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THE
CATHOLIC HEALTH
ASSOCIATION
OF THE UNITED STATES

February 8, 1996

TO: System/Facility CEOs & Advocacy Coordinators, and Sponsors

FROM: William J. Cox, Executive Vice President

SUBJECT: GOVERNORS' PROPOSAL TO RESTRUCTURE MEDICAID

CHA.

CHA's Position on Medicaid Reform

Over the past year, CHA has been an advocate for retaining the federal Medicaid entitlement in any restructuring of the program. At the same time, we have argued that the growth rate in the program is not sustainable and that deficit reduction is imperative. Medicaid and Medicare must contribute to that goal.

In addition to the possible repeal of the federal entitlement, we have been gravely concerned that the severity of expenditure reductions proposed in the Balanced Budget Act of 1995 would irrevocably harm the Medicaid program, jeopardizing not only Medicaid beneficiaries, but the overall health care system.

The Governors' Proposal

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This week, the National Governors' Association (NGA) released a long-debated proposal to restructure Medicaid. NGA claims it is a compromise between the Republican block grant approach and the Democratic position to retain the entitlement status with a per-capita spending cap. The proposal would create a new Medicaid program with more federal funding, but far less federal oversight and very few conditions for receipt of the dollars. While its approach may be preferable to the restructuring plan included in the Balanced Budget Act already passed by Congress, the Governors' proposal is unquestionably inferior to the President's plan and that of the "Blue Dogs," the coalition of conservative Democrats working to balance the budget in seven years without a tax cut.

CHA's Preliminary Analysis

While CHA has not yet taken a final position on the proposal, our preliminary analysis -- utilizing the policy positions advocated by CHA members in the 104th Congress -- raises *serious* concerns. Many important details of the proposal are either unknown or still quite sketchy. As they become available, however, we will be able to evaluate definitively the proposal. The attached is based on current information.

ANALYSIS OF GOVERNORS' MEDICAID PROPOSAL

CHA POSITION:

Maintain the individual entitlement guaranteed by Title XIX of the Social Security Act. Oppose a Medicaid block grant.

GOVERNORS' PROPOSAL:

Eliminates the entitlement by repealing Title XIX and replaces it with a "guarantee" of coverage for defined groups, i.e., low income pregnant women, the elderly, and children up to age 12. Other groups, however, who are currently eligible, i.e., children over age 12 and under 100% of poverty, persons who meet the federal definition of disability but do not meet whatever definition a state may choose, and low-income seniors whose income is above SSI level are not covered by the "guarantee."

Eligibility for the Qualified Medicare Beneficiaries (QMB) program -- which pays for Medicare cost-sharing for low income elderly -- is not defined. Additionally, individuals lose their right to enforce their "guarantee" to care in federal court.

The list of covered services for "guaranteed" populations includes many services which are currently mandated, i.e., physician and inpatient/outpatient hospital services, laboratory and x-ray services, etc. But each state will have complete flexibility to decide *how many services* eligible recipients will receive, *at what level* and *for how long*.

* * * * * * * * * * *

CHA POSITION:

Encourage greater Medicaid participation in managed care (with a caveat about moving aged and disabled persons into managed care programs until more experience is gained with regard to the particular needs of these vulnerable populations).

Assure that managed care plans have the capacity to serve the volume and breadth of Medicaid beneficiaries.

Establish federal requirements to protect Medicaid beneficiaries in managed care, i.e., availability of information for informed choice, quality assurance, marketing standards, etc.

GOVERNORS' PROPOSAL:

States will be permitted to expand managed care options to Medicaid beneficiaries -- without first seeking a federal waiver. They would set their own health plan and provider qualifications standards without any federal minimum qualifications standards. Existing managed care protections for consumers are repealed. States are not subject to any federally-imposed limits on the number of beneficiaries who may be enrolled in managed care plans.

* * * * * * * * * *

CHA POSITION:

Reduce the funding cuts called for in the Balanced Budget Act of 1995.

GOVERNORS' PROPOSAL:

The level of federal savings achieved is not mentioned. States would receive a block grant allocation. A contingency fund is established that states may be able to tap into under unspecified conditions if their population growth exceeds predictions. States could, however, cut significantly their share of Medicaid funding because the ceiling on the state share is reduced to 40% from the current level limit of 50%.

* * * * * * * * * *

OTHER FEATURES:

- **The Boren Amendment would be repealed, along with current restrictions on provider taxes and donations.**
- **States would have complete authority to set all health plan and provider reimbursement rates without interference from the federal government or threat of legal action from the provider or the plan.**
- **States would abide by the OBRA'87 standards for nursing homes, but they would enforce the standards with no federal oversight.**

American Medical Association
Physicians dedicated to the health of America

News Release

February 7, 1996

Significant Safeguards Offered
By Governors' Medicaid Plan: AMA

The American Medical Association today commended the efforts of 48 of the nation's governors in reaching unanimous agreement on a policy for Medicaid reform. "It is a significant step forward toward breaking the logjam on this important issue," said James S. Todd, MD, AMA Executive Vice President.

"With reductions in future funding for the Medicaid program, it is crucial that safeguards be in place to protect the most vulnerable of Americans," he said. "We are pleased that the governors' proposal meets major AMA objectives." These include: guaranteed coverage and benefits for certain populations; continued adherence to federal nursing home standards; projected growth factors for each state to reflect changes in caseload and case mix as well as inflation; and a funded "insurance umbrella" to protect states if available funds to not meet the needs of real growth of the state's population.

"The governors' plan also provides states with a great amount of discretion as to how they operate their programs and pay for services," Dr. Todd said. "The AMA will now work with the Congress and the Administration to address concerns we have regarding some of the specifics of the governors' policy that could lead to problems of access and quality of care. Physicians and the AMA will continue to press for Medicaid laws that are fair, and that meet the needs of patients and the institutions and professionals who serve them."

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For further information, contact: James Stacey 202 789-7419
Brenda Craine 202 789-7447

1101 Vermont Avenue,
Washington, DC 20005
202 789-7400

REACTION TO GOVERNOR'S MEDICAID PROPOSAL

The attached includes statements from the following groups:

American Academy of Pediatrics
Children's Defense Fund
American Hospital Association
National Association of Children's Hospitals
Alzheimer's Association
National Association of Public Hospitals
National Association of People with AIDS
National Women's Law Center
Consortium for Citizens with Disabilities
Justice For All
Family Voices

Three statements were signed with the following organizations:

AIDS Action Council
AIDS Policy Center for Children, Youth, and Families
American Counseling Association
American Medical Student Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Psychological Association
American Rehabilitation Association
The Association for Retarded Citizens
Brain Injury Association
Center on Disability and Health
Children's Defense Fund
Cities Advocating for Emergency AIDS Relief
Consortium for Citizens with Disabilities
Families USA
Gay Men's Health Crisis
Housing Works
Human Rights Campaign Fund
InterHealth
International Association of Jewsish Vocational Services
Justice For All
National Association of Child Advocates
National Association of People with AIDS
National Citizens Coalition for Nursing Homes Reform
National Community Mental Healthcare Council
National Health Care for the Homeless Council
National Mental Health Association
National Minority AIDS Council
National Organization for Rare Disorders
National Senior Citizens Law Center
National Women's Law Center
Project Reform
San Francisco AIDS Foundation
Service Employees International Union
Texas AIDS Network
Women's Legal Defense Fund

American Academy of Pediatrics
601 Thirteenth Street, N.W.
Suite 400 North
Washington, DC 20005

News Release

CONTACT: Marjorie Tharp
Leigh Ann Bluestein
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FOR RELEASE: February 7, 1996

GOVERNORS' MEDICAID PLAN BREAKS PROMISE TO CARE FOR YOUNG

Guaranteed coverage for teens eliminated and treatment for others threatened

WASHINGTON, D.C. — Medicaid's promise to expand coverage by the year 2002 to all low-income children and adolescents younger than age 19 will be broken if the National Governors' Association (NGA) Medicaid plan is approved by Congress and signed into law by the president.

"We have entered the Twilight Zone of health care policy," AAP President Maurice E. Keenan, M.D., said. "We certainly commend the governors for their bipartisan effort, however, they have managed to propose a plan that disproportionately impacts upon the health care situation for children of low-income and working families."

The American Academy of Pediatrics takes issue with many of the Medicaid provisions including:

- Failing to guarantee coverage for adolescents, ages 13 and older;
- Potentially denying services that children currently receive through the Early and Periodic Screening, Diagnosis and Treatment Services (EPSDT) program;
- Leaving it to states to define disabilities, which could result in different levels of care for children with special health care needs depending on where they live;

-more-

GOVERNORS' MEDICAID PLAN
2-2-2

- Reversing current law and state policies in regards to prioritizing children's needs. Today's system places children's needs at the head of the line. The NGA plan pushes them to the back.

Children make up well over half of all Medicaid recipients and less than a quarter of the cost. With more and more children of working families losing private health insurance through a decline in employer dependent coverage, the services Medicaid provides are essential.

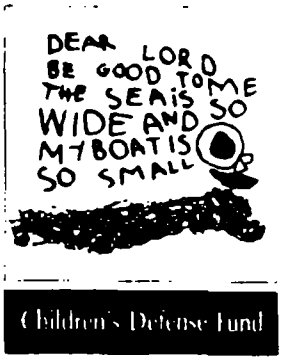
"Why should teens be damned to years without seeing a pediatrician?" Dr. Keenan said. "Why would we deny them the opportunity to talk to a medical professional about all the challenges they will face -- dealing with pressure to experiment with drugs, alcohol and sexual activity, achieving an adequate level of nutrition and coping with a whole new range of emotions?

"To the president and members of Congress, pediatricians implore you not to accept this proposal blindly. Medicaid is not just about federal and state budget savings. It's also about offering adequate health care for those vulnerable populations who otherwise would have no other place to go for help. All children and adolescents deserve a fair chance to be healthy and free from diseases."

# # #

The American Academy of Pediatrics is an organization of 50,000 pediatricians dedicated to the health, safety and well-being of infants, children, adolescents and young adults.

CONTACT: **Dennis Smith**
704-339-6266



Statement by Marian Wright Edelman, president of the Children's Defense Fund
on
the National Governors' Association Welfare and Medicaid Proposals

I am deeply saddened by and oppose strongly the proposals by the nation's governors to dismantle and slash crucial federal health, nutrition, and income safety nets that protect millions of children. Their health and welfare plans would leave many more children poorer, hungrier, sicker, and at greater risk of abuse and neglect. CDF urges the Congress and the President to reject these flawed anti-child proposals. No proposal that leaves children worse rather than better off should become the law of the land.

February 6, 1996

25 E Street, NW
Washington, DC 20001
Telephone 202 628 8787

February 7, 1996

THE NATIONAL GOVERNORS' ASSOCIATION PLAN ON MEDICAID: WHY IT'S BAD FOR CHILDREN

• **It would eliminate guaranteed coverage for poor children 13 through 18 years of age with working parents.** This coverage would be phased in, under current law, by October 2002. But during the twelve months beginning this October, the NGA proposal would end guaranteed Medicaid coverage for 400,000 children in working poor families when they turn 13. In the year 2002, the proposal would deny guaranteed coverage to 3 million poor children ages 13 through 18.

• **It would eliminate current law guarantees that children will receive coverage of all medically necessary health care.** Even the children who would receive coverage under the NGA proposal would not be guaranteed meaningful benefits.

- The proposal would repeal EPSDT's (Early and Periodic Screening, Diagnosis, and Treatment) guarantee that children must receive all medically necessary services. States could flatly deny coverage of prescription drugs, for example, even if a child's doctor says there is no other way to treat an illness or stop severe pain. States could likewise deny coverage for dental care, hearing aids, eyeglasses, physical therapy for children with disabilities, or other services that are crucial to children's development and learning.

- States also would be given unlimited freedom to determine the amount, duration, and scope of services within covered benefits categories. For example, states could limit children to a certain number of hospital days per year--even seriously ill children whose doctors say more care is needed to avoid grave harm.

• **It would eliminate guaranteed health coverage for children who are disabled according to federal SSI definitions.** Instead, states could limit, as they see fit, the number of children with disabilities who receive coverage. This would jeopardize health coverage for more than two million children with disabilities who now receive Medicaid.

• **It would eliminate existing federal guarantees of coverage for children and parents receiving AFDC.** Under the NGA's welfare proposal, states would have no legal responsibility to give AFDC to poor families, who could lose Medicaid along with AFDC. Medicaid coverage would no longer be guaranteed for 1.6 million children who now receive AFDC and are over age 12. Four million parents now receiving AFDC, 88 percent of whom are women, would also lose guaranteed coverage. These are some of America's poorest families, commonly with income below 50 percent of the poverty line.

• **It would deny access to federal courts to overturn illegal state denials of coverage.** Even the limited guarantees that exist on paper could prove meaningless in practice, if states know they will not be enforced.

• **It would allow states to contribute much less to Medicaid, forcing further cutbacks.** States like New York that currently must match federal spending dollar for dollar could instead put up only 67 cents for each federal dollar they receive. To meet even these reduced matching obligations, states could use provider donations and taxes that the Bush Administration and Congress outlawed in the early 1990s. According to the Congressional Budget Office, these practices were used to circumvent state matching requirements in the past. States could withdraw billions of dollars they now spend on Medicaid, dramatically cutting coverage for families.

• **It would let states use federal Medicaid dollars to pay for current state responsibilities.** Medicaid funds could be used, for example, to purchase insurance for state workers and retirees with incomes under 275% of poverty, or to pay the costs of operating state psychiatric hospitals. State funds freed in the process then could be used to fund road construction or other projects, essentially diverting Medicaid funds from their intended purpose of providing health care for low-income families.

For more information on welfare issues, please contact Deborah Weinstein (662-3565) or David Kass (662-3556) in CDF's Family Income Division; on Medicaid issues, please contact Gregg Haifley (662-3541) or Stan Dorn (662-3595) in CDF's Health Division. On these issues or generally on children's issues, please contact Eileen Sweeney (662-3586) in CDF's Office of Government Affairs.

February 7, 1996

THE NATIONAL GOVERNORS' ASSOCIATION PLAN ON WELFARE: WHY IT'S BAD FOR CHILDREN

The National Governors Association unanimously adopted a welfare reform resolution on February 6. Closely following the approach of the welfare bills passed by Congress and vetoed by the President, the governors agreed to abandon the federal guarantee for cash assistance, to be replaced with block grants that would not respond when recessions cause increased need. Under the governors' plan, states could also choose block grants for food stamps, school meals programs, and for foster care and adoption assistance for abused and neglected children. Here's why the governors' plan would hurt children:

- **Needy children and families would no longer be able to count on basic income support.** Like the previous welfare bills vetoed by the President, the governors' plan ends the guarantee that needy families receive at least minimal assistance, and requires states to impose a lifetime limit of five years or less, whether jobs are available or not. While the plan would allow 20 percent of the caseload to be exempt from the time limit, more than that (27 percent) would be unlikely to work because the parent either has or is caring for someone with a disability. Families in areas of high unemployment would also have to compete for the scarce exemptions, as would families where parents work continuously, but at very low wages.

- **When unemployment and poverty rise, federal funds would not increase enough to meet the need for basic income support.** The block grant for cash aid and work remains flat-funded for 7 years. The governors' plan does include a $2 billion contingency fund that states could tap when unemployment or food stamp use rises, but it is not nearly enough to meet actual need during a recession. During the downturn of the early 1990's, federal AFDC funding grew almost $6 billion, three times the amount in the contingency fund.

- **The plan would allow states to make further cuts in cash aid or work programs.** The governors' resolution allows states to cut up to 25 percent of their spending without losing any federal funds, the same as in the bill vetoed by the President. In addition, states could shift up to 30 percent of funds for income support and work to other programs.

- **Federal standards for child care quality would be eliminated.** While the governors' proposal takes the positive step of adding $4 billion over seven years for child care, this plan, like the bill vetoed by the President, would gut federal health and safety requirements for child care, and cut funds to improve and expand the supply of child care.

- **The plan would put more children at risk of abuse and neglect.** The proposal would undermine the guarantee of foster care and adoption assistance for abused and neglected children. It would give states the option of capping funds for foster care, adoption, and independent living services, in exchange for the flexibility to use these formerly guaranteed dollars for any of a range of child protection activities. It is likely that eligible children in these states would no longer be guaranteed foster care and adoption assistance when they cannot live safely at home. Even if a state did not opt for a cap, most other federal child protection programs, including those aimed at child abuse prevention and family support, would be repealed and replaced with a child protection block grant.

- **The plan would undermine the nutritional safety net for children.** States would be allowed to end the guarantee of food stamps and convert the program to a block grant. The governors' plan also accepts $27 billion in food stamp cuts over seven years, reducing food assistance to 14 million children.

For more information on welfare issues, please contact Deborah Weinstein (662-3565) or David Kass (662-3556) in CDF's Family Income Division; on Medicaid issues, please contact Gregg Haifley (662-3541) or Stan Dorn (662-3595) in CDF's Health Division. On these issues or generally on children's issues, please contact Eileen Sweeney (662-3586) in CDF's Office of Government Affairs.

FAX UPDATE

Wednesday, February 7, 1996

Contact: Kelly Fisher (202) 626-4629

***TALKING POINTS ON NGA PLAN** -- The National Governors Association's Medicaid proposal is a mixed bag. The NGA acknowledges in part the concerns of many, including AHA, on coverage and benefits, and the proposal is an improvement over the reconciliation conference agreement. But it falls short of current law, the White House proposal, the conservative Democrat "Blue Dog" approach, and our principle of guaranteed coverage for vulnerable populations. With too little detail and no legislative language it's impossible to issue a definitive statement -- but here is a summary of the NGA plan:*

Coverage -- Mandated coverage for those currently eligible under Medicaid, such as the elderly, pregnant women, and children up to 12, is a step in the right direction. These are populations in desperate need of guaranteed coverage. However, several other groups have not been provided a guarantee, particularly the disabled, who will be defined by individual states, and children ages 13 to 17 who, while not currently covered, are scheduled to be phased in as a result of OBRA '90. There needs to be further guarantees for these populations.

Benefits -- The plan mandates coverage for physician, inpatient hospital and outpatient hospital benefits, another improvement over the conference agreement. But, states are free to alter the amount, scope, or duration of these and other services, which could weaken the coverage mandate.

Boren Amendment -- Not only does the NGA repeal the Boren Amendment, but it gives states the authority to set all health plan and provider reimbursement rates without interference from the federal government or threat of legal action by the provider or plan. This could have a devastating impact on providers who deliver care to the vulnerable populations covered under the program, threatening their financial stability and, as a result, beneficiaries' access to care.

Provider taxes -- The plan repeals current-law protections against increased reliance on provider taxes. This allows states to shift their fiduciary responsibility to providers -- taxes that could also be levied inequitably among providers.

State match -- The NGA plan lowers the floor on the amount states must contribute in order to get federal matching funds. This could cut additional billions of state dollars from Medicaid, harming Medicaid's financial integrity and its ability to meet the guarantees made to the people who rely on it.

National Association of
Children's Hospitals

N · A · C · H

Statement

Lawrence A. McAndrews
President and CEO
National Association of Children's Hospitals

GOVERNORS' MEDICAID PROPOSAL: BETTER THAN CONGRESS' MEDIGRANT PROPOSAL BUT STILL SHORT OF CHILDREN'S NEEDS

While better than Congress' MediGrant legislation, which would replace Medicaid with a largely unfettered block grant, the National Governors Association's (NGA) Medicaid compromise still falls short of children's need for national minimum standards for medically necessary care and access to pediatric specialty providers, leaving children with special health care needs especially vulnerable.

Nor does the governors' proposal target federally mandated Medicaid payment adjustments to hospitals devoted to serving a disproportionate share of low income patients. Instead, the NGA proposal eliminates the federal requirement for such adjustments as well as federal requirements for adequate payment to all hospitals. Disproportionate share payment adjustments are critical to the ability of children's hospitals to serve children in their communities, regardless of economic need.

A stronger proposal for guaranteeing coverage for vulnerable populations has been advocated by conservative Democratic and moderate Republican balanced budget advocates. They would control spending with a cap on federal funds per eligible individual, while maintaining national standards for children's eligibility, medically necessary care, access to specialists, and targeted disproportionate share payments.

The NGA Compromise

NGA proposes to modify Congress' block grant to replace Medicaid. The most important modification for children is the NGA recommendation that every state must cover, at a minimum, all pregnant women and children under age six with family incomes below 133% of the federal poverty standard, and all children between age 6 and 12 with incomes below 100% of poverty, as required under current law. Congress' MediGrant only requires states to cover children under 13 with family incomes below 100% of poverty. NGA also would require every state to cover the disabled, leaving the definition of the disabled to each state, subject to federal review.

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(703) 684-1355 Fax (703) 684-1589

While agreeing to a minimum set of benefits all states must cover, NGA would allow any state to impose limits on the amount, duration, and scope of such benefits covered individuals may receive. Until Congress established a national standard for medically necessary care for children in 1989, many states limited the amount, duration, and scope of benefits regardless of a patient's condition. For example, before 1989 many states limited inpatient hospital care to a fixed number of days, regardless of how sick or injured a child was. Congress' MediGrant also eliminates the federal requirement of coverage for medically necessary care for children.

In addition, NGA's proposal does not include standards to ensure that children have appropriate access to pediatric specialists expert in the health care needs of children. Congress' MediGrant also eliminates the current law's requirements to protect children's access to pediatric providers.

The proposal prohibits providers from pursuing enforcement of the law through the courts and makes the federal courts available to individuals, only after they have exhausted state administrative and judicial review.

Children with Special Needs

Children with special health care needs, such as children with chronic conditions, disproportionately rely on Medicaid. They are especially vulnerable under NGA's proposal for one or more of the following reasons:

- States would have the ability to limit the number of disabled children who qualify for eligibility.

- It is precisely children with special needs who are the most vulnerable to arbitrary limits on coverage. Even limits that may be appropriate for children overall can impede the ability of children with special health care needs to have access to the medically necessary care they require.

- Children with special needs often have the greatest sustained need for access not just to an individual pediatric specialist but to a team of such specialists who can meet their complex needs. Without protections for children's access to pediatric specialists, they are especially vulnerable.

The need for protections for children with special needs was underscored last week by the National Committee for Quality Assurance, the managed care industry's accreditation body. It released a new tool to evaluate Medicaid managed care. But it explained that the tool contains few performance measures targeted exclusively to the special needs of children with rare conditions, because they have not been developed. The absence of such evaluation measures makes it all the more important to have standards for medically necessary care and access to pediatric providers for children.

QUESTIONS ABOUT THE NGA PROPOSAL ON MEDICAID

1. **Will it really "guarantee" coverage for vulnerable populations?**

   It's not clear. NGA emphasizes that its proposal will guarantee coverage, because funds will not be limited to an arbitrary block grant cap. A state can seek supplemental funds if its eligible population grows more than expected. However, it is unclear whether the supplemental funds will be unlimited, and it is unclear whether the state still will be obligated to cover vulnerable populations if they run out of block grant and supplemental funds.

2. **Do the eligibility standards cover all children now receiving Medicaid?**

   No. NGA keeps most of current federal law's eligibility requirements for children, with two exceptions. First, it drops federal law's commitment to phase in eligibility for poor teenagers over the next six years. Second, it allows states to establish their own definition of disabled children who qualify, subject to federal approval, instead of requiring all states to meet a minimum federal definition, as now is the law.

3. **Does the proposal require every state to provide medically necessary care for children?**

   No. Under the "T" provisions of "EPSDT," current federal law requires a state to cover all benefits -- mandatory and optional – that a child may require for medically necessary care. The NGA proposal says it will "limit" the "T" portion of EPSDT. It also says that states should have "complete flexibility in defining amount, duration, and scope of services." Congress amended the "T" portion of EPSDT in 1989 precisely to prevent states from limiting amount, duration, and scope of benefits in ways that deny medically necessary care to children.

4. **Does the proposal guarantee children's access to pediatric specialists?**

   No. It gives states total flexibility in defining provider access and reimbursement standards. It specifically says, "States must...be unburdened from any federal minimum qualification standards such as those currently set for obstetricians and pediatricians."

5. **Does it target disproportionate share payments to high DSH hospitals?**

   No. The proposal eliminates all payment protections for providers, including disproportionate share (DSH) and Boren. It folds each state's current federal funding for DSH into its block grant. The proposal only would require states to use such DSH funds for "health care for low income people." In addition, the proposal specifically prohibits providers from having any legal rights to challenge a state's Medicaid program in either state or federal courts.

ALZHEIMER'S ASSOCIATION
Someone to Stand by You

STATEMENT ON GOVERNORS' AGREEMENT ON MEDICAID
February 6, 1996

Today the nation's governors agreed on a proposal to restructure Medicaid. It is written in general terms and leaves many questions unanswered. However, it raises many of the same critical issues that caused the Alzheimer's Association to oppose the Medicaid proposal the President vetoed. Congress most resolve these issues in a way that guarantees persons with Alzheimer's disease and others who depend upon Medicaid the basic health and long term care coverage they need.

- Adequate funding to guarantee coverage. The governors' proposal purports to guarantee coverage for certain groups of beneficiaries and to allow states to maintain coverage for all optional groups in the current Medicaid program. That "guarantee" will have little meaning, however, unless the funds states need to provide that coverage are also guaranteed. The governors' proposal does not appear to give states that guarantee.

  First, it provides for an aggregate cap on federal funds according to a formula not yet defined. (The formula in the vetoed bill was not adequate to guarantee coverage.) Once the aggregate cap is reached, there is no requirement that a state maintain coverage for persons in the program. An "insurance umbrella" would be available in certain unanticipated circumstances. Whether or not that "umbrella" would guarantee coverage depends upon the amount of money available and the circumstances under which a state could draw from it. The per capita cap proposed by moderates in the House and Senate and endorsed by the President is a much more certain and straightforward way to guarantee coverage while restraining spending.

  Second, states would have to put up less money of their own to draw down federal funds. In some of the largest states, the match would be cut by as much as 20%. Further, the governors would eliminate provisions in current law that prohibit states from using provider taxes to get around the matching requirement. And they appear to drop current rules that preclude states from using other federal funds as their match.

- Long term care coverage. The governors' proposal "guarantees" long term care coverage for elderly persons only if they meet the income and resource standards for SSI. This does not include most of the people who now receive Medicaid long term care. They fall into the optional categories -- either their income falls within a cap set by the state or they are "medically needy" (i.e. they do not have enough money to pay the total cost of their long term care). While the governors would allow states to serve these optional groups, if states are not guaranteed the money to pay for those services, they will have to cut them out of the program.

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
Washington Office 1419 F St., NW, Suite 410 • Washington DC 20004 • Phone: (202) 393-7737 • Fax (202) 393 2109

Coverage of persons with disabilities is even more problematic. Current law sets uniform definitions of disability. The governors would let states define disability however they want. No one with a disability would any longer have any federal guarantee of coverage.

- Enforcement of guarantees. Guarantees are meaningful only if they are enforceable. The governors' would limit individuals' access to federal courts to enforce their rights under federal law.

- Spousal impoverishment. The governors' make no provision for the spouse of a nursing home resident. Spousal impoverishment protections of current law, which protect a minimum amount of income and resources for the community spouse and allow states to provide additional protection, must be retained.

- Home and community based care. The governors indicate they would "significantly broaden" long term care options. If their proposal eliminates barriers in current law to expansion of home and community based care, this is a positive development and one the Association would enthusiastically support. However, this cannot be used to deny nursing home benefits to persons who need that level of care and for whom there are no acceptable options in the community.

- Nursing home quality. The governors indicate that "states will abide by the OBRA'87 standards for nursing homes". If they are referring to the watered-down version of those standards in the vetoed bill, that is not acceptable. Current federal nursing home standards must be maintained, as must the standards for institutions for persons with mental retardation and developmental disabilities. The Association is also concerned about the governors' statement that would give states "flexibility to determine enforcement strategies" for nursing home standards. This cannot be interpreted to eliminate federal responsibility for ensuring enforcement.

- Nursing Home Discrimination. The governors' proposal is silent about provisions of current law that protect Medicaid beneficiaries from discrimination in admission to, transfer and discharge from nursing homes. Those protections must be retained.

- Rules Regarding Family Assets. Current law sets reasonable limits on transfer of assets and rules about liens on property of Medicaid beneficiaries, and it makes clear that states may not hold adult children responsible for their parents' long term care bills. The governors' proposal does not address these issues. Provisions of current law should be retained.

N A P H

MEMORANDUM

TO: Interested Parties

FROM: Larry S. Gage
President, National Association of Public Hospitals

DATE: February 7, 1996

RE: Preliminary Assessment of National Governors' Association Medicaid Reform Proposal

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The National Governors' Association (NGA) yesterday approved a proposal to reform the Medicaid program. In their words, the proposal represents a compromise that "blends the best aspects of the current program with congressional and administration alternatives toward achieving a streamlined and state-flexible health care system that guarantees health care to our most needy citizens." The National Association of Public Hospitals (NAPH) is deeply concerned about the impact the proposal would have on Medicaid recipients and other low income populations, and on the ability of safety net providers to care for their patients and communities.

Our initial review of the available summaries indicates that the Governors' proposal appears to be designed primarily to reduce state spending on medical assistance, not to responsibly reform the Medicaid program to better care for the nation's vulnerable populations. As today's New York Times' editorial accurately summed up, the Governors' reforms are "harsher toward the poor in key respects than anything Congress has passed or that the Republicans privately negotiated with President Clinton."

This Memorandum will summarize some of our principal initial concerns with the Governors' Medicaid proposal.

1. Retreat from the Current Federal Entitlement

The Governors' proposal would guarantee some as-yet undefined level of benefits to some (but not all) currently eligible population groups, but would repeal the current individual entitlement to a defined level of benefits (including all current federal requirements as to the amount, duration, and scope of benefits). This retreat from the current level of coverage for low income populations comes at a time when recent data from the Employee

Benefits Research Institute reveal that the number of uninsured Americans has increased to 39.7 million. Such a retreat will exacerbate an already tremendous burden of uncompensated care on hospitals and other providers who treat large numbers of low income patients, including the 64 NAPH member hospitals which provided over $4 billion in bad debt and charity care in 1993. Eliminating the individual entitlement without guaranteeing coverage to populations for a defined amount, scope, and duration of benefits will dangerously undermine an already fragile health care safety net.

2. Repeal of Provider Payment Standards

The Governors' proposal would repeal the Boren Amendment and other statutory provisions governing the rates at which providers are reimbursed and would give states complete discretion to set provider payment rates at any level they choose. NAPH believes that the provisions in current law governing provider payment must be retained. Without these protections, there is no assurance that safety net providers will be adequately reimbursed for the care they provide to vulnerable populations.

In addition, the Governors' proposal would eliminate the federal private right of action in current law for both beneficiaries and providers. Beneficiaries would have a limited ability to seek to enforce the Medicaid laws in state court, but providers would have no private right of action in state court *or* federal court. NAPH believes that any compromise Medicaid legislation must retain a private cause of action for both beneficiaries and providers. This important enforcement mechanism allows individual beneficiaries and the providers which care for them to enforce the Medicaid laws and has been an effective way for safety net providers to achieve state accountability on behalf of the patients they serve.

3. Reduced State Matching Requirements

Several provisions in the Governors' proposal would work in tandem to permit a dangerous erosion of states' responsibilities to finance care for their most vulnerable populations. As the New York Times states, these features of the Governors' proposal are designed to give the governors "plenty of room to reduce state Medicaid funds." NAPH strongly urges the Congress to refocus the debate on finding more efficient ways to deliver health care to vulnerable populations, not on simply reducing state spending.

For example, the Governors' proposal would set the minimum federal matching percentage for all states at 60%. Many states would therefore have their state matching percentages reduced, with the result that the state would have to spend fewer state dollars on medical assistance to draw down its federal allocation than it the current federal matching percentage remained in effect. For all states, once a state has drawn down its entire federal

allocation, there would be no incentive for a state to expend additional state dollars on medical assistance because there would be no additional matching federal funding. The likely effect will be a dramatic reduction in state medical assistance funding in addition to, and at the same time as, the anticipated reduction in federal Medicaid funding. The New York Times estimates that *states* would save over $200 billion under this proposal over the next seven years--or over *twice* the anticipated federal savings.

4. Repeal of Provider and Local Government Protections

The Governors' proposal would also repeal the provider-specific tax and intergovernmental transfer (IGT) restrictions in current law. There would therefore be nothing prohibiting states from shifting their match requirements on to health care providers or local governments--or from expanding provider tax and IGT programs to finance their entire Medicaid program. NAPH supports retaining these protections in current law.

5. Repeal of the Medicaid Disproportionate Share Hospital Program

While the Governors' proposal would include the funding associated with current disproportionate share hospital (DSH) spending in each state's federal allocation, it would repeal any requirement that any or all of these funds be paid to those hospitals that serve a disproportionate number of low income patients. While the proposal would appear to require that these funds be spent on care for low income populations, there is no methodology specified by which this would be accomplished--a provision that is basically meaningless in that it is no different than the purpose of the overall program. Moreover, when coupled with the proposed repeal of the current provider tax and IGT provisions, this recommendation simply opens the door to the same state abuses of the DSH program that the provider tax and IGT provisions were enacted to curb, while locking in the current level of federal spending ***even in the states which have abused the DSH program.*** These well-publicized abuses stand as a good example of what happens when states are given tremendous flexibility to use federal funds but are provided with inadequate oversight on how they spend those funds.

Rather than writing the states a blank check, NAPH urges the Congress instead to support a more fiscally responsible DSH proposal that targets DSH funds directly on hospitals serving the highest proportion of low income and uninsured patients. DSH funding is essential to those urban public hospitals and health systems that provide a substantial volume of uncompensated services to the poor. These are the hospitals for which DSH funds were primarily intended when Congress created the program. This proposal recognizes that some savings could be generated from reduced DSH spending, because not all DSH funds are currently used by states for their intended purpose. As in proposals currently under consideration, such savings should be phased in over time (e.g., DSH funding should be reduced only after the first two years of the seven-year cycle proposed for the budget

agreement), with the remaining DSH funds targeted on those hospitals serving a high volume of low income and uninsured patients. This is the approach of the conservative House Democratic "Coalition" proposal, and one being given bipartisan Senate consideration as well. They would reduce federal DSH spending but maintain a federal DSH funding pool that would be proportionally allocated among hospitals with a low income utilization rate of greater than 25%.

* * * * *

NAPH shares the Governors' goal of guaranteeing health care to our nation's vulnerable populations. But that guarantee must be a meaningful one, a federal guarantee ensuring that low income and uninsured patients receive a specified level of benefits. It must be supported by adequate state and federal financial resources for the safety net providers which care for these populations, and by an effective enforcement mechanism for achieving state accountability. Anything less will damage the safety net health system in many urban and metropolitan areas, and will deny access to care for truly needy citizens.

NATIONAL WOMEN'S LAW CENTER

Congressionally-Approved Medicaid Transformation Act Harmful to Women and Children

The Medicaid Transformation Act-- the Congressionally-approved plan to convert Medicaid from an entitlement program into a block grant, and simultaneously to slash its budget by $163 billion over the next seven years --will be particularly harmful to women and their families. Women comprise over 69% of Medicaid beneficiaries between the ages of 18 and 64 with at least eight percent of women overall and 11% of women in the 18-24 age range depending on Medicaid as their only source of health insurance. Dismantling the program and turning it over to the states with very few federal standards or protections could leave nearly 9 million people, including 6.3 million low-income women and children, without access to critical health services. Passed by both the House and Senate, the Act was vetoed by President Clinton when he vetoed the Budget Reconciliation Act.

Poor Women and Children Will Lose Vital Health Insurance Coverage

- Without a guarantee that all who are eligible can obtain necessary medical services, many poor women will simply forgo essential health treatments or show up in emergency care settings - at great cost both to their health and to a health care delivery system trying to curb costs.

- The relatively high rate of women -13% vs. 8% of men- who receive Medicaid has been an important factor in women's lower rates of uninsurance than men's: 13.8% of women, as opposed to 17.8 % of men, are uninsured. Without Medicaid, the uninsurance rate for women will rise.

- The only provision that would afford even minimal protection to individuals now entitled to Medicaid is a requirement that states provide coverage to families with incomes up to 100% of poverty and that include a child under 13 or a pregnant woman. However, states would have such wide discretion in determining what benefits to offer that major health needs of pregnant women and kids could be ignored.

- The Medicaid Transformation Act contains set asides for certain groups: low-income families, low-income elderly, and low-income disabled. However, the requirement that states spend 85% of what they spent in previous years (1992-94) on these groups comes with conditions that are likely to result in state expenditures of only about 44% of what states have spent in recent years on these key populations. Under this formula, hundreds of thousands of poor women and children could lose coverage.

- The disabled are further harmed by a provision that permits the states to define "disabled", with few protections to ensure that whole groups of disabled people are not dropped from the rolls. The only requirement is that disabled individuals who qualify for Supplemental Security Income (SSI) would automatically qualify for benefits. However, as a result of the states' authority to define the disabled and SSI cuts of $20 billion in the Welfare Reform Bill, huge numbers of disabled people would find themselves cut off from SSI-- and thus with no guarantee of benefits.

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• The Act sets the income level for eligibility at 300% of the poverty line. However, this merely means that people below this income level could receive benefits. There is no guarantee that they will actually receive coverage, or that crucial types of services will be covered. Moreover, there is the possibility of tremendous variation within and between states, resulting in a system of potentially arbitrary, inequitable, and inadequate health care coverage. In fact, the Act specifically exempts states from any requirements to provide uniform statewide coverage (including across political subdivisions), or to guarantee equitable coverage to similarly situated individuals.

• In addition, the Act explicitly denies applicants, beneficiaries, and others the right to sue to enforce eligibility determinations and other provisions - a right they have under current law. In essence, this means that people will be deprived of an important mechanism for ensuring that even the minimum standards contained in the Act are actually enforced, at the same time that states are granted license to treat low-income individuals in very disparate ways.

Critical Health Services Can Be Denied

• The Act eliminates almost all current guarantees of coverage, giving the states near-total discretion in deciding which benefits to provide. The only guaranteed services would be child immunizations and (state-specified) family planning services. This leaves the provision of essential medical services subject to the whims of cash-strapped state leaders. Women's health services that would be jeopardized include:

Clinical preventive services such as Pap smears, mammograms, and screening for sexually transmitted diseases.
Medicaid coverage of these the services is especially vital, because low-income women are less likely to have cancer detected at an early stage and hence more likely to suffer severe consequences than women from higher income brackets. Despite the fact that early detection and treatment saves taxpayers the expense of later, more costly treatment, these preventive services are at grave risk in such an underfunded program.

Prenatal, maternity care, and services to young children.
Prenatal and maternity care are vital to the health of women and infants, reducing the incidence of life and health - endangering pregnancy complications, low birth weight babies and infant mortality. States would be required to cover children under 13 and pregnant women, but there is no requirement that certain benefits be offered. Moreover, with prenatal and infant care services competing with other health services for a limited amount of money, vital benefits (such as prenatal care) that are required under current law could be eliminated. State budgets as well as women and children will be adversely affected, as every dollar spent on prenatal care saves $3.38 in the cost of caring for low birth weight infants.

Abortion Services
In contrast to all other aspects of the proposal which would grant wide latitude to the states in deciding how to spend federal dollars, the abortion provision would prohibit the states from using federal funds for abortion except to save the life of the woman or when the pregnancy results from rape or incest. This provision casts the Hyde amendment into permanent law, denying poor women a critical health service and precluding the possibility that this restriction be addressed annually through the appropriations process, as it has been in the past two decades.

• Even if a particular service is offered, the Medicaid Transformation Act would allow states to impose deductibles, premiums, co-payments, and other types of cost-sharing for the provision of services. There are no limits on these cost-sharing requirements, except that for families with pregnant women or children under 13 living below 100% of poverty the costs should be "nominal". All types of cost-sharing are a burden on low-income families, and present a disincentive to seek medical care, no matter how serious or painful a condition may be. Underfunded state programs will have a financial interest in deterring people from using services, and there are few limits on how much states can charge.

A Few Specific Provisions Could Help Women Obtain Essential Benefits

• Family Planning Services

Medicaid is the single largest source of public funding for contraceptive services. The Act retains the current and important requirement that all states cover family planning services. However, the elimination of the 90% federal match, and the fact that these services will be competing with other health services, means that family planning services could be reduced considerably. While this may cut costs in the short-term, putting resources into family planning saves money down the road: each dollar spent on family planning saves an average of $4.40 in health and welfare costs.

• Mental Health

Another important issue for women's health is coverage of mental health services. A combination of physiological, social, environmental, and cultural factors contributes to higher rates of some mental illnesses, particularly depression, among women. The Medicaid Transformation Act prohibits the imposition of treatment limits or financial requirements on mental illness services that are not imposed on other services. This will allow low-income women the freedom to seek help, without discriminatory restrictions on mental health services.

• Pre-existing Conditions Exclusion

The Act also provides protection for women with pre-existing conditions. It prohibits states from denying or excluding coverage for certain services on the basis of a preexisting

condition. This is very important for low-income families, which disproportionately consist of women and children. One family member with an uninsurable chronic or pre-existing condition could bankrupt a low-income family overnight.

Elderly Women Will Be Hard Hit

• Federal nursing home standards would be weakened because current quality assurance standards for nursing facilities would be eliminated, threatening 1.3 million nursing home residents, 75% of whom are women (65 and older). Instead, states would have the option to establish and self-enforce all standards for safety, adequacy of care, and treatment of residents. Federal enforcement would only be allowed in the case of a state's failure to correct deficiencies– a judgment based upon reports generated by the state itself. Prior to the enactment of federal standards in 1987, conditions in many nursing homes ranged from inadequate to deplorable, and enforcement was both weak and inconsistent. With its weakened enforcement and remedy requirements, the Act would do little to prevent conditions from deteriorating again.

• While a nursing facility may have every intention of providing the highest quality of care, the Medicaid Transformation Act would make it very difficult to do so. The proposed funding cuts would force homes to cut staff and reduce services. The Act appears to anticipate this, as it reduces minimum staffing requirements and training for nurses' aides, and establishes weaker protections against unwanted transfers and discharges.

• Another cost-cutting option the Act provides for nursing homes is simply to refuse Medicaid patients. Because homes would no longer be required to accept Medicaid patients, many will not, because Medicaid pays less than other payers. The Act opens the door for discrimination against Medicaid beneficiaries in the admissions process, and will leave many beneficiaries with no alternative for long-term care.

• Many families of women in nursing homes would also be harmed by the Act. While it retains current protections against spousal impoverishment, the Act unduly burdens middle-class adult children of nursing home residents, because it permits nursing homes to require adult children to pay for their parents' care. Only adult children living below the state's median income are exempt from this requirement. However, the median household income in America is $32,264, and the average cost of nursing home care is $36,000. Even a middle-class family would be placed under extreme financial stress, once its savings were depleted, if forced to pay for this expensive care.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

06-Feb-1996 07:14pm

TO: justice

FROM: owner-justice

SUBJECT: NGA agrees on Medicaid

Justice For All

beckyo@names.org

NGA Nedicaid Plan

JFA has obtained a copy of the National Governors' Association plan to restructure Medicaid. The following is the text of what was disseminated at their semi-annual meeting in Washington, D.C.(For simplification the only portions that appear below will be what pertains to people with disabilities. For the full summary, please call BeckyO.

THE NEW PROGRAM
Within the balanced budget debate, a number of alternatives to the existing Medicaid program have been proposed. The following outlines the nation's Governors proposal that blends the best aspects of the current program with congressional and administration alternatives toward achieving a streamlined and state-flexible health care system that guarantees health care to our most needy citizens.

PROGRAM GOALS: The program is guided by four primary goals.
1. The basic health care needs of the most vulnerable populations must be guaranteed.
2. The growth in health care expenditures must be brought under control.
3. States must have maximum flexibility in the design and implementation of cost-effective systems of care.
4. States must be protected from unanticipated program costs resulting from economic fluctuations in the business cycle, changing demographhics, and natural disasters.

ELIGIBILITY:Coverage remains guaranteed for:
*Pregnant women to 133 percent of poverty;
*Children to age 6 to 133 percent of poverty;
*Children age 6 through 12 to 100percent of poverty;
*The elderly who meet SSI income and resource standards;
*Persons with disabilities as defined by the state in their state plan. States will have a funds set-aside requirement equal to 90 percent of the percentage of total medical assistance funds paid in FY 1995 for persons with disabilities.
*Medicare cost sharing for Qualified Medicare Beneficiaries.
*Either:
-Individuals or families who meet current AFDC income and resource standards (states with income standards higher than the national average may lower those standards to the national average);or
-States can run a single eligibility system for a new welfare program as defined by the state. Consistent with the statute, adequacy of the state plan will be determined by the Secretary of HHS. The Secretary should have a time certain to act.

Coverage remains optional for:
*All other groups in the current Medicaid program.
*Other individuals or families as defined by the state but below 275 percent of poverty.

Benefits:
*The following benefits remain guaranteed for the guaranteed populations only....
-Inpatient and outpatient hospital services, physician services, prenatal care, nursing facility services, home health care, family planning services and supplies, laboratory and x-ray services, pediatric and family nurse practitioner services, nurse midwife services and Early and Periodic Screening, Diagnosis and Treatment Services. (The "T" in EPSDT is redefined so that a state need not cover all Medicaid optional services for children.)
*At a minimum, all other benefits defined as optional under the current Medicaid program would remain optional and long term care options significantly broadened.
*States have complete flexibility in defining amount, duration and scope of services.

PRIVATE RIGHT OF ACTION:
*The following are the only rights of action for individuals or classes for eligibility.
-Before taking action in the state courts, the individual must follow a state administrative appeals process.
-States must offer individuals or classes a private right of action in the state courts as a condition of participation in the program.
-Following action in the state courts, an individual or class could appeal directly to the U.S. Supreme Court.

-Independent of any state judicial remedy, the Secretary of HHS could bring action in the federal courts on behalf of individuals or classes but not for providers or health plans.
*There should be no private right of action for providers or health plans.

SERVICE DELIVERY
*States must be able to use all available health care delivery systems for these populations without any special permission from the federal government.
*States must not have federally imposed limits on the number of beneficiaries who may be enrolled in any network.

PROVIDER STANDARDS AND REIMBURSEMENTS
*States must have complete authority to set all health plan and provider reimbursement rates without interference from the federal government or threat of legal action of the provider or plan.
*The Boren amendment and other Boren-like statutory provisions must be repealed.
*"One hundred percent reasonable cost reimbursement" must be phased out over a two year period for federally qualified health centers and rural health clinics.
*States must be able to set their own health plan and provider qualifications standards and be unburdened from any federal minimum qualification standards such as those currently set for obstetricians and pediatricians.
*For the purpose of the Qualified Medicare Beneficiaries program, the states may pay the Medicaid rate in lieu of the Medicare rate.

NURSING HOME REFORS
*States will abide by the OBRA '87 standards for nursing homes.
*States will have the flexibility to determine enforcement strategies for nursing home standards and will include them in their state plan.

PLAN ADMINISTRATION:
*States must be unburdened from the heavy hand of oversight by the Health Care Financing Administratio.
*The plan and plan amendment process must be streamlined to remove HCFA micromanagement of state programs.
*Oversight of state activities by the Secretary must be streamlined to assure that federal intervention occurs only when a state fails to comply substantially with federal statutes or its own plan.
*HCFA can only impose disallowances that are commensurate with the size of the violation.
*This program should be written under a new title of the Social Security Act.

FINANCING:
Each state will have a maximum federal allocation that provides the state with the financial capacity to cover Medicaid enrolles. The allocation is available only if the state puts up a matching percentage (methodology to

be defined). The allocation is the sum of four factors: base allocation, growth, special grants (special grants have no state matching requirement) and an insurance umbrella, described as follows:
1.Base.In determining base expenditures, a state may choose from the following-1993 expenditures, 1994 expenditures. Some states may require special provisions to correct for anomalies in their base year expenditures.
2.Growth.This is a formula that accounts for estimated changes in the state's caseload (both overall growth and case mix) and an inflation factor. The details of this formula are to be determined. This formula is calculated each year for the following year based on the best available data.
3.Special Grants. Special grant funds will be made available for certain states to cover illegal aliens and for certain states to assist Indian Health service and related facilities in the provision of health care to Native Americans. States will have no matching requirements to gain access to these federal funds.
4. The Insurance Umbrella. This insurance umbrella is designed to ensure that states will get access to additional funds for certain populations if, because if unanticipated population. Funds are guaranteed on a per-beneficiary basis for those described below who were not included in the estimates of the base and the growth. These funds are an entitlement to states and not subject to annual appropriations.

POPULATIONS AND BENEFITS. Access to the insurance umbrella to cover the cost of care for both guaranteed and optional benefits. The umbrella covers ALL guaranteed populations and the optional portion of two groups-persons with disabilities and the elderly.
ACCESS TO THE INSURANCE UMBRELLA. The insurance umbrella is available to a state only after the following conditions are met:
1. States must have used up other available base and growth funds that had not been used because the estimated population in the growth and base was greater than the actual population served.
2. Appropriate provisions will be established to ensure that states do not have access to the umbrella funds unless there is a demonstrable need.

5.MATCHING PERCENTAGE. With the exception of the special grants, states must share in the cost of the program. A states's matching contribution in the program will not exceed 40 percent.

6.Disproportionate Share Hospital Program. Current disproportionate share hospital spending will be included in the base. DSH funds must be spent on health care for low income people. A state will not receive growth on DSH if these funds constitute more than 12 percent of total program expenditures.

So, the above in a nut-shell is a broad summary of the text that was handed out at the closed door press conf. at the NGA meeting.
>From first read of their framework and without seeing

detailed legislative language it is difficult to know where to begin to respond. Allowing states the right to define disability, to decide scope, duration and benefits and taking away the private right of action pretty much spells TROUBLE FOR PEOPLE WITH DISABILITIES.

The action should be simple: Call President Clinton and thank him for hanging in there for a federal definition for people with disabilities and encourage him to stand firm.
Call Congress and object to the Governors' proposal
Call the media and explain to them why the Governors' proposal spells trouble for people with disabilties.
JUSTICE FOR ALL!!!

Becky Ogle
E-mail: beckyo@names.org
Voice: 703-836-6263

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

07-Feb-1996 11:34pm

TO: justice

FROM: owner-justice

SUBJECT: Defending Definition of Disability

Justice For All

beckyo@names.org

Defending the Federal Definition of Disability

There are multiple aspects of the NGA's proposal to Restructure Medicaid that are worrisome for the disability community, and it is our hope that each and everyone is activating their networks to speak out against the NGA attempt to rob people with disabilities of their right to Medicaid...

When defending our stance on why Medicaid Must Retain A Standard Definition of Disability, the following arguments or talking points should come in handy.

-"Flexibility" to define "disability" for Medicaid is just "flexibility" to eliminate the MEDICAID SAFETY NET FOR PEOPLE WITH DISABILITIES who are currently eligible. There is absolutely no other logical or rational reason for such flexibility.

-Under current law, in order to qualify for Medicaid a person with a disability must meet TWO CRITERIA:

The person must be poor, and
The person must meet the SSDI/SSI definition of total disability.

-The SSDI/SSI standard is basically an inability to work (i.e., a person is unable to maintain substantial gainful activity), but it has developed significan precedents and refinements.

-The SSI standard has been developed and FINE-TUNED through regulation and precedent over the years to address complex disability cases, such as:

*conditions that are sometimes disabling and sometimes not(so-called "intermittent disabilities") that may make a person unemployable, but not

necessarily permanently disabled(e.g., multiple sclerosis, epilepsy, asthma);

*diseases that are progressive(e.g.,Parkinson's HIV/AIDS)

*disorders with non-apparent symptoms or effects (e.g., severe fatigue associated with lupus or with lyme disease);

*illnesses without standard medical profiles or which do not show up on lab tests (e.g.,high functioning developmental disabilities or other mental and emotional disabilities);or

*diseases that have different manifestations in different groups(e.g.,cervical cancer in women with immune deficiencies).

-Without such a well-defined and uniform Federal standard, people with disabilities will be CUT OUT FROM THE MEDICAID PROGRAM AND, IN MOST CASES, FROM HEALTH CARE ALTOGETHER.

-Operating under an overall funding cap and without clear disability eligibility guarantees, States will have incentives to limit or eliminate coverage for those people with disabilities who may require more complex medical care.

-People with intermittent, progressive, or other complex disabilities will have no reliable precedent on which to rely and will be forced to re-define and re-ligigate their disability for Medicaid.

-States will seek inexpensive healthy people to count toward their funding formulae and neglect to find those with chronic and complex needs.

-Without uniform standards, PEOPLE WITH DISABILITIES WILL BE FORCED TO MOVE TO FIND STATE MEDICAID PROGRAMS THAT MEET THEIR NEEDS.

*If some states provide eligibility and benefits and neighboring states do not, people will have to move to get necessary health care and services. (For example, in the early days of the AIDS epidemic, many people moved to California to get access to the health care and services denied them elsewhere.)

-This, in turn, will create a "RACE TO THE BOTTOM" in which no State will want to provide benefits that might attract more poor, disabled people to their program.

-This competition to provide the least will ULTIMATELY LIMIT BENEFITS TO PEOPLE WITH DISABILITIES NATIONWIDE.

-Without uniform standards, people with disabilities in States providing care will experience "Medicaid-lock," similar to the job lock of employed people with insurance.

*If a person with a disability is eligible for health care in one state and not in another, this person and if a child their family will not be able to move for fear of ineligibility in another state.

-Without uniform standards, people with disabilities and their families will be caught in CONFUSING AND TOTALLY UNNECESSARY BUREAUCRATIC DELAYS.

*The Social Security Act will continue to have a functioning definition of disability for purposes of its SSDI/SSI programs.

*In addition, each State will have a different definition of disability for purposes of Medicaid.

*People with disabilities and their families will be forced to undergo tireless, duplicative State and Federal tests, processes, and paperwork-often at a time when health care is needed immediately. The cost of this duplicative process should be factored into the equation as well.

-Without coverage under Medicaid, low-income people with disabilities will be shut out of the health care system altogether.

*Since Medicaid is currently, by defintion, limited to people who are poor and who cannot work, if a State finds a person to be inelible for the new program, that person will have no employment-related insurance and no personal income or other assets to use for health care.

THESE ARE THE PEOPLE WITH NO PLACE TO GO.

THE ELIMINATION OF A FEDERAL DEFINITION OF "DISABILITY" ELIMINATES THE FEDERAL GOVERNMENTS COMMITMENT TO GUARANTEE HEALTH CARE TO LOW-INCOME PERSONS WITH DISABILITIES AND MUST BE REJECTED.

(The above talking pts. or arguments were developed in concert with Georgetown Federal legislation clinic. Many thanks.)

Justice For All will continue to place other talking points on-line for everyone's use. Please use them often and widely, because we all have a lot to lose if this proposal were to make it into law.
JUSTICE FOR ALL!!!!!!!!!

Becky Ogle
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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. letter	Personal (Partial) (1 page)	02/03/1996	P6/b(6)

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RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

FAMILY VOICES

To: Marilyn Yeager
From: Polly Arango
About: MediGrant II/Meeting with Governors
Date: February 3, 1996

[001]

MediGrant II: Its Implications for Children with Special Health Needs

I am responding to the newest information on MediGrants (b)(6) (b)(6) as one of the co-founders and the director of Family Voices. My focus is on children with special health care needs (disabilities and/or chronic conditions). In the deliberations around MediGrants, please remember that while most children who are Medicaid recipients are poor, there are many Medicaid recipients from middle-class families who have been financially devastated by the health and other costs associated with their child's condition. I have attached the Family Voices one-pager that describes the importance of a strong Medicaid program for our children, as well as another description of the combined impact of the many changes taking place in the programs that enable us to raise our children with special health care needs at home, as all children should be.

1. Coverage:

- What will happen to youngsters with special health care needs now covered by Medicaid who happen to be between 12 and 18 years of age? If their families cannot pay for their health care, who will? In many ways, adolescents are especially in need of health care because of the environments in which they live and go to school.

- What will happen to children with special health care needs in states where Medicaid eligibility is above the poverty rates listed for children in Medigrant II? For example, New Mexico's Medicaid program just went to 185% of poverty. If New Mexico retains its commitment to pay for health care for youngsters ages 6-12 who are below 185%, but above 100%, state dollars, not match will be used. Do the governors want that?

- Who will pay for the health care of those children who do not fit within the poverty guidelines? Do the governors understand that these children will still get sick, break bones, have accidents? When it comes to children with special health care needs, who will pay for their care, much of it quite expensive? Total state dollars? County funds? Hospitals, through ER visits? Will families have to institutionalize their children with disabilities (at much greater expense for all concerned) so that their children receive the health care they need in order to survive?

- Allowing each state to define "disabled" invites chaos: people with disabilities will move to states with broader definitions; ADA will be invoked; families with children with disabilities, especially those who are poor or who have become poor, will be forced to relocate to a state with a more favorable Medicaid program.

- The eligibility related to "SSI standards" also varies from state to state — and in most states is quite low. Again, as with poverty guidelines for children, there will be many individuals with disabilities who have been covered by Medicaid who do not meet the SSI eligibility threshold, but who will still need health care, and will only be able to receive it if state dollars are used, or if they enter an institution.

- Thousands of children with special health care needs whose families could not find them adequate health care coverage (because of pre-existing conditions, Medicaid income guidelines, inadequate benefits packages, etc.) have been able to live at home through the Katie Beckett Waivers and other home and community-based waiver programs. What will be the status of such waiver programs? Will the federal legislation at least not prohibit states from continuing or enacting new waivers?

2. Benefits:

- How specifically defined are the benefits listed? For example, does outpatient hospital services include therapies? For rehabilitation or habilitation?

- The benefits listed are definitely less adequate than EPSDT. Who will pay for those necessary and cost-effective services once included in EPSDT and not listed in MediGrant II — equipment (wheelchairs), outpatient therapies, many early intervention services, etc.?

- Most long-term care dollars are eaten up by nursing homes institutions, and ICFMRs. Data show that home-care and the use of personal assistants are much more cost effective for the elderly, people with disabilities, and children with special health care needs. In order to save more health care dollars, will MediGrant II shift the bias and the formulas to home care?

3. Funding Set-Asides

- If there is true interest in saving Medicaid dollars, there should be some investigation into the set-aside formulas, especially those that favor institutional care (nursing homes, state institutions, ICFMRs, etc.) over care in the community.

4. Overall Impact

- On Vulnerable populations. Referring to children with special health care needs alone, the impact of all the health care changes being discussed and taking place could be disastrous. We are fast approaching a revolution in how health care is financed and delivered through a mass of state, federal, and administrative changes, with very little information about its combined impact. Has anyone calculated the total impact on one small child who might need Medicaid for preventive, acute and habilitative care? The title of MediGrant II says "Special Protection Provisions." Would it be possible to at least continue to protect those citizens already enrolled in Medicaid by maintaining their eligibility, even if they do not meet income and other requirements?

- On the Health Infrastructure. Most health care providers, whether physicians, hospitals, or clinics, depend on a combination of government and private insurance reimbursements. When one piece of the equation is cut/changed drastically and swiftly, what is the impact on the health care infrastructure in the states?

- On State Budgets. What projections have been made on the impact on state budgets as the down-sizing of Medicaid takes place? Projections should factor in not just the loss of federal dollars, but the populations uncovered, the effect on hospitals, clinics, and other providers.

- Effects of Cuts Beyond Medicaid on Vulnerable Children. Proposed federal budget cuts in education, (IDEA and Part H), developmental disabilities, AFDC, and SSI will have devastating effects on children with disabilities. We receive calls everyday from state leaders about even greater cutbacks in state budgets for programs that support and assist our children. The overall impact of federal and state funding reductions on our most vulnerable children should be part of Medicaid discussions.

CCD-04-1996 13:27

VOICES

July/August, 1995

Family Voices: A national grassroots network of families and friends speaking on behalf of children with special health care needs

When the Bough Breaks: It's the Combination of Untested Congressional Cuts That Will Hurt Our Children

Families who have children with special health needs have learned to combine services from the following programs:

1. **Medicaid** - Federal funds matched by states pay for health care for children who are poor or disabled
2. **Public Health Service** - Maternal Child health (MCH) block grant funds state Children with Special Health Care Needs (CSHCN/Title V) child health programs; Indian Health Service (IHS) funds health services on and off reservations
3. **Children's SSI** - Provides cash benefits and Medicaid for poor children with severe disabilities
4. **IDEA** - Parts B and H protect kids with special needs and fund some education and related services. Parent Training & Information Centers (PTIs) assist families with education services. Many PTIs work with Family Voices.

Congress proposes to change each of these programs. Even one Congressional action will affect hundreds of thousands of children with special health needs. If all four programs change, the results could be disastrous for the 10 million American children who have a chronic health condition. Examples follow.

DAVID

Now. David is a baby of six months who lives in the rural South. Weighing less than three pounds at birth, he had cardiac and other complications and was airlifted to the Newborn Intensive Care Unit (NICU) of a large children's hospital. The costs for David's two-month NICU stay and cardiac surgeries reached his family health insurance lifetime cap. His mother quit her job to care for David, so he is now income-eligible for Medicaid. An American Indian, David is also eligible for IHS services. David is expected to have a normal childhood if he can receive weekly therapies and infant stimulation, visit cardiac and neurology pediatric specialists regularly, and be cared for by his pediatrician. He should also attend a developmental preschool and receive special education services through his first years of elementary school.

Future? Medicaid cuts will limit children's hospitals in providing the NICU care that saved David's life and assured his healthy future. Now that David is on Medicaid, he relies on Medicaid managed care for specialty care, pediatric visits, a developmental program, and therapies. But so far, managed care will not pay for either pediatric specialists or therapies. Although David could use IHS health services, IHS budget reductions forced cuts in child health care; besides, his IHS unit is six hours away. Low reimbursement from Medicaid and IDEA Part H mean David can receive only minimal services at the local developmental preschool. David's family will need care coordination, peer counseling, and some specialized health services from the state's Title V/CSHCN program. However, because the state Title V budget was slashed when David's state decided to use health block grants funds for adults rather than children, the trained personnel and programs needed by David and his family are gone. If David cannot receive special education services during his formative years, much of the medical investment made in David will be lost.

BEN

Now: Ben is seven, lives with his parents and sisters in an East Coast city, and has chronic asthma controlled by medications and monthly visits to a university children's hospital clinic funded by Title V. Because his asthma often causes absences from school, Ben receives special education assistance to keep up with his classmates. Neither of his parents' employers provides health insurance, nor can his parents afford to buy [illegible] ith insurance. Ben's condition and family income qualify him for Supplemental Security Income (SSI), which also makes him eligible for Medicaid. Ben's monthly SSI benefit (about $120) pays for transportation to medical appointments, utility c[illegible] for heating and air conditioning, annual duct cleaning, air fi[illegible] and special after-school program.

Future? If SSI is cut, Ben loses his SSI check and no longer receives Medicaid. Ben's parents cannot possibly pay for his daily asthma medications, frequent visits to the pediatrician, trips to the asthma clinic, and high electric bills. If Title V and [illegible] Icaid are cut or block-granted, the university asthma program will probably close. Ben's health will deteriorate and he will be hospitalized more frequently. Because they cannot afford after-school specialized child care, Ben's mother will have to quit work to take care of Ben. Without her income, the [illegible]y will have to move to an apartment in a less safe neighborhood. If his special education program disappears, Ben will fall behind, require remedial work, and eventually drop out of school.

TRACY

Now: A bike accident two years ago left 13 year old Tracy, who lives in a suburb in the West, with a traumatic brain injury. She can no longer walk, talk, or eat by herself. Tracy qualifies for a Medicaid Waiver which pays for doctor visits, physical therapy, wheelchair and other equipment, hospitalizations, home-nursing, and medicines. Tracy goes to her neighborhood school, where she is mainstreamed and receives education-related therapies. Tracy's mother attends support groups [illegible] a local parent center funded through IDEA and Title V; Tracy's brother enjoys the sibling groups and activities at the center.

Future? If Medicaid funds are reduced or block-granted, Tracy's state will probably cut many of the benefits that keep [illegible] at home. There will be a domino effect. Without home-nursing after school or when Tracy is sick, Tracy's mother will have to quit work and will not be able to make mortgage payments. Fewer physical therapies or reduced equipment replacements will cause Tracy to lose abilities she has worked to restore, so she will not do as well in school and will probably not be employable as an adult. This will be compounded by special education cuts. On top of Tracy's losses, her mother's emotional well-being will be tested if she has to quit her job and l[illegible] her home. If IDEA and Title V no longer fund the parent center and its parent and sibling groups, Tracy's mother [illegible] brother will find it harder to cope. After awhile, her family will be so exhausted that Tracy will probably have to live in an institution, at an annual state/federal cost of at least $60,000.

FAMILY VOICES

Some Important Facts About Medicaid and Children with Special Health Care Needs

1. Medicaid Provides Access to Essential Health Care Services for Children with Special Health Care Needs

Fewer and fewer of America's children with special health care needs are now covered under private insurance. In fact, the number of children with special health care needs whose parents can keep them insured under the family's health insurance plan declines every year. Many other children with severe special health care needs, even when covered by private health insurance, have inadequate coverage that often does not provide them the type or extent of care that they require. Medicaid has allowed eligible children with special health care needs to receive important preventative and restorative health services while being nurtured at home by their families in their communities. Medicaid thus saves society the cost of keeping children with disabilities in institutions.

2. Children with Special Health Care Needs Qualify for Medicaid in Several Ways...None of T Simple

- Children under the age of six whose family income is up to 133% of poverty, and children who were born after September 30, 1983, whose family income is up to 100% of poverty now qualify for Medicaid in every state. Some states have expanded coverage to even more children who live in families with a low income.

- As of now, children who have qualified for the Supplemental Security Income (SSI) Children's Program also receive Medicaid in 38 states. Children with disabilities must first meet the poverty guidelines. Then they must have a disability that is on the SSI medical listing; or their disability must be so severe that it prohibits them from functioning like other children. About 900,000 children are in the SSI program, but not all of them live in states where they can also receive Medicaid. The current Personal Responsibility Act (PRA) puts limits on eligibility and benefits in the SSI Children's Program.

- Children in more than 30 states may qualify for Medicaid through special home and community-based waivers and amendments. Children must meet state determined definitions of disability, but parents' income is not taken into account. These waivers provide children with critical home care services that might not be covered under their private insurance plans. The waivers also provide health coverage to children whose health care expenses have been so great that they have run through their private health insurance coverage and would have to live in an institution in order to qualify for Medicaid.

3. Medicaid Guarantees that Eligible Children will Receive All Medically Necessary Health Care through the EPSDT (Early Periodic Screening, Diagnosis, and Treatment) Program

While private health insurance plans might not include all health care services required by a child with special health care needs, EPSDT mandates that any health care service approved by Medicaid which is considered medically necessary for a child must be provided. This provision allows children who are eligible for Medicaid to receive appropriate corrective and preventative services, supplies, and equipment (including assistive communication devices, durable medical goods, nutritional supplements, personal assistance, speech therapy, physical therapy, and occupational therapy, among others).

A National Grassroots Network of Families and Friends Speaking on Behalf of Children with Special Health Care Needs
P.O. Box 769, Algodones, New Mexico 87001 / Tel 505/867-2368 / Fax 505/867-6517

February 5, 1996

Dear Governors:

We are writing to express our grave concern about Medicaid proposals under discussion at this week's meeting of the National Governors' Association. We are extremely troubled by many potential features of the proposal we understand you are considering. Of course, we have only limited information about the details of the proposal. However, if our understanding is correct:

- The proposal substantially cuts back current guarantees of health coverage for seniors, children, people with disabilities and women.
- The proposal under discussion, in fact, may not provide a true guarantee of health insurance coverage to anyone. After a state's reduced federal and state allotments have run out, it is not clear whether any beneficiary would be guaranteed health insurance coverage or whether a state could turn away every sick, qualified applicant and put him or her on a waiting list.
- The proposal greatly reduces the benefits guaranteed to anyone who does wind up eligible, whether a senior, child, person with disabilities or other adult. It could eliminate many categories of guaranteed benefits as well as basic federal coverage rules requiring states to furnish medically necessary care.
- The proposal dramatically reduces funds states must contribute to Medicaid. States could avoid $200 billion in projected Medicaid spending over the next seven years, forcing enormous cuts in coverage.
- The proposal makes it impossible for beneficiaries and providers to hold states accountable in federal court for breaking federal law. Even the limited federal safeguards that do exist in the proposal could prove meaningless in practice without this basic right.

These proposals would cause terrible harm to more than 35 million Americans who depend on Medicaid for essential coverage of health care and long-term care.

Sincerely,
AIDS Action Council
American Counselling Association
American Medical Student Association
American Network of Community Options and Resources
American Rehabilitation Association
The Arc
Center on Disability and Health
Children's Defense Fund
Consortium for Citizens with Disabilities
Families USA
InterHealth
International Association of Jewish Vocational Services
Justice for All
National Association of Child Advocates
National Association of People with AIDS
National Citizens Coalition for Nursing Home Reform
National Community Mental Healthcare Council
National Health Care for the Homeless Council
National Mental Health Association
National Organization for Rare Disorders
National Senior Citizens Law Center
National Women's Law Center
San Francisco AIDS Foundation
Service Employees International Union
Women's Legal Defense Fund

December 16, 1995

Dear Mr. President:

The undersigned organizations write to support the concept of a per capita cap as a positive alternative to current Congressional proposals to block grant the Medicaid program. The Medicaid program provides basic health and long term-care services to approximately 36 million American men, women, and children. The block granting of Medicaid would jeopardize coverage for families -- especially seniors, children and persons with disabilities -- at a time when fewer Americans are receiving employer-paid health coverage and the number of uninsured persons continues to rise.

By linking federal funds to the number of people eligible for Medicaid services, a per capita cap would allow states the flexibility to respond to changing economic and demographic conditions. Most importantly, a per capita cap -- unlike a block grant -- creates a disincentive for states to remove people from their Medicaid program. We appreciate your commitment to the per capita cap as an important safeguard for the health of America's most vulnerable populations.

Sincerely,

AIDS Action Council
Alzheimer's Association
American Academy of Pediatrics
American Civil Liberties Union
Bazelon Center for Mental Health Law
Catholic Charities USA
Catholic Health Association of the United States
Center on Disability and Health
Child Welfare League of America
Children's Defense Fund
Families USA
Family Service America
Generations United
InterHealth/Protestant Health Alliance
Legal Action Center
March of Dimes
National Association of Child Advocates
National Association of Children's Hospitals
National Association of Counties
National Association of People with AIDS
National Association of Public Hospitals
National Association of Social Workers
National Association of State Ombudsman Programs
National Citizens' Coalition for Nursing Home Reform
National Community Mental Healthcare Council
National Council of Senior Citizens
National Mental Health Association
National Women's Law Center
Older Women's League
San Francisco AIDS Foundation
Service Employees International Union
TB AIDS Citizen Action Project
The Arc
Women's Legal Defense Fund
Worker Options Resource Center

WHAT MAKES A GUARANTEE TO MEDICAID MEANINGFUL?

Overview: A guarantee to Medicaid coverage means three essential things:

I) Eligible people can get care at any time during the year, not just while the money lasts;

II) There is a federally defined set of benefits;

III) Individuals have an individual right to federally enforce their guarantee.

I. Individuals who meet the eligibility criteria must get care at any time during the year, not just as long as the money lasts.

One of the main issues under debate is whether federal spending is limited per beneficiary or by imposing an aggregate cap per state. For a guarantee of coverage to be meaningful there must be an assurance that as enrollment increases, states will continue to receive matching funds. Any "guarantee" within an aggregate cap is not real unless the states agree to cover all eligible people with 100% state money once the federal cap is reached.

Enrollment grows for many different reasons: recessions, demographic changes in a state, changes in employment opportunities. Federal funds must be available for all new enrollees and not limited by an aggregate cap per state. Otherwise, states may be unable to serve seniors or children who become sick late in the fiscal year, after their funding has run out.

II. A benefit package must be federally defined.

Without a federally defined benefits package, beneficiaries are not entitled *to* anything. For example, as Sen. Chafee has said, a state could provide two aspirins a year and call this their benefits package. States could also decide, for example, that certain benefits would be offered only in suburban communities. States could cover benefits by county only if the county government contributed to paying the cost.

III. Individuals must be able to enforce the guarantee to coverage in federal court.

Federal enforcement of federal law is necessary to ensure that billions of federal dollars are spent as Congress intends that they be spent. Without federal enforcement, states could override Congressional decisions. Without federal enforcement, states would have the ultimate authority to decide how the funds are spent and where within the states the money is distributed.

Consortium for Citizens with Disabilities

February 2, 1995

The Honorable Newt Gingrich
U.S. House of Representatives
2428 Rayburn House Office Building
Washington, DC 20515

Dear Mr. Speaker:

We are writing as the co-chairs of the Health and Long Term Services Task Forces of the Consortium for Citizens with Disabilities (CCD) to reassert our common position on Medicaid. CCD's membership includes more than 100 national disability organizations who represent consumers, advocates, professionals, and providers. Medicaid is a critical program that provides health care and long term support and services to people with disabilities that enables them to live full and productive lives in the community.

We strongly urge you to continue to:

- maintain the individual federal entitlement to Medicaid--do not accept reform that creates a block grant or any other aggregate capped payment to the states.
- maintain the current federal definition of disability.
- maintain access to the full range of mandatory and optional services.
- maintain the current private right of action that ensures access to services.
- maintain the critical federal role in quality assurance and consumer protections, a role that is especially important in the area of long term services.

The CCD recognizes that changes must be made to the Medicaid program to make it more efficient. However, we strongly urge you to focus on reforms that improve the program for Medicaid beneficiaries and protect consumers, not simply that strive to accomodate the states' desire for fewer federal requirements.

Based on a long and often ugly history of treatment of people with disabilities in the period prior to federal funding and oversight, people with disabilities strongly support a continued federal role in monitoring and enforcement of the Medicaid program. Indeed, it was widespread mistreatment and abuse of beneficiaries that has led to increased federal involvement and oversight through the Medicaid program. The past experience of people with disabilities foreshadows great danger for substandard care and abuse if the federal government was to dramatically step back from its responsibility to demand accountability from the states.

We implore you to not set back the clock for people with disabilities who depend on the Medicaid program.

Sincerely,

Marty Ford
The Arc

Kathy McGinley
The Arc

Christina Metzler
American Occupational
Therapy Association

Peter Thomas
Brain Injury Association

Jeff Crowley
National Association of
People with AIDS

Bob Griss
Center on Disability and Health

Jeff McIntyre
American Psychological
Association

The National Association of People with AIDS

1413 K Street, NW
Washington, DC
20005-3405
tel (202) 898-0414
fax (202) 898-0435
NAPWA fax
(202) 789-2282

TO: CCD Health Task Force

FROM: Jeff Crowley

Date: February 2, 1995

Re: **Medicaid Letters**

I am enclosing a copy of a letter that the co-chairs of the health and long term services task forces have sent to: Gingrich, Dole, Armey, DeLay, Gephardt, Stenholm, Chafee, Breaux, Daschle, Kassebaum and Jeffords.

We encourage individual organizations to use this letter as a template and send your own letters.

I am also enclosing an outline of the latest "compromise" proposal from the governors. I strongly encourage people to make calls to the Washington offices of governors registering your concern with the proposal. I have only given a cursory glance at the outline, but it looks like a modified block grant. It also allows states to define disability.

Finally, I also suggest that people place calls to the White House to explain why this proposal would be unacceptable and harmful to people with disabilities.

Please call me if you have any questions.

12 pages total

The National Association of People with AIDS

1413 K Street, NW
Washington, DC
20005-3405
tel (202) 898-0414
fax (202) 898-0435
NAPWA fax
(202) 789-2222

TO: The Honorable Leon Panetta
The Honorable Donna Shalala
The Honorable Alice Rivlin
The Honorable Harold Ickes
The Honorable Carol Rasco
The Honorable Chris Jennings
The Honorable Marilyn Yager
Ms. Patsy Fleming
Mr. Jack Ebeler
Ms. Nancy-Ann Min

FROM: Jeffrey S. Crowley, M.P.H. JSC.
Associate Executive Director

DATE: January 30, 1996

Re: AIDS Coalition Letter to the President on Medicaid

Via Facsimile

Attached, please find another AIDS coalition letter regarding possible changes to the Medicaid program. We appreciate the President's continued leadership in fighting to protect Medicaid, and would like to reinforce the importance we place on four critical issues that we have learned are vulnerable to being changed:

- **Protect the current federal definition of disability**

The current SSA definition for determining disability must be maintained for eligibility determinations for Medicaid. People who suffer from alcoholism and/or drug addiction must not be excluded from eligibility for Medicaid.

- **Protect an individual's access to federal courts to enforce provisions of the Medicaid statute**

The experience of people with AIDS in fighting for Medicaid eligibility and to access services has demonstrated that individuals need access to the federal courts to ensure that they receive the health coverage for which they qualify.

- **Protect consumer choice of managed care plans**

Choice among provider plans is necessary in order to create market pressures for providers to locate in underserved areas and to create incentives for plans to address systemic problems such as insufficient capitation rates, poor oversight and poor monitoring.

- **Protect current comparability and statewideness provisions**

Comparability of benefits among all beneficiaries and the same level of services throughout a state are fundamental principles of fairness that should not be altered.

February 7, 1996

The President
The White House
Washington, DC 20500

Dear Mr. President:

We are writing to express our extreme concern regarding the National Governors Association (NGA) Medicaid reform proposal. We are appalled at the implication from your recent comments that you may support this plan.

Over the past few months, we have written to you on numerous occasions regarding the need for a strong federal commitment to protecting the guarantee to high quality health care for low-income Medicaid beneficiaries--and we have frequently recognized your strong leadership in advocating for this program. The NGA plan would be devastating to people with AIDS and other Medicaid beneficiaries. The governors' plan repeals Title XIX--the backbone of a meaningful guarantee to health coverage for eligible beneficiaries--and it does not meet any of the criteria you have established for acceptable Medicaid reform. The NGA proposal is nothing more than a block grant, which you have opposed, dressed up in language meant to provide assurances and guarantees that are, in fact, meaningless. If you were to support this plan, it would betray the commitments you have made to people with AIDS at your December summit and on several other occasions.

We believe that there are three critical questions you must ask yourself in assessing any reform plan:

Who is covered?
The governors' plan fails the beneficiary because it would allow states to define disability for purposes of Medicaid eligibility. The NGA plan contains assurances that the disabled would receive coverage. By removing the existing federal disability definition, however, current disabled beneficiaries are vulnerable to becoming ineligible. Indeed, before we had the current federal disability definition there were great inequities in access to Medicaid among the disabled. It is easy to imagine that some states would seek to define disability in a way that intentionally excludes some or all people with HIV/AIDS.

What services are covered?
The governors' plan fails the beneficiary because it would repeal current law provisions related to statewideness, comparability and amount, duration and scope. It is not enough simply to state that a specific benefit will be provided. Benefits and services must be provided equally in all parts of a state, benefits must be provided equally to all categories of beneficiaries, and they must be provided in amounts determined by a health care provider to be effective and medically necessary. States should not be free to arbitrarily limit access to services.

How are individuals ensured of receiving the coverage for which they qualify?
The governors' plan fails the beneficiary because it takes away an individual's private right of action. This provision of the law is absolutely necessary to ensure that individuals have recourse if a state does not provide them with a service for which they qualify. A guarantee to coverage or benefits is relatively meaningless unless there is a means to enforce it. People with AIDS have used a private right of action to fight discrimination and to gain the same access to prescription drugs and other services as other Medicaid beneficiaries within their states. If these provisions are lost, people with AIDS could find that, on paper, they are guaranteed access to a medication or a service, but in reality it is denied to them.

It is essential that any reform plan be able to provide satisfactory answers to all of these questions. Failing even one, then the proposal should be rejected. Medicaid payments represent the federal government's largest form of financial support to the states, totaling nearly $100 billion per year. We believe that you and the Congress owe it to the American people to insist that states are held accountable for the federal money they receive.

We urge you to stand firm, as you have done to date, in opposing the current NGA Medicaid proposal and any other plan that could threaten health care for millions of vulnerable low-income Americans.

Sincerely,

AIDS Action Council

AIDS Policy Center for Children, Youth and Families

Cities Advocating for Emergency AIDS Relief

Gay Men's Health Crisis

Housing Works

Human Rights Campaign

National Association of People with AIDS

National Minority AIDS Council

Project Inform

San Francisco AIDS Foundation

Texas AIDS Network

January 30, 1996

The President
The White House
Washington, DC 20500

Dear Mr. President:

We are writing regarding your strong leadership in fighting to protect the integrity of the Medicaid program and we would like to urge you to remain resolute in opposing destructive changes to the program, including proposals for which various governors have been advocating. Although we have already written to you on numerous occasions, we would like to share with you the perspective of people with AIDS as you consider an ever changing set of reform options. While we support efforts to improve the Medicaid program, we urge you to continue to:

Protect the current federal definition of disability

Over the past few months, various proposals have circulated to permit states to define for themselves what is meant by a disability for purposes of eligibility for Medicaid. Failing that, others have advocated for modifying the federal definition of disability in a way that would exclude persons whose alcoholism or drug addiction is a material factor in a disability determination. We strongly oppose any changes to the current federal definition of disability for eligibility for Medicaid from the definition of the Social Security Administration (SSA) for the social security disability income (SSDI) and supplemental security income (SSI) programs. Furthermore, any federal definition of disability must be explicitly designated as a floor. States should retain the flexibility to use a broader disability definition, at their discretion.

We support the SSA definition of disability not because it is a perfect definition, but because it is a practical compromise that has worked for the past thirty years. It is broad enough to cover persons whose disability makes health care absolutely necessary, but it also sufficiently narrow to exclude persons who would not otherwise qualify for Medicaid benefits. In many regards, this definition actually does not serve people with HIV disease well. This is because the majority of people with HIV disease are ineligible for Medicaid benefits until they are in the advanced stages of their illness (generally requiring an AIDS diagnosis). In effect, people with HIV disease who are asymptomatic and who could most benefit from relatively low-cost prophylactic treatments are denied coverage, and they only become eligible once they are symptomatic and then require more expensive medical interventions.

Nonetheless, the current SSA disability definition has been tested over many years, and it satisfactorily defines persons with various types of disabilities ranging from people with AIDS who express a wide variety of symptoms to persons who are physically disabled and functionally impaired, as well as persons who have mental impairments. The SSA definition is the best definition that is viable in the current political context and it should be used as a minimum floor for disability determinations.

We oppose changes to the Medicaid statute that would give states discretion to define disability because this could only translate into a loss of coverage for disabled individuals. Relative to other categories of beneficiaries, the disabled are often the most vulnerable to loss of coverage and are frequently the least organized to counter efforts to deny them coverage. We also

oppose changes to the Medicaid statute that would deny coverage to persons whose alcoholism or drug addiction is material to their disability because this would also exclude coverage to people in dire need of health care. This particular policy proposal really amounts to a moral test of our society's commitment to its most vulnerable citizens. Persons who suffer from alcoholism or drug addiction include many people living with HIV disease. This category of beneficiary tends to be the poorest among the poor, and the loss of Medicaid eligibility would place these individuals at risk of being completely neglected by society. While we will only support changes to Medicaid that protect eligibility for all persons who are currently eligible, persons who suffer from alcoholism and drug addiction are especially in need of federal protection.

Recently, in debating welfare reform, a considerable amount of time was spent on a national discussion of whether or not it is appropriate to give cash benefits to persons who are alcoholics or are addicted to drugs. The thinking on the part of some is that cash benefits serve as an incentive to purchase more illicit substances--with the federal government, in effect, supporting an individual's addiction. Leaving the merits of this line of reasoning aside, this same argument clearly cannot be made concerning access to health care benefits. It would require perverse logic to think that people would make themselves sick just to qualify for health benefits. Medicaid eligibility should be a route for overcoming one's addiction, but it in no way does access to health care foster further drug dependence. We urge you not to support any changes to the Medicaid program that would deny eligibility to any category of currently eligible beneficiaries.

Protect an individual's access to federal courts to enforce provisions of the Medicaid statute

People with AIDS, unfortunately, have faced a long history of discrimination. Various provisions in the Medicaid statute and various other federal laws, not the least of which is the Americans with Disabilities Act, have been instrumental in fighting and winning access to Medicaid benefits and access to vital services, including prescription drug coverage. It would be excessively harmful to beneficiaries if the Medicaid statute were reformed in any way that limits access to federal courts. An individual's private right of action is an absolutely essential enforcement mechanism that holds states and providers accountable for delivering the care that they must provide.

Protect consumer choice of managed care plans

We are also concerned that your Administration may eliminate from your Medicaid proposal the requirement for choice among provider plans. Insufficient capitation rates, poor oversight and monitoring, and poor plan administration are systemic problems that would be isolated from any market pressure to improve if there is only one managed care plan within a state. In order to create a Medicaid system that is efficient and that provides high quality care to its beneficiaries, individual consumers must be able to choose among managed care plans and they must have a choice of providers within a plan.

Many of the problems that will arise regarding inappropriate health care or substandard care are not caused exclusively by individual health care providers. Additionally, our current health care system is problematic in that there are great disparities in provider access from one community to another. One part of a city may have an extensive choice of providers, whereas another part of the same city may have no providers. This problem is even greater when considering disparities between urban and rural areas and among historically underserved populations, such as people of color. In addition to a choice among managed care plans,

information is necessary to make informed choices among plans. This information must be both culturally sensitive and appropriate for the diverse audience of beneficiaries. Informed consumers choosing among various plans are needed to make provider plans responsive to their beneficiaries and to exert pressure on plans to locate providers in underserved areas. Given the enormous share of federal resources that support the Medicaid program, the federal government must ensure a greater level of accountability by insisting on choice among provider plans.

Protect current comparability and statewideness provisions

The principles of comparability and statewideness are fundamental notions of fairness that should not be altered. It is particularly disconcerting that governors who profess a desire to improve their Medicaid programs have advocated for the freedom to provide a service or benefit in one place that they would not provide in another. Alternately, they seek flexibility to provide a particular benefit or service to one category of beneficiary that they would not provide to another. This is a nonsensical policy position that does not merit your support.

Throughout these past months, many of our nation's governors have asserted that they could do a better job of administering their state Medicaid programs if they are given greater flexibility by the federal government. However, greater flexibility in administration is far different from repealing the basic protections that go to the heart of the Medicaid program: guaranteed eligibility to a guaranteed package of health benefits, and the means to enforce the law.

Thank you, once again, for your strong leadership on behalf of people with AIDS and other Medicaid beneficiaries.

Sincerely,

AIDS Policy Center for Children, Youth and Families

Cities Advocating for Emergency AIDS Relief

Gay Men's Health Crisis

Housing Works

Human Rights Campaign

National Association of People with AIDS

National Minority AIDS Council

Project Inform

San Francisco AIDS Foundation

Texas AIDS Network

Worker Options Resource Center