

FOIA MARKER

**This is not a textual record. This is used as an
administrative marker by the William J. Clinton
Presidential Library Staff.**

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: Chief of Staff

Series/Staff Member: Leon Panetta

Subseries:

OA/ID Number: 7755

FolderID:

Folder Title:

[Disability Perspectives and Recommendations on Proposals to Reform the Medicaid and Medicare Programs - National Council on Disability November 9, 1995] [loose]

Stack:

S

Row:

23

Section:

2

Shelf:

4

Position:

3

DISABILITY PERSPECTIVES AND
RECOMMENDATIONS ON PROPOSALS
TO REFORM THE
MEDICAID AND MEDICARE PROGRAMS



National Council on Disability
November 9, 1995

**National Council on Disability
Disability Perspectives and Recommendations
on Proposals to Reform the Medicaid and Medicare Programs**

Publication date: November 9, 1995

**National Council on Disability
1331 F Street NW
Suite 1050
Washington, DC 20004-1107**

**(202) 272-2004 Voice
(202) 272-2074 TT
(202) 272-2022 Fax**

The views contained in the report do not necessarily represent those of the Administration, as this document has not been subjected to the A-19 Executive Branch review process.

DISABILITY PERSPECTIVES AND
RECOMMENDATIONS ON PROPOSALS
TO REFORM THE
MEDICAID AND MEDICARE PROGRAMS



Prepared under contract by:
Peter W. Thomas, Esq.

National Council on Disability



NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and the Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

LETTER OF TRANSMITTAL

November 9, 1995

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am providing you with an important time-sensitive report from the National Council on Disability (NCD) entitled, *Disability Perspectives and Recommendations on Proposals to Reform the Medicaid and Medicare Programs*. NCD believes that the proposed changes to these programs will have a serious adverse impact on approximately 9 million people with disabilities who depend on them to meet their critical health care needs.

While NCD recognizes the need for constructive reforms in the Medicaid and Medicare programs, NCD believes that Medicaid and Medicare changes must be enacted in the context of system-wide reform in order to maintain the quality and effectiveness of our nation's health care system. Further, if the national goals of independence, economic self-sufficiency, and inclusion of people with disabilities—embodied in the Americans with Disabilities Act of 1990—are to become a reality, access to affordable quality health care is a necessity.

NCD is concerned about proposed changes to both programs, but is particularly concerned about Medicaid. The human side of the Medicaid program is compelling. Medicaid serves as the financing of last resort for the health and long-term care needs of some of the most marginalized individuals in society: a child with mental retardation or cerebral palsy; an adolescent with a traumatic brain injury or spinal cord injury; a young adult with Multiple Sclerosis or serious mental illness; a middle-aged person with cancer; an elderly person with a stroke or Parkinson's Disease. These and other people with disabilities are dependent on the continuation of this vital government program, often because no other options exist for health care coverage.

America needs your leadership on this critical issue. It is our hope that the information contained in this report will help you and the Members of the 104th Congress in constructing a Medicaid and Medicare system that is productive and just.

Sincerely,

A handwritten signature in cursive script that reads "Marca Bristo".

Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

NCD MEMBERS AND STAFF

Members

Marca Bristo, Chairperson
John A. Gannon, Vice Chairperson
Yerker Andersson, Ph.D.
Ellis B. Bodron
Larry Brown, Jr.
John D. Kemp
Ela Yazzie-King
Audrey McCrimon
Bonnie O'Day
Lilliam R. Pollo
Debra Robinson
Shirley W. Ryan
Michael B. Unhjem
Rae E. Unzicker
Kate P. Wolters

Staff

Ethel D. Briggs, Executive Director
Speed Davis, Executive Assistant to the Chairperson
Billie Jean Hill, Program Specialist
Jamal Mazrui, Program Specialist
Mark S. Quigley, Public Affairs Specialist
Brenda Bratton, Executive Secretary
Stacey S. Brown, Staff Assistant
Janice Mack, Administrative Officer

TABLE OF CONTENTS

Introduction	1
The Current Medicaid Program	1
The Current Medicare Program	2
The Importance of Private Insurance Reforms	3
Statement of Policy	4
The Proposed Medicaid Reforms	5
Recommendation No. 1	6
The Consequences of the Proposed Medicaid Changes	6
Block Grants and the Individual Federal Entitlement	7
Alternatives to Block Grants and the Loss of the Individual Federal Entitlement	8
Recommendation No. 2	9
The Private Right of Action and Application of Federal Civil Rights Law	10
Recommendation No. 3	10
Consumer Representation in Decision-Making	10
Recommendation No. 4	11
The Elimination of Federal Standards in Nursing Homes and Managed Care Plans	11
Recommendation No. 5	12
The Proposed Medicare Reforms	12
The Proposed Level Medicare Reductions	13
Recommendation No. 6	13
Managed Care and People with Disabilities	14
Medical Underwriting Should be Prohibited in Medicare and Medicaid Managed Care Plans	15
Recommendation No. 7	16

Medical Savings Accounts May Act as a Drain on the Medicare Trust Fund . .	16
Recommendation No. 8	17
Quality Assurance in Medicare Managed Care Plans	17
Recommendation No. 9	18
Shifting to Managed Care Requires Federal Standards to Ensure	
Access to Quality	18
Recommendation No. 10	19
Conclusion	19
Appendix A: Summary Recommendations	21
Appendix B: NCD: A Brief Description	25

INTRODUCTION

The 104th Congress is considering the Omnibus Budget Reconciliation Act of 1995, (the "budget bill") which seeks to balance the federal budget by the year 2002, significantly restructure the Medicaid and Medicare programs, reform federal welfare programs, and provide substantial tax relief to many taxpayers. Medicaid and Medicare are among the fastest growing sectors of the federal budget. Because Medicaid expenses are shared between the federal government and the states, many governors have called for reforms in the program. Medicare is a federal program that the trustees of the Medicare Trust Fund have forecasted will be in bankruptcy by 2002 under current law. While Medicare and Medicaid spending represent 17% of the annual federal budget, 45% of the spending reductions necessary to balance the federal budget by 2002 will come from these two programs under the current version of the budget bill.

THE CURRENT MEDICAID PROGRAM

The Medicaid program is the primary federal program providing health and long-term care to low-income families, the elderly, and people with disabilities. Of the 36 million people covered by Medicaid, 4.9 million are children or adults who are blind or have other significant disabilities. In fact, 15% of Medicaid beneficiaries (blind and disabled) accounted for 39% of expenditures in 1993. Medicaid is a means-tested entitlement program that is funded by states and the federal government and is administered by the states. People who meet federal eligibility criteria are entitled to be covered by the program (i.e., people receiving Supplemental Security Income "SSI" or pregnant women and children with incomes under a certain level of poverty), but states determine additional financial eligibility criteria and have the option of covering additional groups of individuals. States that meet the federal eligibility and benefit guidelines receive federal matching payments ranging from 50% to 80%, depending upon the state's per capita income and other factors.

States must provide mandatory Medicaid services—such as hospitalization, physician services and EPSDT (early and periodic screening, diagnosis and treatment) for

children—and states may choose to provide a wide array of "optional" services including rehabilitation therapies and devices, mental health services, personal care services, case management, and prescription drugs. The primary source of long-term care for poor elderly individuals and younger individuals with significant disabilities is the Medicaid Long-Term Care Program. Approximately 85 percent of Medicaid expenditures in this area are for institutional care, including nursing home care. Only 15 percent of expenditures are for home and community-based services.

The current Medicaid program maintains a bias toward institutional care rather than home and community-based services and supports. Currently, home and community-based care is only covered under a state Medicaid waiver and is usually only provided if the beneficiary would qualify for institutional care. Recent studies have demonstrated the cost-effectiveness of home and community-based care for a large percentage of persons at risk of being institutionalized.

The human side of the Medicaid program is compelling. Medicaid serves as the financing of last resort—assuming both financial and disability eligibility criteria are met—for the health and long-term care needs of some of the most marginalized individuals in society: a child with mental retardation or cerebral palsy; an adolescent with a traumatic brain injury or spinal cord injury; a young adult with Multiple Sclerosis or serious mental illness; a middle-aged person with cancer; an elderly person with a stroke or Parkinson's Disease. These and other people with disabilities are dependent on the continuation of this vital government program, often because no other options exist for health care coverage.

THE CURRENT MEDICARE PROGRAM

Although Medicare serves the health care needs of approximately 36 million senior citizens, the program also covers 4.2 million people with disabilities below 65 years of age. These people with disabilities qualify for Medicare coverage through the Social

Security Disability Insurance (SSDI) program after a two-year waiting period, through the End Stage Renal Disease (ESRD) program after their private insurance is exhausted, or as a disabled dependent of a retired, deceased, or disabled worker. Eligibility is based on work history and other eligibility criteria.

Medicare has two parts: Part A covers hospitalization through the Medicare Hospital Insurance Trust Fund which is funded through FICA taxes representing 2.9 percent of earned income of all employed persons; Part B covers physician services and non-physician provider services such as therapists, rehabilitation devices, and home health care. Medicare Part B services are paid for out of the Supplementary Medical Insurance Trust Fund which includes general government revenues and premiums paid by beneficiaries. Beneficiaries also pay deductibles and co-payments for some Part B services. Notable exclusions in Medicare benefits include outpatient prescription drugs and many forms of assistive technology for people with disabilities.

According to the Congressional Budget Office (C.B.O.), over 90 percent of Medicare beneficiaries receive health services under the fee-for-service program which allows unlimited choice of health care provider regardless of the beneficiary's level of income. Approximately 7 percent of beneficiaries have chosen to enroll in Medicare managed care plans under the Medicare Risk Contract Program, which limit choice of provider but often cover additional benefits.

THE IMPORTANCE OF PRIVATE INSURANCE REFORMS

The National Council on Disability (NCD) has a strong interest in reform of our nation's health care system based on the disability community's principles of nondiscrimination, comprehensive-ness, appropriateness, equity and efficiency. Only through reforms based on these principles can we ensure that our nation's health system serves the needs of all Americans, including Americans with disabilities. See, "*Making Health Care Reform Work for Americans with Disabilities: Summary Information on Five*

"Town Meetings" on Health Care Reform" A Report to the President and the Congress of the United States, NCD, July 26, 1994.

The dramatic growth in the Medicaid and Medicare programs can be attributed, in part, to the private insurance sector's reluctance to adequately provide for the health care needs of the populations covered by these programs. In this respect, the Medicare and Medicaid programs represent large high risk pools. The number and need for services of Medicaid beneficiaries continues to rise as employer-sponsored health care is declining and those who are privately covered tend to be less frequent users of health services. In fact, over one million people under age 65 become uninsured each year which currently represents over 41 million people.

STATEMENT OF POLICY

NCD recognizes the need to reduce the rate at which the costs of the Medicaid and Medicare programs are rising and supports constructive change in these programs to promote the goals of enhanced coverage and quality, increased efficiency, elimination of fraud, waste, and abuse, and delivery of benefits that meet the health and long-term care needs of people with disabilities and chronic illnesses. NCD believes that Medicaid and Medicare changes must be enacted in the context of system-wide reform in order to maintain the quality and effectiveness of our nation's health care system. Further, if the national goals of independence, economic self-sufficiency, and inclusion of people with disabilities—embodied in the Americans with Disabilities Act of 1990—are to become a reality, access to affordable and quality health care is a necessity.

While NCD recognizes the need for constructive reforms in the Medicaid and Medicare programs, NCD has concerns that key elements of both the House and Senate approved budget bills could significantly and negatively impact the health, independence, and dignity of all Americans with disabilities. Nationally, ten percent of the population accounts for 72 percent of total health care expenditures. Generally, NCD's reservations

with the current Medicaid and Medicare proposals reflect the concern that quality will be jeopardized as unrealistic cuts in these programs are pursued.

The proposals also fail to promote the cross-subsidization which is necessary to meet the higher health care costs of people with disabilities and chronic conditions. The proposals miss the opportunity to use the leverage that government has in the health care marketplace to require managed care plans to cover high users of care, e.g. people with disabilities. Finally, the proposals fail to promote home and community-based care rather than institutional placement. NCD's specific concerns are outlined below and recommendations have been provided where appropriate.

THE PROPOSED MEDICAID REFORMS

The Medicaid provisions included in the House and Senate versions of the budget bill represent dramatic change in the nation's health care program for low income families, children, and people with disabilities. Congress proposes to reduce spending in the Medicaid program by \$170 billion over the seven-year period ending in 2002 by completely eliminating the individual entitlement to Medicaid coverage in the House budget bill and reducing the rate at which program spending increases in future years. In the Senate, the budget bill calls for the same level of savings but proposes to continue some form of individual federal Medicaid entitlement for certain pregnant mothers, children through the age of 12, and people with disabilities.

The House and Senate bills would place a cap on federal Medicaid payments to states based on a complex funding formula designed to bring the rate of annual Medicaid growth down to approximately 4.5 percent. Federal Medicaid funds would be sent to the states in the form of block grants with few federal requirements for use of federal dollars. Medicaid is the largest single source of federal funds to the states and many of the nation's governors support the block grant approach. They have assured Congress that by allowing the states flexibility in the design and implementation of their Medicaid

programs, the states will adequately provide for the health and long-term care needs of their residents.

Recommendation No. 1: The National Council on Disability recommends that Congress significantly reduce the level of proposed Medicaid cuts over the next seven years in order to ensure the continued vital assistance that Medicaid provides to people with disabilities.

The Consequences of the Proposed Medicaid Changes

If the final budget bill eliminates the individual entitlement to Medicaid and block grants the program to the states, as in the House bill, people with disabilities will lose access to critical health and long term services. For people with disabilities and chronic health conditions, the lack of access to health and health-related services and supports could lead to an exacerbation of existing health problems and/or disabilities, as well as the emergence of additional health problems and secondary disabilities. In some cases, inappropriate institutionalization of adults and children with disabilities may be the result.

According to the Urban Institute's Medicaid Expenditure Growth Model, the loss of the individual federal entitlement to Medicaid will result in the loss of Medicaid coverage for as many as 1.2 million people with disabilities nationwide by the year 2002, many of whom are children. Because Medicaid often provides items such as wheelchairs, communication devices, therapy at home, respite care, and home modifications, the loss of Medicaid coverage for children with disabilities could mean that parents have no choice but to seek institutional placement.

For people with long term care needs, the lack of Medicaid coverage may lead to the loss of services and supports that help these individuals live more independent lives in their homes and communities, in some cases resulting in homelessness or unnecessary institutionalization. The lack of Medicaid coverage will place unreasonable pressures on

family members, many of whom will have their own economic security undermined as they attempt to pay for health and long-term care costs, and in some cases, forego employment to care for relatives.

The loss of the individual entitlement under Medicaid will greatly affect people who are dually eligible for both programs, such as low-income elderly persons. Medicaid currently provides subsidies to low-income elderly persons who cannot afford Medicare Part B premiums, deductibles, and co-payments. An open question remains whether low-income Medicare beneficiaries will be able to receive the services they need when they cannot afford these premiums, deductibles and co-payments without Medicaid subsidies to help cover these costs.

Finally, the current Medicaid proposals fail to address major transitional issues that, upon signature of the bill into law, will immediately place persons with disabilities and chronic conditions at risk of losing critical access to care. In some cases, preserving or eliminating access to care will have life and death consequences. The monumental change to which state governments must adapt in Medicaid and other programs formerly run at the federal level is simply not taken into account in the current House and Senate budget proposals.

Block Grants and the Individual Federal Entitlement to Medicaid

Proposals to eliminate the individual federal entitlement to Medicaid and block grant the program to the states with virtually no federal standards constitute a major threat to the health and independence of people with disabilities. The current House and Senate Medicaid proposals establish no mandatory benefits that states must provide to beneficiaries except childhood immunizations and, in the Senate bill, pre-pregnancy family planning services. The proposals, however, include state level “set-aside” categories for certain vulnerable populations, i.e., families with pregnant women and children, elderly individuals, and low-income persons with disabilities under age 65.

States would be permitted within these broad categories to determine which health and long-term services to cover.

The set-aside proposals under the House and Senate bills differ but generally require each state to annually spend in future years a minimum of 85 percent of the state's average Medicaid spending in prior years for people in each set-aside category. The 85 percent spending levels are based on services that are currently "mandatory" and do not take into account spending on so-called "optional" services, i.e., those services that states now choose to cover. Optional Medicaid services are a misnomer because they are medically necessary and are of critical importance to children and adults with disabilities. Optional services currently provided in many states include rehabilitation therapies and devices, prescription drugs, home and community-based services, personal assistance services, and case management.

The disability set-aside would significantly understate the level of Medicaid services provided to people with disabilities and could result in a substantial reduction in Medicaid spending for this population. With no entitlement, no requirement for the provision of specific services, and underfunded set-asides, states would be unable to provide the range of medically necessary services and supports that they now provide for children and adults with disabilities. In short, the disability set-aside is a weak substitute to the current Medicaid guarantee to specific health and long term services.

Alternatives to Block Grants and the Loss of the Individual Federal Entitlement

Reductions in the rate of growth of Medicaid spending could be achieved in a number of ways that preserve the individual federal entitlement to Medicaid. For instance, a per capita cap would limit the growth of Medicaid spending to a reasonable rate for each person in the program without placing an artificial program-wide cap on Medicaid spending. The guarantee of Medicaid coverage would be maintained while states with growing populations would be able to cover their Medicaid costs. Significant

Medicaid savings could also be achieved—without losing the individual federal entitlement to the program—by establishing incentives for the use of home and community-based care and disincentives for the use of institutional care in appropriate circumstances. Home and community-based care is often cost-effective and promotes independent living among people with disabilities. Home and community-based care has also been required to be provided by state Medicaid programs based on legal challenges involving federal civil rights laws. See, Helen L., et al, v. Albert L. DiDario for Norristown State Hospital, No. 94-1243 (3d Cir., Jan. 31, 1995).

The Senate version of the budget bill retains a guarantee of Medicaid coverage to certain low-income pregnant mothers, children through the age of 12, and people with disabilities. The definition of "people with disabilities" in the Senate bill relies on the SSI definition of disability (as amended by the welfare bill) which currently applies to 3.9 out of 4.9 million people with disabilities receiving Medicaid services. This individual federal Medicaid entitlement for people with disabilities has been strongly opposed by many of the nation's governors who would prefer that the definition of disability be determined on a state by state basis, or that no federal entitlement remain for people with disabilities.

Recommendation No. 2: The National Council on Disability recommends that Congress retain the current individual federal entitlement to Medicaid and not block grant this vital program to the states. To control the rate of growth in Medicaid spending, options such as a per capita cap on federal Medicaid dollars and incentives for home and community-based care—instead of institutional care—should be considered. The Senate language, which only retains the individual federal entitlement for people with disabilities and other at-risk populations, is a major setback from current law and is only supportable in comparison to the complete elimination of the individual federal Medicaid entitlement as in the House bill. Any significant changes in the Medicaid program should be phased-in to ensure a smooth transition for Medicaid beneficiaries.

The Private Right of Action and Application of Federal Civil Rights Law

The House Medicaid proposal expressly denies a private citizen—including a beneficiary, a provider, or a health plan—the right to bring a federal cause of action against a state to enforce compliance with provisions of the Medicaid program. This proposal removes the existing right of a Medicaid beneficiary to sue to require enforcement of the Medicaid statute and regulations. The Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973 would no longer be available to Medicaid beneficiaries with disabilities in challenging the Medicaid decisions of states. Provisions eliminating the federal cause of action were struck from the Senate bill before passage.

Recommendation No. 3: The National Council on Disability recommends that Congress maintain the existing federal private right of action against states to enforce compliance with the Medicaid statute and regulations and to ensure that state Medicaid programs fully comply with the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973.

Consumer Representation in Decision-Making

With the emphasis on state flexibility, the nexus of decision-making will devolve to the states under the proposed reforms. Many people with disabilities and their families remember when states had complete control over the health and long-term care decisions of persons with disabilities and other marginalized populations. These memories bring to mind the future ethical dangers at stake when many people consider a life with a disability as a life not worth living.

To promote greater public accountability, it is critical that representatives of consumer groups, particularly people with disabilities, are accounted for and actively participate in every level of decision-making concerning the provision of health and long-term services and supports to each states' Medicaid population. Consumers should be represented on all state, regional, and local advisory boards, policy panels, and

Medicaid committees. This includes the creation of ombudspersons to represent the interests of consumers within each state's Medicaid program and in all managed care plans serving Medicaid beneficiaries. The current versions of Medicaid reforms are wholly inadequate with regard to consumer participation.

Recommendation No. 4: The National Council on Disability recommends that Congress include specific provisions in its Medicaid reforms to ensure the active participation of persons with disabilities at every level of decision-making in the Medicaid program.

The Elimination of Federal Standards in Nursing Homes and Managed Care Plans

The House proposal dramatically reduces, and in some cases, eliminates consumer and quality assurance protections and federal oversight in Medicaid services and in Medicaid-funded facilities. This includes the elimination of current federal nursing home and ICF-MR regulations, as well as standards related to community-based care. The Senate bill does maintain current federal standards for nursing homes but allows states to receive waivers from the federal government if their standards are equal to or stricter than federal standards. Because there is no private right of action, however, minimum federal standards for nursing homes appear to be in jeopardy. In addition, the basic requirement that Medicaid funds must be spent on "active treatment" for individuals in institutional settings, rather than merely custodial care, would be eliminated under the Medicaid proposals.

The House and Senate proposals permit states to shift Medicaid beneficiaries into managed care plans with inadequate consumer protections related to access and quality of care. For instance, the proposals eliminate the federal requirement that managed care plans which serve Medicaid beneficiaries must maintain at least 25% of their enrollees as private purchasers of health coverage. In addition, the health status of people with disabilities who are often underserved in capitated health plans may be placed at risk under provisions that allow states to use mandatory managed care for

Medicaid beneficiaries. In fact, HCFA recently denied a waiver request from New York City based on federal civil rights law to use mandatory managed care for its Medicaid population until it could demonstrate appropriate quality assurance protections for people with disabilities.

Recommendation No. 5: The National Council on Disability recommends that federal standards of consumer protection and quality assurance be maintained in Medicaid-funded facilities—such as nursing homes, ICFs-MR, and community-based programs—and in all Medicaid-funded managed care. Managed care should be an “option” and not the only choice for Medicaid beneficiaries with disabilities and should include strong protections for timely and appropriate access to all necessary services, supports, and providers.

THE PROPOSED MEDICARE REFORMS

Currently, Medicare beneficiaries may choose any provider and/or specialist they wish under the fee-for-service Medicare program or can choose to enter into the Medicare Risk Contract Program to receive health care through a managed care plan. The Congressional leadership’s Medicare proposals represent a substantial restructuring of the nation’s health program for senior citizens and people with disabilities under 65 years of age. Congress proposes to reduce spending in the Medicare program by \$270 billion over the seven-year period ending in 2002 by sharply reducing the rate of growth in fees to hospitals and other providers, creating incentives to shift large numbers of beneficiaries from the Medicare fee-for-service program into private managed care plans, and by increasing the share that beneficiaries will pay under the program. The House and Senate bills are designed to bring annual Medicare growth in spending down from just over 10 percent to approximately 7 percent.

The Proposed Level of Medicare Reductions

Removing \$270 billion from the Medicare program over the next seven-year period is a level of spending reductions never before considered by Congress. These spending reductions have been characterized as "cuts" by opponents and "reductions in the rate of growth" by proponents. From a disability perspective, removing this magnitude of resources from Medicare, before reforms have occurred throughout the entire health system, will decrease the quality of care, reduce health benefits, and decrease access to necessary medical services.

Under the Medicare proposals, some beneficiaries will spend significantly more for health care than under current law through increases in Part B premiums and increases in out-of-pocket expenses through balance billing. In the Medicare fee-for-service program, providers' fees will grow at a much slower pace than currently projected and new budget mechanisms will allow the government to further reduce fee-for-service provider fees if cost containment goals are not met. Providers serving beneficiaries in Medicare managed care plans will have to offer discounted rates in order to compete against other providers, thereby further limiting provider payments.

While this approach may be effective in reducing the growth of Medicare spending, these significant fee reductions for Medicare providers will likely cause access and quality concerns for Medicare beneficiaries. Access concerns are raised when Medicare provider fees become so low in comparison to other payors that providers simply refuse to treat Medicare patients. Quality concerns are raised as providers cut corners in the provision of care (i.e., shortened office visits; less comprehensive examinations) in order to limit the impact of lower reimbursement levels.

Recommendation No. 6: The National Council on Disability recommends a significant reduction in the proposed level of spending cuts to be taken out of the Medicare program in order to maintain access and quality of health care services for people with disabilities.

Managed Care and People with Disabilities

Enticing a greater percentage of Medicare beneficiaries into managed care arrangements and out of the Medicare fee-for-services system is a major objective of the bills currently under consideration in Congress. As managed care continues to sweep the health care marketplace, however, dissatisfaction with many of these plans among people with disabilities and chronic illnesses continues to grow.

Anecdotal and empirical data suggest that managed care plans may not adequately meet the needs of high users of health care services. Many beneficiaries with significant health conditions, therefore, may opt to remain in the fee-for-service Medicare program. The fee-for-service system ensures access to appropriate specialty care and avoids the potential danger of underservice which often occurs when people with disabilities are served by managed care plans, particularly capitated systems.

This form of "adverse selection" could result in program cost increases to the fee-for-service Medicare sector as relatively young and healthy beneficiaries move to Medicare managed care plans, leaving beneficiaries with the greatest health care needs in the fee-for-service system. The average Medicare outlay per beneficiary was \$4,020 in 1993. The healthiest 90 percent of Medicare beneficiaries, however, received an average of \$1,340 of Medicare outlays in that same year. By contrast, 10 percent of Medicare beneficiaries with the greatest health care needs averaged \$28,120 in Medicare expenditures in 1993.

As a result, Medicare managed care plans stand to benefit from windfall profits by attracting the healthiest Medicare beneficiaries and receiving inflated payments which reflect the health care expenditures for the most expensive Medicare beneficiaries. Many of the Medicare beneficiaries with conditions that are expensive to treat will likely stay in the fee-for-service program. Because of this, the shift to Medicare managed care may result in higher Medicare program outlays for health services, not savings as are currently

anticipated. In fact, the C.B.O. estimates that savings from managed care will result from lower capitated payments provided to managed care plans, not more effective care.

Medical Underwriting Should Be Prohibited In Medicare Managed Care Plans

Increased numbers of Medicare beneficiaries with significant health care needs will be more likely to join Medicare managed care plans if adequate federal safeguards are established to ensure access and quality to high users of care and to protect against underservice. Two provisions in the House and Senate proposals address the problem of adverse selection in Medicare managed care plans. The current Medicare proposals contain provisions that guarantee issue and renewability of managed care policies to Medicare beneficiaries so that young and healthy enrollees will be less apt to be "cherry picked" by managed care plans. The proposals also provide for risk adjustments to the Medicare managed care premium paid to managed care plans based on the beneficiary's age and other factors, potentially accounting for health status and disability in the amount of the premium paid by Medicare.

Unfortunately, the current version of the Senate bill does not prohibit managed care plans which will service Medicare beneficiaries from charging the beneficiary the difference between the amount the Medicare program will pay for a beneficiary's premium and the cost of a medically underwritten managed care policy for that individual. The House-approved version of the Medicare bill would significantly resolve this problem by requiring Medicare managed care plans to accept the government contribution as the full premium for the individual. If the Senate version prevails in the final budget bill, many people with disabilities will be effectively priced out of the managed care market and have no choice but to remain in the fee-for-service system.

The Medicare proposals maintain the long-standing prohibition against balance billing in the fee-for-service program and in Medicare managed care plans, but the federal prohibition against balance billing will be eliminated for all out-of-network services accessed by Medicare managed care beneficiaries. Balance billing occurs when a

physician or other Medicare provider is allowed to charge the patient directly for the difference between the amount that Medicare pays and the provider's customary fee. This provision will likely lead to increased out-of-pocket expenses for Medicare managed care beneficiaries who access out-of-network services or providers, particularly where there is a lack of competition in the managed care marketplace.

Recommendation No. 7: The National Council on Disability recommends that the premium collected by Medicare managed care plans be limited to the government contribution for the individual beneficiary, adjusted for the age and health status of the enrollee. NCD further recommends that Congress maintain the provisions related to guaranteed issue and renewability of Medicare managed care plans and continue the prohibition against balance billing throughout the Medicare program.

Medical Savings Accounts May Act as a Drain on the Medicare Trust Fund

The House Medicare proposal allows a Medicare beneficiary to establish a Medical Savings Account (MSA) in conjunction with a high deductible catastrophic insurance plan which is intended to increase the Medicare beneficiary's awareness of the price of health services. Medicare would pay the premiums for the catastrophic insurance plan and deposit in the beneficiary's MSA the difference between the average Medicare outlay (per person per year) and the premium for the catastrophic plan.

Medicare beneficiaries would be expected to pay for the cost of health services out of their MSA and their own funds until their annual out-of-pocket expenditures reached a high deductible threshold—probably between \$3,000 to \$10,000—when their catastrophic plan would begin paying for their care. The Medicare MSA option will likely appeal to relatively young and healthy beneficiaries who are currently at low risk of using significant health services. Under the House Medicare proposal, beneficiaries who have funds remaining in their MSAs at the end of the year could use these funds for non-health related purposes, as long as taxes on this income are paid.

From a disability perspective, this proposal could result in a drain of health dollars out of the Medicare Part A Trust Fund at a time when the long term solvency of this Fund is at genuine risk. Establishing MSAs in the Medicare program sets a bad precedent for the private insurance market, where adverse selection becomes a problem for people with disabilities. In the Senate, the Medicare MSA proposal was dropped from the budget bill under the "Byrd" rule because it would have increased the federal deficit by \$3.5 billion over seven years.

Recommendation No. 8: The National Council on Disability recommends that Congress reject Medicare Medical Savings Accounts. If Medicare MSAs are authorized, however, Congress should risk adjust the capitated government contribution toward MSAs and strictly limit the use of MSA funds to health, long-term care, and independent living expenses only.

Quality Assurance in Medicare Managed Care Plans

The Medicare Risk Contract Program currently allows any Medicare beneficiary enrolled in a managed care plan to disenroll from the plan with 30 days notice. This is a key consumer protection for Medicare beneficiaries with disabilities and chronic illnesses. The Medicare proposals eliminate this important protection two years after enactment and only allow disenrollment during an annual open enrollment period.

Another important quality assurance mechanism is the requirement that Medicare managed care plans, particularly closed-panel health maintenance organizations (HMOs), ensure beneficiaries access to out-of-network services through an affordable point-of-service option. A point-of-service option is designed to allow beneficiaries access to out-of-network specialists and other providers when desired by the patient, when the service is a covered benefit under the plan, and when medically appropriate. A problem with the point-of-service option is that it may not be affordable to many of the people who are most likely to need it.

The Senate proposal includes a provision that requires all closed-panel plans serving Medicare beneficiaries to offer a point-of-service option at the time of enrollment. Under the Senate bill, however, the beneficiary could be liable for as much as 100% of the cost of care received outside the managed care network, a major disincentive for accessing out-of-network providers. A point-of-service option must not be allowed to take pressure off the managed care plan to provide appropriate care or pay for the out-of-network referral if the managed care plan cannot provide it. The House bill does not address the point-of-service issue.

Recommendation No. 9: The National Council on Disability recommends that the 30-day disenrollment provision be maintained in order to ensure that Medicare managed care plans provide access, quality, and accountability to all Medicare beneficiaries. In addition, Medicare managed care plans should ensure access to out-of-network providers through an affordable point-of-service option.

Shifting to Managed Care Requires Federal Standards to Ensure Access and Quality

In order to ensure that the shift of large numbers of Medicare and Medicaid beneficiaries into managed care plans does not compromise health care access and quality, minimum federal standards for managed care plans have been considered by Congress, but thus far few of these standards have been included in the Medicare and Medicaid proposals. Examples of these important safeguards can be found in several bills including H.R. 2400, introduced by Congressman Norwood (R-GA) and Congressman Brewster (D-OK); H.R. 2350, introduced by Congressman Coburn (R-OK), and H.R. 2329, introduced by Congressman Brown (D-OH).

The Medicare and Medicaid managed care standards at issue include the disenrollment provision detailed above. Other important safeguards for consumers with disabilities—and the providers who serve them—include requirements that managed care plans establish and maintain consumer and provider due process standards, adequate

grievance and appeals mechanisms for denials of benefits and access to specialists, and utilization management protocols to ensure informed determinations of medical necessity.

Ensuring access to specialty care is a primary concern of people with disabilities in managed care plans. The point-of-service option described above is an effective method of improving access to specialists but additional consumer safeguards are necessary. These safeguards include provisions allowing beneficiaries with disabilities and chronic illnesses to choose a specialist as a primary care "gatekeeper," allowing direct and ongoing access to specialists when medically indicated, ensuring access to centers of specialized treatment expertise, and the prohibition of physician incentive plans that reward physicians for not making referrals to specialists.

Recommendation No. 10: The National Council on Disability recommends the inclusion in the Medicare and Medicaid proposals of federal standards for managed care plans. These standards should address the critical issues of access and quality of care for Medicare and Medicaid beneficiaries with disabilities and chronic illnesses who enroll in managed care plans. Without adequate quality assurance standards, managed care is likely to be discriminatory against people with disabilities in the near term and against all people in managed care over time.

CONCLUSION

NCD encourages Congress and the President to assess in detail the far-reaching impact of the current Medicare and Medicaid proposals on people with disabilities and chronic illnesses. NCD welcomes the opportunity to advise policymakers as to the disability perspective on Medicare and Medicaid issues and provides these recommendations for your consideration.

APPENDIX A: SUMMARY RECOMMENDATIONS

Recommendation No. 1: The National Council on Disability recommends that Congress significantly reduce the level of proposed Medicaid cuts over the next seven years in order to ensure the continued vital assistance that Medicaid provides to people with disabilities.

Recommendation No. 2: The National Council on Disability recommends that Congress retain the current individual federal entitlement to Medicaid and not block grant this vital program to the states. To control the rate of growth in Medicaid spending, options such as a per capita cap on federal Medicaid dollars and incentives for home and community-based care—instead of institutional care—should be considered. The Senate language, which only retains the individual federal entitlement for people with disabilities and other at-risk populations, is a major setback from current law and is only supportable in comparison to the complete elimination of the individual federal Medicaid entitlement as in the House bill. Any significant changes in the Medicaid program should be phased-in to ensure a smooth transition for Medicaid beneficiaries.

Recommendation No. 3: The National Council on Disability recommends that Congress maintain the existing federal private right of action against states to enforce compliance with the Medicaid statute and regulations and to ensure that state Medicaid programs fully comply with the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973.

Recommendation No. 4: The National Council on Disability recommends that Congress include specific provisions in its Medicaid reforms to ensure the active participation of persons with disabilities at every level of decision-making in the Medicaid program.

Recommendation No. 5: The National Council on Disability recommends that federal standards of consumer protection and quality assurance be maintained in Medicaid-funded facilities—such as nursing homes, ICFs-MR, and community-based programs—and in all Medicaid-funded managed care. Managed care should be an “option” and not the only choice for Medicaid beneficiaries with disabilities and should include strong protections for timely and appropriate access to all necessary services, supports, and providers.

Recommendation No. 6: The National Council on Disability recommends a significant reduction in the proposed level of spending cuts to be taken out of the Medicare program in order to maintain access and quality of health care services for people with disabilities.

Recommendation No. 7: The National Council on Disability recommends that the premium collected by Medicare managed care plans be limited to the government contribution for the individual beneficiary, adjusted for the age and health status of the enrollee. NCD further recommends that Congress maintain the provisions related to guaranteed issue and renewability of Medicare managed care plans and continue the prohibition against balance billing throughout the Medicare program.

Recommendation No. 8: The National Council on Disability recommends that Congress reject Medicare Medical Savings Accounts. If Medicare MSAs are authorized, however, Congress should risk adjust the capitated government contribution toward MSAs and strictly limit the use of MSA funds to health, long-term care, and independent living expenses only.

Recommendation No. 9: The National Council on Disability recommends that the 30-day disenrollment provision be maintained in order to ensure that Medicare managed care plans provide access, quality, and accountability to all Medicare beneficiaries. In addition, Medicare managed care plans should ensure access to out-of-network providers through an affordable point-of-service option.

Recommendation No. 10: The National Council on Disability recommends the inclusion in the Medicare and Medicaid proposals of federal standards for managed care plans. These standards should address the critical issues of access and quality of care for Medicare and Medicaid beneficiaries with disabilities and chronic illnesses who enroll in managed care plans. Without adequate quality assurance standards, managed care is likely to be discriminatory against people with disabilities in the near term and against all people in managed care over time.

APPENDIX B: NCD: A BRIEF DESCRIPTION

OVERVIEW AND PURPOSE

NCD is an independent federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

SPECIFIC DUTIES

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; and all statutes and regulations pertaining to federal programs that assist such individuals with disabilities in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities;
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts

on individuals with disabilities, access for health care, and policies that operate as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, the Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing the Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information that NCD or the Congress deems appropriate;
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.);
- Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended;
- Providing advice to the Commissioner with respect to the policies of and conduct of the Rehabilitation Services Administration;
- Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities;

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of NCD to promote the full integration, independence, and productivity of individuals with disabilities;
- Preparing and submitting to the President and the Congress an annual report titled *National Disability Policy: A Progress Report*; and
- Preparing and submitting to the Congress and the President a report containing a summary of the activities and accomplishments of NCD on an annual basis.

CONSUMERS SERVED AND CURRENT ACTIVITIES

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became ADA. Our present list of key issues includes personal assistance services, health care reform, the inclusion of students with disabilities in high-quality programs in typical neighborhood schools, equal employment opportunity, community housing, monitoring the implementation of the Americans with

Disabilities Act, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

STATUTORY HISTORY

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.