

FOIA MARKER

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Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: Public Liaison

Series/Staff Member: William White, Jr.

Subseries:

OA/ID Number: 14205

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Folder Title:

Meeting on Budget with Disabilty Groups 12/1

Stack:

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Row:

31

Section:

2

Shelf:

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Position:

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Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. list	Budget Meeting for Disability Groups; RE: Personally Identifiable Information [partial] (1 page)	11/30/0000	b(6)
002. list	Budget Meeting for Disability Groups; RE: Personally Identifiable Information [partial] (1 page)	11/30/0000	b(6)
003. list	Budget Meeting for Disability Groups; RE: Personally Identifiable Information [partial] (1 page)	11/30/0000	b(6)
004. agenda	Budget Debate Meeting; RE: Personally Identifiable Information [partial] (1 page)	12/01/1995	b(6)
005. memo	Debbie Fine for Distribution; RE: Personally Identifiable Information [partial] (1 page)	12/01/1995	b(6)

COLLECTION:

Clinton Presidential Records
Public Liaison
William White, Jr.
OA/Box Number: 14205

FOLDER TITLE:

Meeting on Budget with Disability Groups 12/1

2007-0143-F
db4562

RESTRICTION CODES

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PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

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Hi, I am calling from the White House Domestic Policy Council on behalf of Debbie Fine to invite you to a meeting this Friday, December 1, to discuss the budget debate. The meeting begins at 2:30 pm and should last about one hour.

Please come to the entrance on Pennsylvania Avenue at around 1:45. If you need an accessible entrance, come to the 17th and G street entrance. Bring a photo id.

Get DOB for everyone.

Find out if they need a sign language interpreter (from NAD, SHHH, and Gallaudet)

Invitees for Budget Meeting for Disability Groups

Date: Friday, December 1, 1995

Time: 2:30PM

Room: 180 OEOB

Administration Reps: Chris Jennings, DPC
Jennifer Klein, DPC
Nancy Ann Min, NEC
Diana Fortuna, DPC
Marilyn Yager, OPL
Debbie Fine, DPC/OPL
Bob Jones, OPL

1. CCD

Paul Marchand, Dir of Government Relations
785-3388

Handwritten signature: Marilyn Yager

2. United Cerebral Palsy

Alan Bergman, Director of Government Relations
842-1266
(Substitute: Celane McWhorter)

Handwritten signature: Alan Bergman

3. National Easter Seal Society

Katy Beh Neas
347-3066

4. American Speech Language Hearing Association

Roger Kingsley
301/

5. American Association of Occupational Therapists
Christina Metzler, Sr Leg Rep, Govt Rels Dept
301/652-2682 (or 301/948?-9626 x314 ???)

6. Self Help for the Hard of Hearing
Brenda Battat
301/

7. National Association for the Deaf
Nancy Bloch
301/

8. Gallaudet University
Dr. Roslyn Rosen
202/

9. National Association of People with Aids
Amy Slemmer
898-0414

10. AIDS Action Council
Christina Lubinski, Dpty Director
986-1300 x3046

(sub: Gary Rose, Leg Rep, 986-1300 x3026)

11. Bazelon Center for Mental Health
Rhoda Shulzinger

12. National Council for INdependent Living
Ann Marie Hughey
703/525-3406

13. Epilepsy Foundation
Julie Ward
301/459-3700

Handwritten:
Patty Smith
703/
259 9484

14. National Parent Network on Disability

Patty Smith

703/684-6763

15. American Rehabilitation Association

Tony Young, Director of Residential and Community Support; Govt Rels

789-5700

17. National Mental Health Association

Al Guida

703/

18. Democratic National Committee

Bob Seigny

479-5110

19. American Council of the Blind

Julie Carol, Dir of Government Relations

467-5081

20. American Foundation for the Blind

Scott Marshall, VP of Government Relations

457-1487

21. National Federation for the Blind

James Gashel, Dir of Government Relations

410/659-9314

22. Justin Dart

Equal Access for All

488-7684

23. Peter Thomas

Powers, Pyles, Sutter, & Verville

466-6550

24. Becky Ogle
NAMES
703/836-6263

PVA? Maureen McCloskey

14. National Parent Network on Disability
Patty Smith
703/684-6763

15. American Rehabilitation Association
Tony Young, Director of Residential and Community Support; Govt Rels
789-5700

17. National Mental Health Association
Al Guida, *Alguida*
703/ *684 7722*

18. Democratic National Committee
Bob Seigny
479-5110

19. American Council of the Blind
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703/836-6263

PVA? Maureen McCloskey

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As of Thursday, 11/30, 9:30am

**BUDGET MEETING FOR DISABILITY GROUPS
ATTENDANCE LIST**

<u>Name</u>	<u>Status</u>	<u>Date of Birth</u>
Paul Marchand	Sending Substitutes:	
•Martha Ford	Attending	
•Kathleen McGinley	Attending	
Alan Bergman	Attending	
Katy Beh Neas	Attending	(b)(6)
Roger Kingsley	Attending	
Christina Metzler	Attending	
Brenda Battat	Attending	
Brenda needs an SM or N-frame or a computer assisted real time translator. She does not use sign language. Her number is 301-657-2248 and the Maryland relay number is 1-800-735-2258.		
Nancy Bloch		
Dr. Roslyn Rosen	Sending substitute:	
•Andrew Firth	Attending	
(needs a sign-language interpreter)		
Amy Slemmer	Attending	
Christina Lubinski	Left message	
Rhoda Schulzinger		
Ann Marie Hughey	Attending	
Julie Ward	Attending	
Patty Smith	Attending	(b)(6)
Tony Young	Sending substitute:	
•George D. Krumbhaar	Attending	
Al Guida	Attending	
Bob Sevigny	Attending	
Julie Carol	Attending	
Scott Marshall	Sending substitute:	
•Alan Dinsmore	Attending	
James Gashel	Unable to attend, please fax him any handouts from meeting at 410-685-5653	
Justin Dart	Attending	
Peter Thomas	Attending	
Becky Ogle	Attending	
Maureen McCloskey	Sending substitute:	(b)(6)
•Robert Eastman	Attending	
Rick Schultz	Attending	
Tom Miller	Left message	

(•denotes substitute)

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Meeting on Budget with Disability Groups 12/1

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As of Thursday, 11/30, 3:00pm

**BUDGET MEETING FOR DISABILITY GROUPS
ATTENDANCE LIST**

<u>Name</u>	<u>Status</u>	<u>Date of Birth</u>
Paul Marchand	Sending Substitutes:	
•Martha Ford	Attending	
•Kathleen McGinley	Attending	
Alan Bergman	Attending	
Katy Beh Neas	Attending	(b)(6)
Roger Kingsley	Attending	
Christina Metzler	Attending	
Brenda Battat	Attending	
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Nancy Bloch	Left message	
Dr. Roslyn Rosen	Sending substitute:	
•Andrew Firth	Attending	
(needs a sign-language interpreter)		
Amy Slemmer	Attending	
Christina Lubinski	Left message again	
Rhoda Schulzinger	Sending substitute:	
•Chris Koyanangi	Attending	
Ann Marie Hughey	Attending	
Julie Ward	Attending	
Patty Smith	Attending	(b)(6)
Tony Young	Sending substitute:	
•George D. Krumbhaar	Attending	
Al Guida	Attending	
Bob Sevigny	Attending	
Julie Carol	Attending	
Scott Marshall	Sending substitute:	
•Alan Dinsmore	Attending	
James Gashel	Unable to attend, please fax him any handouts from meeting at 410-685-5653	
Justin Dart	Attending	
Peter Thomas	Attending	
Becky Ogle	Attending	
Maureen McCloskey	Sending substitute:	(b)(6)
•Robert Eastman	Attending	
Rick Schultz	Attending	
Tom Miller	Left message again	

[002]

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Meeting on Budget with Disability Groups 12/1

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As of Wednesday, 11/29, 9:30am

BUDGET MEETING FOR DISABILITY GROUPS
ATTENDANCE LIST

Celane McWhorter

(b)(6)

[003]

Name

Status

Date of Birth

Paul Marchand

Sending Substitutes:

•Martha Ford

Attending

•Kathleen McGinley

Attending

Alan Bergman

Attending

Katy Beh Neas

Attending

Roger Kingsley

Left message

Christina Metzler

Left message

Brenda Battat

Attending

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Nancy Bloch

Sending substitute:

Dr. Roslyn Rosen

Attending

•Andrew Firth

(needs a sign-language interpreter)

Amy Slemmer

Attending

Christina Lubinski

Left message

Ann Marie Hughey

Attending

Julie Ward

Attending

Patty Smith

Attending

Tony Young

Sending substitute:

•George D. Krumbhaar

Attending

Al Guida

Attending

Bob Sevigny

Attending

Julie Carol

Attending

Scott Marshall

Sending substitute:

•Alan Dinsmore

Attending

James Gashel

Unable to attend, please fax him any handouts from meeting at 410-685-5653

Justin Dart

Attending

Peter Thomas

Attending

Becky Ogle

Attending

Maureen McCloskey

Left message

Rick Schultz

Attending

Tom Miller

Left message

Howard Moses

(•denotes substitute)

Constance Ganner

Simon Litvak

Chris Koyanagi

[wee far]

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004. agenda	Budget Debate Meeting; RE: Personally Identifiable Information [partial] (1 page)	12/01/1995	b(6)

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Find out if they need a sign language interpreter (from NAD, SHHH, and Gallaudet)

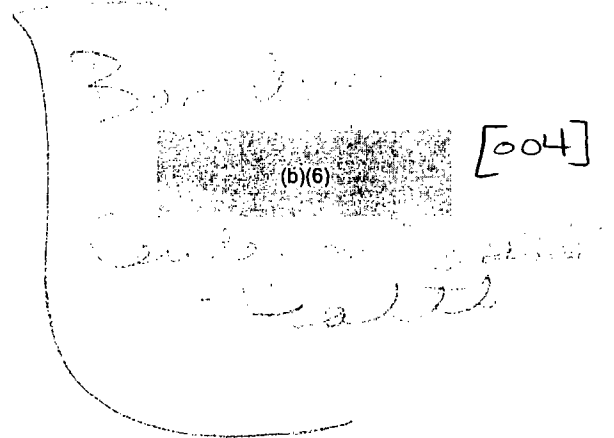
Invitees for Budget Meeting for Disability Groups

Date: Friday, December 1, 1995

Time: 2:30PM

Room: 180 OEOP

Administration Reps: Chris Jennings, DPC
Jennifer Klein, DPC
Nancy Ann Min, NEC
Diana Fortuna, DPC
Marilyn Yager, OPL
Debbie Fine, DPC/OPL
Bob Jones, OPL



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Paul Marchand, Dir of Government Relations
785-3388

2. United Cerebral Palsy

Alan Bergman, Director of Government Relations
842-1266
(Substitute: Celane McWhorter)

3. National Easter Seal Society

Katy Beh Neas
347-3066

4. American Speech Language Hearing Association

Roger Kingsley
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005. memo	Debbie Fine for Distribution; RE: Personally Identifiable Information [partial] (1 page)	12/01/1995	b(6)
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concerning wells [(b)(9) of the FOIA]

→ Sum Litvak
(b)(6)
[005]

December 1, 1995

MEMORANDUM FOR DISTRIBUTION

FROM: Debbie Fine

SUBJECT: Meeting with Disability Groups on the Budget

Date: Friday, December 1, 1995
Time: 2:30 PM
Location: Room 180, OEOB

AGENDA:

- I will welcome participants, open the meeting, and turn it over to Marilyn Yager to moderate.
- Marilyn will make brief remarks.
- Chris will give an overview of the Congressional process and our strategy.
- Nancy Ann will give an overview of where we are substantively with Medicare and Medicaid.
- Marilyn will open for questions on the above until Chris and Nancy Ann need to leave.
- Diana will give an overview on SSI.
- Marilyn will open it up for more questions.

(Please note that Chris and/or Nancy Ann may need to leave this meeting at 3pm. Jennifer, Marilyn and Diana will stay for the whole meeting to answer questions.)

BACKGROUND:

Generally, the disability groups have been very supportive of the President and the leadership he has shown in the past couple of months. They have been active both in Washington and in the states -- I am told by organizers here that the grassroots seem to be more energized now than they have been in some time. One activity to note is a national Save The Health Care Safety Net Day (December 7th) that several constituencies are organizing.

In spite of their support, the current negotiations process makes the groups across constituency very nervous. This is a good opportunity for us to bring in the disability groups to give them an overview of the Congressional process, our strategy, and to brief them on where things are substantively -- particularly with Medicare, Medicaid and SSI. It will also give us an opportunity to hear from them what they are most concerned about, what kinds of activities they are organizing around the country and on the Hill, and with what message.

Attached are the following: a position paper on the Republican Medicare and Medicaid proposals from Consortium of Citizens with Disabilities, and a couple of examples of alerts going out from Justice For All, a disability grassroots network.

Thanks so much for your help.

PARTICIPANTS:

From the White House:

Diana Fortuna
Skila Harris
Chris Jennings
Bob Jones
Jennifer Klein
Nancy-Ann Min
Marilyn Yager

Please note that also sitting in from Department of Education will be Howard Moses and Constance Garner from Judy Heumann's office.

From the Groups:

American Association of Occupational Therapists, Christina Metzler
American Association of University Affiliated Programs, Donna Meltzer
American Council of the Blind, Julie Carol
American Foundation for the Blind, Alan Dinsmore
American Rehabilitation Association, George Krumbhaar
American Speech-Language-Hearing Association, Roger Kingsley
The Arc, Martha Ford
Bazelon Center for Mental Health, Chris Koyanagi
Consortium of Citizens with Disabilities, Kathy McGinley
Disabled American Veterans, Rick Schultz
Democratic National Committee, Bob Sevigny
Epilepsy Foundation, Julie Ward
Gallaudet University, Andrew Firth
Justice For All, Justin Dart (and Becky Ogle)
National Association of Medical Equipment Suppliers, Becky Ogle
National Association of People with AIDS, Amy Slemmer
National Council on Independent Living, Ann Marie Hughey
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National Parent Network on Disability, Patty Smith
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Self Help for the Hard of Hearing, Brenda Battat
United Cerebral Palsey Association, Alan Bergman and Celane McWhorter

54269

Sue Livak, WID
AIDS Action Council
Blinded Veterans
Bob Quinn

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

FOR MORE INFORMATION CONTACT:

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

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 mean 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.

- **The CCD strongly urges you to carefully reconsider how to “reform” the Medicaid program and not to support the passage of the provisions in the Medicaid Transformation Act of 1995 as part of the budget reconciliation bill.**

We ask you not to eviscerate a program that has allowed millions of children and adults with disabilities to live fuller and more productive lives in the community because they now have access to both acute health care and needed long term services and supports. The CCD does not support the status quo on Medicaid. We do believe, however, that there are changes to the program that can be made that will not penalize those who now benefit from the program. These changes include the elimination of the current incentives for institutional care and the provision instead of incentives for home and community-based long term services and supports.

Finally, the CCD supports efforts to reduce the federal deficit. However, the CCD strongly believes that it is unfortunate that most of the programs on the table for deficit reduction are those of importance to children and adults with disabilities, such as Medicaid, children's Supplemental Security Income, housing, social services, jobs, and education. It is also unfortunate that Congress is endeavoring to balance the budget using only 48% of the federal budget and that 48% comes at the expense of programs of critical importance to the lives of people with disabilities.

Summary Recommendations

- **The CCD asserts that the individual entitlement status of Medicaid to a mandated set of benefits for children and adults with disabilities must be maintained.**
- **The CCD asserts that federal reimbursement should be maintained for the full range of acute and long term services and supports that are presently available, including optional services which states now choose to provide through their Medicaid programs. In addition, the states should be required to continue to contribute at least their current share of funds to finance Medicaid services and supports.**
- **The CCD asserts that the federal requirements that states meet certain standards of care and continue appropriate quality assurance measures, as well as due process and other consumer protections must be maintained.**
- **The CCD asserts that managed care should be an “option” and not the only avenue of service for people with disabilities and that strong consumer protections, including timely and appropriate access to all necessary services, supports, and providers must be ensured.**
- **The CCD asserts that current incentives for institutional care built into the Medicaid program must be eliminated and replaced with incentives for the provision of home and community-based long term services and supports.**

For more information, contact the CCD Co-Chairs listed on the first page of this document.

Consortium for Citizens with Disabilities

CCD HEALTH TASK FORCE CO-CHAIRS:

Kathy McGinley (202) 785-3388

Peter Thomas (202) 466-6550

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 out 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: Shepharding 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 status 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 believes 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.

Revised October 23, 1995

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

24-Nov-1995 05:33pm

TO: justice

FROM: owner-justice

SUBJECT: Alert: Budget Battle Escalates!

jdart@tsbbs02.tnet.com

JUSTICE FOR ALL

TRUTH TEAM '95

BECKY OGLE: CHAIR, MARK SMITH: TRUTH TEAM COORDINATOR, 754 NORTH
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* * * * * ALERT!!!

BUDGET BATTLE
ESCALATES!

THE NEXT THREE WEEKS WILL BE DECISIVE.
FLOOD THE MAIL, THE PHONES, THE FAXES,
THE FORUMS, THE MEDIA WITH TRUTH.

To the President:

Congratulations! Hang tough! We are with you!

To the Congress, the Governors and the media:

- A balanced budget, yes! A weakening budget, no!
- No weakening of the federal role in guaranteeing the rights of U.S. citizens to the basic services of civilized society.
- No weakening of federal or state guarantees of Medicaid and Medicare for low income Americans. Strengthen community based long term care and personal assistance services.
- No weakening of the basic educational transportation, job and other services that empower people with and without disabilities to achieve a prosperous, balanced-budget economy.
- No cuts in taxes for the well-to-do. No increases in taxes for low income workers.
- No cuts in SSI benefits for children with disabilities.

CONGRATULATIONS COLLEAGUES! Your messages have made a difference. The President has made Medicaid and disability much more visible in his budget battle dialogue. He has taken a strong stand for principle. He has won apparent pledges from Congress that programs for the poor will not be devastated. The Istook, "Silence America" amendment was defeated. The public seems increasingly aware.

BUT THE CONGRESSIONAL STEAMROLLER ROARS ON. In spite of their pledges to the President and the people, Congressional leaders indicate no intention to modify any of their disastrous tax and program cuts, or any of their transfers of American citizenship rights to the states.

WASHINGTON POST, November 22, "Republican Governors and House Speaker Newt Gingrich vowed today to resist any Clinton administration efforts to impose limits on state discretion in welfare programs during the coming negotiations on a balanced budget."... "Gingrich offered repeated promises that the final version of the seven-year budget, to be hammered out by Dec. 15, will retain virtually unlimited powers for the states to reshape Medicaid and welfare programs when they take over from Washington."

Senator Chafee's effort to include a uniform federal definition of disability for Medicaid eligibility was defeated. Each state will be able to create its own definition. The Istook amendment probably will be brought up again. The ADA and the IDEA continue in danger.

Communicate!

The President *

Your Senators

Your Representative

Your Governor

Senator Bob Dole *

Senator Tom Daschle *

Speaker Newt Gingrich

Rep. Dick Gephardt *

Senator John Chafee *

Senator Bill Frist *

Senator James Jeffords *

Senator Tom Harkin *

Senator Paul Wellstone *

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U.S. Senate

Washington, D.C. 20510

Address For All Representatives:

U.S. House of Representatives

Washington, D.C. 20515

Address For The President:

The White House

Washington, D.C. 20500

* Has earned our thanks.

Advocate as if your life depends on it. It does!
And the lives of your children and grandchildren!/

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

28-Nov-1995 01:38pm

TO: justice

FROM: owner-justice

SUBJECT: FYI: Budget Showdown Update

Justice For All

beckyo@names.org

Budget Showdown Update

The White House and congressional Republican leaders are expected to begin deliberations this week on budget and tax cut issues. There is definitely a shadow of doubt concerning a resolution by both parties, but despite these sentiments both sides will proceed for the time being.

There are two major tasks that have to be completed before December 15th to avert another government shutdown when the short term spending bill expires. First, work needs to be finished on seven of the 13 spending (appropriations) bills for fiscal 1996 or agree to a long term continuing resolution that would keep the government up and running. Beyond that the two parties need to negotiate their way through the 'precarious long-term budget reconciliation' (Medicaid/Medicare....etc.).

What will happen to these negotiations is unknown at this time. Will there be a compromise? Will there be a stalemate of sorts? Some suggest that the differences between priorities of the Clinton Administration and the GOP balanced budget goal are unreachable within a seven year period, and no compromise will be achieved. If that happened, Medicaid, Medicare and others would continue as status quo, but it is reported that President Clinton would work toward an agreement on welfare reform. As priorily mentioned, it is anybody's guess what will happen.

The grassroots message should remain consistent regardless of the mess here in Washington. We should all be stressing that the cuts are too severe to Medicaid, Medicare, education and many others and some cuts never heal.

We support a balanced budget, but oppose a \$245 billion dollar tax cut while attempting to achieve this worthy goal, (According to projections by the Joint Commission on Taxation, Congress's nonpartisan tax analysis group, the GOP plan would lower federal revenue by an average of about \$35 billion annually between 1996 and 2002).

Priorities, principles and morality should be our guide through the labyrinth political battle currently being debated. It is our job and responsibility to raise the debate off the dollar and back to the people where it belongs.

JUSTICE FOR ALL!!!!!!!!!!!!!!!!!!!!!!

Keep up the fantastic grassroots work and we will continue to keep everyone alerted to the developments as they occur.

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

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WASHINGTON WATCH

DEPENDABLE, TIMELY INFORMATION FOR AMERICA'S DISABILITY COMMUNITY

Volume 1, Issue 32

December 5, 1995

Clinton Responds to Disability Community on Medicaid

In response to the thousands of calls to the White House on the potentially devastating impacts of the Congressionally proposed Medicaid block grants, President Clinton has taken a very strong stand regarding the need to continue Medicaid as a national entitlement for people with disabilities. Congratulations to the "grass roots". You are making a difference and need to keep up the pressure.

On November 24th, President Clinton's chief of staff, Leon E. Panetta, sent a letter to Senate Majority Leader Robert Dole, Speaker of the House Newt Gingrich, Senate Budget Committee Chairman Pete Domenici and House Budget Committee Chairman John Kasich listing nine principles *that will have to be addressed to the President's satisfaction before he can sign a balanced budget plan*. This letter was in response to the agreement made by the President in the new Continuing Resolution (CR) that reopened government until December 15th in which the President agreed to a "good faith" effort to balance the federal budget in seven years *if it protects our commitment to health care, education, the environment and tax fairness*.

The letter went on to state:

Ensure adequate funding for Medicaid by:

- *Maintaining Medicaid as a national guarantee of specified and adequate benefits for low income families with children, Americans with disabilities and elderly Americans.*
- *Maintaining the quality of health care received by nursing home residents.*

The President also addressed the needs of people with disabilities who receive Medicare.

Continue Medicare's guarantee of high quality medical care for senior citizens and people with disabilities by ensuring trust fund solvency and protecting beneficiaries.

- *Ensure the viability of the Medicare Trust Fund for at least 10 years.*

- *Protect Medicare beneficiaries from premium increases beyond current law and from programmatic changes that would drive up their overall health costs.*
- *Keep Medicare first-class medical care by ensuring that resources available for each Medicare beneficiary keep pace with growth in private health care costs.*
- *Ensure the viability of hospitals and other critical health care providers in underserved rural and urban areas.*

The President also insisted on maintaining tax fairness with no tax increases on families or individuals with incomes less than \$30,000 a year and to concentrate tax relief on the middle class.

Clinton's strong commitment to people with disabilities is very welcome and must be supported in the coming weeks of negotiations since the few gains which we had achieved in the Senate version of the Medicaid block grant (see *WW* No. 27) were lost in the Senate-House Conference Committee Reconciliation Bill. These losses included the Chafee/Conrad amendment for a national disability definition based on SSI and the Wellstone/Chafee amendment to allow states to provide Medicaid to children with severe disabilities above 250% of the federal poverty level (Katie Beckett). The Medicaid block grant is totally unacceptable to the disability community.

The President, Senate Democrats, and a coalition (Blue Dog) of conservative and moderate House Democrats have been discussing a "per-capita cap" as an alternative to the block grant to reduce Medicaid spending in the future. The per-capita cap is not proposed as a limit on the dollars to be spent on each person but is proposed as a formula by which states will draw down federal funds. *Washington Watch* will keep you apprised as this alternative concept develops.

In the meantime we urge you to use our 800 number to call the White House and thank President Clinton for supporting Americans with disabilities and urge him to hold the line on his demand for a national guarantee of Medicaid benefits to children and adults with disabilities.

UCPA's toll free action line to White House: 800-284-7324
(action line is open from 9:00 am to 5:00 pm Eastern Standard Time)

White House phone number: 202-456-1111

White House fax number: 202-456-2461

Email: president@whitehouse.gov