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Disability Meetings

Stack:	Row:	Section:	Shelf:	Position:
S	29	6	3	2

Disabilities Mtg
7/27
2:45 PM RR
Briefing 2:35 PM
Oval

Briefing

1. ADA enforcement: DPC/HHS working on strategies

2. Health Care Reform: We will include money for home based long term care, although it will be phased in. We will make sure health plans cannot discriminate

3. PAS: - looking at issue in health reform task force
- Nat'l Council on Disabilities will be looking at the non-health related issues of PAS

4. Personnel: - We're very proud of the appointments we've made
- we've got more announcements in the works, and we'll keep working on it

5. ~~Exclusion / lack of~~ Lack of paternalism

6. Jocelyn Elders —

THE WHITE HOUSE

WASHINGTON

JULY 27, 1993

MEETING WITH THE DISABILITY COMMUNITY

DATE: JULY 27, 1993
LOCATION: The Roosevelt Room
TIME: 2:45 PM
From: Marsha Scott

I. PURPOSE

You will meet with Michael Ehman, who has cerebral palsy and Brian Bolokowski, who is blind. Both are students from Chicago's Homewood-Flossmoor High School in the Americans with Disabilities in Action Job Training Partnership Program. You met Michael last Saturday night in the Hotel Washington lobby.

II. BACKGROUND

For the past five weeks, 10 to 15 students at a time have been working in Presidential Correspondence opening and stapling the mail. The program works with young Americans with special disabilities and showcases their employability by producing crafts such as silk floral arrangements and tool boxes. Three of their boutonnieres were aboard the Shuttle Discovery and over 10,000 boutonnieres were used for the Reunion on the Mall. (The First Lady saw some of the students on the Mall and encouraged them to come back to Washington.)

III. PARTICIPANTS

Michael Ehman
Brian Bolokowski

Mike -
Danny omitted
Dominee for
Bobby Simpson.
He has not
yet been
announced.
D

Charge: In testimony before the U.S. Senate Labor and Human Resources Committee in 1990, Dr. Elders said,

> Abortion has had many important and positive, public health effects. Abortion has reduced the number of children afflicted with severe defects; the number of Down's Syndrome infants in Washington State in 1976 was 64 percent lower than it would have been without legal abortion.

Response: In 1990, Dr. Elders testified before the Senate Committee representing the Association of State and Territorial Health Officers (ASTHO). She began her testimony with the statement, "As a state health officer, my primary concern is the health and well-being of the residents of my state. In the 17 years that it has been legal nationwide, abortion has had an important, and positive, public health effect."

Citing the information reflected above, she then focused on the safety factors involved in abortion, including the need to reduce delays in women securing abortions, and the need to ensure that licensing requirements protect the health of the abortion patient. She ended her testimony by stating that, "early abortion is a medically safe procedure. It is an important component of a comprehensive public health strategy to protect and promote the health of women."

Charge: Does her statement about the decrease in the number of Down's Syndrome babies in Washington State mean that she does not value these children?

Response: Dr. Elders has stated, "As a physician, I value all human life." She very much supports these children and their families. As a doctor she has cared for Down's Syndrome children, and she has a beloved Down's Syndrome cousin. She knows that these children are delightful and lovable -- and that they thrive in families who have the resources and wherewithal to care for them.

However, she cited this fact when she was testifying for the Freedom of Choice Act -- and she feel strongly that <u>all</u> parents should have the choice in this instance. Dr. Elders has said, "I am not wise enough, I am not good enough, and I cannot love enough to make this choice for them."

Good morning Senator Metzenbaum, and members of the committee on Labor and Human Resources, I am Joycelyn Elders, director of the Arkansas Department of Health. I am here representing the Association of State and Territorial Officers, the public health concerns and many women in America.

I am pleased to be here to discuss the Freedom of Choice Act (FOCA), which would require states to adopt a very important principle in their regulation of abortion services: This act would allow states to regulate abortion services, buy only in ways that are "medically necessary to protect the life or health of the pregnant woman."

As a state health officer, my primary concern is the health and well-being of the residents of my states. In the 17 years that it has been legal nationwide, abortion has had an important, and positive, public health effect.

- Abortion is extremely safe. Abortion-related deaths have fallen from 17 percent of maternal deaths to almost 3 percent and less than one half of one percent of abortion patients are hospitalized. Abortion is 11 items safer than childbirth and safer than a shot of penicillin.
- More women are having abortions earlier when they are safer. The percent of abortions at or below 8 weeks rose from 20 percent in 1970 to 53 percent in 1985; more than nine in 10 abortions are performed in the first trimester.
- Abortion was the single most important factor in the significant decrease in neonatal mortality between 1964 and 1977; abortion was responsible for a reduction of 1.5 neonatal deaths per 1000 live births among white and 2.5 per 1000 live births among blacks.
- Many families at high risk of genetic defects are willing to become pregnant only because of the option of abortion. Further, abortion has reduced the number of children afflicted with severe defects; the number of Down's syndrome infants in Washington state in 1976 was 64 percent lower than it would have been without legal abortion.

Many types of abortion regulation have been proposed. Some of these proposals appear reasonable and medically necessary at first. In reality, however, many serve no public health purpose. And some even pose a public health threat. Although each proposal differs, many would share a common outcome. Whether by reducing the number of abortion providers, increasing the cost of the procedure, necessitating long-distance travel to receive abortion services or imposing administrative obstacles -- these measures cause delays.

- Delay increases risk. Abortion at 11 or 12 weeks are three times more dangerous for the woman than at or before eight weeks. Risks rises further later in gestation. Morbidity follows same pattern.
- Delay increases cost. Average cost of clinic abortion is $231 at eight weeks but $400 at 16 weeks. Increases costs cause additional delay.
- Delay reduces number of providers. One-third of abortion clinic will not perform abortions after 12 weeks; three-quarters of abortion providers will not perform abortions after 16 weeks. Inability to find providers can cause even further delay.

Most freestanding abortion providers in the United States, according to a 1981 study, are licensed by some state, county or local government. When clinic licensing requirements serve to protect the health of the pregnant woman, they serve a legitimate public health goal. However, not all licensing requirements further such a legitimate purpose.

- Examples (but not an exhaustive list) of state requirements that are designed to protect the health of the abortion patient are:
  - provisions for the licensing and oversight of physicians (State medical boards -- peer-review panels that are charged with ensuring that medical care is delivered safely and in a manner consistent with the standards of the profession -- often have wide latitude to see that unsafe practitioners are unable to practice medicine in a state.);

- written protocol for medical procedures;
- provisions for emergency care in the event of complications such as requiring emergency equipment for such procedures as cardiopulmonary resuscitation, transporting and admitting patients to local hospitals under the care of a physician familiar with abortion care and establishing 24-hour emergency telephone numbers;
- requirements for proper medical screening and health histories of patients; and
- guidelines for basic sanitation.

• Abortions are as safe in clinics as in hospitals. Therefore, licensing requirements that turn clinics into the "functional equivalent of small hospitals" are unnecessary and serve only to increase the cost to the facility, and ultimately the patient. Examples of such unnecessary requirements are those that mandate specific corridor widths, central screening desks, sex-segregated locker rooms and elaborate ventilation systems. No evidence exists that such requirements promote patients' safety.

Waiting periods do little to foster informed decision-making, but do cause serious problems for women by increasing the cost of the abortion and creating delays that raise the health risks of the procedure. This problem is especially acute in rural states such as mine, where women could be forced to travel great distances for an extra visit to the abortion clinic that does nothing to protect her health.

• Women having abortions have thought seriously about their decisions. Patients give an average of four reasons for their abortions. Nine in 10 women consult with at least one other person.

• One study of abortion patients who had complied with a waiting period found that 93 percent were unable to name a single benefit.

- Two-thirds of patients said the waiting period caused problems such as mental anguish, transportation and logistical problems and additional physical discomfort.
- Delay may be much more than 24-48 hours for some women:
  - six percent of abortion patients have to cross state lines
  - one-third of abortion patients cross county lines;
  - 68 percent work and have to arrange additional time off;
  - 42 percent have children and may have to arrange child care; and
  - 31 percent are in school and would miss additional classes

Informed consent is a fundamental principle of medical practice. Unfortunately, the so-called informed consent laws that have been proposed are designed, according to the Supreme Court, "not to inform the woman to obtain her consent but rather to persuade her to withhold it altogether."

- Informed consent requirements are embodied in the basic standards of the medical profession and the organizations to which abortion providers belong. These codes require physicians to tell women about the alternatives to abortion and to obtain informed consent before performing an abortion. There is no health-related justification for additional state informed consent requirements.
- Requirements that mandate a discussion of excessive risks or risks that are not germane to a particular patient serve no legitimate purpose. For example, a discussion either of the risks of a later abortion or of fetal development late in pregnancy is irrelevent to a woman having an abortion at 8 or 9 weeks.
- Provisions are inherently biased if they require only a discussion of the risks of abortion and not the risks of pregnancy and childbirth.

Requirements that all abortions after the first trimester be performed in hospitals serve no public health purpose. According to the CDC, abortions may be performed as safely in non-hospital settings at least until the middle of the

second trimester for women who are not at high-risk. The American College of Obstetrics and Gynecology (ACOG) considers abortions outside of hospitals appropriate during the first 14 weeks of pregnancy.

- Limiting abortions to hospitals would greatly limit access. Less than half of all hospitals in which early abortions are performed will perform abortions after the first trimester. In nine states, no in-hospital, second-trimester abortions were performed in 1985. Locating a hospital provider could result in a substantial delay.
- Because abortions in hospitals are typically two to three times as expensive as abortions in non-hospital settings, a hospital requirement would make abortions much more expensive, even prohibitive to some low-income women, and cause additional delay.

A ban on abortions in public hospitals, even if the woman paid the entire cost of the procedure herself, could easily be written to preclude abortions in virtually any hospital in the nation, since all hospitals have some involvement with government. Such a ban would have a disproportionate effect on low-income women, would make abortions unavailable to some women and cause serious delays.

- Since medical education in this country relies on hospitals, a ban on abortions in hospitals would seriously decrease the number of physicians trained and experienced in performing abortions. Adequate training and experience is closely related to safety.
- Forty percent of women having abortions in hospitals, compared with only 30 percent of patients in clinics, have annual incomes below $11,000. Half of all patients who have abortions in hospitals are members of minority groups, compared with less than one-third of clinic patients.
- A prohibition of abortions in hospitals is tantamount to prohibiting abortions in cases of fetal defect, which almost always are performed in hospitals.

- In one of three U.S. counties with an abortion provider, the only provider is a hospital; in 13 percent, the only provider is a public hospital. Women in these counties would be forced to travel long distances, and probably delay their procedures, or carry their pregnancies to term.

Conclusion:

Early abortion is a medically safe procedure. It is an important component of a comprehensive public health strategy to protect and promote the health of women. The Freedom Of Choice Act takes a balanced approach toward the abortion issue. Appropriately, and necessarily, it places priority on the health of women, which is the standard by which any effort to regulate abortion must be measured.

THE WHITE HOUSE

WASHINGTON

July 27, 1993

MEMORANDUM FOR THE PRESIDENT

FROM: Mike Lux

SUBJECT: Addendum to Briefing for Meeting with Disability Leaders

The following changes have been made on your 2:45 PM meeting with leaders from the disability community. Roy Neel will now begin the meeting at 2:30 PM, following the agenda below. I will brief you at 2:35 PM, and you will join the meeting in the Roosevelt Room at 2:45 PM. You will begin by placing a call to Frank Harkin, Senator Harkin's deaf brother.

You should also note one correction: Bobby Simpson has not yet been announced as Commissioner of the Rehabilitation Services Administration as listed in your briefing. He is currently the head of the Arkansas Rehabilitation Services Administration.

BACKGROUND

On July 26, 1993, TITLE IV of the Americans with Disabilities Act came into effect, requiring that all telephone carriers nationwide provide relay services for customers who are deaf, hard of hearing, or speech impaired. This is facilitated through a Text Telephone device ("TTY" -- the Y has been added to TT to avoid confusion, as TT is short for toilet in conversational American Sign Language.) At the time the ADA was passed, only six states had established relay systems, and even those in existence were not always of high quality.

To demonstrate this communications breakthrough, you will be phoning Senator Harkin's brother Frank, who is deaf, and lives in Cummings, Iowa. You will be phoning Frank Harkin through the Federal Relay System (although the link will have already been made when you enter the Roosevelt Room.) There will be an operator translating your speech into text, and then translating Mr. Harkin's answer when it is received back. This process causes a delay effect - much like consecutive translation with a foreign Head of State - so it is important to pace yourself carefully. When you make a statement, the operator types the

statement into the TTY device, which then displays the statement for Mr. Harkin. He will then write out his response, which will then be read back to you. Since this conversation will take place over speaker-phone, it will provide a graphic demonstration of how convenient it now is to communicate with hearing or speech impaired persons.

SEQUENCE OF EVENTS

- Roy Neel opens the meeting

- Introduction of all Presidential appointees with disabilities who are in attendance; introduction of Senator Harkin and Congressman Hoyer.

- Kathy Way from Domestic Policy Council will make remarks on Domestic Policy Council's work on disability policy; there will be questions and answers until the President arrives.

- The President arrives and makes the call to Frank Harkin.

- The President ends call and makes opening remarks.

- Presentation by several members of the disability community.

- The President makes closing remarks and departs.

- Roy Neel thanks people for coming and closes the meeting.

Pat Wright
Ed Smith
Marca Bristo
Bob Williams
Mike Auberger
(Paul Marchand)

Consortium for Citizens with Disabilities

June 14, 1993

Dear Senator,

As you prepare to finalize the FY 1994 reconciliation bill, the undersigned member organizations of the Consortium for Citizens with Disabilities call your attention to the impact of your decisions on persons with disabilities and their families. The CCD clearly recognizes the difficult choices facing you as you seek to reduce the deficit, invigorate the economy and maintain and expand critical programs. We also realize that persons with disabilities and their families, like all Americans, must be willing to sacrifice to produce a sound economy and a strong nation. However, the CCD is greatly concerned that people with disabilities, who comprise one of our country's most vulnerable populations, may be forced to bear a disproportionate burden to achieve our economic goals.

For millions of people with disabilities, Medicaid and Medicare provide desperately needed health care, as well as financing living environments, in either community-based or institutional settings. As we understand a number of Senate proposals within the reconciliation bill, these vital health care and residential supports are the targets for substantial cuts beyond the House-passed bill which already cuts them by more than $50 billion.

We find it incredible that poor people with disabilities continue to bear the brunt of deficit reduction rather than asking all Americans to share the burden through equitable and progressive changes in tax policy. On behalf of the tens of millions of citizens with disabilities in our country, we urge you to be fair to these people. We strongly oppose and urge you to reject any cap on entitlements or further cuts to Medicaid and recipient-based benefit reductions to Medicare.

(continued)

On behalf of

American Association of University Affiliated Programs
American Association on Mental Retardation
American Council of the Blind
American Foundation for the Blind
American Speech-Language-Hearing Association
Bazelon Center for Mental Health Law
Child Welfare League of America
Council for Exceptional Children
Epilepsy Foundation of America
Goodwill Industries of American, Inc.
Learning Disabilities Association
National Association of Developmental Disabilities Councils
National Association of Private Residential Resources
National Association of Protection and Advocacy Systems
National Association of Rehabilitation Facilities
National Council of Community Mental Health Centers
National Easter Seal Society
National Head Injury Foundation
National Parent Network on Disabilities
NISH
The Arc
The Association for Persons with Severe Handicaps
United Cerebral Palsy Association, Inc.

The Arc

ACTION ALERT

U.S. SENATE STARTS WORK ON FY 1994 RECONCILIATION BILL

Governmental Affairs Office, 1522 K Street, N.W., Suite 516, Washington, D.C. 20005
(202)785-3388 / FAX (202)467-4179 / TDD (202)785-3411

June 8, 1993

Following its narrow approval in the U. S. House of Representatives, the FY 1994 Reconciliation bill faces very tough sledding in the Senate. Substantial opposition to the House bill (H.R. 2264) has surfaced from Senate conservatives and those from states particularly affected by the bill's energy related tax increases. An alternative to H.R. 2264 has been offered by Senator David Boren (D-OK) that would significantly reduce energy related and other revenue raising provisions, replacing these revenues with huge cuts ($114 billion over 5 years) in human services spending. Most of these reductions would come from capping or cutting entitlements such as Medicaid and Medicare. More savings would be secured by reducing Social Security cost-of-living increases.

Clearly, the Boren plan would place a significant burden on deficit reduction on persons with mental retardation who are Social Security recipients and/or received their health care from Medicaid or Medicare.

It is critical that the Senate Finance Committee hear from the disability community within the next week, urging the committee not to cap or make further cuts to Medicaid or Medicare in order to help balance the federal budget. President Clinton's Economic Plan, as embodied in H.R. 2264, would already reduce Medicaid and Medicare spending by $56 billion over 5 years. These cuts are difficult for the disability community to bear, but would be more fair than the punitive Boren approach.

Please contact each and every member of the Senate Finance Committee, particularly any from your state, urging them to:

- Reject the Boren approach to deficit reduction which will greatly jeopardize the lives of hundreds of thousands of persons with mental retardation and other disabilities.
- Reject any approach which caps Medicaid or Medicare.
- Reject any approach which reduces Social Security cost-of-living increases.
- Reject any approach which reduces new tax revenues by further slashing programs and benefits which serve people with mental retardation and other disabilities.

Attached is a list of the Senate Finance Committee members with their addresses. Please write, fax or call them within the next 7 days. Your message is critical to avoid drastic and harmful reductions to vital disability programs.

103RD CONGRESS SENATE FINANCE COMMITTEE

MAJORITY (DEMOCRATS)

Daniel P. Moynihan (NY), Chairman
464 Senate Russell Office Building
Washington, DC 20510
(202) 224-4451 (office)
(202) 224-9293 (fax)

Max Baucus (MT)
706 Senate Hart Office Building
Washington, DC 20510
(202) 224-2651 (office)
(202) Non published (fax)

David L. Boren (OK)
453 Senate Russell Office Building
Washington, DC 20510
(202) 224-4721 (office)
(202) Non published (fax)

Bill Bradley (NJ)
731 Senate Hart Office Building
Washington, DC 20510
(202) 224-3224 (office)
(202) 224-8567 (fax)

George J. Mitchell (ME)
176 Senate Russell Office Building
Washington, DC 20510
(202) 224-5344 (office)
(202) Non published (fax)

David Pryor (AR)
267 Senate Russell Office Building
Washington, DC 20510
(202) 224-2353 (office)
(202) 224-8261 (fax)

Donald W. Riegle, Jr. (MI)
105 Senate Dirksen Office Building
Washington, DC 20510
(202) 224-4822 (office)
(202) 224-8834 (fax)

John D. Rockefeller (WV)
109 Senate Hart Office Building
Washington, DC 20510
(202) 224-6472 (office)
(202) 224-7665 (fax)

Thomas Daschle (SD)
317 Senate Hart Office Building
Washington, DC 20510
(202) 224-2321 (office)
(202) 224-2047 (fax)

John H. Breaux (LA)
516 Senate Hart Office Building
Washington, DC 20510
(202) 224-4623 (office)
(202) Non published (fax)

Kent Conrad (ND)
724 Senate Hart Office Building
Washington, DC 20510
(202) 224-2043 (office)
(202) 224-7776 (fax)

MINORITY (REPUBLICANS)

Bob Packwood (OR), RM
259 Senate Russell Office Building
Washington, DC 20510
(202) 224-5244 (office)
(202) 228-3576 (fax)

Robert Dole (KS)
141 Senate Hart Office Building
Washington, DC 20510
(202) 224-6521 (office)
(202) Non published (fax)

William Roth (DE)
104 Senate Hart Office Building
Washington, DC 20510
(202) 224-2441 (office)
(202) 224-2805 (fax)

John Danforth (MO)
249 Senate Russell Office Building
Washington, DC 20510
(202) 224-6154 (office)
(202) Non published (fax)

John H. Chafee (RI)
567 Senate Dirksen Office Building
Washington, DC 20510
(202) 224-2921 (office)
(202) Non published (fax)

David Durenberger (MN)
154 Senate Russell Office Building
Washington, DC 20510
(202) 224-3244 (office)
(202) 224-9931 (fax)

Charles Grassley (IA)
135 Senate Hart Office Building
Washington, DC 20510
(202) 224-3744 (office)
(202) 224-6020 (fax)

Orrin G. Hatch (UT)
135 Senate Russell Office Building
Washington, DC 20510
(202) 224-5251 (office)
(202) 224-6331 (fax)

Malcolm Wallop (WY)
237 Senate Russell Office Building
Washington, DC 20510
(202) 224-6441 (office)
(202) 224-3230 (fax)

Consortium for Citizens with Disabilities

July 22, 1993

Dear Budget-Reconciliation Conferee:

Attached for your consideration are recommendations of the Consortium for Citizens with Disabilities (CCD) regarding the disability-related aspects of the Omnibus Budget Reconciliation Act of 1993. CCD is the coalition of national organizations which advocates on behalf of our nation's 43 million citizens with disabilities.

This letter is supplementary to our letter of July 20th on the reconciliation conference deliberations. We wish to convey to you more detailed information on those conference items most pertinent to the disability community. We urge you to support the positions contained within the attached document.

CCD thanks you for your support now and in the past.

Sincerely,

Paul Marchand

Paul Marchand, Chairman
Consortium for Citizens with Disabilities
202/785-3388

Roger Kingsley

Roger Kingsley, Co-Chair
CCD Budget & Appropriations Task Force
301/897-0125

Katy Neas

Katy Neas, Co-Chair
CCD Budget & Appropriations Task Force
301/588-8252

Judith Shaw

Judith Shaw, Co-Chair
CCD Budget & Appropriations Task Force
202/347-3066

Attachment

Entitlement Programs

CCD opposes arbitrary caps on entitlement programs. However, should the conferees consider entitlement review proposals, the CCD urges that these proposals contain two key provisions. First, the proposal must allow the entitlement targets to be adjusted for inflation. Second, the proposal should allow for the entitlement target to have a margin of error.

Medicaid - Personal Care Amendments

Language is included in the House and Senate bills to repeal the personal care mandate and, instead, to establish in the statute an option for personal care. In establishing the statutory option, the bills would limit authorization for personal care services to physicians, with supervision of such services by nurses. The CCD urges the conferees to adopt language that gives the states authority for flexibility in the delivery of personal care services in a manner that does not require physician authorization or nurse supervision. Recommended language has been provided to Committee staff.

Medicaid - Transfer of Assets

CCD supports the inclusion of clarifying changes in the House and Senate Medicaid Transfer of Assets sections to assure that competent adults are permitted to establish special needs trusts, as are other people with disabilities, and to assure that pooled trust arrangements are protected. Suggested language and background information have been provided to Committee staff.

Medicaid - Prescription Drug Formularies

CCD acknowledges and applauds the efforts of both the House and Senate to include meaningful consumer protections in the provisions allowing state Medicaid programs to establish restrictive formularies; however, we remain concerned about the possible effects of formularies on access to medically necessary medications for Medicaid beneficiaries who have chronic conditions and disabilities. In particular, for those individuals who are in need of medications that are not included in the formulary, experience has shown that existing prior authorization programs may be inadequate mechanisms for ensuring medically necessary access to excluded drugs. Accordingly, we recommend that the provisions relating to formularies be amended to create a presumption that, if the Medicaid agency has not made a decision within 24 hours, as currently required by law, the medication is then presumed to be authorized. We believe this change would go a long way toward ensuring access to needed medications for people with chronic conditions and disabilities.

Medicaid - Permissive Exclusion Authority for Medicaid Drug Programs

CCD is concerned about a provision contained in the Omnibus Budget Reconciliation Act of 1990 (OBRA '90) which extended the "permissive restrictions" authority in state Medicaid drug programs to include all barbiturates and benzodiazepanes. While we understand that this change was made to address reports of widespread abuses of these classes of drugs, the provision could prohibit access to valid, medically necessary treatments for persons with epilepsy, panic disorders, and agitated psychoses. CCD is concerned that the OBRA '90 provision is overly broad and could deny indigent Medicaid beneficiaries safe and effective medications which represent the best, or in some cases, the only available treatments for serious medical conditions. Often these medications prevent the need for far more costly alternative treatments. CCD urges the conferees to consider this issue as it deliberates the provisions relating to Medicaid drug formularies.

Medicare - Home Medical Equipment Ethics Provisions

CCD recommends that Congress retain the home medical equipment (HME) ethics provisions in the reconciliation bill. The ethics provisions - which Congress passed last year - help protect Medicare beneficiaries and legitimate HME suppliers from unscrupulous individuals who damage the reputation of the HME industry, and save precious federal dollars that the country can ill-afford to waste. CCD also opposes efforts to curtail reimbursement rates for HME, which would limit consumer access to HME, and urges Congress to support adequate reimbursement for HME.

Medicare - Coverage of Speech-Language Pathologist and Audiologist Services

CCD supports the inclusion of Section 13475 in H.R. 2264, Coverage of Services of Speech-Language Pathologists and Audiologists, in the final reconciliation package. Many individuals with disabilities have communication disorders and are assessed and treated by speech-language pathologists and audiologists under the Medicare program. Section 13475 clarifies the services and the qualifications of the professionals who provide the services. There is no cost associated with this provision. CCD also agrees with the American Speech-Language-Hearing Association that individuals in their Clinical Fellowship Year should be included in the definitions of speech-language pathologists and audiologists.

Supplemental Security Income (SSI) - State Administration Fee

CCD opposes the provisions to charge the states a fee for administering their supplementation program. The federal government's role in administering state supplementation was intended as an incentive for states to supplement federal benefits. With many states experiencing serious budget cutbacks, this additional administrative expense may serve as a disincentive for continued state supplementation. Any action which would directly or indirectly result in states reducing or eliminating their supplementation program would hurt SSI beneficiaries.

Restoration of Pre-Suter Beneficiary Rights

CCD urges passage of the House provision to restore pre-Suter law regarding beneficiary rights. Prior to the U.S. Supreme Court's decision in Suter v. Artist, individuals who were being harmed by a state's failure to comply with a state plan had a well recognized right to sue in federal court. In a case dealing with the Title IV-E foster care program, the Court eliminated those rights. The Suter decision is thought to have far-reaching impact in all of the Social Security Act titles and, in fact, has been interpreted to apply to other federal laws. The House bill has a provision (Sec. 13234, under child welfare and family preservation) which would restore the law to pre-Suter status, restoring the right to seek redress of violations of the foster care provisions and affirming that this right still exists in other state plan programs under the Social Security Act. This provision has been agreed to by the National Governor's Association, the National Conference of State Legislatures, the American Public Welfare Association, the American Civil Liberties Union, and consumer advocates.

Human Resources Programs

Maternal and Child Health (MCH) Block Grant

CCD supports the House provision to increase the authorization level of Title V of the Social Security Act, the Maternal and Child Health (MCH) Block Grant. The House bill raises the authorization ceiling from $686 million to $705 million. This amount is equal to President Clinton's fiscal year 1994 request. Last year, the MCH block Grant provided basic health care services to well over 5 million women and young children as well as special services to children with chronic illness and children with disabilities. The block grant also supports valuable interdisciplinary training, research, and genetic screening and counseling activities which are key components to the existing health care infrastructure.

Family Preservation

Since its inception family preservation legislation has recognized the critical importance of addressing the needs of children most at-risk of abuse, neglect and out-of-home placement and their families. These children are identified by their involvement in one or more of the primary children's service systems serving children at-risk: children's mental health, child welfare and juvenile justice. By focusing on coordination and augmentation of these services children most at-risk are identified early with greater chance of successful interventions and, in addition, scarce resources are more effectively utilized. In order to clarify the intent of family preservation legislation, CCD is requesting that provisions on demonstration projects in H.R. 2264 be amended to conform to the comprehensive services projects sections found in all previous family preservation legislation and S. 596, which is pending in the Senate. This change would identify the purpose of the demonstration projects section as coordination of children's mental health, child welfare and juvenile justice services and development of comprehensive services within those systems. This is a cost-neutral issue which simply allows greater flexibility to states for the use of current appropriations.

Childhood Immunization

CCD supports the House childhood immunization initiative because it will assist more millions of children by preventing the incidence of illness and disability. Moreover, the House bill includes Medicaid immunization improvements such as parent education, coordination with WIC and Maternal and Child Health programs.

Mickey Leland Childhood Hunger Relief

CCD supports the inclusion of the Mickey Leland Childhood Hunger Relief Act in the final budget reconciliation bill. This legislation is needed to reduce hunger among poor children and to help bring working families out of poverty. Individuals with disabilities are among our nation's poorest citizens. The Leland bill is critical to the overall fairness of the reconciliation package.

Public Works/Transportation Programs

Funding for Mass Transit

CCD recommends that budget reconciliation conferees support a provision directing at least the traditional 20% of the revenues raised by any gas/energy tax for deposit into the Mass Transit Account. The Senate version would deposit the revenues in the Highway Trust Fund, but made no provision for any credit to the Mass Transit Account. The importance of accessible public transportation to millions of people with disabilities cannot be overstated, and provisions for adequate funding must be made in the reconciliation bill. The Americans with Disabilities Act has many specific requirements to allow people with disabilities access to public transportation - an important link to securing gainful employment. Adequate funding for mass transit is necessary in order for public transit systems to move forward with implementation of these requirements.

Revenue Provisions

Housing - Permanent Extension of Low-Income Housing Credit

Although both the Senate and House adopted provisions permanently extending the low-income housing credit, the CCD urges the conferees to adopt the House provision Sec. 8142 (4) which prohibits the refusal to lease to a holder of a Section 8 housing voucher or certificate. Since many people with disabilities utilize Section 8 housing certificates/vouchers, we believe this type of non-discrimination protection is critical.

Housing - Permanent Extension of Qualified Mortgage Bonds

CCD urges the conferees to adopt the House provision which permanently extends qualified mortgage bonds as an important financing tool in assisting low and moderate income first-time home buyers, including people with disabilities, to obtain mortgage rates below conventional market rates.

Employment - Permanent Extension of Targeted Jobs Tax Credit

CCD supports provisions in H.R. 2264 that 1) contain a permanent extension of the Targetad Jobs Tax Credit (TJTC); 2) include the President's recommended new target group for work-study (student apprenticeship) jobs for 11th and 12th graders; and 3) make TJTC applicable to economically disadvantaged enterprise zone workers. Collectively, these provisions will help mitigate the tax burden on employers by providing a $2 billion reduction in employer wage

costs, and will continue the progress made in providing greater opportunities for individuals with disabilities in the competitive work force.

Earned Income Tax Credit (EITC)

CCD supports the House provisions related to the earned income tax credit.

Repeal 3% Floor on Charitable Deductions

CCD urges Congress to repeal the 3% floor for charitable deductions. Under current law, this provision is scheduled to expire at the end of 1995; however, the House and Senate reconciliation bills include language to make it permanent. The 3% floor on charitable deductions is reducing charitable giving at a time when the nonprofit sector is experiencing increased demands for services to fill the voids created by federal and state government cutbacks.

Consortium for Citizens with Disabilities 7/22/93

ADDITIONAL MATERIALS FOR MEMORANDUM TO PRESIDENT
ON CONSORTIUM FOR CITIZENS WITH DISABILITIES EVENT

RESPONSES TO CCD STATEMENTS

1. Entitlement Programs

The 1994 budget did not propose any form of broad limitation on entitlements.

The House-passed reconciliation bill contains an "entitlement budget" provision. It requires the President to advise the Congress, when entitlements exceed projections, on whether: (1) added savings should be adopted; (2) added revenues should be sought; or (3) no action should be taken (deficit financing). Congress would have to vote on the same three choices.

The Senate bill contains no such provision.

2. Medicaid -- Personal Care Amendments

The Administration proposed a personal care amendment that would correct a drafting error that inadvertently made this benefit mandatory in all states. Restoring personal care as an optional benefit would return Medicaid policy to the original intent of the law. The change would take effect prospectively for FY 1995.

Both the Senate and House reconciliation bills would restore personal care as an optional benefit, as was proposed by the Administration.

The Administration has not taken a position on the specific language proposed by the CCD, which would give the states authority for flexibility in the delivery of personal care services in a manner that does not require physician authorization or nurse supervision.

3. Medicaid -- Transfer of Assets

The Administration proposed strengthened transfer-of-asset provisions in order to ensure that individuals with substantial assets pay their fair share of Medicaid long-term care costs. Any proposed changes that would weaken these provisions would lead to decreased program savings.

Both the Senate and House bills would strengthen transfer of assets provisions in general accordance with the President's Budget proposals.

CCD support language assuring that competent adults are permitted to establish special needs trusts and to assure that pooled trust arrangements are protected.

4. Medicaid - Prescription Drug Formularies

The Medicaid prescription drug formulary provisions under Congressional consideration include a variety of protections for Medicaid recipients. Drugs excluded from the formulary must be considered for coverage on a case-by-case basis at the request of the patient's physician, if the State has given prior authorization for payment. We believe that States will act responsibly and consider requests for prescription drugs not included in the formulary in an expeditious manner. The Administration has taken no position on the refinement

proposed by CCD and no similar provision is being considered by either the House or Senate. That refinement would create a presumption that, if the Medicaid agency has not made a decision within 24 hours, the medication is then presumed to be authorized.

5. Medicaid - Permissive Exclusion Authority for Medicaid Drug Programs

CCD is concerned about a provision contained in the 1990 reconciliation bill which extended the "permissive restrictions" authority in state Medicaid drug programs to include all barbiturates and benzodiazepenes. It does not recommend a specific change. The Administration has taken no position on the issue, and no change is being considered by either the House or Senate.

6. Medicare -- Home Medical Equipment Ethics Provisions

The House and Senate bills both include Medicare savings proposals that reduce payments for DME, prosthetics and orthotics. The House bill also includes DME ethics provisions that were passed in the previous Congress but not signed into law. CCD supports these provisions. The Administration has not taken a position on the specifics of the ethics provisions.

The Administration shares CCDs interest in ensuring access to home medical equipment and rooting out unscrupulous suppliers. To ensure program integrity, HHS plans to convert this year to an enhanced system of reviewing claims for durable medical equipment (DME), prosthetics, orthotics and parenteral and enteral nutrients and supplies. Four regional carriers with specialized fraud and abuse units will review all DME claims, and will implement standards that all suppliers must follow. The Administration proposed some DME payment revisions that result in Medicare savings based upon a GAO study that found suppliers were achieving higher profit levels from Medicare business than from private business; and an HHS Inspector General study that found Medicare providing higher reimbursements than many other payers.

7. Medicare - Coverage of Speech-Language Pathologist and Audiologist Services

The Administration does not oppose this House-passed provision, which clarifies the services and qualifications of the professionals who provide speech-language pathology and audiology services. The Administration has not studied the proposal of the American Speech-Language-Hearing Association to include individuals in their Clinical Fellowship Year in the definitions of these service providers, and therefore does not take a position on this specific point, which CCD favors.

The House Ways and Means provision supports the redefinition of speech-language pathologists and audiologists, but it does not include the Association's proposal. The Senate bill does not contain such a provision.

8. SSI State Administrative Fee

The Administration's proposal would charge states for the federal administration of their state supplement to the federal Supplemental Security Income (SSI) benefit. Currently, SSA administers supplements for 27 states and the District of Columbia. The proposal gradually phases in a 5% administrative fee over three years (1.67% in FY94, 3.33% on FY95 and 5.0% in FY96 and thereafter.) The fee is expected to save $710 million over five years. The

House adopted the President's proposal and the Senate adopted the proposal but delayed the fee for one fiscal year.

CCD opposes the Administration's proposal.

9. Suter v. Artist M Provision

The Family Preservation and Family Support legislation instructs the judicial system to ignore the Supreme Court's Suter v. Artist M decision as a precedent for future court decisions. The plaintiffs in Suter brought legal action against a State to enforce the "reasonable efforts" provision of the Social Security Act (which provides that reasonable efforts must be made to prevent a child from being placed in foster care). The decision was overturned by the Supreme Court, which argued that if a State had a State plan that complied with the Social Security Act, it was not necessarily liable for individual instances in which there was a failure to comply with State plan provisions. Estimated 5 year costs: unavailable, although CBO predicts that this provision may be costly.

10. Maternal and Child Health Block Grant

The FY94 Budget contains $705 million for the MCH Block Grant, a $40 million increase over FY 1993 enacted levels. States use MCH block grant funds to support prenatal care and case management services, primary care services for children, and services for children with special needs. Of the additional $40 million in the FY94 Budget, $30 million will be distributed to states by formula, 5 million will be allocated for special demonstration projects, and $5 million is to be spent on the development of integrated service delivery projects.

The House-passed reconciliation bill increases the FY 1994 authorization for the MCH block grant from $686 million to $705 million. The Senate bill does not include a similar provision. CCD supports the House provision.

The House-passed version of the FY94 Labor/HHS appropriations bill would provide $665 million, $40 million less than requested in the FY94 Budget and the same as the FY93 enacted level.

11. Family Preservation and Family Support Proposal

The Administration's proposed Family Preservation and Family Support legislation -- included in the House bill but not the Senate bill -- would establish a new capped entitlement under Title IV-B of the Social Security Act to: provide services to strengthen and stabilize families; prevent family dissolution; and improve parenting skills. The proposal recognizes that today's families face increased stress from causes such as increasing teen pregnancy, substance abuse and violent crime rates and that such stresses are reflected in steadily rising foster care caseloads. By devoting more resources to preventing family dissolution, both through preventive services before a crisis occurs and through intensive services at the time of crisis, the proposed program hopes to reduce today's high level of foster care placements.

CCD is requesting that the measure be amended to conform to the comprehensive services projects sections found in previous family preservation legislation, which they say would be cost-neutral but would allow greater flexibility to

states for the use of funds.

12. Childhood Immunization

The House-passed reconciliation bill contains a version of the President's immunization initiative. CCD supports the House-passed measure. The Senate bill does not contain that provision.

In addition, the FY94 President's Budget included a $326.5 million investment for a nationwide immunization initiative. In addition to expanded vaccine purchase, the investment would support infrastructure development (including certain personnel expenses and information and outreach efforts). The investment would also support the development of a nation-wide immunization monitoring system.

13. Mickey Leland Childhood Hunger Relief

The House has included in the reconciliation bill the Mickey Leland Childhood Hunger Prevention Act, supported by the Administration, which would increase Food Stamp benefits, simplify and improve program administration and assure the integrity of the Food Stamp program. Most of the benefits of this bill would go to low-income families with children. The Senate bill does not contain the Leland initiative. CCD supports its inclusion in the final bill.

14. The Energy Tax and Funding for Mass Transit

CCD supports providing the Mass Transit Account of the Highway Trust Fund with the traditional 20% of funds raised by any gas/energy tax. The Administration has not officially taken a position on this issue. The Senate bill would provide all of the 4.3-cent gasoline tax increase to the Highway Trust Fund but none specifically to the Mass Transit Account. The House bill contains the Btu tax, with nothing going to the Highway Trust Fund or mass transit. The conferees have tentatively agreed to place the revenues of whatever emerges in the general fund, not the trust fund.

The House passed the Administration proposal to place 20% of the 2.5-cent gasoline tax extension in the Mass Transit Account.

15. Earned Income Tax Credit

The Administration's proposal would expand the EITC and increase the credit by the amount necessary to lift a four-person family out of poverty. The increase in the credit would take place over a two-year period and be completed by 1995. When fully phased in, the maximum credit would be $2,062 (in 1994 dollars) for families with one child, and $3,371 (in 1994 dollars) for families with two or more children. The EITC would also be extended to workers without children, for a maximum credit of $306 (in 1994 dollars). The supplemental young child credit and the supplemental health insurance credit would be repealed. The five-year cost of the provision is $28.6 billion.

The House has essentially adopted the President's proposal; the Senate has adopted a less generous plan. CCD supports the House-passed EITC provisions.

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DOCUMENT DESCRIPTION: ISSUE PAPER ON DISABILITY POLICY & THE FEDERAL JUDGES PROCESS

REMARKS: FYI. I HOPE THIS ISSUE IS AMONG THE TOPICS ADDRESSED AT TOMORROW'S MEETING WITH PRESIDENT CLINTON. PLEASE CALL IF YOU HAVE ANY QUESTIONS OR CONCERNS.
HAPPY ADA ANNIVERSARY!

ISSUE PAPER

DISABILITY POLICY AND THE FEDERAL BUDGET PROCESS

Background

During the last dozen years, most federal disability programs have experienced fairly steady growth. For the most part, this has been achieved with the support of the Democrats who controlled both the House and Senate Appropriations Committees. The Congress usually ignored or rejected the Reagan/Bush budget requests which offered little promise, even during the free spending Reagan years, of significant expansion for disability programs. Thus the Congress, not the Republican Administrations, must receive what credit there is for maintaining and expanding disability programs.

Upon the arrival of President Clinton, the disability community eagerly awaited his budget requests for FY 1994. Despite the bleak economic outlook and heightened pressure to reduce the federal deficit, disability advocates held out hope that some disability programs, particularly those which address needs reflected in President Clinton's campaign priorities, might receive substantial increases in the President's budget.

These hopes were dashed, however, when the Clinton budget request was released in April. Most disability programs were frozen at their FY '93 levels, a few received cost-of-living increases and a couple (Technology Assistance and Early Intervention) received increases above inflation.

Further exacerbating this problem was the President's economic stimulus proposal which totally ignored disability programs which might have played a role in jobs development and other priority areas. Disappointment by the disability community would have been lessened had all other human services been treated similarly. However, there were some "winners" such as Headstart and Youth Employment in the President's budget requests. While the disability community applauds President Clinton's proposed increases to Headstart and Youth Employment, it is concerned that those programs serving people with disabilities which have similar objectives are not provided with similar resources. Three programs within the Individuals with Disabilities Education Act (Early Childhood Projects, Part H Early Intervention, and Preschool) serve young children with disabilities. The President' FY 1994 budget froze the Early Childhood Projects and provided a 5.5% increase for Preschool and a 30% increase for Part H. This is compared to a 32% increase for Headstart. Job Training Partnership Act programs are also increased by approximately 30% while the Vocational

Rehabilitation State Grant, the primary source of jobs training for people with disabilities, is increased by only 3%.

Clearly disability programs highly related to President Clinton's priorities of jobs stimulus and early intervention were not provided comparable increases. While an argument can be made that people with disabilities are eligible for Headstart and Job Training Partnership Act programs, the fact remains that these programs are often not prepared to address the unique needs of children and adults with disabilities.

Another potential solution to solve this dilemma seems to be unavailable. That is the Congress making adjustments through the appropriations process. That is not likely this year and in the foreseeable future for several reasons. First, the Congress may have the will but lacks the resources to do so. It is well known that the House and Senate Appropriations Subcommittees on Labor, Health and Human Services and Education have approximately $6 billion less available for them to allocate than President Clinton's' budget. This significant constraint greatly lessens, if not outright removes, any opportunity to go above the President's budget requests. Second, the Congress is treating the Clinton budget requests with much greater credibility. The closer cooperation between the White House and the Congress has made it more difficult for advocates to secure increased funding.

Although the final tally can't be determined until the Senate completes its FY '94 Labor, Health and Human Services and Education Appropriations bill in September and the Congress finalizes action on it, it is clear that the Administration's original budget request for a fiscal year will have a much greater bearing on the final appropriations outcome.

<u>Recommendations</u>

Given the enhanced Administration role in the appropriations process, the "rules of the game" have changed. Disability advocates need to work much more cooperatively with the Clinton Administration on fiscal issues. Conversely, the Administration, from the highest levels of the Office of Management and Budget to the departmental budget and policy officials, must reach out to the disability community to become more knowledgeable of the needs, priorities and recommendations of the disability community.

Hopefully, President Clinton can send the right signals to those who develop the budget, urging them to work with the leaders of the disability community. Since the FY 1995 budget process is already well underway, it is vital that action in this regard be taken soon.

NOTE: This paper reflects a comprehensive budget analysis of disability-related programs except for those which are related to AIDS.