with the HIV virus. People living with the HIV disease rely almost completely on the Medicaid program for outpatient services, hospitalization and nursing home care, diagnostic and laboratory services, life-saving—and often prohibitively costly—prescription drugs, and home health care because the disease is such an impoverishing affliction.

Under the reform plan, the federal government would send 50 individual block grants to the states, no strings attached. The proposals call for abolishing all federal provisions and requirements that are now in place and that insure that medically needy Americans do not fall through the cracks in this country's ailing health-care system. That plan calls for the states to decide how and for which diseases or groups of people to spend scarce, vastly reduced Medicaid funds.

We agree with Mark Barnes, executive ddirector of the AIDS Action Council, that maintaining a safety net for poor and disabled Americans should be the guiding force in shaping Medicaid's future.

Says Barnes: "Advocates for people with HIV/AIDS realize that Congress has difficult fiscal decisions to make. But Congress must not undertake far-reaching changes without careful thought; must not end entitlement status before examining the full impact on these AIDS care partnerships and the growing number of people with AIDS; must not [create] block grants when that means less money for urgent, growing needs; and must not rush into Medicaid managed care without careful planning about how to maintain access to care, including tough federal standards assuring adequate provider rates and quality assurance."

Medicaid cuts could threaten AIDS benefits

Proposed spending cuts in the Medicaid program could reduce health benefits for AIDS patients, AIDS activists warn.

BY JOHN A. NAGY
Staff Writer

Congress' plan to turn over the federal Medicaid health insurance program to states could curtail health benefits for thousands of people with AIDS, a national AIDS lobbyist warned Tuesday.

Mark Barnes, executive director of the AIDS Action Council, said North Carolina would lose billions of dollars in Medicaid funding over the next six years, and AIDS patients may be hit the hardest.

Almost half of the nation's 200,000 people diagnosed with AIDS receive health insurance through Medicaid. But they represent a small percentage. Most of the Medicaid dollars go toward health care for the elderly and for poor women and children.

Medicaid has been one of the fastest growing segments of the federal budget for the past several years. Congress, looking to balance the budget and still produce a tax cut, wants to reduce the future growth of Medicaid by $182 billion over the next six years.

"If that safety net is shredded, clients and patients are going to be banging on your doors for health care services."

Mark Barnes, *executive director of the AIDS Action Council*

Barnes, whose AIDS Action Council represents close to 1,000 AIDS support organizations, warned that politicians may end up reducing the money that goes to AIDS patients.

"If that safety net is shredded, clients and patients are going to be banging on your doors for health care services they can't get at the hospitals or physicians' offices," he said to a small group of public health workers and AIDS volunteers Tuesday.

The federal budget plan approved by Congress — and rejected so far by President Clinton — would allocate a set amount of money each year and turn it over to the states for Medicaid. Each state then would be responsible for deciding how to divide the funds, known as block grants.

Under that plan, North Carolina would receive $29 billion over the next six years, according to the latest analysis by the U.S. Department of Health and Human Services.

That's about $7.7 billion less than the state would receive under the current method of allocating Medicaid dollars.

States, faced with receiving less money, still would have to compensate for increased medical costs and expanding Medicaid rolls. Advocates like Barnes say that's where AIDS patients may get hurt.

Health care for AIDS patients is very expensive.

Please see **AIDS,** *Page* **B2**

Greensboro News & Record, 11/22/95

AIDS

Continued from page B1

Medicines, hospitalizations and doctor visits can total more than $40,000 a year. In contrast, it may only cost $1,000 a year to care for a poor woman or child.

But politicians may not only look at cost. Few politicians would go on the record opposing health care for poor women and children, Barnes said. Likewise, powerful lobbyists for the elderly would protect Medicaid funding for them.

AIDS patients, however, may not have much political clout.

"It's obvious, given the sheer political dynamics at the state level of what could occur," Barnes said. "That means the block grant, without conditions (protecting AIDS patients) ought to be of enormous concern."

Ben McFadyen, executive director of the Triad Health Project, a local AIDS support organization, worries what the loss of Medicaid would do to AIDS patients needing a doctor.

"Medicaid is such a little incentive now" for doctors, he said. "You take that away, there's no incentive."

Barnes said AIDS activists are continuing to lobby the White House to protect the interests of AIDS patients.

Clinton has called for an AIDS summit Dec. 6.

"We are going to use that opportunity as a way to hold Clinton's feet to the fire," Barnes said.

A18 *** Saturday - 1/27/96

San Francisco Chronicle
THE VOICE OF THE WEST

EDITORIALS

Medicaid a Savior For AIDS Patients

IN DRAWING BATTLE lines for the 1996 presidential race during his State of the Union address, President Clinton vowed to hang tough on protecting Medicaid, which guarantees medical care for the poor, elderly and disabled.

That is one promise the president must keep. Transformation of the federal entitlement into a block grant that would strip the program of all but the most minimal federal guidelines threatens health care to those who desperately need it, including poor children and pregnant women and elderly nursing home patients whose families could face bankruptcy without federal rules.

Medicaid block grants will pit the poor, elderly and AIDS patients against each other

Another group that could be devastated by a switch to Medicaid block grants are people with AIDS, now the leading killer of Americans between the ages of 25 and 44.

The $89 billion Medicaid program provides coverage for approximately 50 percent of patients with AIDS at a cost of about $4 billion.

While some states, including California, would be likely to maintain at least a moderate level of care for people with the HIV virus under a block grant program, other states that have been clearly hostile to AIDS programs might not.

The idea of backtracking to a time when one enlightened state treated its people with sensitivity and compassion while a neighboring state allowed the most vulnerable and sick to fend for themselves is unconscionable. Infectious diseases do acknowledge state lines. The federal government should not abrogate its responsibility to treat and prevent them.

What likely would happen with a Medicaid block grant is that the burden would fall to already overburdened counties to fill the gap in medical coverage. As much as they might want to assume the responsibility, they might not have the funds to do the job.

Even those states wanting to support Medicaid programs for AIDS patients may find that because of decreased funding (block grants rarely keep pace with inflation) they must choose among recipients. And the winners in such an unseemly tug of war likely would be the nursing homes, which enjoy considerable political clout compared with either AIDs patients or poor children and pregnant women.

There is almost universal agreement about the need to cut Medicaid costs, but there are reasonable alternatives to the extremist Republican solution of block grants.

One possibility may be to put a cap on the amount spent per individual rather than disregard need and limit the amount spent on the program.

Also, the Clinton administration has liberalized the waiver process, a trend that should be continued. With 30 Medicaid mandates imposed on states by the federal government between 1987 and 1992, it is no wonder that states want more independence in determining what works for their regions. There is every indication that this move toward state flexibility will continue, as it should.

Medicaid spending has increased dramatically, and will continue to do so without controls and innovation. But block grants for Medicaid are not the answer. They may reduce costs, but they will result in denial of care to the sickest and poorest among us.

October 13, 1995 • Vol. 26, No. 41

The Washington Blade

THE GAY WEEKLY OF THE NATION'S CAPITAL

Viewpoint

Medicaid proposal spells out deadly reform

by Mark Barnes

If ever a case could be made for the federal government's role in guaranteeing health care coverage, it could be made in the waiting rooms of community clinics around the country. It is in these noisy waiting rooms, often full beyond capacity, that most of this country's medically needy — the elderly, children, and people with disabilities, including HIV disease — sit and wait. They know that even if they face a long wait, at least they are guaranteed quality medical care under Medicaid. It is in the waiting rooms of clinics such as the Whitman-Walker Clinic's Austin Center, where 80 percent of patients rely on Medicaid for medical coverage, that Gay men and Lesbians with AIDS sit and wait, thankful that because a safety net exists to catch those Americans who cannot afford medical care, they do not have to choose between treating opportunistic infections and paying rent or buying groceries.

As obviously important as Medicaid is to the lives of more than one in 10 Americans now on Medicaid, today this program is in great jeopardy. The threat lies in a congressional proposal now winding its way through the legislative process. The proposal would abolish the existing Medicaid program and turn over to the states control of what has become this country's "safety net" health care program for the medically needy in the last 30 years. The proposal calls for converting the Medicaid program into annual checks to the states with few, if any, provisions about how that money should be spent. The proposal also calls for cutting $182 billion in projected federal expenditures on Medicaid over the next seven years. This proposal poses a grave danger to thousands of people with AIDS, because it would end the government's guarantee of medically appropriate care to them and all other poor and disabled Americans who meet minimum federal guidelines.

Issuing such a dire warning may be regarded as "crying wolf" once too often. After all, AIDS advocates used words such as "great jeopardy," and "grave danger" immediately after the November 1994 Republican sweep of Congress. There was great fear then that a slash-now/ask-later approach to balancing the federal budget might decimate an AIDS infrastructure that has taken years to build. I cannot remember ever having been more grateful that these predictions did not become reality. Despite efforts by some to derail its reauthorization, the Ryan White CARE Act is finally nearing reauthorization for another five-year term. Although the Centers for Disease Control and Prevention (CDC) did not see an increase in its HIV prevention funding, it also did not sustain any decreases. And the Housing Opportunities for People with AIDS (HOPWA), which subsidizes housing for low-income people with AIDS, survived challenges.

This time, however, there definitely is a wolf — congressional plans to curtail and block-grant the current Medicaid program with few minimum standards. Despite our community's very significant victories on Ryan White, CDC funding, and HOPWA, all of these programs combined cannot take the place of the existing Medicaid program. For example, while Ryan White provides more than $600 million a year to cities and states hardest hit by AIDS, more than $3 billion in Medicaid funds are spent annually on medical services for the poorest and sickest people with HIV disease. In its role as a safety net, the Medicaid program finances clinic, hospital, and nursing home care and lifesaving AIDS drugs for more than half of the Americans living with HIV disease. These people are either poor to begin with or are impoverished by a disease which gradually makes them too sick to work.

We would never take the national defense budget, divide it by 50, [and] write checks without conditions to the states ...

The federal government has a compelling humanitarian and financial interest in ensuring that all poor people with life-threatening diseases have access to quality medical care — an interest that 50 individual states cannot be relied upon to understand and act on. Each state has interests or priorities for their slice of the Medicaid pie that likely are different from the federal government's. We would never take the national defense budget, divide it by 50, write checks without conditions for the states, and rely on them to provide a common national defense. Why should we expect the states to take care of medical treatment for millions of Americans who have no where else to turn for quality care? We cannot and should not. With this Medicaid proposal for block grants without meaningful restrictions, Congress has gone down a path of spending almost $100 billion a year in taxpayer money without any guarantee that states will provide medical care to people with chronic serious illnesses, including HIV disease.

Today, with both the Senate and House of Representatives moving toward block granting and drastically cutting projected Medicaid costs, the AIDS community is facing a threat that could unravel all of our gains. Those threats we have encountered in this fiscally and socially conservative 104th Congress have been successfully met by a strong-willed AIDS community. But we must put those battles into perspective. These threats to date, although by no means insignificant, have all been to programs that complement or supplement Medicaid. The full frontal assault today is on the very safety net that assures people with AIDS do not fall through the cracks in our medical system. In our attempts to defend programs that contain the word AIDS in their legislative titles, the AIDS community cannot ignore the fact that Ryan White, HOPWA, and any number of other supplemental AIDS care and service programs cannot help treat a person with AIDS who, without medical care, will suffer needless pain and a hastened death.

The AIDS community cannot afford to have a wait-and-see attitude about Medicaid. Instead we must fight now, through grassroots pressure and congressional lobbying, to sustain the vital Medicaid safety net. The cost of doing nothing would be measured in lost lives.

Mark Barnes is executive director of AIDS Action Council.

Richmond Times-Dispatch

RICHMOND, VIRGINIA 23293 Copyright © 1995 145th Year No. 301 VIRGINIA'S NEWS LEADER • CITY EDITION • SATURDAY, OCTOBER 28, 1995

HURTING THE POOR

. . .But Beware the Cuts in Medicaid

If ever a case could be made for the federal government's role in guaranteeing health-care coverage to this country's poor and medically needy, it could be made in the waiting room of Virginia Commonwealth University's Medical College of Virginia Hospitals' Infectious Diseases (HIV) Clinic in Richmond. It is here where almost one-third of the clinic's more than 1,200 patients with HIV infection — among them 100 pediatric cases — know they will receive quality medical care they otherwise could not afford, but to which they are guaranteed access under the Medicaid safety net.

LISA KAPLOWITZ

As obviously important as Medicaid is to the lives of these Virginians and the more than 1-in-10 Americans now on Medicaid, today this program, and with it the public-health interest in AIDS treatment, is in great jeopardy. The threat lies in congressional proposals to block-grant Medicaid, abolish its time-honored guarantee of basic medical care, and allow the states to decide how and on what to spend greatly reduced amounts of federal Medicaid dollars.

MARK BARNES

> *"As obviously important as Medicaid is to the lives of these Virginians and the more than 1-in-10 Americans now on Medicaid, today this program, and with it the public-health interest in AIDS treatment, is in great jeopardy."*

■ *Lisa Kaplowitz, M.D., is director of the HIV/AIDS Center of Virginia Commonwealth University. She has provided care for persons with HIV infection since 1981. Mark Barnes is executive director of AIDS Action Council, the only national organization solely dedicated to shaping federal AIDS policy.*

Established in 1965, Medicaid finances clinic, hospital, and nursing-home care, as well as prescription drugs, for about half of all people with AIDS nationwide. That number continues to rise as the epidemic expands and the average income of people living with AIDS continues to decline. While the Ryan White CARE Act provides more than $650 million per year for the care of people with AIDS, more than $3 billion annually in federal Medicaid dollars goes for medical services for the poorest and sickest of people with AIDS. There are other infectious diseases of major public-health importance, such as tuberculosis. Although funding from the Centers for Disease Control and Prevention (CDC) helps enormously with tuberculosis testing and prevention, hospital and outpatient care for people with tuberculosis is largely funded by Medicaid dollars. With tuberculosis, as with AIDS, people affected tend to be poor and disproportionately reliant on Medicaid.

TO SAVE $182 billion over the next seven years, Congress is moving at lightning speed toward capping expenditures and block-granting of Medicaid — toward ending the "entitlement" status of Medicaid, or the concept that all poor and disabled Americans who meet minimum federal eligibility requirements will receive medically appropriate care. By capping Medicaid's growth and converting the program into a series of 50 annual checks written to the states, shorn of most minimum federal guidelines, congressional leaders hope to put a permanent stop to rapid increases in federal Medicaid expenditures — from $800 million in 1965 to almost $98 billion in 1995. Their concern for the budget is understandable: No one can deny the need to balance the federal budget and control spending, whether on entitlement programs or defense.

The danger here is that in block-granting Medicaid and relinquishing to the states almost all control over eligibility, coverage, and benefits, Congress also is irresponsibly relinquishing control over what are indisputably federal (interstate) interests in the treatment and prevention of infectious diseases of major public-health significance. For infectious diseases such as AIDS, tuberculosis, and emerging bacterial infections, neat state lines matter not a whit. Ultimately, aside from the essential humanitarian interest in making sure that all poor people with life-threatening diseases get good medical care, the federal government has a compelling interest in maintaining baseline treatment for medical conditions with important public-health components — a federal interest that individual states cannot be relied upon to understand and act upon, since each has interests or priorities for its slice of the Medicaid pie likely different from those of the federal government. For example, we would never take the national defense budget, divide it by a factor of 50, write checks without conditions for the states, and rely on them for defense against foreign aggression. Why then should we expect the states to take care of the overarching national interest to ensure medical treatment for millions of poor Americans who have nowhere else to turn for the care they need to combat major infectious diseases?

OF COURSE, taking care of people with infectious diseases is designed to do more than cure the individual patient; treatment of diseases like meningitis, tuberculosis, and syphilis is designed to cure the illness and thus stop transmission to others altogether. For AIDS, for which there is yet no cure, the overriding goal in treatment is to help patients live and work longer. However, treatment also includes counseling patients about risk behaviors and curbing HIV transmission to others. Very significantly, in psychiatric, mental health, and substance abuse treatment services targeted to people with AIDS, stabilizing the patient leads directly to reduced drug use, and reduced needle sharing, and reduced unsafe sexual behavior. This helps patients, and it helps us all — the infected and the uninfected, the taxpayer and the Medicaid recipient — in lowering public-health risks and in reducing future costs.

The word in Washington is that President Clinton intends to veto the congressional budget reconciliation bill, of which Medicaid is a component, and to take a firm stand in favor of maintaining Medicaid's entitlement status. Whether by presidential veto or by a last-minute change of heart among congressional leaders — maintaining a safety net for poor and disabled Americans should be the guiding force in shaping Medicaid's future. If Congress and the Clinton administration care to preserve the unique federal interest here, and thus to discharge their joint responsibility to protect the public health and safety, they must ensure that poor Americans with infectious diseases, including HIV disease, are guaranteed the medical treatment they need — for their own sake and for the nation's.

11-19-95 Greensboro (NC) News & Record

Local AIDS patients need Medicaid

By handing Medicaid over to the states, the federal government would be relinquishing its role in fighting infectious diseases.

BY BEN MCFADYEN AND MARK BARNES

If ever a case could be made for the federal government's role in health care coverage for this country's poor and medically needy, it could be made in the waiting room of the HealthServe Medical Center or at the Clinic at Moses Cone Memorial Hospital in Greensboro.

At HealthServe and at Cone, up to 60 percent of Guilford County's more than 500 patients with AIDS — among them some 20 pediatric cases — often sit and wait, knowing that their wait is for quality medical care they could otherwise not afford, but to which they are guaranteed access under the Medicaid safety net.

Ben McFadyen

As obviously important as Medicaid is to the lives of these 500 North Carolinians with HIV and the more than one in 10 Americans now on Medicaid, our elected officials in Congress have placed this program, and with it the public health interest in AIDS treatment, in great jeopardy.

Both the House of Representatives and the Senate last month passed budget bills complete with language that would shred the health care safety net Medicaid has come to represent. Both bills block grant Medicaid, abolish its time-honored guarantee of basic medical care to millions of poor and medically needy Americans and allow the states to decide how and on what to spend greatly reduced amounts of Medicaid federal dollars.

Mark Barnes

The only key improvement enacted during limited debate on an issue of vital importance to more than 36 million Americans was an amendment which would require states to guarantee eligibility to low income people with disabilities who are now eligible for Supplemental Security Income (SSI).

Established in 1965, Medicaid today finances essential care. This 30-year-old program finances clinic, hospital and nursing home care and prescription AIDS drugs for about half of all people with AIDS nationwide, and that number continues to rise as the epidemic expands and the average income status of people living with AIDS continues to decline.

Despite the more than $650 million per year the Ryan White CARE Act provides for the care of people with AIDS, more than $3 billion each year in federal Medicaid dollars goes for medical services for the poorest and sickest of people with AIDS.

The danger here is that in block granting Medicaid and relinquishing to the states almost all control over eligibility, coverage and benefits, Congress also is irresponsibly relinquishing control over what are indisputably federal, interstate interests in the treatment and prevention of infectious diseases of major public health significance. Neat state lines do not matter to infectious diseases like AIDS, tuberculosis and emerging bacterial infections.

We would never take the national defense budget, divide it by a factor of 50, write checks without conditions for the states, and rely on them for defense against foreign aggression. Why, then, should we expect the states to take care of the overarching national interest to assure medical treatment for millions of poor Americans who have nowhere else to turn for the care they need to combat major infections diseases? The answer is simple: We cannot and should not.

"Neat state lines do not matter to infectious diseases like AIDS ..."

Of course, taking care of people with infectious diseases is designed to do more than cure the individual patient: treatment of diseases like meningitis, tuberculosis, and syphilis is designed to cure the illness and thus stop transmission altogether. For AIDS, for which there is yet no cure, the overriding goal in treatment is to help patients live and work longer.

This helps patients and it helps us all — the infected and the uninfected, the taxpayer and the Medicaid recipient — in lowering public health risks and in reducing future costs.

Clinton administration officials have indicated that the president will take a firm stand in favor of maintaining Medicaid's entitlement status. In the end, whether it is by presidential determination or by a last-minute change of heart among Congressional leadership, maintaining a safety net for poor and disabled Americans should be the guiding force in shaping Medicaid's future.

If Congress and the Clinton administration care to preserve the unique federal, interstate interest here, and thus to discharge their joint responsibility to protect the public heath and safety, they must ensure that poor Americans with infectious diseases, including HIV disease, are guaranteed the medical treatment they need — for their own sake and for the nation's. We must have more than politics to prevent the needless pain and hastened deaths caused by irresponsible public heath policies.

Ben McFadyen is director of Triad Health Project, a local organization that provides HIV/AIDS service, support and prevention.

Mark Barnes is executive director of AIDS Action Council, a national organization dedicated to shaping federal AIDS policy.

Bangor Daily News - Dec. 6, 1995

Poor and sick need Medicaid

By Nancy O'Neill and Mark Barnes

The case for the federal government's role in guaranteeing health care coverage to this country's medically needy could easily be made in the waiting rooms of physicians' offices across Maine. Here in my Presque Isle practice, 40 percent of my HIV-AIDS patients are also on Medicaid, a staggering percentage consistent with national trends that reflect the difficulty for people with AIDS to afford private insurance once they are too disabled to work.

As obviously important as Medicaid is to the lives of so many people in Maine, Congress has placed this program, and with it the public health interest in AIDS treatment, in great jeopardy. Both the House of Representatives and the Senate passed late last month budget reconciliation bills complete with language that would shred the health care safety net by block-granting Medicaid and thus abolishing its time-honored guarantee as basic medical care to millions of medically needy Americans. This then allows the states to decide how and on what to spend greatly reduced amounts of federal dollars. The only key improvement in the bill was an amendment which would require states to guarantee eligibility to low-income people with disabilities who are now eligible for Supplemental Security Income (SSI). Yet, as the amendment's co-author, Sen. John Chafee, R-R.I., said in debate, this amendment is not enough to salvage the health care safety net shredded by a Congress intent on reform at any cost: "Do we say what kinds of coverage, what the health care package is?" Chafee asked rhetorically, "No. One aspirin a year could be the (state's) health package."

Established in 1965, Medicaid today finances much more than just one aspirin a year. This program finances clinic, hospital and nursing home care, and prescription AIDS drugs for about half of all people with AIDS nationwide, and that number continues to rise as the epidemic expands and the average income status of people living with AIDS continues to decline. Despite the more than $650 million a year the Ryan White CARE Act provides for the care of people with AIDS, more then $3 billion each year in federal Medicaid dollars goes for medical services for the poorest and sickest of people with AIDS. Similarly, for people with tuberculosis — a disease once nearly eradicated, but which has re-emerged with the AIDS epidemic — hospital and sanitarium care for tuberculosis is largely funded by Medicaid dollars. Tuberculosis, like AIDS and other infectious conditions, tends to affect the poor proportionately.

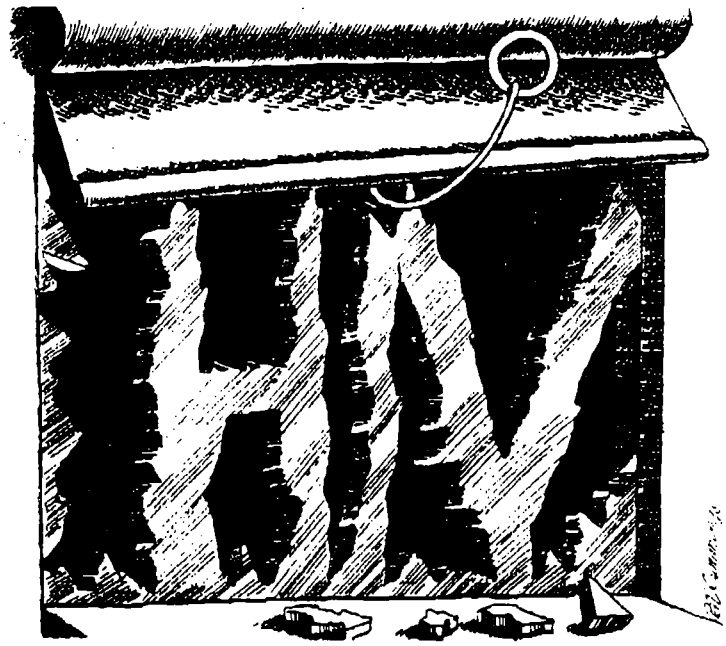
To save $170 billion over the next seven years, Congress has moved at lightning speed — less than one day's worth of debate in each chamber — toward the capping of expenditures and the block-granting of Medicaid — toward ending the "entitlement" status of Medicaid. By capping Medicaid's growth, congressional leaders hope to put a stop, for good, to the rapid increases in federal Medicaid expenditures — from $800 million in 1965 to almost $98 billion in 1995. Their concern for the budget is understandable: No one can deny the need to balance the federal budget and control out-of-control spending, whether on entitlement programs at one end of the political spectrum, or defense on the other.

Financing much more than an aspirin a year

The danger here is that in block granting Medicaid and relinquishing to the states almost all control over eligibility, coverage and benefits, Congress is also irresponsibly relinquishing control over what are indubitably federal, interstate interests in the treatment and prevention of infectious diseases of major public health significance. Diseases like AIDS and tuberculosis do not recognize state lines. Ultimately, aside from the essential humanitarian interest in making sure that all poor people get good medical care, the federal government has a compelling interstate interest that individual states cannot be relied upon to understand and act upon. We would never, for example, take the national defense budget, divide it by a factor 50, write checks without conditions for the states, and rely on them for defense against foreign aggression. Why, then, should we expect the state to take care of the overarching national interest to assure medical treatment for millions of poor Americans who have no where else to turn for the care they need to combat major infectious diseases?

The answer is simple: We cannot and should not. Taking care of people with infectious diseases is designed to do more than cure the individual patient but to stop transmission to others altogether, thereby saving money in the long run. With AIDS, for which there is yet no cure, the overriding goal in treatment is to help patients live and work longer. Treatment is an opportunity to counsel patients about risk behaviors, thus curbing HIV transmission. Stabilizing the patient leads directly to reduced drug use, reduced needle sharing and reduced unsafe sexual behavior. This helps patients, and it helps us all — the infected and the uninfected, the taxpayer and the Medicaid recipient — in lowering public health risks and in reducing future costs.

The word in Washington, D.C., these days is that President Clinton intends to veto the budget reconciliation bill ultimately approved by the House and Senate after conference committee negotiations. The president continues to take a firm stand in favor of maintaining Medicaid's entitlement status. In the end, whether it is by presidential determination in the form of a veto or by a last-minute change of heart among Congressional leadership, maintaining a safety net for poor and disabled Americans should be the guiding force in shaping Medicaid's future. If Congress and the Clinton administration care to preserve the unique federal, interstate interest here, and thus to discharge their joint responsibility to protect the public health and safety, they must ensure that poor Americans are guaranteed the medical treatment they need — for their own sake and for the nation's. One aspirin a year will not be enough to prevent the needless pain and hastened deaths caused by irresponsible public health policies.



BARBARA CUMMINGS/OP ART

Nancy O'Neill is a family physician in Presque Isle; Mark Barnes is executive director of AIDS Action Council in Portland.

The Herald (Miami, FL)
December 26, 1995

Losers in budget battle could be persons with AIDS

Mark Barnes is executive director of the Washington, D.C., based AIDS Action Council, which represents community-based AIDS service organizations.

MARK BARNES

THE beleaguered Medicaid program hangs in balance while President Clinton and congressional leaders dicker. Hanging in the balance, too, are the lives of more than 36 million poor and medically needy Americans — including about half of the Americans living with AIDS.

These are the people who are likely to suffer under any plan that cuts and sends Medicaid dollars to the states in block grants without meaningful guidelines for how the money should be spent.

Some in the AIDS community consider the Ryan White CARE Act the "single most important program" for people living with HIV. While that act provides more than $630 million annually to care for people with AIDS, more than $3 billion in federal Medicaid dollars goes annually to medical services to the poorest and sickest victims of AIDS.

The Medigrant program that would replace Medicaid makes drastic cuts in projected spending over the next seven years. The Congressional Budget Office estimates the cuts at $163 billion; the Washington-based Center on Budget and Policy Priorities includes reduced state contributions and estimates the loss at a staggering $420 billion. The center assumes that states will provide just enough funding to qualify for their federal allocations, but provide no additional dollars.

Medigrant guarantees no one a minimum benefits package, though it requires states to provide some level of coverage to pregnant women, children under 13, and the disabled. States have discretion in defining "disabled."

There are viable, practical alternatives that are much less painful. The Clinton administration and key congressional Democrats are proposing to establish a cap on the growth of spending per beneficiary. They call it a "per-capita cap." It would allow states to receive a fixed amount of federal dollars per beneficiary; the amount would vary with the category of beneficiaries — pregnant women, children, the disabled, the elderly. Eligibility criteria and the basic benefits package would also be maintained. But by also capping the rate of spending increases on each beneficiary, the plan reduces federal Medicaid spending. Cuts would not be so drastic, and change would not be as disruptive.

In the current political climate, a per-capita cap on federal Medicaid spending may be the most viable alternative to Medicaid block grants.

The budget debate is not about politics as usual; it is about profound decisions on the role of the national government in taking care of people.

In the eleventh hour, the nation is rightly questioning the fine print scrawled somewhere in the Republican leadership's blueprint for balancing the budget in seven years. What Americans are discovering is that the Medicaid part of the plan is heartless and avoidable.

No one can deny that harnessing health-care costs is necessary — it was necessary last year when the Congress lacked the political will and prudence to guarantee universal health care, and it is necessary today. The effort to balance the federal budget should not, however, deprive vulnerable people of needed health care.

For 30 years Medicaid has guaranteed health care to vulnerable Americans. Medicaid must be preserved.

San Francisco Frontiers Newsmagazine
January 18, 1996

Happy New Year and Get Ready to Fight for AIDS Funding

BY MARK BARNES

With the start of a new fiscal year, AIDS advocates usually take a well-deserved breather from daily fighting for funding for every federal program linked to AIDS, and shift gears in preparation for the battle for AIDS funding in the year ahead. Not so going into the third month of fiscal year 1997. Unfortunately, as of this writing, the only answer we in Washington can give to the question, "What can we expect to happen to AIDS research, care and prevention funding in fiscal year 1997?" is, "We'll let you know just as soon as President Clinton and the Congress can agree on fiscal year 1996."

Uncertainty is not new to AIDS advocates—at times it has come to be a state of mind. But never has the AIDS advocacy community experienced the level of uncertainty (read also: frustration) that we now are experiencing with the on-again, off-again budget negotiations, impasse or stalemate (the terms change daily) in which the GOP congressional leadership and the Clinton administration appear to be engaged.

President Clinton and the GOP congressional leadership agreed on Nov. 19 to balance the federal budget by 2002 using congressional Budget Office estimates, provided the budget protects programs for health care (chief among them Medicaid), the environment and education. The commitment to these programs and to the fundamental humanitarian values they embody—commitments to which both sides agreed, at least on paper—are every bit as important as the nation's need for fiscal control. Despite this written agreement, which was signed by President Clinton as a condition for re-opening the government during the first federal shutdown, four days before Christmas the federal government again shut down and more than 250,000 federal employees sat at home waiting for budget negotiators to negotiate in good faith and desist from engaging in partisan attacks against one another. Even now, despite an apparent compromise, there is still uncertainty about whether the two sides can agree on the particulars of a seven-year balanced budget plan, with such key issues as the fate of the Medicaid health-care safety net program hanging in the balance. Indeed, Medicaid's future has emerged as a primary point of ideological disagreement between the president and Congress, with the congressional leadership seeking block grants and thus a final end to poor people's entitlement to basic health care, while the White House seems equally wedded to preserving Medicaid in roughly its present form. And, there is even greater uncertainty about whether the principals in this budget stalemate—GOP congressional leaders and President Clinton—are even willing to breach the philosophical gulf, exacerbated by partisan politics, around how to balance the federal budget.

> **"I have known what the Greeks did not: uncertainty."**
>
> ***Jorge Luis Borges Ficciones***

Perhaps the only certainty in this equation is that, in any scenario, the AIDS community faces great threats to the already insufficient funding appropriated to the programs that keep people with AIDS alive, attempt to prevent the further transmission of this virus, or research a way finally to end this 15-year-old pandemic. It has become clear in these ongoing budget negotiations that both the Republicans and the Democrats have embraced the concept of a balanced budget. Whether politically expedient or fiscally responsible, the embracing of the balanced-budget concept will undoubtedly hurt, directly or indirectly, AIDS programs, because as government tightens its belt, among the first programs to feel the budget scalpel will be domestic discretionary programs. Most importantly, under the budget scenarios, either the president or the congressional leadership, domestic discretionary spending will be severely restricted in all fiscal years between 1996 and 2002. Since all major categorical AIDS funding—prevention at the Centers for Disease Control and Prevention, the Ryan White CARE Act, National Institutes of Health research, and AIDS housing (Housing Opportunities for People with AIDS)—falls into this "discretionary" category, all AIDS funding will be at serious risk in all foreseeable federal fiscal years. Our challenge as AIDS advocates will be to try in increasingly fiscally conservative times to preserve the integrity of our vital programs, and to safeguard an already fragile AIDS care infrastructure.

As uncertain as times are for our community, there is one certainty that must guide our efforts and that we must ensure that federal budget and policy decision-makers in Washington fully understand: Beyond the politics and budget projections, countless human lives, including those of people living with HIV/AIDS, are at stake. As our elected officials on both sides of the political aisle negotiate America's future and that of the programs which benefit so many Americans, they must do so with the understanding that the end-result of their negotiations, although pleasing on paper in the form of diminished expenditures, could mean needless pain and hastened deaths for millions of America's most vulnerable citizens. America cannot afford, nor should it even consider, paying that hefty price.

Mark Barnes is executive director of AIDS Action Council in Washington, D.C.

AIDS shows flaws in block grant plan

MARK BARNES

An important issue separating President Clinton and Congress in their budget negotiations has become Medicaid reform — specifically, whether control of the program should be ceded to the states in the form of largely unregulated block grants.

The matter has taken on great significance for AIDS advocates, who have witnessed the results of state control over Medicaid and AIDS-specific programs in Texas and elsewhere.

Mr. Clinton has pledged full support for Medicaid's entitlement status and for continued federal cost sharing of a program that finances basic health care and prescription drugs for this country's most vulnerable citizens, including half of all people living with AIDS and 90 percent of women and children with AIDS.

Meanwhile, congressional Republicans seem equally committed to ending Medicaid's tap into the federal treasury. Under the GOP's "Medigrant" alternative, each state would receive one check each year as the entire federal Medicaid contribution, a contribution that would be reduced by more than $117 billion from 1996 through 2002.

> In an epidemic that knows no state boundaries, the way to approach Medicaid and other vital prevention and care programs isn't just to punt the issue to the states and hope for the best.

Just as troubling is the Republican proposal to repeal all minimum federal standards relating to coverage, benefits, quality of care and consumer protections. In effect, it would leave the states with total freedom to define their own assistance programs.

That willingness to trust entirely in the kindness and wisdom of the states would put many vulnerable Americans at risk. We can't depend on the states to do what is right. Many examples throughout the country show just why this block-granting-without-strings would be disastrous.

The most common state government response to AIDS has been disappointing at best and negligent in the extreme. A few states, New York among them, devote substantial state tax dollars to AIDS care and treatment. But in many other states, where legislators are allowed the "flexibility" to define optional Medicaid benefits, the results occasionally have been catastrophic for people living with AIDS.

In Missouri, for example, only a lawsuit brought by AIDS advocates in the late 1980s forced the state Medicaid program to pay for the anti-AIDS drug AZT.

More recently, under the flexibility of existing federal standards that leave many Medicaid coverage choices entirely up to the states, the Medicaid programs in South Carolina and Texas pay for a patient to be on only three prescriptions at any given time, even though advanced AIDS or terminally ill elderly patients often require 10 or more drugs to keep them alive.

Even worse, another 14 states don't provide any prescription drugs under their Medicaid programs. In the absence of federal minimum requirements, states can choose, and they have done so.

The troubles with state control aren't confined to state Medicaid programs. Many localities have had difficulty implementing the Ryan White AIDS emergency relief program. Federal authorities overseeing the District of Columbia's program, for example, have been so distraught over its delay to spend federal money on AIDS services that they have threatened to bypass the local government entirely and put the program into trusteeship.

From its inception, the federal government has been charged with assuring the common, national good. In an epidemic that knows no state boundaries, the way to approach Medicaid and other vital prevention and care programs isn't just to punt the issue to the states and hope for the best. Rather, the goal should be to use federal funding as a means to replicate good programs, such as those instituted in New York and elsewhere, and discourage less effective ones.

Simple block-granting without tough federal supervision and high standards doesn't serve the common good. In AIDS, as in all areas of disease control, the costs of block-granting without accountability are measured in lives needlessly shortened and lost.

Mark Barnes is executive director of the AIDS Action Council, which represents more than 1,000 community-based AIDS service organizations nationwide.

VIEWPOINTS

Editor ..... *Bob Moos*

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Letters to the Editor

* * *

Ms. Smith's essay can only be described as myopic. She writes that "for more than a decade, American public health officials have ignored the central tenets of plague control" by failing to endorse nationwide mandatory HIV testing. "The medical establishment," Ms. Smith argues in righteous indignation, "voted for individual rights over public health." Yet Ms. Smith's own proposal that millions of Americans should be subjected to mandatory testing is little more than a stick with no carrot. Glaringly absent from her argument for a mandatory testing program is not only how expensive and counterproductive such a program would be, but how she proposes to care for all those Americans she would subject to mandatory testing.

Mandatory testing for HIV is opposed by, among other groups, the American Medical Association, the American Academy of Pediatrics, the American Hospital Association and the American Public Health Association. Their opposition is not based, as Ms. Smith would have us believe, on the premise that mandatory testing is "a slippery slope toward detention camps." They have each denounced mandatory testing as prohibitively expensive and as a generally ineffective way to reach people at risk. HIV is not, after all, gonorrhea or syphilis, for which a "magic bullet" can stop infection, disease and transmission. Disease-control strategies for HIV instead must be designed around the reality of the epidemic: a fatal infection transmitted in private, intimate situations far beyond the legitimate reach of the state, and for which voluntarism is the most effective approach.

Perhaps the most poignant example of how out-of-touch Ms. Smith is with political reality and the AIDS epidemic is contained in her closing statement: "The nation has a moral duty to care for those who are infected, but the infected also have a responsibility to those with whom they share their lives—and bodies." Does Ms. Smith realize that almost 15 years into the epidemic—15 years in which the AIDS community has fought to establish what remains today a fragile AIDS-care infrastructure—the current congressional leadership is threatening to restrict the content of AIDS prevention programs? To gut substance abuse programs? Is she unaware that Congress is debating legislation that would dismantle the Medicaid program and thus shred the health-care safety net for more than half of all people with AIDS who now rely on Medicaid for access to basic health care and, in many cases, to the very HIV testing she so wants?

MARK BARNES
Executive Director
AIDS Action Council
Washington

The New York Times

Founded in 1851

EDITORIALS/LETTERS TUESDAY, NOVEMBER 28, 1995

Treatment's High Cost

To the Editor:

As someone who has worked in the AIDS community more than 10 years, as a public health official and head of a national AIDS advocacy organization, I agree with Andrew Sullivan (Op-Ed, Nov. 21) that some in the AIDS community have maintained an atmosphere that tends to make hopefulness taboo.

New scientific developments in treatment, although not cures, should transform into hope the despair born of fighting the virus with ineffective drugs.

However, absent from Mr. Sullivan's argument is the chilling social reality of AIDS: Promising treatments are little promise to an increasing number of the H.I.V.-infected who lack access to basic medical care and prescription drugs.

Mr. Sullivan's formula — knowledge of H.I.V. infection plus promising new drugs equals the hope of long life — excludes the reality that most people living with H.I.V. cannot afford a combination drug regime as expensive as 3TC plus AZT, which can cost upward of $8,000 a year. Even those who can afford health care through private health insurance face an almost daily struggle to maintain any type of coverage for medical and drug services.

Also missing is any mention of the frontal assault being waged by the Federal Government against the very public health programs that keep people with AIDS alive, including the Medicaid health care safety net that insures almost half of all people with AIDS.

A 3TC or saquinavir capsule cannot double for a roof over one's head and is not an alternative to food when a person with AIDS must decide between paying rent, buying groceries or paying for health care.

MARK BARNES
Exec. Director, AIDS Action Council
Washington, Nov. 22, 1995

Deadly reform: Congress moves to block Medicaid

If Congress proceeds with plans to dismantle Medicaid, people with AIDS could be left without quality care.

Mark Barnes

> "Civilizations, I believe, come to birth and proceed to grow by successfully responding to successive challenges. They break down and go to pieces if and when a challenge confronts them which they fail to meet." —Arnold Toynbee, *Civilization on Trial*

Facing some very real threats to key AIDS programs in the past few months of budget action in Congress, the AIDS community has forged coalitions and fought successfully to maintain an infrastructure that has been years in the making. Yet we face a challenge that threatens to unravel all gains made to date: a Congressional proposal that would abolish the existing Medicaid program and with it any guarantees of basic medical care for this country's medically needy—children, the elderly, and people with disabilities, including HIV disease.

Medicaid, which pays for the care of one in ten Americans, is the largest source of health insurance for people living with HIV. In its role as a safety net, Medicaid is the primary source of clinic, hospital and nursing home care, and life-saving AIDS drugs, for more than half of all people with HIV disease who are either poor to begin with, or who are impoverished by a disease which gradually forces them to rely almost exclusively on federal assistance and private and family help.

A little less than two months ago, the Senate passed unanimously a reauthorization of the Ryan White CARE Act. Realizing the importance of this vital piece of legislation, the House of Representatives recently passed its own version of the reauthorization bill. The AIDS community breathed a collective sigh of relief that this program, which many had predicted would face tough opposition, if not defeat, had been overwhelmingly passed in a fiscally and socially conservative 104th Congress.

As significant as this victory is, however, Ryan White is but the payor of last resort in many cases for the working poor, uninsured, or underinsured. For this population, Ryan White pays for primary care and life-saving drugs. Yet for those people with HIV who no longer work and who have run through all their assets—which by time of death is a majority of AIDS patients—Medicaid is the ultimate safety net.

In considering the effect of any reform in Medicaid—cost caps, block granting, or a move toward Medicaid managed care for people with HIV—Congress should consider with great care the impact of any of these changes on the still new, in many cases fragile, partnerships for AIDS care that have been built over the past decade. In many clinics and hospital outpatient departments all over the nation, Medicaid funding is the fiscal foundation for AIDS care and treatment. In these mostly not-for-profit, charitable clinics, physicians and nurses—often paid fractions of what they would make in private practice or in academic medicine specialties—work in difficult, trying conditions, with ill and declining patients. Their work is supported by volunteers, by private contributions of money and time, by foundation grants, by Ryan White funds—and at base, by Medicaid reimbursement. Without that underpinning, the private sector and healthcare worker altruism—important as they are—would not be enough.

The AIDS healthcare community itself over the past decade has embraced efficiency in healthcare delivery: by forming volunteer social service networks to keep PWAs at home for as long as possible, by placing emphasis in Ryan White programs on primary care and basic AIDS drugs for the uninsured, and by fighting for adequate Medicaid funding for AIDS care. Advocates for people with HIV/AIDS realize that Congress has difficult fiscal decisions to make. But Congress must not undertake far-reaching changes without careful thought; must not end entitlement status before examining the full impact on these AIDS care partnerships and the growing numbers of people with AIDS; must not block grant when that means less money for urgent, growing care needs; and must not rush into Medicaid managed care without careful planning about how to maintain access to care, including tough federal standards assuring adequate provider rates and quality assurance.

Surely there is room for reform in Medicaid, but unless that reform is accomplished with an eye toward quality care, people with AIDS could be pushed back a decade or more, and all the great effort Congress and the AIDS community have placed into crafting Ryan White and other complementary programs could be for naught. ■

Mark Barnes is the executive director of AIDS Action Council, the Washington-based national advocacy voice of AIDS service organizations. AIDS Action represents more than 1000 community-based AIDS service organizations throughout the Unied States providing care to people and communities affected by AIDS.

Congress votes to shred Medicaid safety net

The new health package could be "one aspirin a year," unless the Clinton Administration holds fast to its promise to veto the inhumane block-grant program passed by the House and Senate in October.

Mark Barnes

For several months, the political clamor in Washington, DC, has centered around Medicare reform, $245 billion in tax cuts, and very little else. The threat to Medicaid, the other "M" program, went mostly unnoticed by a nation—and unreported by media outlets—that could not distinguish one "M" program from another. It was not until the Republican leadership in Congress unveiled its budget reconciliation bills that real attention was paid to accompanying Medicaid "reform" proposals. AIDS advocates quickly came to realize that this so-called reform had the potential to undermine the already fragile healthcare infrastructure upon which millions of Americans, including people living with HIV/AIDS, now rely for basic healthcare.

Despite very vocal opposition by Medicaid advocates and constituents to the Republican majority's cruel and irresponsible scheme to "end federal bureaucratic intermeddling with Medicaid" and to "curb the spiraling cost of Medicaid," the threat became political reality last month [Oct. 26 and 27]. Passed along party-line votes in both chambers of Congress were comprehensive budget bills under which Medicaid's entitlement status would end, the federal-state partnership in providing health insurance to millions of Americans would be transformed into unregulated block grants to the states, and already limited Medicaid funding would be slashed by more than $170 billion over the next seven years.

To understand what the Medicaid provisions in these budget bills represent to HIV/AIDS care, examine the role Medicaid now plays in providing healthcare to almost half of all people with AIDS. Established in 1965, Medicaid has guaranteed access to basic healthcare for millions of poor and medically needy Americans. In its 30-year history, Medicaid has served as a safety net insuring that specific groups of people, such as pregnant women, children, the elderly, and people living with disabilities, including HIV disease, do not fall through the cracks in the healthcare system. Today, 41 million Americans—two-thirds of whom have incomes below 200 percent of the federal poverty level—are uninsured. Thirty-six million of these people are thus forced to rely almost exclusively on already limited Medicaid funding to help finance their clinic, hospital, and nursing-home care, as well as life-saving prescription drugs. Both the population of low-income and medically needy Americans with AIDS and their healthcare costs are growing as the AIDS epidemic expands and the average income of people with AIDS continues to decline.

Despite Medicaid's importance to the lives of more than one in ten Americans, both the House and Senate passed budget reconciliation bills in October shredding the Medicaid healthcare safety net. While the House and Senate bills differ in a number of important ways, they both abolish the existing Medicaid program by ending Medicaid's entitlement status, thus eliminating guaranteed healthcare access for children, the elderly, and people with disabilities, including people with HIV disease. This elimination would be accomplished by block-granting Medicaid—a centerpiece of the GOP's platform when the party swept into Congress last November—and establishing a "Medigrant" program under which the federal government would sign over to the states 50 individual block grant checks shorn of most minimum federal guidelines. Under the Medigrant proposal, states face up to a 37 percent decrease in projected Medicaid funding over the next seven years.

Although initially there were hopes that a fight over state funding allocations could dismantle the GOP's push for Medicaid "reform," the Republican leadership in both the House and Senate quickly pumped additional funds to states which represented critical votes needed for passage. For the majority of our elected officials in Congress, however, strongly worded messages from the Republican leadership were enough to cinch the votes necessary for passage of budget bills in which vital social programs such as Medicaid and welfare are ruthlessly cut. Reminding his forces that they were elected to balance the budget, House Speaker Newt Gingrich (R-Ga.) said if Republicans were to vote against the budget reconciliation bill because of "parochial" concerns, then "ask yourself why you are here." Senate

Majority Leader Bob Dole (R-Kan.) delivered a similar message.

If the 227-203 vote in the House, and 52-47 vote in the Senate, are any indication, in the 104th Congress balancing the federal budget takes precedence over the "parochial" concern around provisions that could devastate this country's healthcare infrastructure.

The Senate did enact a number of key improvements to its Medicaid block grant legislation. And Senate votes on scores of amendments during debate indicate there is a slim majority in support of block-granting the Medicaid program, and could set the stage for future Congress-White House negotiations under which a reconciliation package could be produced that stops short of block-granting the program and decimating its federal funding base.

Of particular interest to people with AIDS is an amendment proposed by Senators John Chafee (R-RI) and Kent Conrad (D-ND). The Chafee-Conrad amendment, which was passed by a vote of 60 to 39, would require states to guarantee eligibility to low-income disabled individuals who are now eligible for Supplemental Security Income (SSI) assistance. What that medical coverage will be, as Senator Chafee said during Senate floor debate, is anyone's guess. This amendment does not require states to provide medically necessary services or even a basic benefit package. "Do we say what kinds of coverage, what the healthcare package is?" Chafee asked rhetorically, "No. One aspirin a year could be the health package." As disheartening as the lack of a minimal package of care may be, at least the Chafee-Conrad amendment offers a small foothold for Medicaid's entitlement status. If enacted as is, it could also provide some modicum of protection for some people living with HIV/AIDS.

There was little progressive movement on Medicaid in the House. A group of conservative Democrats offered the only substitute budget bill allowed on the House floor. Among other provisions, this substitute included $82 billion in Medicaid cuts, but maintained the program's entitlement status by using a per capita cap to control federal spending. The substitute received little support from either Democrats or Republicans. The budget reconciliation bills will next go to House-Senate conference committee, where the differences between the two bills will be ironed out.

President Clinton outlined his expectations on the budget last month by saying the Republicans would pass a final budget reconciliation bill (which they are expected to do before Thanksgiving), he would veto that bill (which AIDS advocates pray he will do), and only then would serious negotiations occur.

AIDS advocates are lobbying the Clinton administration to remain firm in its conviction that while we need to have deficit reduction, we cannot afford to be reckless with the lives of millions of Americans. In the end, however, it is going to take presidential resolve and some much-needed compassion from Congress to avoid the devastating consequences a budget reconciliation bill as currently worded would have on millions of Americans. Whether by presidential veto or by a last-minute change of heart among Congressional leadership, maintaining a safety net for poor and disabled Americans must be the guiding force in shaping Medicaid's future. One aspirin will not be enough to prevent the needless pain and hastened deaths irresponsible public health policies will cause to the most vulnerable of this country's citizens. ■

Mark Barnes is executive director of AIDS Action Council, the Washington-based national advocacy voice of AIDS service organizations. AIDS Action represents more than 1,000 community-based AIDS service organizations throughout the nation providing care to people and communities affected by AIDS.

Risk to Medicaid continues

People with AIDS are the losers in the Congressional budget battle.

Mark Barnes

From Senate Majority Leader Bob Dole and House Speaker Newt Gingrich gleefully swinging golf clubs at a Capitol Hill press conference, to White House Chief of Staff Leon Panetta angrily accusing the GOP leadership of engaging in terrorism, the debate around the GOP plan to balance the budget in seven years devolved into an exchange of barbs during the recent impasse that led to a shutdown of the federal government.

Were one simply to read the headlines—"Gingrich numbers down," "Clinton tees while government closes doors"—one would think that only the loss of political ground in the eyes of the media, and consequently the attention of the American electorate, were at stake. Lost in the debate was the fact that many of the budget components the GOP leadership maintain are essential to "getting America back on track," including plans to dismantle Medicaid, would help finance what are clearly misplaced budget priorities—tax cuts, increased military spending, and much corporate largesse left intact.

While Republicans and Democrats lobbed political salvos at each other, the beleaguered Medicaid program has hung in the balance. More than 36 million poor and medically needy Americans, including about half of all Americans living with HIV disease, would suffer needlessly under the congressional leadership's plan to provide practically unrestricted Medicaid block grants to the states, while providing drastically less federal spending.

Some in the AIDS community have mistakenly called the Ryan White CARE Act program the single most important program for people living with HIV/AIDS. Yet, as many discovered during the budget battles, Ryan White is but a gap-filler, the payer of last resort for uninsured or underinsured people with AIDS who qualify neither for Medicaid nor for private, employer-provided medical insurance.

For almost 40 percent of all Americans with HIV disease who can no longer work and have thus been impoverished by the disease, Medicaid is the last safety net. Besides the more than $630 million per year the Ryan White CARE Act provides for the care of people with AIDS, more than $3 billion Medicaid dollars pay for medical services for the poorest and sickest of people with AIDS.

The final Congressional budget bill, passed largely along party-line votes on November 17, would replace the current Medicaid program with a program of block grants to the states with very few minimum federal requirements. The "Medigrant" program also cuts projected Medicaid spending over the next seven years—anywhere from the conservative Congressional Budget Office (CBO) estimate of $163 billion to a staggering $420 billion cut in total federal and state Medicaid contributions, as predicted by the Washington-based Center on Budget and Policy Priorities (CBPP). This level of cuts, the CBPP says, assumes that the states would provide just enough funding to receive their full federal block grant allocations, but would not voluntarily provide funds on top of that—a very real possibility in a radically reformed program shorn of federal requirements.

There are viable, practical alternatives that are much less painful than the radical surgery the GOP leadership is intent on performing on Medicaid. The Clinton administration and key Democratic members of Congress have proposed a cap on the growth of spending per beneficiary, called a "per capita" cap, instead of a rigid block grant formula.

A per capita cap would give states a fixed amount per beneficiary, with different caps for pregnant women, children, disabled individuals, and the elderly. The cap would allow the number of Medicaid beneficiaries to grow, and would maintain the current eligibility criteria and benefits package. By capping the rate of increase in the amount that a state can spend on each beneficiary, this plan would also reduce federal Medicaid spending, but the cuts would not be as drastic, and changes would not be as disruptive.

If this proposal does not see the light of day, only President Clinton's veto of "Medigrant," and his unwavering commitment to limit cuts to vital social programs, can halt the shredding of the AIDS care safety net that Medicaid represents.

The budget debate is not about politics as usual, but about profound changes in the role of the national government in taking care of its own citizenry. The nation is rightly questioning the fine print scrawled somewhere on the Republican blueprint for balancing the budget in seven years. What Americans are discovering, while Congress and the White House struggle to find room for compromise, is that the centerpiece of the GOP plan—a balanced budget—will be financed not by "savings" but instead by heartless, avoidable cuts to programs of vital importance to this country's most vulnerable citizens. ■

Mark Barnes is executive director of AIDS Action Council, the Washington-based national advocacy voice of AIDS service organizations. AIDS Action represents more than 1000 community-based AIDS service organizations nationwide providing care to people and communities affected by AIDS.

Threat to AIDS funding continues past fiscal 1996 budget battles

Mark Barnes

"I have known what the Greeks did not: uncertainty."

—Jorge Luis Borges, *Ficciones*

With the start of a new fiscal year, advocates for the AIDS community usually take a well-deserved breather from fighting for funding for every federal program linked to AIDS, and shift gears in preparation for the battle for AIDS funding in the year ahead. Not so going into the third month of fiscal year 1997. Unfortunately, as the *Journal* goes to press, the only answer to "What will happen to AIDS research, care, and prevention funding in fiscal year 1997?" is, "We'll let you know just as soon as President Clinton and the Congress can agree on fiscal year 1996."

Uncertainty is not new to AIDS advocates. But never has the advocacy community experienced the level of uncertainty (read also: frustration) that we now are experiencing with the on-again, off-again budget negotiations, impasse, or stalemate (the terms change daily) in which the GOP congressional leadership and the Clinton administration appear to be engaged.

President Clinton and the GOP congressional leadership agreed on November 19, 1995, to balance the federal budget by 2002 using Congressional Budget Office estimates, provided the budget protects programs for healthcare (chief among them Medicaid), the environment, and education. The commitment to these programs and to the fundamental humanitarian values they embody—commitments to which both sides agreed, at least on paper—are every bit as important as the nation's need for fiscal control. Despite this written agreement, which was signed by President Clinton as a condition for reopening the government during the first federal shutdown, four days before New Year's the federal government is again shut down and more than 250,000 federal employees are at home waiting for budget negotiators to desist from engaging in partisan attacks against one another.

On Day 13 of the second federal government shutdown, we do not know if there will be more continuing resolutions to reopen the government. The two sides may never agree on the particulars of a seven-year balanced budget plan, and key programs such as the Medicaid safety net hang in the balance. Indeed, Medicaid's future has emerged as a primary point of ideological disagreement between the President and Congress. The congressional leadership seeks block grants to states—and thus a final end to poor people's entitlement to basic healthcare. The White House, meanwhile, seems equally wedded to preserving Medicaid in roughly its present form. There is even greater uncertainty about whether GOP congressional leaders and President Clinton are even willing to breach the philosophical gulf, exacerbated by partisan politics, of how to balance the federal budget.

Perhaps the *only* certainty in this equation is that in any scenario, the AIDS community faces great threats to the already insufficient funding appropriated for the programs that keep people with AIDS alive, attempt to prevent the further transmission of this virus, or find a way to end this 15-year-old pandemic. Whether politically expedient or fiscally responsible, both parties' call for a balanced budget will undoubtedly hurt AIDS programs, because as government tightens its belt, domestic discretionary programs will be among the first to feel the budget scalpel. Most important, under every budget scenario under consideration, domestic discretionary spending will be severely restricted in all fiscal years between 1996 and 2002. Since all major categorical AIDS funding—CDC prevention, Ryan White, NIH research, and AIDS housing (HOPWA)—falls into this "discretionary" category, all AIDS funding will be at serious risk in all foreseeable federal fiscal years. Our challenge as advocates for people with AIDS will be to try in increasingly fiscally conservative times to preserve the integrity of our vital programs, and to safeguard an already fragile AIDS care infrastructure.

One certainty must guide our efforts: Beyond the politics and budget projections, countless human lives, including those of people living with HIV/AIDS, are at stake. As our elected officials on both sides of the political aisle negotiate America's future and that of the programs that benefit so many Americans, they must do so with the understanding that the result of their negotiations, although pleasing on paper in the form of diminished expenditures, could mean needless pain and hastened deaths for millions of America's most vulnerable citizens. America cannot afford, nor should it even consider, paying that hefty price. ■

Mark Barnes is executive director of AIDS Action Council, the only national organization devoted solely to lobbying the federal government on AIDS policy, legislation and funding. AIDS Action, founded in 1984, represents more than 1000 community-based AIDS service organizations throughout the United States.

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Threatened by reform?

By Christina Kent
AMNEWS STAFF

WASHINGTON — As the GOP Medicaid reforms roll through Congress like a juggernaut, AIDS experts are struggling to grasp the implications. Many experts say the proposals will harm society's most vulnerable members — but a few point out there are also opportunities.

The future of Medicaid is of intense interest to AIDS experts because the program is the single largest source of public funding for HIV/AIDS medical services, financing seven in 10 dollars spent nationally in 1994.

More than 40% of people with AIDS are enrolled in Medicaid, many of them because they meet the disability and income eligibility criteria for Supplemental Security Income. Medicaid also is crucial for children with HIV/AIDS; according to the Kaiser Commission on the Future of Medicaid, it covers more than 90% of children with AIDS.

As a source of funding for medical services for people with AIDS, Medicaid dwarfs the Ryan White CARE Act. Medicaid spent about $2.6 billion on AIDS in fiscal year 1994, compared with nearly $600 million available to state and local governments for both medical and other Ryan White programs.

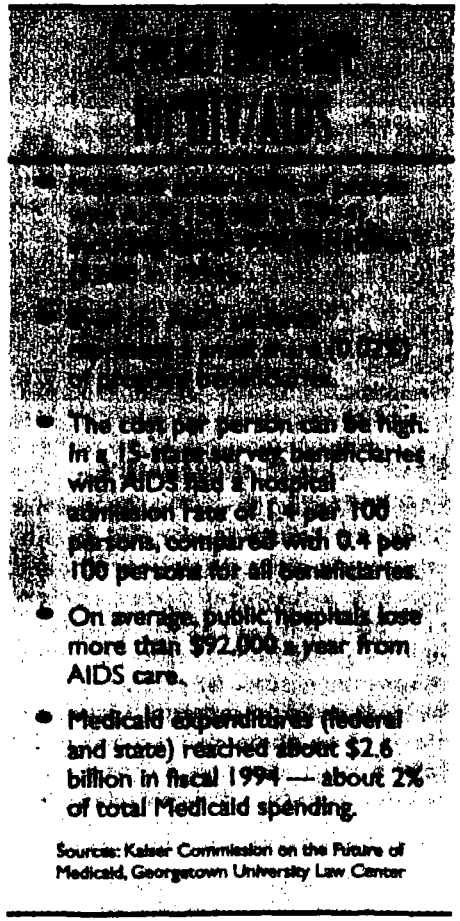
Recently, both the House and Senate voted to reauthorize Ryan White for five more years. The differences between their measures are being worked out in conference committee.

GOP Medicaid plans may hurt HIV/AIDS care

As to Medicaid, House and Senate committees have approved GOP proposals to transform the program into block grants to the states, with no automatic entitlement to aid for targeted populations. The measures were expected to go to the floors of the respective chambers for votes by late this month.

The proposals would give states greater freedom in exchange for less federal money than currently projected — $182 billion less from fiscal 1996

See ***MEDICAID,*** *page 38*



Medicaid

Continued from page 1

to 2002. Annual increases would range from 2% to 9%, depending on factors such as growth in low-income populations.

Few federal strings would be attached to the grants. The Senate version includes a provision added at the behest of Sen. John Chafee (R, R.I.) to require coverage of low-income pregnant women, children and disabled people. "Disabled" has yet to be defined. It might include people with HIV/AIDS, but sources say that the mandate is under attack from governors who oppose any federal restrictions, and it may not survive the Senate floor fight.

Many AIDS experts are vehement in their denunciation of the proposals.

"Block grants coupled with a major reduction in the sheer number of dollars will lead to delayed, deferred and in some cases unobtained treatment for people with HIV disease," says Mark Barnes, executive director of AIDS Action Council, a research and advocacy group in Washington, D.C.

He and other AIDS experts charge that some states will try to stretch their Medicaid dollars by forcing the chronically ill into health maintenance organizations of dubious quality. Other states will simply cut back on eligibility and benefits, producing "disease and death," Barnes says. "Needless and avoidable disease and death."

Other experts are more sanguine. "While there are substantial challenges here, there are also opportunities," says Mark Smith, MD, executive vice president of the Henry J. Kaiser Family Foundation.

"Most of us who deliver care to AIDS patients think that managed care should be a far superior way of providing care than the fractured services" of fee-for-service medicine, Dr. Smith says. The GOP reforms will, for the first time, give states the opportunity to "deliver on the theoretical promises of managed care."

Sometimes, Dr. Smith adds, "We judge a proposal more by who's for it and against it than by its intrinsic merit." When Oregon Medicaid officials first proposed limiting the number of services the state would cover, the idea was denounced as a cruel form of rationing. But by limiting services, he notes, the state was able to expand the number of people who are covered by Medicaid.

It is true that dire predictions aren't always realized. For example, when Tennessee slashed Medicaid payment rates in order to launch the highly controversial TennCare program, the effort was denounced by physicians and advocacy groups for the poor.

But today, Dan Ramey, a TennCare expert and social worker who serves HIV patients in a doctor's office in Hermitage, Tenn., says that while the program is far from perfect, overall, "people with HIV have been well-served by TennCare."

The key ingredient, says Joe Interrante, executive director of Nashville CARES, an AIDS advocacy group in the state capital, is that health plans that participate in TennCare are prohibited from excluding people on the basis of preexisting conditions.

Now, in a phenomenon that endangers the cost-saving properties of the program, TennCare is "attracting [HIV-positive] people from out-of-state," says Rusty Siebert, TennCare bureau chief. He declined to say how many people with HIV/AIDS have moved to Tennessee to take part in TennCare, but total current enrollment is 1.2 million.

Growing pains

About one thing there is no disagreement: If the federal and state governments are ever to gain control of their Medicaid costs (now rising at 10% a year), they will have to contain the costs of disabled and chronically ill populations.

Even though they consume only 2% of total Medicaid spending, people with HIV/AIDS are disproportionately expensive consumers of care. According to the Kaiser Commission, the average annual cost for a disabled Medicaid beneficiary was almost $8,000 in 1993. A study in California showed that the annual Medicaid cost per beneficiary with AIDS ranged from about $9,500 to $43,000 in 1992-93, depending on the severity of the disease.

Although the savings from managed care are limited, it stands to reason that states would seek to enroll their highest cost populations in HMOs.

The problem is that, overall, "we don't have any model for successfully converting this population to managed care," says James R. Tallon, president of the United Hospital Fund and chairman of the Kaiser Commission on the Future of Medicaid. Of the 23% of Medicaid beneficiaries now enrolled in managed care, almost all are poor children and their parents.

Among other factors, experts say, it is difficult to construct criteria for measuring the quality of care for HIV disease because even reasonable health care practices differ widely.

There also may be a shortage of qualified providers. In New York City, Medicaid officials recently called a halt to their efforts to enroll HIV-infected Medicaid beneficiaries in HMOs after an advocacy group's survey found managed care networks "ill-prepared" to treat those patients.

Such problems make it all the more important for states to begin developing high-quality HMOs for people with HIV/AIDS, says Dr. Smith. "If we don't get on with trying to see how things can be improved at the state and local levels, we'll lose opportunities to try to improve care by fighting yesterday's battles."

There are some models that states can use for guidance, he adds. For example, what may be the first-ever full-service, fully capitated staff-model HMO for people with AIDS was launched last April in Los Angeles. The city's AIDS Healthcare Foundation received a federal grant to enroll Medi-Cal-eligible people. "By using a managed care system, where quality is very strictly controlled and observed, we can, in fact, ensure that quality will be better and not worse," says medical director Charles F. Farthing, MD.

The foundation's president, Michael Weinstein, is equally enthusiastic. But he is worried about the impending GOP reforms. "California will sustain an $18 billion cut over the next seven years, and that is too radical. If they wipe out all the Medicaid regulations, we're concerned about what the standard of care will be. This is a national epidemic, and there need to be some national standards."

Other experts are more dire in their predictions. Tallon says that some states may seek to lower their costs by reducing benefits for high-cost populations, "subtly" encouraging those populations to move to states that provide more generous benefits. The result would be that states with higher-quality programs — such as Tennessee — could be penalized.

The variation between state programs could be exacerbated by the fact that nine states — California, Florida, Georgia, Illinois, Maryland, New Jersey, New York, Pennsylvania and Texas — account for 70% of AIDS cases, says Timothy M. Westmoreland, senior policy fellow at Georgetown University Law Center's Federal Legislation Clinic. "There will be uncontrollable health care costs in those states," Westmoreland says.

The AMA echoes the call for standards to ensure quality care. While the Association has "long recognized the need to restructure Medicaid," wrote Executive Vice President James S. Todd, MD, to Senate Majority Leader Bob Dole (R, Kan.), any reforms should include protections for vulnerable populations as well as quality standards.

Representatives of providers who have traditionally served the poor — including community health centers and public, teaching and children's hospitals — are worried they will end up bearing the brunt of any cost-containment efforts. HIV care is, "in general, a money loser for hospitals," says Louis Z. Cooper, MD, director of pediatrics at St. Luke's-Roosevelt Hospital Center in New York City and a board member of the American Academy of Pediatrics. "In a word, [the GOP proposals are] scary."

Victoria L. Sharp, MD, is medical director of the Spellman Center for HIV-Related Diseases at St. Clare's Hospital and Health Center in New York City. With a daily census of about 2,800 patients, the clinic gets 97% of its reimbursement from Medicaid and has an operating margin of about 1%, Dr. Sharp says.

"If the block grants go through, the first thing I will lose is the funding to hire specialists," and deprived of access to ophthalmologists, some patients will go blind, she says.

Next, social workers, nutritionists and HIV educators will be laid off, and pharmacological options will be restricted. "Rationing will occur, and the providers who remain will be asked to see 40 or 50 patients on the inpatient side, instead of [the current] 15 to 20. Burnout will increase and physicians will leave."

Ultimately, she says, both the Spellman Center and St. Clare's Hospital will close. She makes a plea for lawmakers to go slowly on reforms — at least until more experience is gained in designing and running HMOs for the chronically ill.

The New York Times

NEW YORK, TUESDAY, OCTOBER 31, 1995

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AIDS Groups Fear Loss Of Health Care Benefits

Shift of Medicaid Control to States at Issue

By DAVID W. DUNLAP

AIDS care groups nationwide say they fear that the plan to give states more control over Medicaid, which pays the health costs of half of the nation's AIDS patients, will force thousands of people to forgo benefits like prescription drugs and home health care.

Under the budget legislation passed by the House and the Senate last week, Medicaid spending would be slowed and the Federal Government would make block grants to the states, which would largely set their own standards for eligibility and care. The full Congress has yet to approve the budget bill, and President Clinton has vowed to veto any legislation with health care cuts that he regards as too severe.

But AIDS care groups are worried that block grants will create competition in state legislatures between families, the elderly, other disabled recipients and people with AIDS. And they are fairly certain who would lose.

"People with AIDS are not politically popular to defend," said Mark Barnes, executive director of the AIDS Action Council in Washington, which represents about 1,000 AIDS groups nationwide.

"As a person who grew up in Alabama, I fear, I tremble, for the fate of people with AIDS under a purely state-administered Medicaid program," he said. "If you're asking the average state legislator in Montgomery to choose between an elderly person in long-term care and a person with AIDS, given the social stigma and opprobrium directed toward people with AIDS, it's a no-brainer."

As Republicans see it, state legislatures are closer to the health problems faced by their constituents than is the Federal Government. Craig Murphy, a spokesman for Representative Joe L. Barton, a Texas Republican who is a member of the House Commerce subcommittee that oversees Medicaid, said, "There's no reason to assume that there's anything wrong with the priorities a state would make."

In New York, Lois Uttley, public affairs director of the state Health Department, said, "If resources are finite, the state would target resources to the most needy, and certainly people with H.I.V. and AIDS are in that category."

Kim Belshé, director of the California Department of Health Services, said block grants could give states more flexibility in addressing the special needs of their citizens, instead of accommodating a "Federal, one-size-fits-all mentality."

But neither Ms. Belshé nor any other state official can fully assess the impact of the proposed changes, which have moved rapidly through Congress.

Ms. Belshé finds herself gazing into a snow dome, rather than a crystal ball, as she and her colleagues seek answers about the future of Medi-Cal, the California Medicaid program. "We are frantically trying to figure out what's behind all those snowflakes," she said.

Medi-Cal supports 40 percent of the 3,000 clinic patients and 50 percent of the 2,000 hospice residents served by the AIDS Healthcare Foundation in Los Angeles.

The proposed changes in Medicaid would be "disastrous," said César A. Portillo, director of government affairs for the foundation.

"The political atmosphere in Sacramento is extremely hostile to people who are medically indigent," he added. "And when you're talking about AIDS in Los Angeles County, you're talking about a substantial number of immigrants."

Hispanic people account for 30 percent of the AIDS patients in Los Angeles, Mr. Portillo said, and a majority of those are immigrants.

At the Infectious Diseases Clinic of the Medical College of Virginia Hospitals in Richmond, about 30 percent of the 1,200 patients depend on Medicaid. Nearly one-fourth are black women; half are black men.

"I'm very concerned about what will happen on the state level," said Dr. Lisa G. Kaplowitz, director of the H.I.V.-AIDS Center of Virginia Commonwealth University, which includes the Richmond clinic. "People are seeing cost savings, but there is very little or no discussion about the quality of care."

Republicans say Congress is not scrimping on care. They cite the Congressional reauthorization earlier this year of the Ryan White Comprehensive AIDS Resource Emergency Act, which assists people with AIDS and H.I.V., the virus that causes AIDS.

Grateful as they are for that legislation, AIDS care groups say it is not enough. "Ryan White dollars pale in comparison to the funding that Medicaid provides for so many people with AIDS," said Dr. R. Scott Hitt, chairman of the Presidential Advisory Council on H.I.V./AIDS.

In the 1994 fiscal year, public spending on health care for people with AIDS and H.I.V. amounted to $3.75 billion, according to the Henry J. Kaiser Family Foundation, which has studied Medicaid issues. Of that, nearly 70 percent was paid by Medicaid, 15 percent by the Ryan White Act and 13 percent by Medicare.

More than half of all the AIDS patients in the United States, or roughly 100,000 people, depend on Medicaid to pay for their health care, said Patricia S. Fleming, director of the Office of National AIDS Policy, a White House agency. "The epidemic is moving directly into poor communities," she said, "so it's not surprising that so many people are eligible for Medicaid."

Medicaid spending on people with advanced cases of AIDS may range from $9,500 to $43,000 a year per person, depending on the severity of the illness, Kaiser Foundation officials said. In contrast, about $9,300 per person a year is spent on the elderly, $8,000 on the blind and disabled and $1,200 on children.

Although requirements vary from state to state, Medicaid generally covers those with incomes of less than $625 a month and who cannot engage in substantial gainful activity because of a physical or mental impairment that is expected to result in death or last at least a year.

Often, Mr. Barnes said, people with AIDS who have no private health insurance quickly spend themselves into poverty.

He and other advocates for people with AIDS envision a destructive competition for care.

"No civilized society should ever find itself at that point," said Representative Gerry E. Studds, a Massachusetts Democrat who is a member of the Commerce Committee. "The ultimate obscenity is, 'Who shall we treat — this gentleman with Alzheimer's, or this gentleman with AIDS?' "

Mr. Studds mentioned new antiviral drugs, known as protease inhibitors, which he said "will likely become the standard of care for people with AIDS." If states are not required to pay for these "prohibitively expensive" treatments, he said, "patients in need of them will simply be out of luck."

David Tuzo, 33, of the Bronx, who has AIDS and depends on Medicaid, said that the "cost of medication alone would be too much for me." His regimen now includes an antiviral drug called Zovirax, an antifungal drug called Mycelex and an antiprotozoal drug called Bactrim. The cost runs about $300 to $400 a month.

"Without Medicaid," he said, "I would have died."

Chris Maynard for The New York Times

"Without Medicaid, I would have died," David Tuzo, foreground, said last week at his apartment on the Grand Concourse in the Bronx. Mr. Tuzo, 33, who has AIDS, depends on Medicaid and worries about cuts in the program. With him were his sons, Kevin Quinones, 14, left, and Omar Nieves, 16.

'I fear, I tremble, for the fate of people with AIDS.'

The Washington Post

TUESDAY, OCTOBER 31, 1995

Veterans, AIDS Patients May Lose Benefits

2 Cabinet Secretaries Outline Consequences of Medicaid Changes

By Spencer Rich
Washington Post Staff Writer

Hundreds of thousands of veterans and people with AIDS could lose existing health benefits as a result of Medicaid changes approved by congressional Republicans, two Cabinet members and the AIDS Action Council said yesterday.

Department of Veterans Affairs Secretary Jesse Brown and Health and Human Services Secretary Donna E. Shalala said an analysis by the two departments found that "more than 600,000 veterans are enrolled in Medicaid," the federal-state health program for the poor, but only 100,000 of them receive any care from the VA.

"Under the House proposal to block-grant the Medicaid program" and reduce projected spending by $182 billion over the next seven years, Brown and Shalala said, "as many as 172,000 veterans could lose their Medicaid coverage by 2002," many of them severely disabled and ineligible for Medicare.

The reason is that not only does the House reconciliation bill allow less money for benefits than under existing law, but it also would repeal any individual guarantees to Medicaid and allow state governments wide discretion to determine eligibility, administration officials said.

The problems of these veterans are "some of the most costly, including AIDS and psychiatric care," Brown and Shalala said. Brown said the VA is threatened already with "devastating congressional budget cuts" and "will not be able to care for veterans pushed out of other health care programs." They added that because of proposed changes in Medicare, it is possible that 400,000 veterans on Medicare "may find it financially necessary to try to use VA health care."

Richard Fuller, an official of Paralyzed Veterans of America, said the scenario raised by the two secretaries is "serious."

Meanwhile, Mark Barnes, AIDS Action Council executive director, said House Medicaid changes could "devastate health care for the AIDS community" by reducing funds and allowing states to decide who will be covered. He said a large proportion of people with AIDS have no other health care or if they do, it is does not cover some of their most vital needs, such as anti-AIDS drugs. An

THE BUDGET BATTLE
WINNERS AND LOSERS

HHS official said yesterday that of nearly 200,000 people known to have AIDS, almost half are on Medicaid, including 90 percent of children with AIDS. Barnes said he believes these figures understate the number of AIDS patients on Medicaid.

Rep. Tim Hutchinson (R-Ark.), chairman of the health and hospitals subcommittee of the House Veterans Affairs Committee, disputed the Brown-Shalala charges.

"They're crying wolf one day after the other," he said. "They're assuming Medicaid and Medicare are somehow not going to handle veterans, but we are providing more money for Medicare, Medicaid and veterans' benefits than we are now spending. . . . I don't think there's going to be any forcing of veterans onto the VA for health care, but if there were, they'll be able to handle it because there's going to be a 25 percent reduction in the number of veterans in the next seven years."

A spokesman for the House Commerce Committee, which wrote the Medicaid provisions, said the potential difficulties facing veterans and AIDS patients are based on Medicaid grants to the states in the committee bill, but that ignores the addition of $12 billion nationwide for the program by the House. He said half of that would go to states identified by Brown as having the most veterans: California, Florida, New York and Washington. Moreover, the spokesman said, the House bill requires each state to set aside a fixed portion of its total Medicaid spending for the disabled.

Barnes said that with proper medication, a person with AIDS can live as long as five to 10 years in reasonable health, but without Medicaid, many can't afford the drugs they need.

David Tuzo, a 33-year-old New York transportation worker, said in an interview that after he contracted AIDS, "I became ill and weak" and had to stop work. He qualified for Social Security disability benefits and Medicare although he had not reached retirement age.

"But," he said, "I needed drugs which were not covered by Medicare," which offers no outpatient prescription drug benefit. And "with Social Security income of $704 a month, I couldn't afford $400 a month for the drugs" and sought help from Medicaid.

Under the Medicaid "block grant" provisions passed by the House, no individual would be guaranteed Medicaid benefits, and each state would make its own rules on eligibility.

The Senate reconciliation bill also offers no guarantees of coverage, with the exception of an amendment by Sen. John H. Chafee (R-R.I.) that would require states to cover all low-income pregnant women and children under 13 and people qualifying for welfare under the federal Supplemental Security Income program for the aged, blind and disabled.

But as Chafee stated on the Senate floor, the states would decide what the benefits would be for each category.

"The states could say, 'For this group there will be one aspirin a year' . . . but at least you have to cover everybody in the group," Chafee said.

AT RISK

Medicaid reform threatens benefits for people with AIDS and HIV infection

By J. Jennings Moss

The Republican rush to reform the nation's public health care system has profound implications for people who have AIDS or HIV infection, according to AIDS activists, who paint a bleak picture of the future if Congress's GOP majority gets its way.

"People will get sick quicker and die sooner," said Christine Lubinski, deputy executive director of the AIDS Action Council, a Washington, D.C.-based lobbying group. "It really is a life-and-death issue for people with AIDS."

About 36 million people are covered this year by medicaid, the joint federal-state program that provides health care to the poor and disabled—nearly 1 in 7 Americans, including, AIDS activists estimate, about half of all people with AIDS or HIV infection.

Currently the federal government lays out a number of strict requirements that states must follow to get federal dollars. If states offer certain optional services, they are eligible for more federal help. Any American who meets federally established eligibility requirements is guaranteed to get benefits. But Republicans, who are trying to shift power across the board from Washington back to the states, want to end that entitlement and instead give states block grants based primarily on a state's population. States then would decide who is eligible for help and what benefits they get. The GOP goal is to reduce federal medicaid spending by $182 billion, or 19%, over seven years.

"Medicaid is broken, and it's time to fix it," said Rep. Thomas J. Bliley (R-Va.), chairman of the House Commerce Committee, which has jurisdiction over medicaid. One of the main problems with medicaid is skyrocketing costs: Medicaid spending doubled from 1988 to 1992 and has risen about 10% each year since, according to the Kaiser Family Foundation, an independent national health care philanthropy.

But Democrats, along with some moderate Republicans, mocked the block-grant approach as House and Senate committees passed similar reform bills in late September. "We might as well just throw the money up in the air and hope it falls down and does good," said Sen. John Breaux (D-La.).

A final medicaid reform plan will be included in a massive budget and tax bill that will likely land on President Clinton's desk in early November. Clinton, who backs a plan that would lead to a less drastic $54 billion in medicaid savings over seven years, has vowed to veto the package.

Because of the swiftness of congressional action on the issue—Democrats in the House did not get the legislation until the morning the committee met to approve it—the impact it would have on those with HIV infection and AIDS was largely ignored by lawmakers. Still, the House committee and the Senate Finance Committee accepted amendments that made the separate reform bills slightly less unsavory.

Rep. Gerry Studds (D-Mass.), who is gay, convinced his colleagues to accept an amendment to prevent states from denying medicaid coverage to those with preexisting medical conditions. Still, Studds voted against what he called a "god-awful" bill. "I wouldn't call this reform; I would call it repeal," Studds told *The Advocate*.

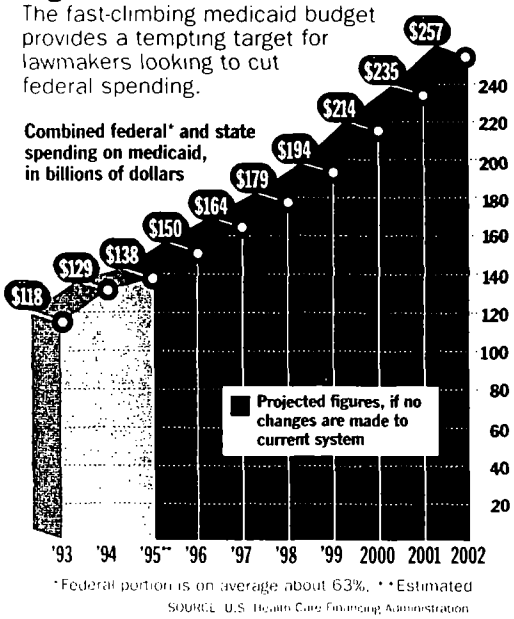
Sen. John Chafee (R-R.I.) pushed through an amendment in the Senate that would require states to provide coverage to low-income pregnant women, children under 12, and people with disabilities. Left open, however, was the definition of *disabled*. A conservative definition could mean that some HIV-positive people would not be eligible.

The bottom line is that if the Republican proposals become law, those with AIDS and HIV could lose prescription benefits, and more of the infected may end up without any health coverage at all. "Can you imagine what would happen to our health care system if medicaid wasn't providing coverage to roughly half the people with AIDS?" asked Jeffrey Crowley, senior policy associate at the National Association of People With AIDS. "The epidemic could get much worse."

But at least one conservative AIDS activist, Shepherd Smith, president of Americans for a Sound AIDS/HIV Policy, said he was open to giving more power to the states and concerned about medicaid's long-term financial health: "If you kill the goose that laid the golden egg, there aren't going to be any more eggs down the road." ●

High-rise health care

The fast-climbing medicaid budget provides a tempting target for lawmakers looking to cut federal spending.



*Federal portion is on average about 63%. **Estimated

SOURCE: U.S. Health Care Financing Administration

Houston Chronicle

Vol. 95 No. 22 Saturday, Nov. 4, 1995 50 C

AIDS advocates fear brunt of Medicaid cuts

By BENNETT ROTH
Houston Chronicle Washington Bureau

WASHINGTON – A Republican proposal to overhaul Medicaid has advocates for AIDS victims increasingly fearful that they will lose out in the expected scramble at the state level for scarce health care dollars.

Medicaid, the federal health insurance program for the poor, has been the primary safety net for many AIDS patients who have lost their jobs and health insurance and can't rely on family to pay medical bills.

But the GOP House Medicaid plan approved last month would scrap the federal guarantee that certain groups, including indigent AIDS patients, are covered.

Instead, a limited amount of federal dollars would be shipped back to the states in the form of block grants, and state legislatures and governors would determine who gets the money.

The Senate version of the bill would still require states to cover certain groups including people disabled by AIDS.

Both versions would dramatically reduce the rate of growth of Medicaid, whose costs have been increasing at about 10 percent annually.

AIDS advocates are particularly nervous that officials in Texas and elsewhere, when faced with the choice of covering poor children and pregnant women and long-term care for the elderly or expensive disabilities such as AIDS, will take the politically expedient route .

"I see them(AIDS patients) as way at the bottom of the list," said Margot Morris, director of the Omega House, a hospice for AIDS patients in Houston.

Morris said people with AIDS end up relying on the government for help because of the debilitating nature of the disease, which makes it increasingly difficult to work.

"Furthermore, many of these people do not have the traditional family configuration that would provide the traditional safety net," she said. "They are young single people when their resources run out."

However, Morris said her fear that the Texas Legislature might cut Medicaid funding for AIDS does not mean that she approves of the current system.

"What we've got now hasn't worked well. It is a huge bureaucratic nightmare," she said.

In fact, Republicans have argued that by eliminating onerous federal requirements states will be able to stretch their health care dollars farther.

"States are closer to the problem. They know what is happening in Texas more than the federal government," said Craig Murphy, a spokesman for Rep. Joe Barton, R-Ennis, who sits on the Commerce Committee that approved the Medicaid legislation.

Murphy noted that it was interesting that AIDS advocates "feel like the Republican Congress with Newt Gingrich is going to be the fairest possible place to make decisions on AIDS funding rather than state legislatures."

Texas Health Commissioner Dr. David Smith said he doubted the state would cut back funding for AIDS because it would merely mean passing costs onto locally funded public health facilities.

"It is important to keep those folks covered or they will fall back on systems that have no federal grants," said Smith.

Medicaid is the largest source of public funding for AIDS nationally , with about 40 percent of AIDS patients enrolled in the program, according to a study by the Kaiser Family Foundation.

The other major sources of federal funding are Medicare and the Ryan White Care Act.

In 1993, Medicaid spent about $2.3 billion on AIDS, about 2.1 percent of the total program spending.

But while AIDS is only a small portion of the Medicaid budget, it is much more expensive to treat those patients than some of the program's other beneficiaries.

The Kaiser study found that in California, Medicaid costs per beneficiary with AIDS ranged from $9,516 to $43,224. This compares to the average cost for a disabled beneficiary of $7,956.

For that reason, AIDS advocates fear state officials will view treatment of that population as not cost effective.

"The scary part is people with AIDS represent a high-ticket item and many states will go through contortions to avoid providing services," said Christine Lubinski, deputy executive director of the AIDS Action Council, which represents community AIDS groups across the nation.

Diane Rowland, a researcher with Kaiser, said that as medical breakthroughs have made it possible for people with AIDS to live longer, the costs of the disease has gone up. Many of the new treatments and drugs are extremely expensive, she said.

Rowland also said that AIDS is perfect example of the pitfalls of the block grant concept, which does not take into account the unforeseen costs of treating diseases that may develop in the coming years.

Health officials in Texas said $6.1 million from Medicaid funds was spent on AIDS patients in 1994, excluding long-term care and drug expenses.

Though the state could offer no data on what percentage of the AIDS population relies on Medicaid, they believe it is lower than the national average because Texas eligibility requirements are much tighter than many other states.

At the Harris County Hospital District, which is the major provider of services for AIDS patients in the Houston area, about 16 percent of those patients are enrolled in Medicaid.

However, that is up from 10 percent in 1991, largely because of the increasing number of pregnant women with AIDS using the public hospitals. Medicaid income eligibility requirements in Texas for pregnant women are higher than for other groups.

King Hillier, who handles government relations for the hospital district, said that if Medicaid allotment for AIDS is not provided by the state lawmakers, the costs will be borne by the local taxpayers.

When asked if he was confident the Texas Legislature would place a high priority on funding for AIDS he replied, "absolutely not. It is clear they will go with the elderly and women and children before going to the disability groups."

High Point Enterprise, November 22, 1995
(High Point, NC)

AIDS activists fear fund cuts

By Robert J. Warren
STAFF WRITER

President Clinton has waffled before, and AIDS activists fear he'll waffle again.

If so, activists say, AIDS patients and others with disabilities will suffer greatly under crippled Medicaid funding.

Greensboro

"The President will veto the reconciliation bill," Mark Barnes said. Barnes is executive director of the Washington-based AIDS Action Council.

"The question is: How tough will he hang afterward? It's by no means certain Clinton will hang tough and protect our community."

Barnes said people who are HIV positive have a lot to lose in the budget debate. If Medicaid gets chopped up into block grants with increases in funds cut, Barnes said AIDS patients will end up on the bottom of the barrel.

"We are in a crisis," Barnes said. "This is one of the worst times for the AIDS community."

Barnes gave a presentation on the proposed Medicaid cuts and their potential effects on the AIDS community to about 20 church, media, health and AIDS organization members at the Triad Health Project office in Greensboro. He said local AIDS organizations will be directly affected if AIDS patients lose Medicaid funds.

"This is not only important to hospitals and health-care providers," Barnes said. "If they can't get service at hospitals and health-care centers, they will be banging on your door."

The U.S. Congress wants to cap Medicaid funding at 1995 levels - more than $3 billion for AIDS patients - and begin giving each state block grants

(See MEDICAID on 2A)

Mark Barnes

■ Mark Barnes became executive director of the AIDS Action Council in February. He is also administrator of the AIDS action foundation.

■ The AIDS Action Council represents more than 1,000 community AIDS organizations and lobbies the federal government on AIDS policy.

■ In 1994, Barnes was a special health-care counsel for a law firm. From 1992 to 1994, he was associate commissioner for medical and legal policy for the New York City Department of Health and was named to the White House National Health Care Task Force in 1993.

■ He was named AIDS policy director for the New York State Department of Health in 1989. He joined the faculty of Columbia University Law School in 1986 and began the AIDS Law Clinic. He holds degrees from Columbia and Yale universities.

MEDICAID: Fear of waffling surfaces

(FROM 1A)

with no strings attached.

Congress plans to cut more than $165 billion from increases in spending for Medicaid through this process. According to Barnes, North Carolina would lose more than a quarter of its projected Medicaid funding during the next seven years.

"What's troubling is not only the cuts, but at the state level, everyone will struggle for that one check," Barnes said. "And all the requirements making sure people with disabilities get treated will be gone."

Three groups get Medicaid funds - poor women with children, elderly people who need long-term care and people with disabilities.

Barnes said the first two groups have political backing, but those with disabilities - including AIDS patients - "will get left out when the musical chairs stop in the state legislature."

Barnes said Medicaid could be reduced in the ballpark of $50 billion and still be effective, but if Clinton compromises in the $80 million to $100 billion range, AIDS patients and others with disabilities will be severely affected.

And he says he fears Clinton may cave.

"This is a very weak administration, it is no secret," Barnes said. "They say one thing and do another."

But Barnes said there are Republicans sympathetic to the AIDS cause, including Richard Burr of Winston-Salem.

"The AIDS agenda is not just for the Democrats," he said. "It a mainstream America agenda. It's an agenda about caring for people."

Barnes will join about 150 AIDS activists for an AIDS summit at the White House in December, he said.

If Clinton doesn't hang tough, they will put his feet in the fire and it will be a public relations disaster, he said.

If the future is block grants, the future is bleak, Barnes said.

He used tuberculosis block grants as an example. The disease was almost wiped out when the Reagan Administration changed federal funding to block grants in the early 1980s, he said. The grants had no requirements and supervision was lax.

As a result, the tuberculosis infrastructure decayed while the disease made a comeback, connected to the AIDS epidemic, and is now at very high levels.

Local activists must get a "fire in their belly" and act now before it's too late, Barnes said.

"It's all up for grabs," he said. "That's why right now constituent action at the local level is very important."

The Washington Post

THURSDAY, DECEMBER 7, 1995

Clinton Pledges to Protect AIDS Funding

By Ann Devroy
Washington Post Staff Writer

President Clinton yesterday pledged to protect funding and health care programs for AIDS patients during a White House conference where activists from around the country asked him to do more to find a cure and a vaccine.

The undertone of the first White House conference on AIDS and HIV—and the direct complaint of protesters outside the White House—was that while Clinton has done more than other presidents to combat AIDS through increased funding and research, it has not been enough. Several speakers compared the disease to the civil war in Bosnia and said the Clinton administration should put it on the top of its domestic priority list.

"I support what you're doing for the Bosnia people to keep peace and end the war," said Shawn Sasser, an activist who introduced Clinton to the more than 250 people who attended the one-day conference. "But we also have a war raging right here for the last 15 years. Let's fight and pay whatever it costs to defeat the war on AIDS right here at home."

AIDS is now the leading killer of Americans between the ages of 25 and 44. Earlier this month, the Centers for Disease Control and Prevention (CDC) reported that the country's 500,000th AIDS case had been diagnosed and more than 300,000 have died.

After Clinton's opening remarks to the conference he participated in a discussion of needle-sharing among addicts, mandatory AIDS testing for pregnant women and pediatric AIDS.

Clinton said he had ordered the preparation of a government-wide research plan, including a coordinated research budget, within 90 days.

He also said he had asked Vice President Gore to convene a meeting of scientists and pharmaceutical industry leaders to study ways of speeding up the development of vaccines, therapeutics and other ways of protecting people from HIV and the infections it causes.

"A cure and a vaccine. That must be our first and top priority," Clinton told the conference. At the end of his speech, a heckler in the room complained that the Clinton administration had not done enough. "I am very sorry that there is not a cure. I am very sorry that there is not a vaccine," Clinton replied.

Clinton used the opportunity of the conference to attack Republican plans to pare projected Medicaid spending and to pledge to fight those reductions. Medicaid pays the health care costs of nearly half of all Americans with AIDS, including more than 90 percent of the children.

"Medicaid is the lifeline of support," Clinton said. "It is the one thing that we have done that has helped us to drive down infant mortality [due to HIV] among poor people who otherwise would never see a doctor."

Mark Barnes, executive director of the AIDS Action Council, a Washington-based advocacy group, said AIDS activists attending the meeting were heartened by Clinton's words, particularly his commitment to federal funding for AIDS research and to safeguarding the Medicaid program.

"When President Clinton said today that these [congressional] Medicaid proposals would be a stake through the heart of AIDS care, he really offered some fresh hope to the AIDS community," Barnes said. "But the real test of his leadership is not a speech. The real test is what he intends to do in the budget negotiations over the next four weeks with Congress over the fate of that Medicaid program."

Staff writer John Schwartz contributed to this report.

San Francisco Chronicle
NORTHERN CALIFORNIA'S LARGEST NEWSPAPER
FRIDAY, DECEMBER 8, 1995

FDA OKs New Drug For AIDS

It attacks virus at later stage than AZT

By Sabin Russell
Chronicle Staff Writer

Federal regulators approved the first of a new class of AIDS drugs yesterday, but the encouraging news was tempered by fears that the government is running out of money to help the uninsured pay for a new generation of expensive medicines.

The Food and Drug Administration approved sales of saquinavir in a record 97 days, and manufacturer Hoffmann-La Roche pledged that supplies will reach drugstores by tomorrow.

Saquinavir is the first approved "protease inhibitor," which attacks a different piece of the AIDS virus than the one targeted by older drugs such as AZT, ddI and ddC. The new Roche drug is not a cure for AIDS, but tests show that when used in combination with the older drugs, the number of infection-fighting white blood cells increases, and the amount of virus floating in the bloodstream decreases.

The new drug — and a number of similar competitors undergoing clinical trials — strips the AIDS virus of protease, one of the chemical tools it uses to make copies of itself inside a human blood cell. Earlier drugs interfere with a different enzyme, reverse transcriptase, which plays a role in one the earliest steps of viral replication.

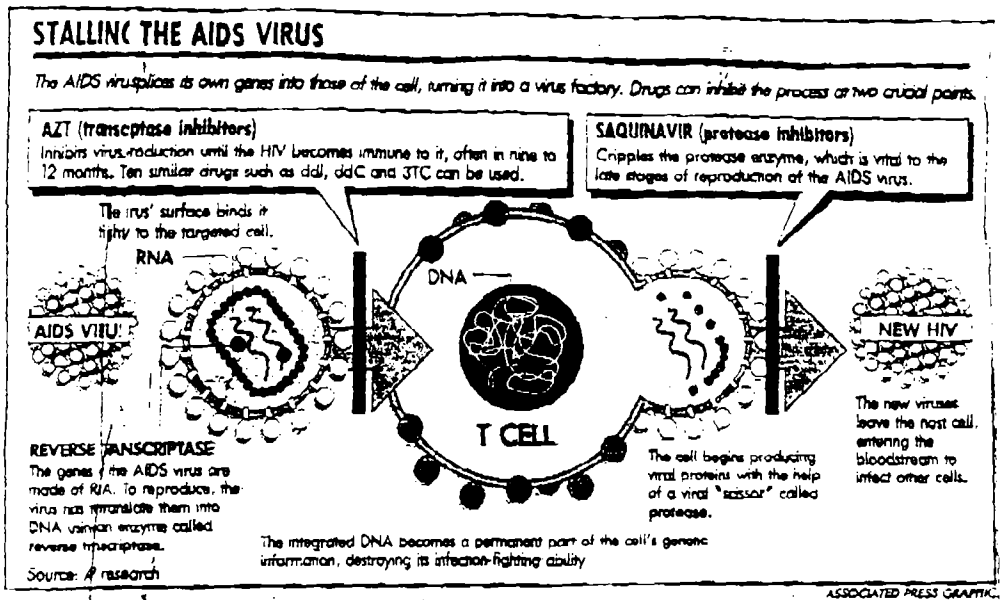
The idea is to attack both targets at once. "It's about cornering the virus," said Dr. Jacob Lalezari, an AIDS specialist at the University of California at San Francisco's Mount Zion Hospital. "Maybe at some point, it runs out of options."

FDA Commissioner David Kessler said protease inhibitors are "perhaps the most important class of drugs in the fight against HIV so far." The approval follows by only 20 days the FDA's marketing clearance for 3TC, a drug made by Glaxo Wellcome that boosts the effectiveness of its chemical cousin AZT.

But at a wholesale price of $5,800 a year for saquinavir and $2,270 for 3TC, the swift approvals will add to the mounting financial burden on people with AIDS who do not have insurance to cover the

AIDS: *Page A23 Col. 1*

(front page)



AIDS: FDA Approves Sale of New Drug

From Page 1

cost of their medications.

California's AIDS Drug Assistance Program, which uses federal funds to cover the cost of drugs for thousands of state residents, is already projected to outspend its 1995 budget by $3 million. With Congress in a budget-slashing mood, the outlook for additional money to pay for new drugs is dim.

State Department of Health Services spokesman Ken August said early estimates suggest that adding both drugs to the program would cost $6.8 million a year. Before that can happen, he said the state will have to find new sources of money. This year, the state budgeted $17.5 million for the AIDS drug program.

Proposed reductions in the federal budget for Medicaid, which pays for AIDS drugs for the poorest of the poor, pose another problem. Although current rules require the program — called Medi-Cal in California — to pay for it, that could change with new legislation in Washington.

"Let's face it. With Medicaid 'reform,' the first thing to go will be pharmaceutical coverage. We have a crisis here, and I don't know how we are going to deal with it," said Gary Bose, who monitors treatment and research issues for AIDS Action Council, a Washington, D.C.-based lobby.

"Given the price of these drugs, the cost of therapy now for people with AIDS is unconscionable," said Brenda Lein, a spokeswoman for Project Inform, the San Francisco-based AIDS patient advocacy group.

Compounding the problem of individual drug prices is the fact that people with AIDS have to take so many different ones. Many doctors recommend a triple punch of AZT, 3TC and saquinavir. The combined wholesale cost of all three drugs is $10,900 a year — with retail costs adding another 20 percent to 30 percent to the price tag.

For months prior to the approval of 3TC and saquinavir, thousands of AIDS patients had been taking them for free under compassionate treatment programs run by the drug companies. The FDA clearance puts an end to the free distribution program, although both Roche and Glaxo have set up programs they say will make the drugs available to people who cannot afford them.

Roche spokeswoman Joy Schmitt defended the high price for saquinavir, noting that the product itself is difficult to manufacture, requiring 15 months and 17 separate steps. The drug's development is the culmination of more than 10 years of research.

Despite the financial hurdles, doctors said the approval of saquinavir is another milestone in the effort to tame the AIDS virus. "We are entering a new era in AIDS drugs," said Lalezari. "For the first time, we can offer patients true combination therapy."

His tests indicate that saquinavir can produce a tenfold reduction in the level of human immunodeficiency virus in the bloodstream, compared to only a 50 percent reduction brought by the AZT family of drugs. Lalezari said a new formulation of saquinavir, which is more efficiently absorbed in the patient's gastrointestinal tract, shows the promise of a 100-fold reduction in HIV level — comparable to other protease inhibitors undergoing tests by other manufacturers.

The new formulation of saquinavir will not be ready for the market for another year. Because the virus builds resistance to each type of drug, many doctors recommend that patients delay taking saquinavir until the better formulation, or a competing protease inhibitor, is ready.

AIDS Action council

January 26, 1996

The Honorable William Jefferson Clinton
The White House
Washington, D.C.

VIA FACSIMILE

Dear Mr. President:

On January 23, 1996, I wrote to you on behalf of AIDS Action Council, the Washington representative for 1,400 community based AIDS service and training organizations, requesting, respectfully, that you veto S. 1124, the defense authorization bill conference report, when it reached your desk. I now understand that this bill will reach your desk today, and that you will sign it.

As you may be aware, this legislation contains a blatantly discriminatory provision which will result in the immediate separation from the armed services of some 1,200 active military personnel living with HIV disease. Moreover, these individuals who have devoted many years of productive service to the nation's defense and continue to do so, will be discharged without the benefit of a military pension and without access to the quality health care they now enjoy. This provision singles out individuals solely on the basis of their HIV status, while other military personnel who live with other chronic illnesses will continue to be permitted to work as productive members of the military until their illness prevents them from doing so.

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When this measure was initially passed by the Congress with this provision, you vetoed the bill and cited this provision among numerous others in your veto measure. Regrettably, Administration officials who represented you in negotiations with the Congress on a compromise measure appear not to have highlighted this provision as unacceptable to the White House. Other provisions of the vetoed measure identified by Administration representatives in the subsequent negotiations were deleted from the measure. Only a small number of Congressional principals on the defense authorization bill were strongly committed to the anti-HIV provision. We believe that if the White House had insisted on its omission, it much more likely have not made its way into the final conference report.

At this juncture, therefore, AIDS Action respectfully requests that you undertake a number of measures immediately in order to ameliorate, insofar as possible, the extremely harsh effects and the negative public policy consequences of this provision. These measures include:

1. In your signing message, highlighting the utter absence of public policy or public health rationale for this exclusion of HIV-infected military personnel, and reiterate your strong personal opposition to it;

2. In your signing message, expressing your Administration's profound doubts, including those of your Justice Department, regarding the constitutionality of this provision, including its failure to treat HIV-infected military personnel in the same way that service members with other chronic illnesses are treated; and

3. In the event that this provision is implemented, treating these service members as medically discharged with 100 percent service-connected disability, and providing for those service members being discharged a package of full retirement and severance benefits, including:

    - Job placements into Department of Defense and related civilian jobs commensurate with their experience, rank and seniority, with relocation and settlement expenses;

    - Continuation of the same health, life and disability insurance benefits and quality of health care to which these service members and their dependents would be entitled if they were allowed to continue in active duty;

    - Sensitive, immediately available transitional counseling for these affected personnel and their families regarding this provision and its consequences for them;

    - Immediate vesting of any pensions or retirement funds to which these military personnel would be entitled had they been allowed to continue to serve until such pension or retirement funds would have vested; and

    - To the extent allowed by this provision, offering of National Guard and/or Reserve placements to these service members, commensurate with their experience, rank and seniority.

All in all, Mr. President, the enactment of this provision marks one of the darkest, saddest days in the history of the AIDS epidemic in this country. The message that is being sent to people living with HIV and their families is profound: namely, that they are not welcome in the workplace, in our communities, and in our nation -- that they are dispensable. Although we are deeply distressed that you appear to be poised to sign this bill, we ask respectfully that in doing so, you consider these ways of helping these patriotic Americans and their families. Finally, we ask that you signify your commitment to this issue by immediately working with Congress to draft and pass legislation reversing this appalling provision.

The families and communities affected by this epidemic need your help on these issues, and they await your response.

Respectfully,

Mark Barnes
Executive Director