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UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY

FAX TRANSMITTAL

TO: Jex Blue

ORGANIZATION: The White House

PHONE NUMBER: 456-2620

FAX NUMBER: 456-2878

FROM: Leslie Thornton, Deputy Chief of Staff and Counselor to the Secretary

PHONE NUMBER: 401-3001

MESSAGE: More real people stories regarding disabled Children.

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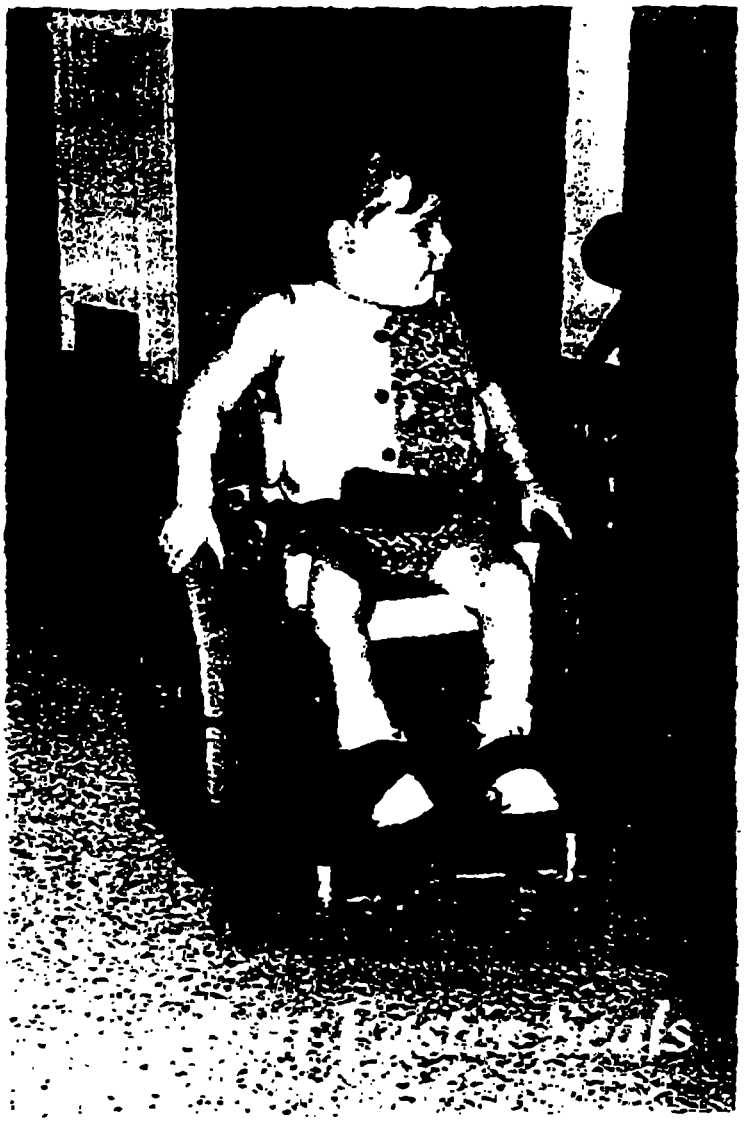
[001]

Lynn A. Sinnott
President
Easter Seal Society of (b)(6)
(b)(6)

Carli – see attached picture

Carli is a bright little girl who has spina bifida and has high paralysis. Both of Carli's parents work and rely on Medicaid to support the services that Carli needs to develop into an independent adult. When she was two years old, she received a wheelchair provided by Easter Seals and Medicaid. This wheelchair has allowed her to navigate her own environment, a major child development milestone. With the use of this wheel chair, Carli began to get into the typical things a two year old wants to do. Easter Seals has provided her with occupational, physical and speech therapies. Her therapies have prevented developmental impairments of her limbs and circulation. They have helped to ensure the growth and density of Carli's long bones and to strengthen her skin and muscles, thereby preventing weak bones and sores.

Carli's wheelchair cost $2500, a price that her family was unable to pay without support from Medicaid and Easter Seals. The Easter Seal Society of (b)(6) (b)(6) receives approximately 12 percent of its budget from Medicaid. Twenty percent of its budget comes from donated funds. Currently the society uses these donated funds to fill in the gaps where Medicaid support does not meet the current needs of the children. In an increasingly competitive climate, the society does not expect to be able to make up the loss of Medicaid funds with donated funds. Without the continued entitlement to Medicaid for children like Carli, the society would have more difficulty in providing essential therapies and assisting families pay for critical devices like wheelchairs.



Susan Boklund
President
Captial Area Easter seal Society
(b)(6)

Dalvenus (b)(6)

"Over the last three years, I have had the privilege to see Dalvenus Choyce make incredible developmental gains. Dalvenus was diagnosed with a seizure disorder. As an infant Dalvenus would seizure to the extent that he would respond to CPR only after several minutes. Fortunately, the seizure disorder today is controlled with medication.

At 18 months of age, Dalvenus would not sit up, crawl or allow food to touch the outside of his mouth and could not communicate. With intensive occupational therapy, physical therapy and speech therapy that he received at the Capital area Easter Seal Society in (b)(6) this energetic three year old boy uses sign language to communicate his basic needs, feeds himself with a spoon, plays with toys appropriately and walks and runs out on our playground. Nothing is stopping Dalvenus.

Important to note that under proposed funding cuts for medicaid, services for Dalvenus would not be funded.

Lea (b)(6)
104 N. Brownleaf Road
(b)(6)

Lea is a 32 year old woman with Multiple Sclerosis (MS). She refereed herself to Easter Seals in June, 1995 and currently receives occupational and physical therapy and counseling assistance from the social worker. She receives both Medicaid and Medicare benefits. Lea lives with her parents.

Lea has a high school diploma and was scheduled to begin post-secondary schooling in 1990 to become an optical apprentice. She was unable to begin school because she required back surgery for a herniated disc. Shortly after the surgery, she was diagnosed with MS. In October 1994, she required surgery to her left leg, after which she spent three months in rehabilitation.

Lea is determined to continue her rehabilitation. Lea' goal is to live independently. The therapy and counseling support she receives will enable her to be more self sufficient, to live on her own, and to secure a job.

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National Easter Seal Society
Office of Public Affairs

1350 New York Avenue N.W., Suite 810
Washington, D.C. 20005
202 347.3066
202 347.7393 (TDD)
202 737.7914 (fax)

[002]

September 27, 1995

The Honorable Robert Dole
141 Hart Senate Office Building
United States Senate
Washington, DC 20510

Dear Senator Dole:

The National Easter Seal Society is deeply concerned that proposed changes to the Medicaid program would diminish and, in many cases, eliminate access to vital services and supports for millions of children and adults with disabilities. Medicaid is a lifeline to low-income Americans of all ages, offering an array of otherwise unattainable services and supports that enhance and extend life.

Easter Seals is dedicated to helping people with disabilities achieve independence, productivity and full participation in society. A nationwide network of 135 Easter Seal affiliates serves over one million people annually, providing home and community-based services, supports and advocacy. A significant share of persons served by Easter Seals rely on Medicaid for essential services.

Easter Seal volunteers and staff are alarmed by the potential ramifications of proposed reforms to Medicaid. They understand that Medicaid makes a critical and positive difference in the lives of people served by Easter Seals. An Easter Seal director shared this story:

Over the last three years, I have had the privilege to see Dalvenus (b)(6) *make incredible developmental gains. Dalvenus was diagnosed with a seizure disorder. As an infant, Dalvenus would experience seizures to the extent that he would respond to CPR only after several minutes. Fortunately, the seizure disorder today is controlled with medication.*

At 18 months of age, Dalvenus would not sit up, crawl or allow food to touch the outside of his mouth. He could not communicate. With intensive occupational therapy, physical therapy and speech therapy that he has received at Easter Seal, this energetic three and a half year old young boy now uses sign language and spoken language to communicate his basic needs, feeds himself with a spoon, plays with toys appropriately, and walks and runs out on the playground. Nothing is stopping Dalvenus. Services for Dalvenus would not be funded should proposed funding cuts and other changes to Medicaid go forward.

Dalvedus' considerable achievements are representative of the experiences of thousands of persons served by Easter Seal societies across the country every day. For these individuals, Medicaid and Easter Seals are essential resources to their ability to realize health, productivity and independence.

As a member of the Consortium for Citizens with Disabilities, the National Easter Seal Society joins the national disability community in support of maintaining the individual entitlement status of Medicaid, adequate program funding, and the preservation of federal oversight protections. Easter Seals prefers adoption of a per capita cap on Medicaid services to a block grant approach, or - at a minimum - assured entitlement to services for children, elderly persons and other vulnerable populations. To this end, the national society urges you to support amendments offered by Senator John Chafee of Rhode Island.

Should Congress opt to transform Medicaid into a block grant and employ a "disability set-aside" to ensure services for people with disabilities, Easter Seals recommends that the set-aside be adequately and realistically funded, reflecting actual spending on services used by persons with disabilities and not just that amount spent on mandatory services from 1992 through 1994.

The national society cautions you against embracing Medicaid reforms that would so limit program spending that service quality, scope of coverage and availability would be ravaged. Leading proposals make no requirement for specific services of importance to people with disabilities, including physical and occupational therapy, case management, and personal care. They would repeal the mandate for EPSDT early intervention services for children, undermine innovative home and community-based waiver programs, and eliminate valuable federal protections for persons living in congregate group, such as nursing homes and ICFs/MR. In the aggregate, these reforms directly and indirectly strip away those Medicaid services and supports most needed by people with disabilities.

The national society urges you to carefully review Medicaid and make policy and process changes that improve program efficiency and effectiveness. Your actions in this debate will significantly affect the lives of 36 million Americans, including millions of people with disabilities who rely on Medicaid for their independence.

Thank you for considering Easter Seals' views.

Sincerely,

Randall L. Rutta

Randall L. Rutta
Vice President, Government Relations

cc: Marie Mareda, President
The Goodwill Industries/Easter Seal Society
of Kansas, Inc.

Give Ability A Chance

National Easter Seal Society
Office of Public Affairs

1350 New York Avenue N.W., Suite 915
Washington, D.C. 20005
202 347.3066
202 347.7385 (TDD)
202 737.7914 (fax)

October 24, 1995

Dear Senator,

The National Easter Seal Society joins its local affiliates in your state and the national disability community in urging you to support a definition of disability for the proposed transformation of the Medicaid program. Senators John Chafee and Kent Conrad intend to offer such an amendment when the budget reconciliation bill is considered by the full Senate this week.

Easter Seals is dedicated to helping people with disabilities achieve independence, productivity and full participation in society. A nationwide network of 135 Easter Seal affiliates serves over one million people annually, providing home and community based services, supports and advocacy. For a significant share of persons served by Easter Seals, Medicaid offers an array of otherwise unattainable services and supports that enhance and extend life.

The Chafee-Conrad amendment will require states to cover in their Medigrant program children and adults with disabilities who receive cash assistance through the Supplemental Security Income (SSI) program, as revised by the Senate's welfare reform bill. As you know, this definition was amended to ensure that only those children with medically determinable physical or mental impairments which result in marked and severe functional limitations are eligible. For adults to be eligible, their disability must be so significant as to prohibit them from working. Even if these very low income individuals could afford the premiums, pre-existing conditions prohibit them from obtaining private insurance.

The National Easter Seal Society is deeply concerned that proposed changes to the Medicaid program would eliminate access to vital services and supports for millions of children and adults with disabilities. At a minimum, states must be directed to provide critical acute and long term services to adults and children with the most significant disabilities as defined by the Supplemental Security Income program.

Thank you for considering Easter Seals' views.

Sincerely,

Randall L. Rutta

Randall L. Rutta
Vice President, Government Relations

cc Chris Jennings
Jen Klein
Fr: Diana Fortuna
I pushed Robyn Stone's staff a little to try to do a memo.

The MEDSTAT Group

Cambridge, Massachusetts

MEMORANDUM

To: Ruth Katz
From: Brian Burwell
Date: October 20, 1995
Re: Data on Disabled Children on Medicaid

As you know, in our disabled children's study using the Medicaid Tape-to-Tape files, we have identified children with severe disabilities on Medicaid using a range of diagnostic and utilization criteria available to us on Medicaid claims. Using these criteria, we developed the following estimates of children with severe disabilities on Medicaid in the four states included in the study.

Children on Medicaid with Severe Disabilities, by State, 1992

State	On SSI	Not on SSI	Total	Ratio
Michigan	22,869	20,233	43,092	1.13
Georgia	23,485	12,049	35,534	1.95
New York[1]	47,501	33,618	81,119	1.71
California	59,577	62,173	121,750	0.96
			Average ratio	1.44

Attachment 1 from the Summer 1995 issue of the Social Security Bulletin indicates that there were 919,500 children on SSI in March of 1995 (this is probably the John Klemm number). However, if we use the average ratio from above to estimate the *total* number of children with severe disabilities on Medicaid, we arrive at an estimate more in the neighborhood of 1.5 million children.[2]

Average Medicaid expenditures per disabled child in 1992 were as follows:

Michigan	$7,152
Georgia	6,141
New York	14,302
California	9,220

If I can be of additional assistance, please let me know.

---

[1] 1991 data

[2] I used a ratio of 1.6 SSI children to non-SSI children, since I am assuming that the ratio increased from 1992 to 1995 due to the high rate of growth in SSI children over the 3-year period.

PEOPLE WITH DISABILITIES AMONG THE HARDEST HIT BY THE REPUBLICAN MEDICARE AND MEDICAID PROPOSALS

- Medicare and Medicaid provide a basic safety net of health and long-term supports to people with disabilities of all ages, including children, people with mental retardation, people with chronic mental illness, people with AIDS and the frail elderly and their families.

  - In 1995, more than six million individuals with some form of disability will be served by Medicaid, and 4.1 million disabled people under age 65 will be served by Medicare.

  - 930,000 children with disabilities are covered under Medicaid.

- In fiscal year 1995, Medicaid payments for people with disabilities totaled $52.8 billion; for the same period Medicare payments for people who are eligible for Medicare because of disability were $18.4 billion.

- Medicaid provides coverage for approximately 734,000 working age adults (age 21-64) with mental retardation or other developmental disabilities (MR/DD). Of these, about 120,000 receive services in intermediate care facilities for the mentally retarded, and 122,000 receive home and community-based services.

- In 1994, total Medicaid spending on ICF/MR services was $9.2 billion; on Home and community-based services (including waivers, personal care, and other optional services)for the MR/DD it was $3.0 billion. **While the MR/DD population is not large, spending for MR/DD long-term care accounts for nearly 10% of all Medicaid spending.**

- People with disabilities are more likely to be low income, use more health and long term care services, and incur higher costs than people without disabilities.

  - because the disabled are less likely to have private health insurance, they are much more likely to use federal assistance--through Medicaid and Medicare--to meet their more extensive health care needs.

cc Chris J.
Nancy-Ann
Jen Klein

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

From
Diana Fortuna

FYI.

(2nd pg. - 1st may have been only odd numbered pages.)

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

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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.

1331 F Street, N.W. ■ Suite 1050 ■ Washington, D.C. 20004-1107
(202) 272-2004 Voice ■ (202) 272-2074 TT ■ (202) 272-2022 Fax

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,

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

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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.

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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.

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

26-Oct-1995 11:26pm

TO: justice

FROM: owner-justice

SUBJECT: FYI: CCD Opposes Medicaid/Medicare Proposals!

CCD Press Releases and Attachments
Thursday, October 26, 1995

Consortium for
Citizens with
Disabilities

CCD HEALTH TASK FORCE CO-CHAIRS:

Peter Thomas (202) 466-6550
Kathy McGinley (202) 785-3388

PRESS STATEMENT FOR IMMEDIATE RELEASE
October 24, 1995

CCD STRONGLY OPPOSES MEDICAID AND MEDICARE PROPOSALS

Washington, D.C. The Consortium for Citizens with Disabilities (CCD), a coalition of over 100 national disability-related organizations, announced today its strong opposition to the Congressional leadership's proposals to "reform" the Medicaid and Medicare programs, two of the most important government programs for children and adults with disabilities and chronic illnesses.

"Some cuts never heal," stated Kathy McGinley, Ph.D. "Congressional leaders would have you think this is merely a budget issue. But the proposed changes in Medicaid will put all children and adults with disabilities on that program at genuine risk of losing their health and long term services and supports, the kinds of services that enable them to live healthy, independent lives in their homes and communities. In short," warned Dr. McGinley, "we could be taking a quantum leap backward to the time when people with disabilities were warehoused in institutions receiving custodial care at best."

"The Medicare proposals are just as threatening to people with disabilities and chronic illnesses," stated Peter W. Thomas, J.D., "when you consider the dismal track record that most managed care plans have in serving enrollees with significant health needs. There are very few federal standards in the Medicare and Medicaid proposals that will protect consumers--and the providers who serve them--in managed care plans." Stated Mr. Thomas, "these proposals will

be a windfall for insurance companies and managed care organizations at the expense of people with disabilities and chronic illnesses and all consumers of health care."

Medicaid

The Congressional leadership proposes to decrease Medicaid spending by $182 billion over seven years by eliminating (in the House) and limiting (in the Senate) the federal entitlement to the program, block granting the program to the states, and capping the federal share to be contributed to the program over the coming years. States would be able to determine their own eligibility criteria and benefit package available under Medicaid, possibly eliminating all mandatory health services currently available to Medicaid-qualified children and adults with disabilities.

The Disability Set-Aside: The House and Senate proposals create a set-aside for people with disabilities where states will be required to spend in the future on this population at least 85% of what they spent in prior years on mandatory services for people with disabilities. This set-aside provision does not require states to consider the amount spent on optional services for this population, the kinds of services most likely to be of critical importance to children and adults with disabilities.

Optional Services Not Counted in Set-Aside Amount: Optional services include rehabilitation therapies and devices, psychological services, prescription drugs, home and community based services, services of Intermediate Care Facilities for persons with Mental Retardation (ICF-MR), personal care services and case management. The proposed funding formula for the disability set-aside, therefore, will vastly underestimate the level of disability services currently provided by states and will likely lead to dramatic reductions in health and long term services and supports for children and adults with disabilities in future years.

Loss of Federal Standards: The House and Senate Medicaid proposals would eliminate all federal standards for nursing homes and ICF-MRs, as well as the minimal requirement that federal funds be spent on active treatment for individuals in institutional settings, rather than merely custodial care. This represents a major setback for vulnerable people with disabilities and for all Americans who one day may reside--or have loved-ones who reside--in these or similar institutions.

A Quantum Leap Backward: CCD asks Congress to recognize the well-warranted and deep-seeded fears of the disability community that the loss of minimum federal standards represents. Coupled with intensifying fiscal pressures, CCD believes that some states will return to institutional-based custodial care with the consequent loss of individual freedom, rights, and quality of life of people with disabilities. This is, of course, if these people with disabilities receive any Medicaid services at all.

Medicare

The Congressional leadership proposes to reduce spending in the Medicare program by $270 billion over the next seven years by shepherding large numbers of beneficiaries into managed care plans, cutting the growth of provider fees, and imposing additional costs on Medicare beneficiaries through increased Medicare Part B premiums and the allowance of balance billing. The Medicare program currently serves the

health care needs of 4.2 million people with disabilities and chronic illnesses below 65 years of age.

The Proposed Level of Medicare Savings Must be Reduced: Gouging an unprecedented $270 billion out of the Medicare program over the next seven years for the purposes of budget balancing and tax cutting is just plain wrong. All beneficiaries, particularly those who remain in the Medicare fee-for-service system will be forced to pay more out-of-pocket for health care services. The rate of growth of provider fees will be sharply reduced, leading to decreases in quality care, health benefits, and access to the provider of one's choice. CCD believes the reduction in the rate of growth of Medicare should be commensurate with the amount needed to strengthen the Medicare Part A Trust Fund, not the amount needed by Congressional leadership for non-medical issues.

Managed Care Often Fails People with Disabilities: Because managed care often reduces costs by limiting access to specialists and treatments, managed care plans often fail people requiring significant health services, particularly people with disabilities and chronic illnesses. CCD supports the Congressional leadership's provisions requiring Medicare

managed care plans to guarantee issue and renewability to all Medicare beneficiaries, but remains deeply concerned with the potential for "cherry picking" and adverse selection through experience-based premium rating.

Because of this problem, CCD believes that insurance companies and managed care organizations may reap windfall profits under the Medicare proposals while more costly beneficiaries stay in the Medicare fee-for-service system. CCD is also concerned that the proposed Fail-Safe and "BELT" mechanisms will only serve to increase the costs of remaining in the Medicare fee-for-service program, thereby eliminating this as a viable option for low and moderate income Medicare beneficiaries.

Federal Standards Needed for Managed Care to Ensure Access and Quality: CCD believes a reasonable response to shifting large numbers of Medicare beneficiaries into managed care plans is the maintenance of existing standards and the creation of additional federal standards that will safeguard the interests of consumers and providers in managed care plans. These standards include consumer and provider due process procedures, grievance and appeals mechanisms to challenge benefit denials, inclusion of a point-of-service option in every managed care plan, ensuring access to specialists, allowing beneficiaries with disabilities to choose specialists as primary care "gatekeepers," and establishing utilization management protocols to ensure informed determinations of medical necessity.

For more information, please see the enclosed position papers on the Medicaid and Medicare proposals or contact one of the Co-Chairs listed on the first page of this release.

Consortium for
Citizens with
Disabilities

CCD HEALTH TASK FORCE CO-CHAIRS:

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CCD Health Task Force Position on Medicare Reform

The CCD Health Task Force, comprised of over sixty-five national disability-related organizations, agrees that aspects of the Medicare program are in need of reform, but strongly opposes key elements of the House and Senate leadership's reform proposals. While Medicare serves the health care needs of nearly 40 million senior citizens, the program also covers 4.2 million people with disabilities below 65 years of age. Coupled with the dramatic dismantling of federal protections in the current Medicaid program, these reforms constitute a serious threat to the health, independence, and dignity of all Americans with disabilities.

Reform for the Wrong Reasons

If Medicare and Medicaid are growing at unsustainable rates of increase, it is largely because the private sector has failed to adequately provide for the health care needs of the populations covered by these programs. In this respect, the Medicare and Medicaid programs represent enormous high risk pools that skew rates of medical inflation in publicly subsidized versus privately funded health programs.

Comparing the growth in Medicare spending to the recent decline in the growth of private insurance spending fails to recognize that the number of Medicare beneficiaries is growing and these persons tend to use more health care services, while employer-sponsored health care is declining and those who are 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.

CCD Supports Medicare Reform for the Right Reasons

The CCD Health Task Force ("CCD") supports constructive change in the Medicare program and acknowledges the importance of fiscal responsibility. Medicare and Medicaid reform should be driven by the goals of enhanced coverage and quality, increased efficiency, decreased waste and abuse, and delivery of benefits that meet the health care needs of the elderly and disabled populations. CCD, however, opposes efforts to dramatically overhaul these programs for the purposes of budget balancing or tax cutting.

CCD's Concerns with the Congressional Leadership's Medicare Reform Proposals

CCD has five major areas of concern that Congress must consider and address if it is to truly protect and strengthen the Medicare program.

1. The Proposed Level of Medicare "Savings" Must be Reduced

Gouging $270 billion out of the Medicare program over the next seven years would represent an unprecedented assault on the stability and effectiveness of the program. 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 House and Senate leadership's proposals. Whether these deep spending reductions are characterized as "cuts" or reductions in the rate of growth, taking this magnitude of resources cut of the health system will most

assuredly cause decreases in quality care, health benefits, and access to necessary medical services.

In order to accomplish these dramatic savings, consumers will spend significantly more for health care than under current law through increased premiums, out-of-pocket expenses and through balance billing. Providers' fees will be sharply restricted, causing significant access and quality concerns for Medicare beneficiaries. Considering the fact that the majority of the proposed savings will not be dedicated to strengthen the Medicare Part A Trust Fund, the argument that these spending reductions are necessary to save and strengthen the Medicare program seem disingenuous.

The Interaction of Medicare and Medicaid: The effort to "reform" Medicare and Medicaid as separate programs fails to recognize the vital interaction of these programs on beneficiaries who are dually eligible. The House and Senate leadership's Medicare plan allows managed care plans to charge beneficiaries for deductibles and co-payments as high as traditional indemnity plans.

An open question remains whether low income Medicare beneficiaries will be able to receive the covered services they need when they cannot afford these deductibles or co-payments. This problem is crucial because the Congressional leadership intends to eliminate the Medicaid entitlement, thereby eliminating the guarantee of subsidies for low income elderly persons who cannot afford Part B premiums, deductibles, or co-payments.

2. Problems with the Managed Care Approach

Choice: Sheperding a greater percentage of Medicare beneficiaries into managed care arrangements and out of the fee-for-services system is a major component of the Congressional leadership's proposed reform. To suggest, however, that Medicare beneficiaries will have more "choice" under the proposed reforms is to fail to acknowledge that the current Medicare program affords unrestricted choice of provider, the type of choice valued most by beneficiaries. Currently, Medicare beneficiaries may choose any provider and/or specialist they wish or can choose to enter into the Medicare risk contract program to receive health care through managed care plans.

Managed Care Often Fails People with Disabilities: As managed care continues to sweep the health care marketplace, dissatisfaction with these plans among people with disabilities and chronic illnesses becomes more and more apparent. Anecdotal and empirical data suggest that most managed care plans do not adequately meet the needs of high users of health care services. CCD believes that many Medicare beneficiaries with significant health conditions will opt to remain in the fee-for-service Medicare program in order to ensure access to appropriate specialty care and to avoid the dangers of underservice which often occurs with this population in managed care plans, particularly in capitated systems.

A Potential Windfall for Managed Care Organizations: CCD believes the costs to the fee-for-service Medicare program will proportionately increase as relatively young and healthy Medicare beneficiaries move to Medicare managed care plans. The average Medicare outlay per beneficiary was $4,020 in 1993, a figure similar to the probable amount that Medicare will pay managed care plans under the proposed system for each person each year. The healthiest 90 percent of Medicare beneficiaries, however, received only $1,340 of Medicare outlays in that same year.

As a result, Medicare managed care plans will have the potential for windfall profits by attracting the healthiest Medicare beneficiaries--and receiving inflated payments which reflect the health care expenditures for the most expensive Medicare beneficiaries, most of which will not enroll in managed care plans. Because of this, the shift to Medicare managed care may result in higher Medicare outlays for health services, not savings as are currently anticipated.

Fee-For-Service Medicare Must Remain a Viable Option: The costs of remaining in the fee-for-service Medicare system must not be so burdensome on beneficiaries as to effectively deny the option to choose between managed care and the traditional fee-for- service system. With burdensome costs in the fee-for-service program, Medicare runs the risk of becoming a two-tiered system, where affluent beneficiaries

will be able to remain in fee-for-service while moderate and low income beneficiaries will be forced into managed care plans.

CCD believes that increased numbers of Medicare beneficiaries with significant health care needs will 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. (See section 5 of this document). CCD strongly supports two provisions in the House and Senate proposals that begin to address CCD's managed care concerns:

CCD supports the guaranteed issue and renewal requirements on all managed care plans servicing Medicare beneficiaries so that young and healthy beneficiaries will be less apt to be "cherry picked" by managed care plans.

CCD supports adjustments in the Medicare managed care premium based on age. CCD suggests that these premiums should also be adjusted based on health states and disability, enhancing the protections against adverse selection.

Medical Savings Accounts Will Drain the Medicare Trust Fund: The House and Senate proposals allow a Medicare beneficiary to establish a Medical Savings Account (MSA) in conjunction with a high deductible catastrophic insurance plan which is designed to increase the Medicare beneficiary's sensitivity to 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 a high deductible--probably between $3,000 to $10,000--out of their MSA and their own funds before the 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 and Senate proposals, beneficiaries who have funds remaining in their MSAs at the end of the year could use these funds for non-medical purposes, as long as taxes on this income are paid.

CCD believe s this proposal will have the profound effect of draining precious medical dollars out of the Medicare Trust Fund at a time when the long term solvency of this Fund is at genuine risk. In fact, the Congressional Budget Office (CBO) estimates that the MSA option would cost the federal government $2.3 billion if only 1% of Medicare beneficiaries choose to establish MSAs. If Congress is to move forward with the establishment of Medicare MSAs, at the very least, it should strictly limit the use of MSA funds to qualified medical expenses only.

3. The "BELT" or "Fail Safe" Provision Could Seriously Harm the Fee-For-Service System

Because the Congressional Budget Office (CBO) recognizes that Medicare's shift to managed care may not be the cost saver that the proposals envision, the Congressional leadership has included a "Fail Safe" or "BELT" mechanism in their plan. This mechanism allows the Secretary of Health and Human Services in future years to review the savings actually achieved-- from the Medicare program (in the Senate) and from Medicare managed care (in the House)--and, if the savings is

less than expected, to further decrease provider fees under the fee-for-service Medicare program.

The Fail Safe/BELT Mechanism is Inequitable: CCD strongly opposes this provision for two primary reasons: It penalizes fee-for-service providers for the failure of managed care plans to achieve the savings they have projected, and it further negatively impacts people with disabilities and chronic illnesses (and the providers who serve them) who remain in the fee-for-service program to avoid underservice in Medicare managed care plans. This again raises grave concerns related to access and quality. High users of care will be effectively forced into managed care plans as their out-of-pocket costs continue to rise and as the number of providers accepting fee-for-service Medicare patients continues to decline.

4. Quality Assurance Must be Maintained

One of the key consumer protections for Medicare beneficiaries with disabilities and chronic illnesses currently enrolled in risk contract managed care plans is the ability to disenroll from the plan with 30-days notice if the beneficiary's health care needs are not being adequately met. The Medicare leadership's reform proposals eliminate this important protection and only allows disenrollment during an annual open enrollment period.

CCD believes the 30-day disenrollment provision must be maintained in order to ensure that Medicare managed care plans provide access, quality, and accountability. At the very least, every Medicare managed care plan should be required to offer an affordable point-of-service option to beneficiaries in order to ensure access to out-of-network services when medically necessary and appropriate

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

The point-of-service option is just one of the many federal standards that managed care plans servicing Medicare and Medicaid beneficiaries should be required to meet. The tradeoff for shifting large numbers of Medicare and Medicaid beneficiaries into managed care plans should be that such plans adhere to certain minimal standards that will safeguard the interests of consumers and the providers who serve them.

Examples of these important safeguards can be found in several pieces of legislation 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). CCD strongly supports application of the provisions of these bills to Medicare and Medicaid managed care plans, particularly the following requirements:

consumer and provider due process standards

adequate grievance and appeals mechanisms for denials of benefits and access to specialists

inclusion of a point-of-service option in every managed care plan

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

prohibition of physician incentive plans that reward physicians for not making referrals to specialists

establishing utilization management protocols to ensure informed determinations of medical necessity

Conclusion

CCD strongly urges Congress to assess in detail the far-reaching impact of the decisions it will make over the next few weeks and months on Medicare and Medicaid issues. We recognize that reform is necessary in both our publicly-supported and employer- based health care programs, but CCD strongly believes that the Medicare and Medicaid proposals offered by the Congressional leadership to date have the potential to devastate the quality of and access to health care services for people with disabilities and chronic illnesses in this country.

For more information on CCD's positions on Medicare, Medicaid, and private insurance reform, please contact Peter W. Thomas (202) 466-6550 or Kathy McGinley (202) 785-3388.

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PRESS STATEMENT FOR IMMEDIATE RELEASE

A MESSAGE TO CONGRESS

Congressional Medicaid Reform Proposals Will Harm Children and Adults with Disabilities and their Families

Member organizations of the Consortium for Citizens with Disabilities Health and Long Term Services Task Forces are extremely concerned about the impact the House and Senate Medicaid reform proposals will have on the lives of children and adults with disabilities and their families. We strongly urge you not to support these proposals and to carefully reconsider how to reform the Medicaid program so that children and adults with disabilities and other individuals with low and very low incomes are not harmed.

The proposals reported out of the House Commerce and Senate Finance Committees make harmful, fundamental changes to the Medicaid program -- a program which now is the largest source of federal and state funding for services and supports for individuals with disabilities. It has been access to

critically needed health and related services and to essential community-based long term services and supports -- provided through the Medicaid program -- that have enabled families to stay together and children and adults with disabilities to live fuller and more productive lives in their communities.

Specific CCD concerns relate to the following issues.

While the Senate proposal maintains a guarantee of health care coverage for low income individuals with disabilities, the House proposal completely eliminates the current individual entitlement status of Medicaid for people with disabilities.

Neither the Senate or House proposals would require states to provide any specific services, except for childhood immunizations.

If Medicaid is no longer an entitlement and if there is no requirement for the provision of a full range of services, people with disabilities will lose access to critical health and long term services and supports. For people with disabilities and serious health conditions, the lack of access to health and health-related services and supports will lead to an exacerbation of existing health problems and/or disabilities, as well as the emergence of additional health problems and secondary disabilities.

For people with long term care needs, the lack of Medicaid coverage will lead to the loss of services and supports that help them to live more independent lives in the community, in some cases leading to homelessness and inappropriate institutionalization. In addition, families of children with disabilities will have their economic security undermined as they try to pay for essential health and long term services. It is important to remember -- especially in a nation where the number of individuals insured through their employer continues to decrease -- that for many people with disabilities, Medicaid has been the only health care coverage available.

The House and Senate proposals include state level set-asides for certain vulnerable populations, i.e. families with pregnant women and children, elderly individuals, and low income people with disabilities under age 65. The proposed funding formula for these set-asides would mean that states could not continue to provide the full range of services and supports that they now provide for children and adults with disabilities.

States would be permitted within these broad categories to determine what services to provide. According to the House proposal, for each set-aside category states would have to spend 85 percent of the average percentage of the state's Medicaid spending from FY 1992 through FY 1994 devoted to mandatory services (what the state now must cover) for people in that category. According to the Senate proposal, for each set-aside category states would have to spend 85 percent of the state s Medicaid spending in FY 1995 on mandatory services for people in that category.

This proposes formula does not take into consideration

spending on optional services (what the state now chooses to cover). For people with disabilities, this is a major blow. Current optional services are the ones most likely to be of critical importance to children and adults with disabilities and

dollars currently spent towards them would not be counted towards the disability set-aside. Optional services include the following: speech, physical, and occupational therapy, psychological services, clinic services, prescription drugs, dental services, eyeglasses, prosthetic devices, rehabilitative services, home and community based services, ICF-MR services, personal care services, respiratory care services, and case management.

In addition to the loss of the personal entitlement to specific required services and the weak funding formula, both the House and Senate proposals eliminate consumer and quality assurance protections and federal oversight in Medicaid services and in Medicaid funded facilities.

This includes the elimination of federal nursing home and ICF/MR regulations and even the minimum requirement that funds be spent on active treatment for individuals in institutional settings rather than merely custodial care. While Congress continues to speak of the value of devolution and state s rights, the CCD remembers when states could not or would not provide needed services and supports for children and adults with disabilities and their families.

There are well warranted and deep-seeded fears in the disability community that the loss of minimum federal standards coupled with intensifying fiscal pressures will me an that some states return to institution-based custodial care with the consequent loss of individual freedom, rights, and quality of life. The public policy and the original intent behind federal oversight requirements currently attached to funding for certain Medicaid long-term services must be remembered and respected. The proposals also permit the states to move more people into managed care plans with very few consumer protections related to access and quality in these plans

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IMPACT OF MEDICAID CUTS ON PEOPLE WITH DISABILITIES

People with disabilities will be among those hit hardest by the Republican Medicaid plans. Medicaid provides a safety net for people with disabilities of all ages -- children, people with mental retardation, people with AIDS, and the frail elderly and their families. Many families, both lower-income and middle class, receive support from Medicaid.

- **More than 6 million people with disabilities are now served by Medicaid, including over 1 million children.**

- **Up to 1.4 million individuals with disabilities could lose Medicaid coverage** under the Republican plans. Losing Medicaid would be particularly devastating to people with disabilities because they are often shut out of the private health insurance market.

- **Medicaid helps families get services at home so that families can stay together.** Without Medicaid services, people with disabilities and parents of children with disabilities may have to give up their jobs or seek institutional placements. Medicaid pays for equipment like wheelchairs and communication devices; therapy, including teaching family members to perform needed therapies at home; respite care for parents who need an occasional break in caring for a disabled child; and home modifications needed to allow a person with a disability to live at home.

- **Medicaid pays for home and community-based services that allow people with disabilities to live in their communities, hold jobs, or go to school.** In addition to services in hospitals and doctors' offices, Medicaid also pays for home and community-based services that allow people with disabilities to live in their communities, hold jobs, or go to school. Such programs have developed over the past 15 years as an alternative to institutions. Prior to that time, an institution was too often the only option for middle-class and low-income people with disabilities.

  Under a Medicaid block grant, home and community-based programs will find it especially hard to compete with hospitals and nursing homes for scarce Medicaid dollars at the state level.

- **States often use Medicaid funding to provide early intervention services for infants and toddlers with disabilities.** Early intervention and therapies for these very young children is critical to maximize what they can later accomplish in school. Under a block grant, states would be under severe pressure to discontinue such services.

- **The Republican plans to block grant Medicaid threaten quality standards at nursing homes and intermediate care facilities for the mentally retarded.** Not that long ago, most people with mental retardation were relegated to large institutions with substandard conditions. Federal standards have greatly improved conditions in institutions and have created a wider range of choices for families, including services at home and in the community.

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

28-Oct-1995 03:37pm

TO: Jennifer L. Klein

FROM: Diana M. Fortuna
Domestic Policy Council

SUBJECT: Here's a one page draft

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- More than 6 million people with disabilities are now served by Medicaid, including over 1 million children. Under the Republican budget proposals, up to 1.4 million individuals with disabilities could lose Medicaid coverage.

- Cuts in Medicaid would be particularly devastating to people with disabilities because they are often shut out of the private health insurance market.

- In addition to services in hospitals and doctors' offices, Medicaid also pays for home and community-based services that allow people with disabilities to live in their communities, hold jobs, or go to school. Such programs have developed over the past 15 years as an alternative to institutions. Prior to that time, an institution was too often the only option for middle-class and low-income people with disabilities.

- Medicaid pays for equipment like wheelchairs and communication devices; therapy, including teaching family members to perform needed therapies at home; respite care for parents who need an occasional break in caring for a disabled child; and home modifications needed to allow a person with a disability to live at home.

- These home and community-based programs would come under particular pressure in states attempting to cope with a Medicaid block grant. They will find it especially hard to compete with hospitals and nursing homes for scarce Medicaid dollars at the state level.

- Without these services, people with disabilities and parents of children with disabilities may have to give up their jobs or seek institutional placements. Medicaid helps families get services at home so that families can stay together.

- States often use Medicaid funding to provide early intervention services for infants and toddlers with disabilities. Early intervention and therapies for these very young children is critical to maximize what they can later accomplish in school. Under a block grant, states would be under severe pressure to discontinue such services.

- Block grants would force states to put people with disabilities in managed care, although neither the public nor

private sector knows how to set adequate payment rates, ensure referrals to specialists, or assure quality for people with disabilities under managed care.

- The block grant proposal threatens quality standards at nursing homes and at intermediate care facilities for the mentally retarded. Not that long ago, most people with mental retardation were relegated to large institutions with substandard conditions. Federal standards have greatly improved conditions in institutions and have created a wider range of choices for families, including services at home and in the community.

No federal enforcement. And doesn't apply to ICFMRs.

PEOPLE WITH DISABILITIES AMONG THE HARDEST HIT BY THE REPUBLICAN MEDICARE AND MEDICAID PROPOSALS

- o Medicare and Medicaid provide a basic safety net of health and long-term supports to people with disabilities of all ages, including children, people with mental retardation, people with chronic mental illness, people with AIDS and the frail elderly and their families.
  - In 1995, more than 6 million individuals with some form of disability will be served by Medicaid, and 4.1 million disabled people under age 65 will be served by Medicare.
  - 930,000 children with disabilities are covered under Medicaid.
- o In fiscal year 1995, Medicaid payments for people with disabilities totaled $52.8 billion; for the same period Medicare payments for people who are eligible for Medicare because of disability were $18.4 billion.
- o Medicaid provides coverage for approximately 734,000 working age adults (age 21-64) with mental retardation or other developmental disabilities (MR/DD). Of these, about 120,000 receive services in intermediate care facilities for the mentally retarded, and 122,000 receive home and community-based services.
- o In 1994, total Medicaid spending on ICF/MR services was $9.2 billion; on Home and community-based services (including waivers, personal care, and other optional services)for the MR/DD it was $3.0 billion. **While the MR/DD population is not large, spending for MR/DD long-term care accounts for nearly 10% of all Medicaid spending.**
- o People with disabilities are more likely to be low income, use more health and long term care services, and incur higher costs than people without disabilities.
  - because the disabled are less likely to have private health insurance, they are much more likely to use federal assistance--through Medicaid and Medicare--to meet their more extensive health care needs.
- o The Republican response to the needs of people with disabilities would have three impacts: access would be compromised; out of pocket burdens would skyrocket; and quality of care would plummet.
- o **Access would be compromised.**

- Medicaid as we know it disappears. Entitlements to basic health care (e.g., physician and hospital services)--**GONE.** Federal eligibility rules which guarantee low income people with disabilities access to Medicaid--**GONE.** Federal involvement in structuring managed care demonstrations to ensure that all Medicaid beneficiaries (including those with disabilities) are protected--**GONE.**

- States may have to ration care--deciding who among the most vulnerable citizens is more "deserving" of help. Even within the disability community, states would have to choose which groups to serve. **Up to 1.4 million individuals with disabilities could lose Medicaid coverage.**

- Community based long-term care services are essential for people with disabilities to be able to live independently. These services would be especially vulnerable as states attempt to cope with huge budget cuts. Years of progress in building home and community-based service systems would be negated. In 1994, over half a million people received home and community-based services, at a cost of $3.8 billion.

- Access to acute care services would decline as well, with more states attempting to preserve precious block grant funds by offering only managed care systems. States would have increased incentives to force disabled people into managed care even though neither the public nor private sector has the experience to set adequate payment rates, arrange and provide appropriate services, or assure quality.

- A $270 billion Medicare cut would disproportionately affect the disabled and chronically ill beneficiaries who are most in need of Medicare covered services.

- The House welfare reform proposal denies SSI cash to over three-fourths of eligible disabled children, but maintains their Medicaid eligibility.

    - In lieu of direct cash benefits, the Personal Responsibility Act establishes a block grant for states to use to cover services for these disabled children--services not otherwise provided under Medicaid. The SSI block grant is based on 75% of the cash benefits that would have been paid to these children.

    - This arrangement, in concert with the incentives created by the House Medicaid block grant proposal, allows states to determine that the needs of disabled children can be met totally by the SSI block grant. Consequently, these children could be cut out of the Medicaid block grant altogether. **In its extreme, it is possible that the total state spending for health and long-term care for children with disabilities could equal three-fourths of the former SSI cash payments to this group.**

o **Out of pocket burden for the disabled would skyrocket.**

- Medicare premiums would increase dramatically and an arbitrary ceiling on program growth would lead to additional cuts of $1700 per person by 2002. The combined burden of these cuts affects people with disabilities disproportionately.

  - These individuals already experience high out of pocket costs, are unable to obtain private insurance, and are more likely to be poor.

- The Medicaid entitlement to nursing home coverage for eligible individuals would disappear; families would be forced to pay all or part of the $38,000 annual cost of nursing home care. Sixty-eight percent of nursing home residents receive assistance from Medicaid.

- Under the Medicaid block grant proposal, states would be allowed to force adult children to pay for their parents' nursing home costs as a condition of receiving some public support.

- To the extent that states are forced to cut home and community-based services, there will be an increase in costs to those who sorely need and heavily rely on these services.

o **Quality of care will Plummet.**

- In lieu of widely heralded federal quality standards governing nursing home care, the lock grant proposal allows each state to set and enforce its own standards, survey rules and payment rates for nursing homes, leading to increased instances of abuse, neglect, and poor quality care.

- Federal ICF/MR standards would no longer apply. The states would be allowed to return to the days of substandard care in the back wards of large institutions for the mentally retarded.

- The Republican response to the needs of people with disabilities would have three impacts: access would be compromised; out of pocket burdens would skyrocket; and quality of care would plummet.

- **Access would be compromised.**

  - Medicaid as we know it disappears. Entitlements to basic health care (e.g., physician and hospital services)--**GONE.** Federal eligibility rules which guarantee low income people with disabilities access to Medicaid--**GONE.** Federal involvement in structuring managed care demonstrations to ensure that all Medicaid beneficiaries (including those with disabilities) are protected--**GONE.**

  - States may have to ration care--deciding who among the most vulnerable citizens is more "deserving" of help. Even within the disability community, states would have to choose which groups to serve. **Up to 1.4 million individuals with disabilities could lose Medicaid coverage.**

  - Community based long-term care services are essential for people with disabilities to be able to live independently. These services would be especially vulnerable as states attempt to cope with huge budget cuts. Years of progress in building home and community-based service systems would be negated. In 1994, over half a million people received home and community-based services, at a cost of $3.8 billion.

  - Access to acute care services would decline as well, with more states attempting to preserve precious block grant funds by offering only managed care systems. States would have increased incentives to force disabled people into managed care even though neither the public nor private sector has the experience to set adequate payment rates, arrange and provide appropriate services, or assure quality.

  - Medicaid funding has enabled a number of other programs to remain viable in their communities--for example, mental health centers,

community health centers, school health programs, and early intervention programs for disabled infants and toddlers. The availability of Medicaid funding has allowed these types of programs to use their otherwise scarce resources to serve people who are not eligible for Medicaid, and to fill in the gaps where needed.

- The coordination of Medicaid funding with the Individuals with Disabilities Education Act (IDEA) program created in 1986 under PL 99-457, has enabled states to provide needed services to disabled infants and toddlers with disabilities. In some cases, Medicaid has contributed more than 50% of the total budget for such state programs. **Severe reductions in Medicaid funding will devastate this and similar community-based programs.**

- A $270 billion Medicare cut would disproportionately affect the disabled and chronically ill beneficiaries who are most in need of Medicare covered services.

- The House welfare reform proposal denies SSI cash to over three-fourths of eligible disabled children, but maintains their Medicaid eligibility.

  - In lieu of direct cash benefits, the Personal Responsibility Act establishes a block grant for states to use to cover services for these disabled children--services not otherwise provided under Medicaid. The SSI block grant is based on 75% of the cash benefits that would have been paid to these children.

  - This arrangement, in concert with the incentives created by the House Medicaid block grant proposal, allows states to determine that the needs of disabled children can be met totally by the SSI block grant. Consequently, these children could be cut out of the Medicaid block grant altogether. **In its extreme, it is possible that the total state spending for health and long-term care for children with disabilities could equal three-fourths of the former SSI cash payments to this group.**

o **Out of pocket burden for the disabled would skyrocket.**

- Medicare premiums would increase dramatically and an arbitrary ceiling on program growth would lead to additional cuts of $1700 per person by 2002. The combined burden of these cuts affects people with disabilities disproportionately.

    - These individuals already experience high out of pocket costs, are unable to obtain private insurance, and are more likely to be poor.

- The Medicaid entitlement to nursing home coverage for eligible individuals would disappear; families would be forced to pay all or part of the $38,000 annual cost of nursing home care. Sixty-eight percent of nursing home residents receive assistance from Medicaid.

- Under the Medicaid block grant proposal, states would be allowed to force adult children to pay for their parents' nursing home costs as a condition of receiving some public support.

- To the extent that states are forced to cut home and community-based services, there will be an increase in costs to those who sorely need and heavily rely on these services.

o **Quality of care will Plummet.**

- In lieu of widely heralded federal quality standards governing nursing home care, the lock grant proposal allows each state to set and enforce its own standards, survey rules and payment rates for nursing homes, leading to increased instances of abuse, neglect, and poor quality care.

- Federal ICF/MR standards would no longer apply. The states would be allowed to return to the days of substandard care in the back wards of large institutions for the mentally retarded.

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY

FAX TRANSMITTAL

TO: Jen Klien

ORGANIZATION: The White House

PHONE NUMBER: 456-7256

FAX NUMBER: 456-2878

FROM: Leslie Thornton, Deputy Chief of Staff and Counselor to the Secretary

PHONE NUMBER: 401-3001

MESSAGE:

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____ **PAGE(S) TO FOLLOW**

Compiled by The Council of the Great City Schools

APPOX. MEDICAID REIMBURSEMENTS for 1994-1995

Baltimore City Public Schools	$ 2.7 million
Buffalo Public Schools	$ 1.4 million
Chicago Public Schools	$ 40+ million
Cleveland Public Schools	$ 642, 000
Columbus Public Schools	$ 1.2 million
Dallas Independent Schools	$ 1.8 million
Detroit Public Schools	$ 4 million
Houston Independent School District	$ 14.9 million
Los Angeles Unified School District	$ 300,000
Las Vegas/Clark City Public Schools	$ 1.3 million
New York City Public Schools	$ 85.2 million (currently received 16.5 million)
Oakland Unified School District	$215,000
Oklahoma City Public Schools	$ 125,000
Philadelphia Public Schools	$ 2.5 million
Pittsburgh Public Schools	$ 300,000
Providence Public Schools	$1 million
San Diego Public Schools	$ 1 million

FREQUENTLY COVERED SERVICES

Direct services provided by the schooldistricts include the following:

1) Occupational Therapy 2) Physical Therapy 3) Nursing 4) Evaluation and Psychological Services
5) Social Work Services 6) Speech Pathology 7) Special Transportation
8) Case Management 9) Hearing Services

Compiled by The Council of the Great City Schools

Valued Donated Services

A good example of in-kind services may be seen through Columbus Public Schools. Columbus has 63,750 students in their district, 34,000 with Medicaid cards, 36,000 on free and reduced lunch, and a 50/50 racial split.

1) Pre-natal program is provided by Grant Medical Center that is part of US Health Corporation outreach program. Geographical locations with high infant-mortality rates have been targeted for services (16-21 deaths per 1000 while the national average is 7.7). This is a team approach where you have the school, student, parent and outside agency working together to provide direct medical service at the targeted schools. Services are provided with parental consent. This is not an abortion clinic, yet rather a wellness baby clinic. This mobile clinic is staffed by the Medical Center and includes a physician, a mid-wife practicioner, a nurse, a dicrician, a drug and alcohol counselor, and a social worker. For example, an ultra-sound examination and counseling would take place in this clinic.

2) Partnerships in Schools provides 14 mental health social workers who provides services in the Columbus Public Schools.

3) The LEAP Program- Learning Earning and Parenting is a program designed to serve and support returning teen mothers to complete their high school education. The Department of Human Service provides this social service within the school. For example, they will assist the linkage with WIC, Healthy Start, and other necessary support services.

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY

FAX TRANSMITTAL

TO: Jon Klein

ORGANIZATION: The White House

PHONE NUMBER: 456-2620

FAX NUMBER: 456-2878

FROM: Leslie Thornton, Deputy Chief of Staff and Counselor to the Secretary

PHONE NUMBER: 401-3001

MESSAGE: Per our discussion. We're also doing "real life" stories for radio target last states.

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9 PAGE(S) TO FOLLOW

TALKING POINTS

IMPACT OF MEDICAID CUTS ON SCHOOLS

The current medicaid entitlement for basic preventative and acute medical services protects some of the most vulnerable populations from arbitrary decisions of Government. Poor children, disabled children and their families are currently entitled to services that allow them to live healthy, independent lives as part of our community. The proposed elimination of this entitlement put them and the agencies that serve them such as schools and community-based organizations in serious risk. The proposed cuts in Medicaid coupled with the elimination of the entitlement for specific services would likely have the following effect on schools and the children they serve:

(1) SCHOOL HEALTH PROGRAMS:

Many schools utilize the Children's Benefit program under Medicaid to support their school health initiatives. The entitlement that poor children have under EPSDT to basic preventative and acute care services is utilized to develop comprehensive programs. Under a block grant states may choose to discontinue these programs. If they do, the health of poor children could deteriorate and these children will not be in an optimal condition to learn.

(2) CONTRIBUTED SERVICES FROM COMMUNITY-BASED ORGANIZATIONS:

Many school districts receive services from community-based organizations such as mental health centers or social service agencies. These agencies in tern bill Medicaid for the services. These "wrap-around" services are often essential to keep kids in school and maximize their learning. These type of agencies will have difficulty competing at the state level for a piece of the block and again kids and schools could lose.

(3) SUPPORT FOR FAMILIES AND THEIR CHILDREN WITH DISABILITIES:

Many families, both poor and middle class, receive support from Medicaid for their disabled children. This includes in-home support, assistance in purchasing equipment like wheel chairs or communication devices as well as various therapies. This enables families to keep their disabled children at home. Without these services some parents may have to give up their jobs or seek institutional placement for their children. We risk returning to the days when these children were warehoused in institutions. Further, there may be pressure on school districts to fund services currently paid for under Medicaid or the residential placements parents may seek if these lose in-home support.

(4) BILLING FOR REIMBURSEMENT FOR RELATED SERVICES:

Many school districts bill Medicaid for related medically-services (occupational therapy, speech therapy, physical therapy, and counseling) provided under the IDEA. These services are mandated by both EPSDT and IDEA. Given the proposed elimination of the entitlement under Medicaid for these services, States are unlikely to continue to support payment for these services and would shift the total burden to local schools. Last year Chicago received 28 million in direct medicaid support for these services.

(5) THE IDEA EARLY INTERVENTION PROGRAM FOR INFANTS AND TODDLERS WITH DISABILITIES:

The Early Intervention program provides important services to infants and toddlers and their families which serve to maximize development during the critical early years. This program is heavily funded by Medicaid in many states with some states funding over 50% of the program under this entitlement. This program could be seriously jeopardized if the entitlement for these services are eliminated and it becomes one of many competing programs for a block.

The Role of Medicaid Funding in the IDEA Part H Program

Since 1986, when Public Law 99-457 was enacted, States have been working intensely to put into the place the early childhood provisions of that legislation. Among other provisions, this law demonstrated the federal government's commitment to assist States in providing early intervention and preschool services to all young children with disabilities. What the lawmakers envisioned was a service system in every State that could respond to a broad range of children and families and offer whatever early intervention, special education, and related services were needed to meet the special needs of eligible children and their families. Importantly, they also envisioned a service system that would be largely created by coordinating already existing services and funding sources, and then expanding the system where necessary by accessing funds available from a variety of government and private sources.

Funds provided through the Part H Program for Infants and Toddlers with Disabilities were intended to be "glue money" (to coordinate and leverage funds and other resources from other sources within a State) and to serve a payor-of-last-resort purpose. Actual payment for most services was to be made from a variety of federal, state, local, and private sources (including Medicaid, federal and state health funds, State education funds, private insurance, parent fees, and local funds).

As States have fully implemented their service systems, the role of Medicaid funds in paying for services has been crucial. In the great majority of States, Medicaid reimbursement for services represents a substantial portion of the total State budget for the Part H program. Indeed, in some States, Medicaid represents over half of the total early intervention budget.

In Arkansas, for example, the total early intervention budget is $11,930,561, of which $7,465,390 (or 62%) is paid for through Medicaid. In South Carolina, Medicaid expenditures for early intervention services was $4,165,204 in FY 1995, which represented about 32% of the total State budget for Part H (approximately $13 million). In Massachusetts, a relatively wealthy State, the total early intervention budget is $44 million, 25% of which ($11 million) is funded through Medicaid reimbursements. New York received $35 Million in Medicaid reimbursement, which constituted 41% of their Part H budget.

As exemplified above, the Medicaid program is a significant source of funds for early intervention services. It is also clear that the use of Medicaid funds for early intervention services varies substantially across States. The reasons for

this variability include (1) the number of children and families in poverty within the State, (2) the number of children and families enrolled in the Medicaid program within the State, and (3) the number and nature of the services that are billable to Medicaid as defined in the State's Medicaid plan.

Given the significance of Medicaid funds in supporting States' early intervention programs, any diminution of these funds or their entitlement provisions would seriously jeopardize the Part H program. In some States, the very existence of the Part H program would be threatened.

Table AH1

Number of Infants and Toddlers Receiving Early Intervention Services December 1, 1994

STATE	0-1	1-2	2-3	BIRTH THROUGH 2 TOTAL	POPULATION	PERCENTAGE OF POPULATION
ALABAMA	247	439	720	1,301	180,511	0.72
ALASKA	67	121	202	390	33,368	1.20
ARIZONA	225	357	689	1,471	205,039	0.72
ARKANSAS	355	595	692	1,642	101,298	1.62
CALIFORNIA	4,122	6,834	8,515	19,471	1,695,405	1.15
COLORADO	780	1,056	1,623	3,459	159,325	2.17
CONNECTICUT	217	808	1,060	1,993	135,560	1.40
DELAWARE	315	448	514	1,277	29,742	4.29
DISTRICT OF COLUMBIA	35	67	102	204	25,881	0.79
FLORIDA	1,424	2,592	3,099	7,115	567,277	1.25
GEORGIA	598	1,122	1,519	3,239	325,946	0.99
HAWAII	1,407	1,259	1,217	3,883	57,239	6.78
IDAHO	157	302	410	869	51,863	1.68
ILLINOIS	985	2,952	4,000	7,937	549,180	1.45
INDIANA	1,004	1,469	1,665	4,138	242,796	1.70
IOWA	92	345	569	1,006	110,452	0.91
KANSAS	171	375	654	1,200	108,749	1.10
KENTUCKY	208	487	641	1,334	155,144	0.86
LOUISIANA	368	901	1,364	2,633	202,451	1.30
MAINE	19	147	189	475	44,431	1.07
MARYLAND	538	1,132	2,104	3,794	223,953	1.68
MASSACHUSETTS	1,650	2,569	3,892	8,114	247,843	3.28
MICHIGAN	599	1,208	1,791	3,598	407,712	0.88
MINNESOTA	392	732	1,443	2,567	190,219	1.35
MISSISSIPPI	47	142	232	422	124,278	0.34
MISSOURI	516	874	932	2,323	221,299	1.05
MONTANA	91	150	241	482	34,218	1.41
NEBRASKA	70	239	427	736	67,659	1.09
NEVADA	134	260	326	720	67,808	1.07
NEW HAMPSHIRE	118	263	411	792	46,419	1.71
NEW JERSEY	333	1,095	1,582	3,010	341,222	0.88
NEW MEXICO	227	500	753	1,480	82,926	1.78
NEW YORK	824	2,583	6,054	9,461	826,290	1.14
NORTH CAROLINA	474	1,316	4,207	5,997	301,036	1.99
NORTH DAKOTA	25	86	89	210	25,071	0.84
OHIO	3,248	5,036	7,777	16,056	462,468	3.47
OKLAHOMA	309	613	765	1,687	141,495	1.19
OREGON	167	411	678	1,256	121,760	1.03
PENNSYLVANIA	984	2,274	3,091	6,349	467,630	1.36
PUERTO RICO	715	1,401	1,067	4,183	.	.
RHODE ISLAND	121	252	428	801	41,973	1.91
SOUTH CAROLINA	233	585	773	1,591	162,918	0.98
SOUTH DAKOTA	46	98	215	359	31,679	1.13
TENNESSEE	1,927	1,001	628	3,156	217,040	1.45
TEXAS	1,515	3,353	4,602	9,470	939,926	1.01
UTAH	383	385	592	1,360	108,425	1.44
VERMONT	33	109	179	314	22,732	1.44
VIRGINIA	480	1,185	421	3,086	279,008	0.75
WASHINGTON	227	693	1,122	2,242	232,222	0.97
WEST VIRGINIA	337	562	639	1,538	64,196	2.40
WISCONSIN	367	1,069	1,885	3,321	204,350	1.63
WYOMING	57	140	226	423	19,230	2.20
AMERICAN SAMOA	8	16	10	35	.	.
GUAM	19	29	86	134	.	.
NORTHERN MARIANAS	2	9	20	31	.	.
BUR. OF INDIAN AFFAIRS	.	.	.	.	.	.
U.S. AND OUTLYING AREAS	28,560	55,358	80,435	165,253	11,704,510	1.41
50 STATES, D.C. & P.R.	29,930	55,204	80,319	165,053	11,704,510	1.41

POPULATION FIGURES ARE JULY ESTIMATES FROM THE BUREAU OF THE CENSUS.

NO CENSUS DATA ARE AVAILABLE FOR OUTLYING AREAS.

PLEASE SEE DATA NOTES FOR AN EXPLANATION OF INDIVIDUAL STATE DIFFERENCES.

DATA AS OF OCTOBER 1, 1995.

SOURCE: AR_AM1.SFW

TALKING POINTS FOR THE FIRST LADY REGARDING MEDICAID CUTS AND CHILDREN WITH DISABILITIES

The most vulnerable children and families effected by cuts in Medicaid are children with disabilities. Currently, over 18 million children under age 21 are enrolled in Medicaid. Approximately 20 percent can be expected to have a physical, mental or developmental problem requiring treatment at some point. About 5 percent are disabled enough to be limited in their normal daily activities.

The children's benefit (EPSDT) within the Medicaid program has given children with disabilities the opportunity to stay at home with their families; to go to school in their neighborhood communities; to avoid further complications related to their disabilities; and to have the supports they need to participate as productive and integral members of society.

Severe cuts to Medicaid have implications for these children and the systems that support them that extends far beyond traditional medical care. For the past 20 years, this country has recognized the importance and benefit of providing a meaningful education to disabled children. This education includes the supports necessary for the child to be able to learn. These supports include (1) therapies, such as physical, occupational, and speech therapies; (2) assistive devices, such as communication devices; and, nursing assistance--- all necessary for the disabled child to be able to stay in school, learn, become employed and participate as active, productive adult citizens.

State education agencies and school districts across the country are benefitting from the financial support that Medicaid provides in meeting the needs of disabled children. Without this continued support, the cost of and responsibility for providing these medical services will become the sole responsibility of state and local school districts.

There are approximately 4.7 million children aged 6-21 receiving special education and related services under the Individuals with Disabilities Education Act. An estimated 1.3 million of these children are receiving health-related services. The current cost to state and local education agencies is approximately $2.2 billion. Because 40 - 60 % of these children have health coverage through Medicaid, state and local educational agencies receive reimbursement from Medicaid for these services.

The following represents data from states on their use of Medicaid to support disabled children in schools:

Louisiana in 1992 received $4.8 M for services provided to disabled children;

Arkansas in 1992 received $1.2 M for services provided to disabled children;

California in 1994, based on a three year research study, projected $300. M in 1st year's billings/payments.

Baltimore County, MD in 1993 received $1.2 M for services provided to disabled children.

Chicago City Schools in 1994 received $28 M in reimbursement for health-related special education expenditures.

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
003. paper	Personal (Partial) (1 page)	n.d.	P6/b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Jennifer Klein
OA/Box Number: 10855

FOLDER TITLE:
Disabled [3]

2014-0209-S
ms734

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]
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b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
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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]

Penny (b)(6)

[003]

The Medicaid Program Its Impact on our Daily Life

Penny (b)(6)

I have eight kids, and for each one, as time has gone on, I've had only two aspirations: A childhood focused on learning, and an adulthood of contribution. Many times during the early years of my son Joseph's life, I feared that our family's resources were too few to make learning, and learning to contribute, a reality for this youngest, as well as for my other, kids. It is a privilege to know and to care for Joseph, who recently turned 17; for every member of our family, having a person with a disability among us has been a joy. However, I believe that we, as a society, must recognize the need to uphold the gifts of persons with disabilities and their families through concrete assistance. Without that assistance, our contributions are lost. The Medicaid waiver program supporting children at risk for institutionalization, called the Katie Beckett waiver, is making our family's contributions possible through a variety of very real and very needed supports, services and equipment.

Although our family had never accessed government assistance for other purposes (other than financial aid for college for my four oldest children), I applied for the Katie Beckett waiver because we can only do so many things in a day; we can only lift so many pounds; we can only afford so many specialized but basic medical gadgets. This year, although we expect our private health insurance policy to pay more than twelve thousand dollars for wheelchair and other aids for Joe, our share of the equipment bill alone would run to many thousands of dollars. The personal care assistance Medicaid pays for is not even available through our private insurance policy.

In the past, this has meant that while other kids in the family were going to the library, Joe stayed home, because his old wheelchair is not sturdy or safe enough to make the eight block trip over the sometimes uneven sidewalks. While other kids were doing their homework, Joe was waiting for me to finish a business call in my kitchen so that he could get his jacket off and start the seemingly endless task of finishing up one day's work to get into bed and start another. And when his siblings wanted to participate in their own right, contributing to their own school and community, they frequently spent their time as the only back-up care available to Joseph.

Joseph himself has maintained a positive attitude through all of this. Interviewed last summer for a documentary featuring Stephen Hawking, Joe was asked how he manages to do what he does in his daily life. He answered, "I just do whatever I can, and I never give up." This amazing contributor wants to work as an attorney in his adult life. His current Medicaid services are making it possible for him to contribute, and to do so with dignity.

The assistance Joseph receives has made an enormous difference in my life, as well. I am now 47 years old. When I learned that we would be getting this much-needed help, I enrolled in a college program to pursue a bachelor's degree in education. I have been able to take a job far from my home, knowing that at the end of my very long day, I would be able to be just a mom to my kids, and not a weight-lifter, a physical therapist, a speech therapist, or a nurse.

My daughter Jane, who used to act as my back-up in managing Joe's care and equipment during the week of October 22 will star in her school play at (b)(6) West High School. She also has joined the speech club and recently spent an entire Saturday at a speech meet. These activities might have come to pass in any case, but all of us would have sacrificed precious energy and focus to make them possible.

Medicaid is making our contributions possible. It is paying a portion of the bills for an orthopedist who is making sure that Joe's back has every chance to stay straight; for a neurologist who will help us watch out for seizures which could seriously complicate Joe's condition; for a rehab physician who can assist Joe on the road to adult independence. Medicaid for kids like Joe is not a luxury, or a waste of anybody's money. It is about the value that we hold, as a nation, for the gifts of the individual, that none may be left behind.

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[004]

MY WHEELCHAIR

By Joe (b)(6)

The first week of school this year, I went with two of my friends on the gravel at school. We were going around the whole field, and we got to a part with sand, we got stuck, and when we were trying to get out, the motor fell off. One of the teachers came and he had to push my old wheelchair out. When we got it back to the sidewalk, it leaked lubricating oil all over the sidewalk. Through a stroke of genius, the teacher figured out how to put the motor back on.

Just about every day, the footplate fell off my wheelchair. The chair is too big for me, and last week the back fell off of the chair when I got to school. The handle fell off because it was broken. The next morning before school started, the repair man came and made the temporary repairs. But he told us that the repairs will not last long.

A few weeks ago, I went to Children's Hospital to get fitted for a new chair. The new chair will have a seat that fits me, a motor and other parts that do not fall off, and will be able to go on the gravel at school. Medicaid paid for the repairs and will pay the amount for the new chair that my health insurance will not pay. That will be almost two thousand dollars. Blue Cross will pay the other $8,000.

EXECUTIVE OFFICE OF THE PRESIDENT

17-Oct-1995 11:14am

TO: (See Below)

FROM: Diana M. Fortuna
Domestic Policy Council

SUBJECT: katie Beckett

Here's what I have learned from HHS about Katie Beckett waivers, but anyone else feel free to correct me.

They were begun in the early 80's to get around the catch-22 that kids could only get Medicaid if they were in institutions. Ronald Reagan got involved in Katie Beckett's case. Originally these waivers were limited to 50 kids, later expanded to 200. States liked them because they could control spending and target them to whatever kids they wanted.

Today they have been more or less superceded by the widespread use of home and community-based waivers, which are more flexible. As far as I can tell, this situation has only gotten better since the early 80's, but clearly states would be under tremendous pressure to cut these programs if the Medicaid cuts go through.

Marilyn, I suspect Katie Beckett's mother might have been complaining about the children's SSI issue rather than this, but I'm not sure.

By the way, whoever does this conference call should also be briefed on the children's SSI issue, since children who are being served by Medicaid home and community-based waivers (assuming that's who is on this call) are very likely on SSI as well. The parents could raise the issue. Depending on the severity of the disabilities, these kids' SSI payments could be affected by the House or Senate proposals. Should I be talking to anyone about this?

Distribution:

TO: Marilyn Yager

CC: Deborah L. Fine
CC: Kenneth S. Apfel
CC: Nancy-Ann E. Min
CC: Jack A. Smalligan

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

19-Oct-1995 07:01pm

TO: Jennifer L. Klein

FROM: Diana M. Fortuna
Domestic Policy Council

SUBJECT: This is a mess, but it's what I wanted for nat'l &

CHILDREN WITH DISABILITIES	PRESIDENT CLINTON'S BALANCED BUDGET	REPUBLICAN CUTS
SSI Benefits Medicaid		Almost one million children with disabilities are on Medicaid. Republican cuts would endanger services that allow children to remain at home with their families rathe than in institutions. Services to ~~165,000~~ infants an toddlers with disabilities are often funded by Medicaid and would be at risk. Early intervention for these very young children is critical to maximize what they can accomplish later in school.
Education	No cuts?	House cuts training, research, and demonstration for special education
Develop-menta l Disabilities	No cuts?	House cuts programs to support people with developmental disabilities, including children, by 47%.

DRAFT

For Under Disabilities

PEOPLE WITH DISABILITIES: AMONG THE HARDEST HIT BY THE REPUBLICAN MEDICARE AND MEDICAID PROPOSALS

- **Medicare and Medicaid provide a basic safety net of health and long-term supports to people with disabilities of all ages, including children, people with mental retardation, people with chronic mental illness, people with AIDS and the frail elderly and their families.**

- **People with disabilities are more likely to be low income, use more health and long-term care services, and incur higher costs than people without disabilities.**

  - Compared to people without disabilities, they are far more likely to depend on federal assistance for health insurance through Medicare and Medicaid.

- **The Republican response to the needs of people with disabilities would have three impacts: access would be compromised; out of pocket burdens would skyrocket; and quality of care would plummet.**

- **Access would be compromised.**

  - Medicaid as we know it disappears. Entitlements to basic health care (e.g., physician and hospital services) - gone. Federal eligibility rules which guarantee low income people with disabilities access to Medicaid - gone. Federal quality standards - gone. Federal involvement in structuring managed care demonstrations to ensure that all Medicaid beneficiaries (including those with disabilities) are protected - gone.

  - States may have to ration care -- deciding who among the most vulnerable citizens is more "deserving" of help. Even within the disability community, states would have to choose which groups to serve.

  - Community based long-term care, highly valued by people with disabilities, would be especially vulnerable as states attempt to cope with huge budget cuts. Years of progress in building home and community based service systems would be negated.

  - Access to acute care services would decline as well, with more states attempting to preserve precious block grant funds by offering only managed care systems. States would have increased incentives to force disabled people into managed care even though neither the public nor private sector has the experience to set adequate payment rates, arrange and provide appropriate services, or assure quality.

  - A $270 billion Medicare cut would disproportionately affect the disabled and chronically ill beneficiaries who are most in need of Medicare covered services.

For example, by ratcheting down Medicare payments for services typically needed by this population (e.g., hospital care, skilled nursing facility care, certain therapies, and home health care), disabled individuals would be less likely to receive the type and amount of services they need.

- **Out of pocket burden for the disabled would skyrocket.**

  - Medicare premiums would increase and a cap on Medicare growth with cuts of $1,700 per person by 2002 would be imposed. The combined burden of these cuts disproportionately affects people with disabilities.

    - These individuals already experience high out of pocket costs, are unable to obtain private insurance, and are more likely to be poor.

  - The Medicaid entitlement to nursing home coverage for eligible individuals would disappear; families would be forced to pay all or part of the $38,000 annual cost of nursing home care. Sixty-eight percent of nursing home residents receive assistance from Medicaid.

  - Under the Medicaid block grant proposal states would even be allowed to force adult children to pay for their parents' nursing home costs as a condition of receiving some public support.

Quality of Care will Plummet

- In lieu of widely heralded federal quality standards governing nursing home care, the block grant proposal allows each state to set and enforce its own standards, survey rules, and payment rates for nursing homes, leading to increased incidences of abuse, neglect, and poor quality care.

- Federal ICF/MR standards would no longer apply. The states would be allowed to return to the days of substandard care in the back wards of large institutions for the mentally retarded.

Medicaid cuts will hurt disabled, advocates say

By Richard Wolf
USA TODAY

Alison Higginbotham can't speak out on behalf of Medicaid. But the little she can do speaks volumes about its benefits to the disabled.

The 7-year-old girl from Opelousas, La., has a rare seizure disorder that keeps her in diapers, functioning at the level of an 18-month-old child. Without Medicaid coverage for medical, nursing and therapeutic services, her mother says, it would be hard to keep Alison out of an institution.

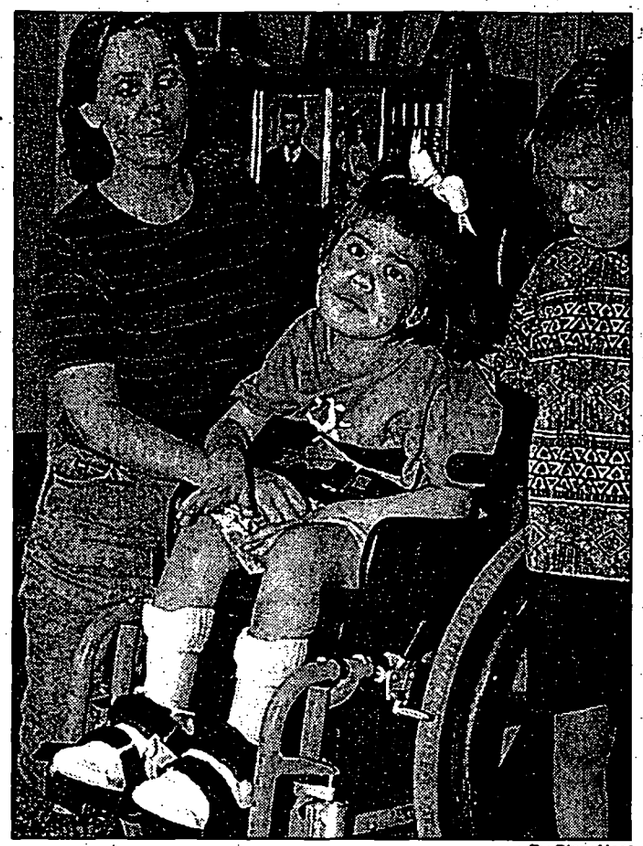
But under a Republican plan to save $182 billion in projected Medicaid spending over seven years, states would be likely to pare back some of the services Alison receives, advocates for the disabled say.

Institutions and intermediate-care facilities for the mentally retarded may not fare much better. Federal standards that led to improved care would be repealed.

"It's legislative manslaughter," says Karen Higginbotham, Alison's mother. Many states will not do what's appropriate.... What's going to happen to the people who depend on this?"

For about 6 million mostly low-income Americans with chronic disabilities, Medicaid is a lifeline, offering the comprehensive health insurance they cannot afford privately.

But to Washington's budget-cutters, Medicaid services for the disabled can seem overly generous: care in the home and community; rehabilitative services; speech, occupational and physical therapies; even the purchase of equipment or communication devices. Advocates of cutting Medicaid note it often surpasses the coverage of private health insurance.



By Stan Alost

LIFELINE: Karen Higginbotham, with daughter Alison, 7, and son Dustin, 6, says without Medicaid Alison may be institutionalized.

Then there is the high price of long-term institutionalization, which includes vocational and transportation services as well as medical care.

"Medicaid is the fastest-growing entitlement of all — a complex, bureaucratic and uncontrolled spending machine, riddled with waste and inefficiency," says House Commerce Committee Chairman Thomas Bliley, R-Va.

The savings that will be needed at the state level if Congress approves the GOP legislation probably would be spread among doctors, hospitals, nursing homes and people who benefit — the elderly, children and pregnant women, as well as the disabled.

But advocates fear the disabled may get caught in the middle. They have less political clout than the powerful elderly lobby, and the cost of their care is far greater than the price tag for pregnant women and children. While the disabled constitute 15% of Medicaid recipients, they account for more than 30% of expenses.

Some of the services — such as health screening, diagnostic testing and treatment for children up to age 21 — are mandated on the states. But many are optional, and advocates for the disabled fear those will be the first to go.

"For a lot of people, it is generous," says Kathy McGinley of the Consortium for Citizens with Disabilities. But the breadth of Medicaid services, she says, "can mean the difference between life and death, between institutional living and freedom, between inactivity and productivity."

Already, states facing budget crunches are cutting back on optional services or putting more Medicaid recipients into managed-care programs that make services harder to get.

That, all sides agree, is the likely way Medicaid cuts would affect the disabled. The cuts would not completely eliminate coverage for a select few, which the Senate plan would not permit, but would reduce services for many.

"Certain kinds of services are going to have to be scaled back, and we're assuming that governors are going to be reluctant to throw people out of nursing homes," says Stephen McConnell of the Alzheimer's Association. "All of the innovation in home and community-based care ... is in jeopardy."

That would hurt families like the Higginbothams, who already have lost state funds that paid for Alison's diapers, some chiropractic services and some hours of skilled baby-sitting relief.

"It's really bad right now," says Karen Higginbotham, whose part-time pay and husband's full-time salary cannot cover Alison's health-care bills. "Families will be forced to place their children in institutions, and the institutions will charge for everything."

Advocates for the disabled, like those for the elderly, also fear that the quality of institutional care would decline if the federal government drops its regulations and leaves standards up to states. Until federal law required "active treatment," many states provided little more than custodial care.

"We fear we may return to that," says Marty Ford of The Arc, which represents the mentally retarded and developmentally disabled. "It will be cheaper, and there will be nobody saying you can't."

Polly Arango has seen that before. For 2½ years her Family Voices, a grass-roots network of families with special-needs children, has battled state legislatures over Medicaid cutbacks and the use of restrictive managed-care plans.

"We already know what's going to happen," Arango says. "But it's just going to happen at a much greater level."

That's what makes Karen Higginbotham nervous about Alison.

"If anything is cut back, it will create hardships financially and physically on us," she says. "I do not ever want to think about having to Alison in an institution."

USA TODAY • WEDNESDAY, OCTOBER 11, 1995

Work copy
IT HAS BEEN SEEN BY THE PRESIDENT HAS SEEN
10/11/95

10-10-95
Todd
Who should get a copy?
Gene Sperling
Jen Klein

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

19-Oct-1995 08:19pm

TO: (See Below)

FROM: Marilyn Yager
Office of Public Liaison

SUBJECT: VPOTUS children's conference call

The Vice President will be doing a disabled children's conference call on Tuesday at 1:15 pm eastern time to kids in the following media markets:

Sioux City, Iowa
Albuquerque, New Mexico
Seattle, WA
Manchester, NH

As you all know, Mrs. Gore's conference call on Monday will be in the following markets:

Denver, CO
Portland, OR
Philly, PA
Baton Rouge, LA
Detroit, MI
Chicago, ILl

Distribution:

TO: Jennifer L. Klein
TO: Jason S. Goldberg
TO: Gene B. Sperling
TO: Lorraine McHugh
TO: Emily Bromberg
TO: Deborah L. Fine
TO: Diana M. Fortuna
TO: Lisa A. Berg
TO: Julia R. Green
TO: Andre Oliver

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

19-Oct-1995 03:53pm

TO: Pauline M. Abernathy
TO: Aaron J. Rappaport
TO: Nancy-Ann E. Min
TO: Lisa B. Fairhall
TO: Jennifer L. Klein

FROM: Diana M. Fortuna
Domestic Policy Council

SUBJECT: Piece on Medicaid for Monday's package

The attached draft is an attempt to add something to Monday's budget package that explains how Medicaid helps kids, especially kids with disabilities, at home and in school. What do you think?

I know least about the school health item; the Department of Education passed on this information to me.

The Department of Education is very nervous about the last bullet, on special education related services. Local school districts are already very mad about the costs of special education mandates, and Education is worried about highlighting this at the same time they are trying to reauthorize the special education program (IDEA). I think my write-up is OK, on balance, but I wonder what Lisa Fairhall of OMB thinks.

Let me know of any concerns/comments.

IMPACT OF MEDICAID CUTS ON
HOME AND SCHOOL-BASED SERVICES TO CHILDREN

In addition to the services that Medicaid provides to children in hospitals and doctor's offices, Medicaid also pays for many other services for children at home and in the schools, especially children with disabilities. These programs would come under particular pressure in states attempting to cope with a Medicaid block grant.

- Infants and Toddlers with Disabilities: The Department of Education funds state efforts to identify infants and toddlers with disabilities and get them into treatment ("Part H"). Early intervention and therapy for these very young children is critical to maximize what they can accomplish later in school. A total of 165,000 infants and toddlers now get help through the Part H program, and many of these services are paid for by Medicaid. For example, Medicaid funds 62% of the Part H program in Arkansas, 32% in South Carolina, 25% in Massachusetts, and 41% in New York State.

  Under a block grant, states would be under severe pressure to discontinue such services.

- School Health Programs: Many schools use Medicaid and other resources to stitch together school health programs, particularly in at-risk neighborhoods. Medicaid's entitlement to basic preventive services for children ("EPSDT") is often used to develop comprehensive health programs. Under a block grant, states may choose to discontinue these programs.

- Support for Families and Children at Home: Many families, both poor and middle class, receive support from Medicaid for their disabled children at home. Such programs have been developed over the past decade as an alternative to placing children in institutions. Medicaid will pay for equipment like wheelchairs or communication devices; therapy, including teaching parents to perform needed therapies at home; respite care for parents who need an occasional break in caring for a disabled child; and home modifications needed to allow a child to live at home.

  Without these services, some parents may have to give up their jobs or seek institutional placement for their children.

- Special Education Related Services: Many school districts bill Medicaid for medically-related services such as speech therapy and physical therapy, to which children are entitled as part of the special education program. If states choose to discontinue Medicaid for these therapies, these costs

would be borne by local school districts.

For state-by-state section:

Add to first paragraph in first section ("Eliminates Medicaid coverage", etc.)

> Medicaid also allows many children with disabilities to live at home with their families.

Add as second bullet to "impact of cuts on Children with Disabilities":

> In addition, many children with disabilities would be at risk of losing Medicaid services that allow them to live at home -- such as equipment like wheelchairs and communication devices, therapy at home, respite care, and home modifications. Without these services, parents may be forced to give up their jobs or seek institutional placement for their children.

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OA/Box Number: 10855

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TO: Debbie Ren
From: Julie Beckett - 319-395-7349 (H) 319-395-7085 (W)
Date 10-19-95

[005]

(b)(6)

Paul (b)(6) - 9 years - CP & medically fragile uses a power wheelchair and augmentative communication. Mom is Sally (b)(6) single parent in graduate school. Waiver eligible, mom very articulate & been very active in a multi disciplin disability group in (b)(6)
(Paul uses a touch talker using a cheek switch to talk)

(b)(6)

Rosemary (b)(6) has two daughter Joy & Alissa. The 15 year old has symptoms mild CP has special assistance in school. She is of African-American heritage. Mom is a part-time receptionist.

(b)(6)

(b)(6)

Alisha (b)(6) has CP requires OT, P.T. hand splint devices for assistance. She's 7 years old & mainstreamed in a public school. Alisha lives with her adopted family. Mom is Susan (b)(6) very articulate. Her family consists of 19 children most are adopted & have special needs.

(b)(6)

(b)(6)

Sharon (b)(6) - African American mom who has 3 children. She is very articulate. I have set tel time to talk directly to her but she is very active in (b)(6) and missing her own support project. Her daughter is the one with special needs.

(b)(6)

(b)(6)

Kristin (b)(6) has many foster children mixed in with her many birth children. Currently the family has 8 kids, 2 of whom have very special needs. Gary 8 mo old with Treacher-Collins syndrome & requires ventilator support & pustule who is 8 who is an adopted child with Clipper-Pile syndrome - MRDD, VA shunt sequelae, visually & hearing impaired but does communicate well.

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[006]

(b)(6) **FAMILY** - Vivian (b)(6) is a single parent who is raising three 14 year old teens with Cerebral Palsy. Ms. (b)(6) is totally responsible for finances for all three of her children. Medicaid has assisted Ms. (b)(6) with wheelchairs, seizures medications, adaptive equipment and medical needs that are not covered elsewhere. Medicaid has allowed Ms. (b)(6) to purchase other items for the teens such as an adaptive bike for gross motor skills and camps for socialization.

BRIAN: Brian is a typical boy who loves to rough and tumble inside and outside. Brian is non-ambulatory and uses a wheelchair to get around. He is non-verbal, legally blind, requires all his self help skills to be met, wears diapers and needs assistance in feeding. Right now Brian is going through alot of frustration that mom thinks is due to him not being able to communicate.

KENNY: Kinny is very aware of his environment and everyone around him He is also non ambulatory, uses a wheelchair, non verbal, legally blind has no use of his hands can not feed himself or play with toys that he needs to pick up. He likes to get up on his knees (a skill he has recently learned) and explore his environment. He understands communication although he can't express his own needs.

CHERYL: Cheryl attends a typical 7th grade middle school classroom in the (b)(6) area. Cheryl, who also has Cerebral Palsy, is ambulatory, has speech and although she is hard to understand she can get her point across. She is outgoing, determine, has a good memory to accomplish tasks through repetition, uses a computer and typewriter to write, and with the help of a Special Education classroom aide is totally included into the classroom.

All the children enjoy sports such as Special Olympics, challenge softball, downhill skiing, swimming and to go to camp.

The Arc of Multnomah County

Advocating for Inclusion of Individuals with developmental disabilities

19 SW 11th Avenue, Suite 234 • Portland OR 97205-2692
hone 503-223-7279 FAX 503-223-1488

FAX

COVER SHEET

O: Debbie Fine Page 1 of 2

ompany The White House

ax No. 202-456-7028 Phone No. _____

rom: Vicki Smead, Manager Child & Family Services

lessage: I apologize for the lateness of this document. We only received the request around 12:00pm Pacific time.

Please let me know if you would like to use this family for the teleconference.

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THE
CHILDREN'S
DEVELOPMENTAL
CENTER

[007]

Oct 19, 1995

Dear Mrs. Gore,

I am writing to give you the name of a precious little girl who receives therapy here. She lives with her grandparents, Delores and Clovis [redacted] Kimberly [redacted] is 4 years old and has cerebral palsy. She also receives Medicaid, which is very important for this family.

Mrs. [redacted]'s phone number is [redacted] She will be home before 10:30 am or after 4:15 pm (the grandmother goes to dialysis M-W-F), & she said she'd love to talk to you. Thank you for anything you can do to help save Medicaid from block granting.

Sincerely,
Janet Ketchum
Director

1805 COLLEGE DRIVE
BATON ROUGE, LA 70808

THE CHILDREN'S DEVELOPMENTAL CENTER
1805 COLLEGE DRIVE
BATON ROUGE, LA 70808
(504) 923-3420 FAX #: (504) 922-9316

Number of Pages: _____ **Date:** 10/19/95 **Time:** _____

To: Debby

Company: White House - Office of Domestic Policy

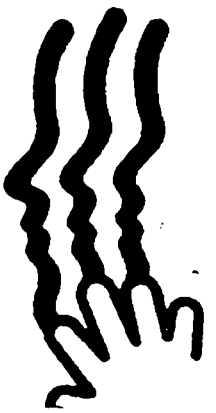
Location: _____

Fax #: (202) 456-7028 **Phone #:** _____

From: Janet Ketchum

Comments: As per your conversation with Becky Ogle, I am sending you the name + phone # of a child with cerebral palsy for Mrs Gore to speak to.

Thank you.



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Penny (b)(6)

Debbie - Got this from Tom Hehir
Right city, good story. Judy Heumann
- Diana

The Medicaid Program Its Impact on our Daily Life

Penny (b)(6)

[008]

I have eight kids, and for each one, as time has gone on, I've had only two aspirations: A childhood focused on learning, and an adulthood of contribution. Many times during the early years of my son Joseph's life, I feared that our family's resources were too few to make learning, and learning to contribute, a reality for this youngest, as well as for my other kids. It is a privilege to know and to care for Joseph, who recently turned 12; for every member of our family, having a person with a disability among us has been a joy. However, I believe that we, as a society, must recognize the need to uphold the gifts of persons with disabilities and their families through concrete assistance. Without that assistance, our contributions are lost. The Medicaid waiver program supporting children at risk for institutionalization, called the Katie Beckett waiver, is making our family's contributions possible through a variety of very real and very needed supports, services and equipment.

Although our family had never accessed government assistance for other purposes (other than financial aid for college for my four oldest children), I applied for the Katie Beckett waiver because we can only do so many things in a day; we can only lift so many pounds; we can only afford so many specialized but basic medical gadgets. This year, although we expect our private health insurance policy to pay more than twelve thousand dollars for wheelchair and other aids for Joe, our share of the equipment bill alone would run to many thousands of dollars. The personal care assistance Medicaid pays for is not even available through our private insurance policy.

In the past, this has meant that while other kids in the family were going to the library, Joe stayed home, because his old wheelchair is not sturdy or safe enough to make the eight block trip over the sometimes uneven sidewalks. While other kids were doing their homework, Joe was waiting for me to finish a business call in my kitchen so that he could get his jacket off and start the seemingly endless task of finishing up one day's work to get into bed and start another. And when his siblings wanted to participate in their own right, contributing to their own school and community, they frequently spent their time as the only back-up care available to Joseph.

Joseph himself has maintained a positive attitude through all of this. Interviewed last summer for a documentary featuring Stephen Hawking, Joe was asked how he manages to do what he does in his daily life. He answered, "I just do whatever I can, and I never give up." This amazing contributor wants to work as an attorney in his adult life. His current Medicaid services are making it possible for him to contribute, and to do so with dignity.

The assistance Joseph receives has made an enormous difference in my life, as well. I am now 47 years old. When I learned that we would be getting this much-needed help, I enrolled in a college program to pursue a bachelor's degree in education. I have been able to take a job far from my home, knowing that at the end of my very long day, I would be able to be just a mom to my kids, and not a weight-lifter, a physical therapist, a speech therapist, or a nurse.

My daughter Jane, who used to act as my back-up in managing Joe's care and equipment, during the week of October 22 will star in her school play at (b)(6) West High School. She also has joined the speech club and recently spent an entire Saturday at a speech meet. These activities might have come to pass in any case, but all of us would have sacrificed precious energy and focus to make them possible.

Medicaid is making our contributions possible. It is paying a portion of the bills for an orthopedist who is making sure that Joe's back has every chance to stay straight; for a neurologist who will help us watch out for seizures which could seriously complicate Joe's condition; for a rehab physician who can assist Joe on the road to adult independence. Medicaid for kids like Joe is not a luxury, or a waste of anybody's money. It is about the value that we hold, as a nation, for the gifts of the individual, that none may be left behind.

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RESTRICTION CODES

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[009]

MY WHEELCHAIR

By Joe (b)(6)

The first week of school this year, I went with two of my friends on the gravel at school. We were going around the whole field, and we got to a part with sand, we got stuck, and when we were trying to get out, the motor fell off. One of the teachers came and he had to push my old wheelchair out. When we got it back to the sidewalk, it leaked lubricating oil all over the sidewalk. Through a stroke of genius, the teacher figured out how to put the motor back on.

Just about every day, the footplate fell off my wheelchair. The chair is too big for me, and last week the back fell off of the chair when I got to school. The handle fell off because it was broken. The next morning before school started, the repair man came and made the temporary repairs. But he told us that the repairs will not last long.

A few weeks ago, I went to Children's Hospital to get fitted for a new chair. The new chair will have a seat that fits me, a motor and other parts that do not fall off, and will be able to go on the gravel at school. Medicaid paid for the repairs and will pay the amount for the new chair that my health insurance will not pay. That will be almost two thousand dollars. Blue Cross will pay the other $8,000.

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THOMAS A. ZIMMERMAN, JR.

[010]

Mr. Zimmerman is a longstanding advocate for people with disabilities.

Currently... He holds a position on the Illinois Planning Council on Developmental Disabilities Speaker's Bureau, centering on mainstream employment for the disabled;

He holds a position as an Illinois State Board of Education Surrogate Parent, concentrating on the educational needs of disabled children; and

He is in the process of forming the Disabled Children's Charities, a non-profit organization focused on the disabled community's integration into independent residential living.

Mr. Zimmerman will be testifying on behalf of Mr. Jason (b)(6) an 18-year-old young man who has been mentally delayed and technology dependent since birth, and who is a Medicaid recipient under the Model Waiver.

TESTIMONY -- 8/24/95

Thank you Dr. Flemming, Senator Moseley-Braun, Representative Durbin, Mr. Bloncado for providing me with the opportunity to testify on behalf of my friend Jason (b)(6) the young man seated here to my right/left. His mother Debra cannot be here today, she is at work. Jason has been mentally delayed and technology dependent since birth, and he is a Medicaid recipient under the DSCC Model Waiver. Jason is 18-years-old, and like many 18-year-olds, he lives at home with his mother.

How are you doing today, Jason? (fine)

The gentleman seated behind Jason is his favorite nurse, Monroe.

The current Federal Medicaid programs offer many benefits to people with disabilities, like Jason. Most of the benefits of the current programs flow from the fact that Jason lives at home with his mother. The DSCC and DORS home services Medicaid Waivers keep the family together.

(a) Debby struggles to earn a living, so she can be with her son every day. If Jason were forced to live in an institution, she could only see him during visiting hours.

Jason, would you like to leave your mother and go live in an institution? (No)

(b) At home, Jason and Debby can:

- play in the park
- go to the zoo, or sporting events
- They can go out to eat

Many of **these** things you or I may take for granted, but they are simply not available in institutional living.

(c) At home, he can go to the school of his choice with his friends, whereas they bring tutors into institutions.

(d) At home, he can work in supported employment positions at companies, side-by-side with co-workers and interacting with customers. And Medicaid pays Monroe to act as Jason's job coach, to help Jason integrate into corporate America. That's not available in an institution.

(e) You see...the Medicaid dollars for in-home services allow Jason to remain part of his community, and I think Jason brings a lot of joy to the people he comes in contact with.

Am I right, Jason? (it's hard to be humble)

(f) There's also DSCC & DORS case management to ensure Jason is receiving the proper services from qualified health care providers, **Ilke Monroe,** who has been with Jason for the past 6 years. That continuity of care ensures stability in Jason's life. Institutions do not provide residents with hiring & firing decisions, and there is no 1-to-1 ratio either...there may be 1 Monroe to care for 5 or 10 Jason's in the institution.

(g) The fiscal beauty is that the cost of providing in-home services to Jason is approx. $15,000/month -v- $55,000/month in an institution. So we're saving just under half-million dollars per year **and** giving Jason a higher quality of life.

Notwithstanding all of these benefits, there are some necessary changes to the current programs that will actually cut costs while improving services:

(a) First, let the families **purchase** the medical supplies, instead of requiring them to rent. It costs $1,000/month to rent 2 ventilators for Jason, whereas it costs $7,000 to **purchase** them. With approx. 50 people on vents in Illinois, that's a cost savings of $600,000/year, **and** the families will own the vents.

(b) Second, eliminate the nursing agency **requirement** under DSCC. Jason's nursing agency **receives** $30/hour, but it only **pays the nurses** $15/hour...the other $15 goes to administrative overhead. If we paid $15/hour directly to the nurses, with approx. 25 people on vents under DSCC, that's a cost savings of $2.25 million/year, **and** the families can hire & fire health care providers, as is done under DORS.

(c) Finally, move as many people as possible out of institutions, and back into their homes and communities. If we moved just 100 people back into their communities in Illinois, that's a cost savings of $48 million/year **and** we're giving them a higher quality of life.

If Medicaid is block granted:

(a) There must be Federal controls to keep some services mandatory... controls on how states have to distribute the money, and to whom... and the states must be required to contribute at least as much money as they did before.

(b) These must be national requirements, so Debby will be able to move to a different state, perhaps in pursuit of a better job for herself, without fear of losing her son.

In conclusion, we've seen Illinois tighten its belt in the Budget Implementation Act of 1996, wherein Illinois has chosen to cut $91 million of Medicaid Optional Services, including cuts in Dental, Vision and Prescription Drugs. If Medicaid funding is cut $182 billion at the Federal level, Illinois may have to further tighten by limiting eligilibility to **both** in-home **and** institutional services...leaving people like Jason with **no** future whatsoever.

SCHNEIDER AND SCHNEIDER, P.C.

1633 N. North Park Avenue
Chicago, IL 60614
Fax No: 642-5810

To: Debbie

Fax: 202-456-7028 Date: 10/19/95

Re: MEDICAID BILL

From: Debby Sloan

No. of Pages: 5 pages including the cover sheet

COMMENTS:

Dear Debbie --

I just received a telephone call from Tom Wilson at Access Living. He said that you were looking for a parent with a child on Medicaid. Jason is currently receiving his services under the "Model Waiver Program". Please call me and I will be happy to explain in detail. A very close family friend, Tom Zimmerman, has been working very closely with me and attending the presentations, due to my work schedule, which is sometimes very difficult for me. Thank you.

Debby

If you do not receive all of the pages, please contact _____ at tel. no. (312) 642-2300.

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[011]

TO: Debbie Fine

FROM: Janet Lonsdale of Parents Union for Public Schools in Phila.

RE: Parent and child with a disability getting services through Medicaid.

DATE: October 19, 1995

Debbie,

The parent who we identified is Elaine (b)(6) Elaine is a single parent of a 14 year old daughter with Cerebral Palsy and a Specific Learning Disability. Elaine works as a special education advocate. Her daughter's name is Alexandria (Alex) and she currently attends a high school program taking a mix of regular education and Special Education classes. Alex receives the following services through Medicaid: braces, bi-monthly occupational therapy evaluation for gait regression, aquatics program, medical, dental and eye care, psycho educational testing and occupational and physical therapy assessments.

Elaine and Alex live at:

1737 W. Bristol Street

(b)(6)

Elaine and Alex can be reached on Monday either at home or at Elaine's workplace. It would be helpful to them to have advance notification to enable Elaine to have Alex home from school.

Thank you so much for your interest.

PARENTS UNION FOR PUBLIC SCHOOLS
IN PHILADELPHIA, INC.
311 S. Juniper Street, Room 602
Philadelphia, PA 19107
(215) 546-1166 (fax 215) 731-1688

Date: 10.19.95

Sent To: Debbie Fine
Fax No. 202-456-7028

Company: 1

Sent From: Janet Lonsdale

No. of Page: 2. (including cover)

Comments: