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President Disability Meeting 9/10/97

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jfa @ TNET.com  
09/15/97 01:27:00 AM

Record Type: Record

To: William H. White Jr.

cc:

Subject: Minutes

JUSTICE FOR ALL

bogle@erols.com

Advocates meet with President

The much anticipated meeting between disability community activists and President Clinton was held on September 10, 1997. The meeting had been scheduled for the spring, but due to the unforeseen injury President Clinton incurred it had to be postponed. Good to their word though, it did occur and in grand surroundings, The Cabinet Room.

Justin Dart, Jr. served as the moderator for the hour and a half meeting. Attendees at the meeting from the disability community were as follows in the order that they spoke: Fred Fay, JFA; Debbie Robinson, Speaking For Ourselves; Paul Marchand, The ARC; Gina McDonald, NCIL; Bob Kafka, ADAPT; Mike Oxford, ADAPT; Nancy Diehl, Parent Network; John Harper, Youth Leadership; Paul Edwards, ACB; Tony Cohelo, Chair PCEPD; Becky Ogle, JFA and Marca Bristo, Chair, NCD.

In addition to

~~Other than the President and Vice President, the others in attendance within the Administration were:~~ PARTICIPANTS INCLUDED  
Assistant Secretary, Office of Special Education and Rehab., Judith E. Heumann; Bob Williams, Deputy Assistant Sec. Office of Aging, Disability and Long Term Care Policy (HHS); Susan Daniels, Associate Commissioner of Disability, SSA; Bill White, OPL Disability Outreach for the White House; Maria Eschavestes, Director, OPL; Chris Jennings, Special Assistant to the President on Health Care; Bruce Vladek, Director HCFA and Diana Fortuna, Domestic Policy Council.

Quite the cast of characters and it is probable that titles have been mislabeled, with the exception of the President and Vice President, so in that event, or misquotes, JFA apologizes.

DIANA,

ATTACHED ARE COMMENTS

I HAVE MADE TO  
FRED & BECKY'S SUMMARY.

Bilo

THE PRES MET W/ US  
IN THE CABINET ROOM OF  
THE WH ON SEPT 10.

John

John

~~As stated,~~ Justin Dart served as moderator and kicked off the meeting, "We are here today to discuss issues that are vital to the life of every American family, because every American family will experience disability."

"Mr. President, we appreciate this meeting, we appreciate you. You have met us before, you have supported us on ADA, IDEA, universal health care, Medicaid, the FDR memorial and other issues. You have appointed great Americans with disabilities to government: Judy Heumann, Marca Bristo, Tony Cohelo, Bob Williams, Susan Daniels, Liz Savage, Debbie Robinson, Rae Unzicker, many others--and there are great friends of people with disabilities in your administration -- Bill White.

Justin went on to add, "Americans with disabilities have come a long way. We have a long way to go. I am convinced that we will never achieve full, productive participation until there is a revolution to establish a culture that systematically empowers all to govern themselves, and to produce lives of quality for themselves and for all."

"You said it better: we need a new government for a new century...Humble enough not to try to solve all of our problems for us, but strong enough to give us the tools to solve our problems for ourselves . . . We are here to talk about those tools."

Justin added, "In this meeting are authentic patriots...they will discuss with you the rights of people with disabilities to access education and society, to work, to have real health care, to be liberated from unjust incarceration in institutions. The rights of kids with disabilities to live in dignity."

In closing his initial comments, "Mr. President, give us the tools and we will work with you to do the job."

With this said the meeting turned to the others' around the table beginning with Fred Fay via speakerphone from Concord, MA. Fred spoke about several issues regarding the political power of the disability vote, personal attendant services, ADA, FDR memorial and employment of people with disabilities. Fred said, "As you know first hand, disability is equal opportunity: anyone can qualify at any moment. You won a lot of hearts from our community by how you handled your recent experience in a wheelchair. You commented that you understood the need for ADA even more. Well ADA needs your help: Ignorance and discrimination are still alive and well in America. We need more resources for ADA enforcement and technical assistance."

Debbie Robinson, Speaking For Ourselves, followed Fred with adding that the President could help us by speaking out more

often on behalf of the ADA and she spoke about more job opportunities for people with disabilities.

The President responded to Fred <sup>Wick</sup> and Debbie's argument <sup>A</sup> for the ADA by stating that he ~~was asking Congress for increased~~ funding for ADA enforcement and technical assistance. The President also added that his budgets had reflected an increase for ADA, but Congress had never granted it, ~~but he wasn't going to give up because he would submit it again this next year.~~

significant

HAD REQUESTED ADDITIONAL  
FUNDING FOR ADA

over the past several  
years,

HE CALLED UPON  
THE DISABILITY COMMUNITY  
TO MAKE IT HAPPEN

Paul Marchand, The ARC, spoke out on behalf of the Supplemental Security Income program, children with disabilities cut off SSI via the welfare law and the multiple problems plaguing the system since the changes took effect. Paul asked for a moratorium on any further denials of benefits until the problems are resolved. He also stated that SSA had set a too harsh standard for children to be under this law resulting in too many children being found ineligible. The President responded to Paul's concerns by stating ~~that his administration was implementing a thirty day review to clean up as many problems as possible. The President did not promise to review the stricter eligibility standards.~~

INSTRUCTING SSA TO REPORT  
TO HIM IN  
30 DAYS

ON THE REEVALUATION  
PROCESS

Gina McDonald, NCIL followed with an eloquent statement concerning personal assistance services. Gina stated, "National Long Term Care policies have traditionally favored institutionalizing people who need PAS rather than assisting them in their own communities. This bias is reflected in the fact that the federal government spends 82% of federal long term care services funds in nursing homes. Six times as many dollars are spent to put people in nursing homes and institutions as is spent on keeping people in the community where they have the potential to be productive citizens."

Bob Kafka and Mike Oxford, both from ADAPT followed Gina in the discussion on home and community attendant care policies with compelling arguments for adopting new policies. Bob and Mike spoke about McCASA introduced recently in the U.S. House of Representatives and asked the President to support the bill. They cited many states that were doing the right thing, but many others weren't doing the best they could.

The President at this point joined in a lively discussion on the pros of enacting legislation, such as CASA. The President also turned to Bruce Vladek, HCFA Director to speak out on the Administration's plan to conduct demonstration projects on PAS in targeted areas, study the states that had programs working and last pointed out that Bob Williams had recently joined the team to help implement these types of new initiatives in HHS.

) ?  
6

From personal assistance services the topic switched to education with Nancy Diehl, Parent Network speaking out on behalf of IDEA and funding for special education. Following with comments related to education issues was John Harper who spoke about

qualified and experienced teachers for students with disabilities.

Tony Cohelo, Chair PCEPD and Paul Edwards spoke on behalf of ADA, jobs for people with disabilities, linkages to health care, welfare to work issues, technology and such. Vice President Gore became animated in his responses on technology, one of his favorite initiatives. The President and Vice President both agreed to watch and follow the issuance of regulations from the FCC.

Marca Bristo summarized the meeting and presented the President with the history of the ADA National Council Book.

--

Becky Ogle  
bogle@erols.com

--

Fred Fay  
jfa@mailbot.com

End  
Teley - pass baton  
mar ca - great

## WELCOMING REMARKS

- deep nd more from yr office

- gives commem edition of making ADA

- count down  
you to take

no to meet ch

embassy access

+ land mines

- EO

- ticket

- he access

P - great mtg

- get go; you've done more

what did should?

- get isolated

- Enc to wk w/ team

Want to be part

of movement

- 2 great ors:

- expand freedom

- very diff yet be united

o But I also know how far we have to go. There are areas where we can and must do more, and I'm looking forward to a substantive discussion.

o Before we begin, I want to give special recognition to Fred Fay who is joining us via speaker phone from his home in Concord, Massachusetts, and Becky Ogle, who worked night and day organizing the disability community both in '92 and '96.

o Justin, why don't you lead us off.

~ 11am

- Oxford: Helmut  
- forgot to take McDowell  
- PAS itself

- forgot LK + Mh family  
- Hqpts  
- MCComm  
- PAS: listen to ADAPT/FDR

Welcome to the Cabinet Room of the White House. Joining me today are several key members of my Administration, including Maria Echaveste, who directs my Public Liaison Office, Chris Jennings, my senior health care advisor, Administrator Bruce Vladeck from HCFA, my friend Tony Coelho from the President's Committee on Employment for People with Disabilities, Judy Heumann from the Department of Education, Susan Daniels from SSA, Marca Bristo from the National Council on Disability, and Bob Williams from HHS.

I understand that people with disabilities are not looking for special treatment, but equal access to the American dream. I understand the importance of integrating disability issues into all policies and programs of the Administration. We couldn't have gotten this far without the support of so many of you around this table today.

On critical civil rights laws, we have vigorously enforced the ADA, and we have defended it from malicious attacks. This year, with the critical assistance of Assistant Secretary Judy Heumann we secured the reauthorization of the IDEA in a manner that reaffirms our nation's commitment to children with disabilities and their parents.

On the key issue of health care for people with disabilities, we haven't gotten as far as I would have liked, as you know. But we fought hard and won our fight to preserve the Medicaid guarantee, when it was under attack in 1995 and 1996, a change that would have been so dangerous for people with disabilities, among many others.

As part of the balanced budget I just signed, we restored SSI benefits to over 300,000 legal immigrants with disabilities. Most observers predicted that Congress would never agree to amend the welfare law to make this change, but we were able to persuade them with your help. As you know, we made people with disabilities our top priority for restorations.

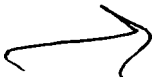
Press

- more ADA enf  
- 30 days (NRT?)

\* Get out word on 30 days SSI  
\* Write up notes, esp. to OMB  
\* CASA - no Gingrich, no w/tp end of Feb.  
\* 50% capable of SGA on SSI/SSDI - Lancet?  
\* But no OMB or COS

## ADA ENFORCEMENT

### Advocates Who Will Discuss:

- 
- Fred Fay, Chair, DNC Disability Advisory Committee
  - Ms. Debbie Robinson, Speaking for Ourselves

### What Advocates Will Say:

- The ADA is so critical to the disability community. We appreciate your strong support for it. We encourage the Administration to increase its enforcement efforts.

### ADA Talking Points:

- Vigorous enforcement of the Americans with Disabilities Act (ADA) has been a top priority of my Administration. The Justice Department, the EEOC, and other federal agencies have established aggressive enforcement programs. We have emphasized voluntary compliance, but have not been afraid to litigate when entities fail to comply with the law.
- Although we have been quite successful, we all know we have a long way to go. Our resources are not sufficient to address the majority of meritorious complaints received in a timely fashion.
- My budgets have consistently called for an increase for ADA enforcement at the Department of Justice. However, the Congress has failed to approve these increases, which is indirectly weakening the important law.

- FY 1998: 5% (\$477,000)
- FY 1997: 3.9% (\$361,000)

- I am committed to significantly increasing ADA enforcement resources in the FY 1999 budget I will submit to Congress early next year. This Administration recognizes additional resources are necessary to strengthen a comprehensive enforcement program that seeks to achieve greater access for persons with disabilities at home, in their communities, and in the workplace. [DOJ's request to OMB calls for a 19% increase of \$2,173,000.]
- The ADA became law because your organizations, both nationally and at the grassroots level, worked together to educate the Congress on why the law was urgently needed. You won because you were well-organized and persistent. I will fight for greater funding, but the only way to make this a reality is if the disability community can make this a priority with the Congress.

*Debbie R  
P: I should talk about more  
Did a lot in all  
budget fight*

*P mentions EEOC  
encl \$*

*Cong: level \$*

## SUPPLEMENTAL SECURITY INCOME ELIGIBILITY FOR CHILDREN

### Advocates Who Will Discuss:

- Paul Marchand, the Arc; Chair, Consortium of Citizens with Disabilities

**Background:** The welfare reform law set a stricter definition of disability for children's SSI, after media reports that children faked disabilities to get benefits, and concerns that the program tripled in size since 1989 to one million children. The new law explicitly eliminated an eligibility test that allowed many children with less severe disabilities to qualify for the program, particularly mental disabilities. Estimates at the time were that 180,000 children would lose benefits. After the law was signed, Senators Conrad, Chafee, and Daschle alleged that SSA had legal authority to recreate the old test via regulation, cutting off only 35,000 children. SSA ultimately determined that doing so was contrary to congressional intent and the bipartisan understanding at the time. SSA's regulation had modest changes that brought the impact down to 135,000 children.

SSA is now more than half-way through reevaluations of the cases of 270,000 children. Over 100,000 children have lost eligibility to date. The final number of children cut off is expected to be close to SSA's estimate of 135,000. However, advocates allege SSA is discouraging appeals and is not implementing the new standard consistently across the country. (Mississippi has a termination rate of over 80%, while California and Pennsylvania are just over a third.)

### What Advocates Will Say:

- Your administration chose an unnecessarily tough standard when interpreting Congress's intent to tighten up on this program. Advocates have suggested more modest changes to SSA's regulation. SSA should stop the cutoffs to consider and respond to these suggestions.

In SSA's reviews, disturbing trends have emerged. Few families are appealing SSA's decisions. SSA may be discouraging appeals. SSA should stop and ensure that families have all the rights and information they are entitled to.

### SSI Kids Talking Points:

I know that Acting Commissioner Callahan met with advocates (including the Arc) last week to discuss this. We appreciate your constructive involvement in this critical process.

I am pleased that, as part of the balanced budget, we were able to grandfather Medicaid benefits for all these children, so that none of them will lose health insurance.

I fought against the SSI block grant and other proposals that would have been far worse than what we ended up with.

When the law was enacted, SSA examined the evidence and interpreted the law to create a standard that was consistent with her best reading of congressional intent. SSA does not believe that a more liberal interpretation is legally possible.

I know SSA is committed to ensuring these reviews are conducted fairly. I have asked Commissioner Callahan to report to me on the concerns you are raising within 30 days.

P-Congress re-stated law → >135,000 → political prefs of states?  
- Daschle et al - could recreate  
- 30 day review  
- People will be back in touch w/ you

- NY Times  
- Ken  
- 30 days?

Marchand  
- only 44% appealing  
- 135K - 85% mh  
- gd comms, SD

- Std too strict;  
m of C letters  
- Moratorium  
- <60  
- Denials @ 46  
- Var among states  
(Ark).  
- Due process  
44% too low

Evidence of intimidation  
- suggestion of  
if lose appeal

- \$4 b / 5 yrs  
- Grandfather MA  
- Fought block grant  
- Law intent

## PERSONAL ASSISTANT SERVICES

### Advocates Who Will Discuss:

- Gina MacDonald, National Center for Independent Living ("nickel")
- Bob Kafka and Mike Oxford, ADAPT

**Background:** ADAPT believes that people with disabilities are "imprisoned" in nursing homes because Medicaid is biased against home and community-based services. Today, states limit these services through waivers that cap the number of participants, while nursing home eligibility is more open-ended.

**CASA:** ADAPT will push for your support of their bill, the Medicaid Community Attendant Services Act. CASA requires states to cover community-based attendant services for those now eligible for nursing home care. It also gives beneficiaries a greater say in how those dollars are spent. Under pressure from ADAPT, Speaker Gingrich introduced CASA in June without endorsing it, instead calling it a "starting point" for an important dialogue and noting it has cost implications. Rep. Gephardt has also signed on as a co-sponsor. (CASA is not the highest priority of other disability groups, some of which have specific reservations about it.)

The Administration has not taken a position on CASA prior to this meeting. We have two major concerns about it. First, although it has a spending cap, CASA would have significant costs. It would require services for as many as one million people who now live at home but are so severely disabled that they could qualify for nursing home care. Further, any nursing home beds vacated by those moving to the community are likely to be filled promptly. Second, giving beneficiaries control of significant Medicaid dollars raises critical questions about quality standards, fraud, and whether Medicaid should pay family members for care.

Although we can't support CASA, we can support CASA's principles while recognizing our serious concerns. In response to a June meeting with ADAPT, HHS just formed a work group to identify next steps, including working with states on demonstrations of these principles. Finally, you can inform the group that you are writing Speaker Gingrich to lay out your position on CASA.

**Date Certain:** Recognizing that CASA raises these concerns, ADAPT is now pushing a more immediate fallback option. Known as the "date certain" concept, it would allow all individuals who are actually in nursing homes as of a certain date to move to community settings if they wish. While this approach solves some of CASA's problems, it would still cost money since the nursing home beds would be filled by new patients.

### What Advocates Will Say:

- People with disabilities are dying in nursing homes, and incremental steps are not enough. We urge you to support CASA, or at least a "date certain" policy.

P. If Randemonstr, like Bruce, can

Paul - 2/6 states NE Eng

no MR inst. at

Good to but -

no need; can be done; wld seek right

Gina - a lot on attendant policy  
- tax credits!

Kafka - all say yes hebs,  
but not when  
rubber hits the road  
- complains in budget  
fight only re  
his protection

Woodcock - ch. health tobacco  
- f was found

Wants  
end of principle

of CASA  
political will

Oxford - gd sc. R letter  
strongly  
but state of

Movs vs  
- one gd vs. 10 yr

1m  
172K

Helen - SC  
refused to  
hear -

might do most  
intelligently

Date certain

minor action  
- low  
- reg  
- demon

Why Bruce

### **Personal Assistant Services Talking Points:**

- As many of you know, this is an issue that I have cared about for a long time, and I am pleased that we have made the progress we have made.
- My Administration has made it easier than ever for states to get waivers for home and community-based services. About a quarter of a million people are now served in these programs, and HCFA is continuing to push states to make these services available.
- Because of a meeting with ADAPT in June, HHS has a new work group that is working with you. By the end of the year, it will complete its policy review to identify provisions that contribute to Medicaid's institutional bias. It will also work with states to develop demonstrations of the principles of CASA, and I have asked them to report to me by the end of February with an action plan.
- I am also asking the work group to examine linking the need for more qualified attendants with state welfare reform work requirements under TANF. Linking the needs of people with disabilities for attendants and the needs of low-income families for jobs seems to be well worth pursuing.
- Although Bruce Vladeck, who has been instrumental in this process as HCFA Administrator, is leaving the Administration shortly, I am pleased that Bob Williams [who is in the room] will play a key role in this process. Bob has just been named Deputy Assistant Secretary at HHS.
- I strongly support the principles of CASA but, as you know, it appears that the bill would have significant costs. In addition, there are unanswered questions about quality, particularly if one were to move quickly toward consumer-directed models that are at this point untested. Nevertheless, I want to send a strong signal that I believe CASA is an excellent vehicle for discussing our mutual goals and allowing us to move forward on them. Therefore, I plan to send a letter to Speaker Gingrich applauding his action in introducing CASA, and seeking to work with him and others on this.
- [If you are pushed on the "date certain" concept:] My understanding is that the date certain concept would also increase Medicaid costs. However, the work group is committed to working with states on demonstrations of this idea, along with others.

Diehl - Thanks  
- show yr leadership by making it a priority  
- Discipline

## INDIVIDUALS WITH DISABILITIES EDUCATION ACT

### Advocates Who Will Discuss:

- Nancy Diehl, Parent Network on Disability
- John Harper, Student with a Disability

P - all

- Funding + 36%

- used to ask for more

- R's putting me in pol & bind I'll do best by IDEA but don't let them

**Background:** IDEA was reauthorized in June of this year, after an elaborate bipartisan process led by Senator Lott that reconciled all the competing interests of schools, parents, teachers, and others. The Administration has been extremely supportive of the disability community on IDEA.

However, advocates are upset that we oppose the Senate's large increases in IDEA funding. The Senate funds IDEA at the expense of Administration priorities (Goals 2000 and America Reads). We said in a recent SAP that IDEA is adequately funded at our requested level, and that the Senate should redirect funds to our priorities. Advocates have misread that SAP to say that we consider IDEA a "low priority program." The Administration has proposed an increase of \$174 million, while the House has proposed \$300 million and the Senate over \$900 million.

take adv. of us on Goals 2000

Meuland - we don't want \$ from other programs wrote letter to Hill

### What Advocates Will Say:

- Thank you for your leadership on IDEA reauthorization. It is critical to our kids' futures.

extra \$ → state \$ ↓

### IDEA Talking Points:

- The passage of the IDEA was a tremendous success for the Administration. The bipartisan approach used during reauthorization enabled us to produce a bill which will help to ensure that disabled children across this country can get a quality education. Our principle from the beginning has been that ALL children must be able to take advantage of the educational reforms occurring across this country. Your active support to ensure that this legislation is effectively understood and implemented is critical.

**IDEA Funding Controversy:** Is IDEA a low priority for the Administration given language included in the SAP on the House and Senate Labor-HHS appropriations bills?

- Special education funding has and always will be a high priority for this Administration. In fact, for the first three budgets of this Administration, Congress funded Special Education programs at levels less than I proposed. Only recently has Congress come around to match or exceed my requests. Because of our leadership, IDEA funding has risen by \$1.1 billion, a 36% increase during this Administration.
- The Administration will work closely with Congress to ensure a balanced education funding bill that makes new investments in a broad range of important education programs, including Special Education programs.
- Finally, IDEA is about much more than funding levels. The Administration worked long and hard with the disability community, the Congress, parents and schools, to construct a reauthorization bill which would ensure that children with disabilities receive a quality education. We think that this has been accomplished, and the Administration's funding request will complement this effort.

resid sch for deaf  
↳ not mentioned

Edwards-

- strengthen SOB

- Access info superhighway

- Regs to implement

- FCC doing little

- SSA + IRS offices

**Advocates Who Will Discuss:**

• Tony Coelho, Chair, President's Cmte. on Employment of People with Disabilities

• Paul Edwards, American Council of the Blind

- Transp - ISTEA - ~~change~~ 4 to public transp to cont to grow

**Background:** The unemployment rate of people with severe disabilities is 75%. The disability community argues that we must focus on barriers to work that prevent people with disabilities from working. These problems include eventual loss of Medicaid or Medicare if they return to work and high costs for personal assistants, computer accommodations, and transportation.

**Medicaid Buy-in:** The balanced budget included a President's budget proposal to help people with disabilities work without losing their health care coverage. Today people on SSI who go to work lose Medicaid if their earnings exceed caps that vary by state. Since it is so difficult for people with disabilities to get private insurance, many people who are eligible for SSI "manage" their income to ensure that they keep Medicaid -- by stopping work when they hit the caps, or turning down promotions. This new state option will allow SSI beneficiaries with disabilities who earn more than these caps to keep Medicaid by contributing to the cost of their coverage as their income rises.

**SSI Ticket Proposal:** The President's budget included a proposal to let SSDI and SSI beneficiaries choose their own rehabilitation providers. Providers who help beneficiaries leave the rolls and return to work would be paid a percentage of the disability benefits saved. Because providers would be rewarded for results rather than for their costs, this should encourage more providers to have a continuing interest in their clients' long term success, which in turn may lead to more beneficiaries returning to work. Republicans and Democrats on the Hill have put forth similar proposals (Rep. Bunning proposed this concept before we did), so there is hope of action.

Note: The Administration's appointees with disabilities, led by Tony Coelho, are urging us internally to issue an executive order that would make this issue a priority and set up a task force to identify further actions to solve this problem.

**What Advocates Will Say:**

• We appreciate the Administration's efforts on this issue. However, more must be done. The most critical area is health care. Treasury should seriously consider offering tax credits to people with disabilities, who so often face higher costs.

**Employment Talking Points:**

• A large and growing number of people with disabilities can work, and want to work, but they face a variety of complex barriers to work. That's why I'm so pleased that our proposal for a Medicaid buy-in for people with disabilities was accepted by the Congress as part of the balanced budget. In addition, I am hopeful that bipartisan interest in the "ticket" proposal, to increase the number of people with disabilities who can return to work, will lead to legislative action soon.

Nevertheless, we must do more. My Administration continues to be actively engaged in identifying further steps we can take, as Tony knows.

Blind - happy to work w/ them

- FCC independent, but give grants

- delay: industry opposition, vacancies

- Fed Empl

- Blind/Te

- EO

\*50% on rolls  
capable of BA???

Coelho - 29m wage  
14.2 swee

50% UE overall

25% UE Sec

1/10b SSI/PI + MA/MC

8m -> 10m during 1/2

-> WTW incentives  
but disabled

-> MA + TKT small

but fig.

EO - keep it moving

Priorities - with

lv SSI/Wks comp

- Tax credits

- framp?

- PAS, transp

\$12-22

tech

- educ + trng

- Just got a task

- Not yet fully

pulpit

- Want to pay taxes

D

Q

- Fed govt as model

- needs do better job

- EO crucial

- Level emp

rate maybe

falling

Coelho -

Trump fought

the most;

watch for

ADA SSI

repeals/tell

NEC)\*

P - load up -

will be more

\$ for transp,

but not

inc mass

transit

Bob W - TANF

SDaniels -

bad if

shift to TANF -> SSI

P! TANF

+ Disab

never made

connection before

Edwards not always

VP. I'll follow up

aggr. by on Edu on info

superhighway - explosion of app.

ADA  
SSI Kids  
PAS  
IDEA  
Employment

## MEETING WITH LEADERS OF THE DISABILITY COMMUNITY

DATE: September 10, 1997  
LOCATION: Cabinet Room  
TIME: 10:30 AM to 11:45 AM  
FROM: Maria Echaveste  
Bill White  
Diana Fortuna

### I. PURPOSE

To discuss policy issues affecting people with disabilities.

### II. BACKGROUND

You are meeting 13 national leaders from the disability community as part of your continuing effort to hear directly from key constituencies. The following are the primary issues that will be raised at the meeting: the Americans with Disabilities Act (ADA), Supplemental Security Income eligibility for children (SSI Kids), personal assistant services (CASA), the Individuals with Disabilities Education Act (IDEA), and employment for people with disabilities. Also in the room will be three of your top Administration appointees with disabilities, who have been included because of their substantive knowledge and credibility within the disability community.

After your opening statement, Justin Dart will set the tone for the meeting and congratulate you for your past leadership on issues important to people with disabilities. Justin will assist in moderating the discussion, calling upon 2-3 people to make short presentations on each issue. You will make remarks after each issue is presented as appropriate (see attached talking points). In addition to Justin, you should give special thanks to Fred Fay, Chair of Disability Outreach for Clinton/Gore in '92 and '96, and Becky Ogle, Director of Disability Outreach for Clinton/Gore '96. Fred will be joining us via phone from Concord, Massachusetts because of a severe disability.

Although a variety of disability views will be represented, most of the leaders will have a civil rights orientation (as opposed to a cure focus), and will be discussing ways to empower people with disabilities and assist them in leading independent lives.

A key agenda item is Supplemental Security Income (SSI) eligibility for children. Last year's welfare law tightened the eligibility standards for childhood disability benefits in the SSI program. The disability community has complained that the Administration's interpretation of the legislation was too restrictive. (Tab 6)

Attending the meeting will be two representatives from ADAPT (Americans with Disabilities for Attendant Programs Today). ADAPT was the group that staged a protest at the Georgia Democratic Headquarters on November 4, 1996, and persuaded Alexis Herman to commit to a Presidential meeting. While we have agreed to include ADAPT in the meeting, we have made it clear that this is not ADAPT's meeting, but a meeting with key representatives of the disability community that would have taken place with or without the protest. ADAPT will focus on the issue of personal assistant services and ask you to endorse the Community Attendant Service Act (CASA). (Tab 7)

The final major issue concerns next year's funding for the Individuals with Disabilities Education Act (IDEA). The Republicans have skillfully pulled money from parts of your new education initiatives and given it to IDEA. Advocates are upset about our position that we should stick with our original budget proposal. (Tab 8)

This will be your last event with Bruce Vladeck as HCFA Administrator. You will do a short photo-op with Bruce and his wife Fredda Vladeck before the pre-brief.

### **III. PRE-BRIEF PARTICIPANTS**

|                      |                    |
|----------------------|--------------------|
| Maria Echaveste      |                    |
| Christopher Jennings |                    |
| Bruce Vladeck        | HCFA Administrator |
| Elena Kagan          | DPC                |
| Diana Fortuna        | DPC                |
| Bill White           | OPL                |

### **IV. PARTICIPANTS**

|                      |                                          |                |
|----------------------|------------------------------------------|----------------|
| Justin Dart          | Justice for All                          | Washington, DC |
| Nancy Diehl          | Parents Network on Disability            | Tennessee      |
| Paul Edwards         | American Council of the Blind            | Florida        |
| Fred Fay (Via Phone) | Chair, Clinton/Gore Disability Campaign  | Concord, MA    |
| John Harper          | Student with a disability                | Illinois       |
| Bob Kafka            | ADAPT                                    | Texas          |
| Paul Marchand        | Consortium of Citizens with Disabilities | Washington, DC |
| Gina McDonald        | National Council on Independent Living   | Kansas         |
| Becky Ogle           | Justice For All                          | Maryland       |
| Michael Oxford       | ADAPT                                    | Kansas         |
| Debbie Robinson      | Person with mental retardation           | Pennsylvania   |

#### **ADMINISTRATION APPOINTEES WITH DISABILITIES**

|               |                                                               |
|---------------|---------------------------------------------------------------|
| Marca Bristo  | Chair, National Council on Disability                         |
| Tony Coelho   | President's Comte. on Employment for People with Disabilities |
| Susan Daniels | Social Security Administration                                |
| Judy Heumann  | Department of Education                                       |
| Bob Williams  | Department of Health and Human Services                       |

### **IV. PRESS PLAN**

Closed press

## **V. SEQUENCE OF EVENTS**

- o You will enter the Cabinet Room, walk around the room and greet the participants, and make opening remarks.
- o You will turn to Justin Dart, who will make remarks and outline the issues to be discussed. Justin will then assist in moderating the issue discussion, calling upon 2-3 people to make presentations on each topic.
- o You will make remarks after each topic is presented (see attachments).
- o After the issue discussion, Tony Coelho and Marca Bristo will thank you.
- o You will make closing remarks and depart.

## **VI. REMARKS**

Talking points attached.

### **Attachments:**

|        |                                                                       |
|--------|-----------------------------------------------------------------------|
| Tab 1: | Seating Chart                                                         |
| Tab 2: | Background on Participants                                            |
| Tab 3: | Tips on Talking with People with Disabilities                         |
| Tab 4: | Welcoming Remarks                                                     |
| Tab 5: | Background and Talkers on the Americans with Disabilities Act         |
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| Tab 7: | Background and Talkers on Personal Assistant Services                 |
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| Tab 9: | Background and Talkers on Employment for People with Disabilities     |

## BACKGROUND ON PARTICIPANTS

1. The Honorable Tony L. Coelho  
Coelho Associates, New York, New York

Original House sponsor of the Americans with Disabilities Act (ADA), the landmark civil rights legislation for people with disabilities. Chair of President's Committee on Employment for People with Disabilities. Person with epilepsy.

2. Mr. Justin Dart  
Justice for All, Washington, DC

The statesman of the disability rights movement. A lifelong Republican who endorsed the President in a speech last year at the DNC Convention. Topic: Justin will congratulate you for open the meeting on behalf of the community. Will act as moderator and provide opening remarks that will get meeting started properly.

3. Dr. Frederick A. Fay  
Chairperson - DNC Disability Advisory Committee, Concord, Massachusetts

Pioneer of disability rights movement. Chair of Clinton/Gore disability outreach in both '92 and '96. Operates largest disability community computer network. Person with severe physical disability. (Via speaker phone.) Topic: The ADA and FDR Memorial.

4. Mr. Paul Marchand  
Chairperson of Consortium of Citizens with Disabilities (CCD), Washington, DC

Chair of CCD, an umbrella organization representing 125 disability organizations. Director of government affairs for the ARC, formerly known as the Association for Retarded Citizens. Topic: Supplemental Security Income eligibility for children.

5. Ms. Gina McDonald  
President - National Council of Independent Living, Salina, Kansas

Executive Director of Kansas Association for Independent Living. Presidentially appointed member of the National Council on Disability. Gina has a hearing disability, but will be using an assistive listening device. Topic: Personal Assistant Services.

6. Ms. Becky L. Ogle  
Justice for All, Bethesda, Maryland

One of the best grassroots disability rights organizers in the country. Director of Disability Outreach for Clinton/Gore '96. National advocate for the President's health care program in '94. (Under consideration for an appointment at Labor.)

7. Mr. Bob Kafka

ADAPT (Americans Disabled for Attendant Programs Today), Austin, Texas

National leader/strategist of ADAPT. Adamant advocate for publicly funded personal care assistance that will allow people with disabilities to get out of nursing homes and participate in their communities. Topic: Personal Assistant Services.

8. Mr. Mike Oxford

ADAPT (Americans Disabled for Attendant Programs Today), Topeka, Kansas

Executive Director of the Topeka Independent Living Resource Center. National leader of ADAPT. Topic: Personal Assistant Services.

9. Ms. Nancy J. Diehl

Director - Parent Training & Information Center in Tennessee, Greenville, Tennessee

Parent of a child with a disability. One of the nation's most articulate and respected parent advocates. Topic: Individuals with Disabilities Education Act.

10. Mr. Paul Edwards

President - American Council of the Blind, Miami, Florida

One of the nation's leading advocates for persons who are blind. Topic: Telecommunications for people with disabilities.

11. Ms. Debbie Robinson

Treasurer - Speaking for Ourselves, Plymouth Meeting, Pennsylvania

National leader of people first movement for the rights of people labeled mentally retarded. Articulate. Presidentially appointed member of the National Council on Disability. African-American. Person with mental retardation. Topic: ADA

12. Mr. John Harper

Student, Jacksonville, Illinois

Youth leader, 17 years old. Person who is deaf. Frequent spokesperson for the National Association of the Deaf. Will use a sign language interpreter at the meeting. Note: When talking to John, speak directly to him, not the interpreter. Topic: Individual with Disabilities Education Act and the importance of qualified teachers for students who are deaf and blind.

13. Ms. Marca Bristo

Chair - National Council on Disability (NCD), Chicago, Illinois

Pioneer of disability rights movement. Appointed by the President in 1993 as Chair of the National Council on Disability. President of Access Living of Metropolitan Chicago.

## **TIPS ON TALKING TO PEOPLE WITH DISABILITIES**

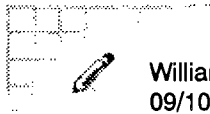
The disability community has a number of sensitivities about language and behavior pertaining to people with disabilities. They are leaders in the emerging civil rights movement for this community, and see this movement as being perhaps 20 years behind African Americans or women in terms of the degree of understanding and sensitivity of the non-disabled community. They believe that denigrating language and behavior is still widely tolerated in our society. In their view, disability is a natural part of life and people with disabilities should be viewed positively, rather than as victims, courageous, or pitied.

The term "people with disabilities" is preferred to "handicapped" or even "the disabled." They often say that, in the spirit of "putting people first," you should look first at the person rather than the disability. People "use" a wheelchair rather than "are in" a wheelchair -- or worse yet, "are confined to" a wheelchair. In general, you should not offer assistance with a basic task such as opening a door or getting seated unless the person appears unable to do so on his or her own.

The Administration's most prominent appointee with a disability is probably Judy Heumann, who is Assistant Secretary at Education in charge of special education and vocational rehabilitation. She played a major role in the development of the independent living movement, which champions people with disabilities living in the community and with their families, and has helped many people leave nursing homes. (The community is very much opposed to nursing homes, viewing them as rarely or never appropriate for people with disabilities.) She is a very constructive internal advocate.

Bob Williams, who is Commissioner of the Administration on Developmental Disabilities (ADD), part of HHS, speaks with a voice machine. When he wishes to speak, he often makes a noise and begins punching into the machine. The etiquette is that other conversations should continue until the artificial voice begins to speak, and then wait until the thought is expressed. Bob is a very thoughtful individual who has also been a leader in the disability movement.

The Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA, which governs special education) are viewed as virtually sacred by the community. The Administration has been extremely strong in supporting these laws. In 1994, the community was very fearful that the Republican takeover of Congress would lead to attempts to weaken these laws. The threat never materialized into proposed legislation, but the community believes it must be ever-vigilant in defending these laws.



William H. White Jr.  
09/10/97 08:23:23 AM

Record Type: Record

To: Maria Echaveste/WHO/EOP, Marjorie Tarmey/WHO/EOP, Mark Hunker/WHO/EOP

cc:

Subject: 10:00 Pre-Brief

As always, say whatever you like, but here are a few thoughts:

For the most part, the room will be filled with friends, Justin, Fred, Becky, Tony C. In addition to Justin, we ask you to pay special recognition to Fred (who will join via speaker phone – I'll bring a picture of Fred so the President can see Fred's set-up.) and Becky who worked day and night on the campaign.

Most folks have a civil rights focus (as opposed to cure focus).

Cross disability representation: blind, deaf, youth, parent, independent living. You will be sitting next to Debbie Robinson, who has mental retardation. She is a self advocate who you appointed to the National Council on Disability.

The main issues will be ADA, SSI Kids, Personal Assistant Services, IDEA, and employment. A few other minor issues may be raised.

We will also have two representatives with ADAPT, who you might recall stirred the pot on election eve in Atlanta and got Alexis to agree to a Presidential meeting. We have made it clear that this meeting would have taken place with or without their protest.

The event will proceed as follows: You go around the room and greet folks at table. (Not staff in room.) You make opening remarks. Turn to Justin, who will open, make a great statement about your leadership, and help to moderate the discussion.

Diana, Bruce, and Bill can go go through some of the issues that will be raised.

## MEETING WITH LEADERS OF THE DISABILITY COMMUNITY

DATE: September 10, 1997  
 LOCATION: Roosevelt Room  
 TIME: 11:00 AM to 12:15 PM  
 FROM: Maria Echaveste  
 Bill White  
 Diana Fortuna

### I. PURPOSE

To discuss policy issues affecting people with disabilities.

### II. BACKGROUND

(Background on meeting.  
 Background on disability community.  
 Background on issues to be discussed.)

### III. PRE-BRIEF PARTICIPANTS

Maria Echaveste  
 Christopher Jennings  
 Bruce Vladek  
 Diana Fortuna  
 Bill White

HCFA Administrator  
 DPC  
 OPL

### IV. PARTICIPANTS

|                      |                                                               |                |
|----------------------|---------------------------------------------------------------|----------------|
| Justin Dart          | Justice for All                                               | Washington, DC |
| Fred Fay (Via Phone) | Chair, Clinton/Gore Disability Campaign                       | Concord, MA    |
| Gina McDonald        | National Council on Independent Living                        | Kansas         |
| Michael Oxford       | ADAPT                                                         | Kansas         |
| Bob Kafka            | ADAPT                                                         | Texas          |
| Paul Marchand        | Consortium of Citizens with Disabilities                      | Washington DC  |
| Paul Edwards         | American Council of the Blind                                 | Florida        |
| Nancy Diehl          | Parents Network on Disability                                 | Tennessee      |
| Debbie Robinson      | Person with mental retardation                                | Pennsylvania   |
| Tony Coelho          | President's Comte. on Employment for People with Disabilities |                |
| Marca Bristo         | Chair, National Council on Disability                         | Illinois       |
| John Harper          | Student with a disability                                     | Illinois       |

### IV. PRESS PLAN

ADA - Fay  
 - Robinson

SSI - March

PBS - M.D.  
 Kafka/Oxford

DEA - Diehl



Harper

Harper/Diehl  
 for day ch.

Employment Coelho  
 - Paul

- 2 issues

Washington, DC  
 Concord, MA

Kansas  
 Texas

Washington DC  
 Florida

Tennessee  
 Pennsylvania

President's Comte. on Employment for People with Disabilities

Illinois

Illinois

Paul Edwards  
 - info on case  
 - info on case  
 - info on case

OD

## MEETING WITH LEADERS OF THE DISABILITY COMMUNITY

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FROM: Maria Echaveste  
Bill White  
Diana Fortuna

### I. PURPOSE

To discuss policy issues affecting people with disabilities.

### II. BACKGROUND

You are meeting 13 national leaders from the disability community as part of your continuing effort to hear directly from key constituencies. The following are the primary issues that will be raised at the meeting: the Americans with Disabilities Act (ADA), Supplemental Security Income eligibility for children (SSI Kids), personal assistant services (CASA), the Individuals with Disabilities Education Act (IDEA), and employment for people with disabilities. In addition, telecommunications and Presidential appointments for people with disabilities will also be raised. Also in the room will be five of your top appointees with disabilities, who have been included because of their substantive knowledge and credibility within the disability community.

After your opening statement, Justin Dart will set the tone for the meeting and congratulate you for your past leadership on issues important to people with disabilities. Justin will assist in moderating the discussion, calling upon 2-3 people to make short presentations on each issue. You will make remarks after each issue is presented as appropriate (see attached talking points). In addition to Justin, you should give special thanks to Fred Fay, Chair of Disability Outreach for Clinton/Gore in '92 and '96, and Becky Ogle, Director of Disability Outreach for Clinton/Gore '96. Fred will be joining us via phone from Concord, Massachusetts because of a severe disability.

Although a variety of disability views will be represented, most of the leaders will have a civil rights orientation (as opposed to a cure focus), and will be discussing ways to empower people with disabilities and assist them in leading independent lives.

Attending the meeting will be two representatives from ADAPT (Americans with Disabilities for Attendant Programs Today). ADAPT was the group that staged a protest at the Georgia Democratic Headquarters on November 4, 1996, and persuaded Alexis Herman to commit to a Presidential meeting. While we have agreed to include ADAPT

in the meeting, we have made it clear that this is not ADAPT's meeting, but a meeting with key representatives of the disability community that would have taken place with or without the protest. ADAPT will focus on the issue of personal assistant services and ask you to endorse the Community Attendant Service Act (CASA), legislation that mandates states to provide people with disabilities who are eligible to be in nursing homes the option of community based attendant services. This is an issue you raised in the '92 campaign, and attempted to address during the health care debate in '94. (FYI, Secretary Slater met with ADAPT yesterday regarding ADA regulations on Greyhound buses and made a commitment to address the issue.)

(See att)

The other key issue is Supplemental Security Income (SSI) eligibility for children. Last year's welfare law tightened the eligibility standards for childhood disability benefits in the SSI program. The disability community has complained loudly that the Administration's interpretation of the legislation was too restrictive. The Social Security Administration, which is monitoring the case review closely, estimates that 135,000 children will lose benefits as a result of the tighter eligibility standards. Children with moderate mental retardation, mild learning disabilities and attention deficit disorder appear to be the types of children most affected. Paul Marchand, who chairs the disability umbrella organization called the Consortium of Citizens with Disabilities (CCD), will raise the issue.

This will be your last event with Bruce Vladeck as HCFA Administrator. You will do a short photo-op with Bruce and his wife Fredda Vladeck before the pre-brief.

### III. PRE-BRIEF PARTICIPANTS

|                      |                    |
|----------------------|--------------------|
| Maria Echaveste      |                    |
| Christopher Jennings |                    |
| Bruce Vladeck        | HCFA Administrator |
| Diana Fortuna        | DPC                |
| Bill White           | OPL                |

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| John Harper          | Student with a disability                | Illinois       |
| Bob Kafka            | ADAPT                                    | Texas          |
| Paul Marchand        | Consortium of Citizens with Disabilities | Washington, DC |
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|               |                                                               |
|---------------|---------------------------------------------------------------|
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| Tony Coelho   | President's Comte. on Employment for People with Disabilities |
| Susan Daniels | Social Security Administration                                |
| Judy Heumann  | Department of Education                                       |
| Bob Williams  | Department of Health and Human Services                       |

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Closed press

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### VI. REMARKS

Talking points attached.

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## Attachment I

|                             |                       |                      |                          |                             |                            |                      |
|-----------------------------|-----------------------|----------------------|--------------------------|-----------------------------|----------------------------|----------------------|
| Michael<br>Oxford<br>Kansas | Bob<br>Kafka<br>Texas | Justin<br>Dart<br>DC | The<br>Vice<br>President | Nancy<br>Diehl<br>Tennessee | John<br>Harper<br>Illinois | Tony<br>Coelho<br>DC |
|-----------------------------|-----------------------|----------------------|--------------------------|-----------------------------|----------------------------|----------------------|

|                        |                            |                                    |                  |                           |                            |                             |
|------------------------|----------------------------|------------------------------------|------------------|---------------------------|----------------------------|-----------------------------|
| Paul<br>Marchand<br>DC | Gina<br>McDonald<br>Kansas | Debbie<br>Robinson<br>Pennsylvania | The<br>President | Becky<br>Ogle<br>Maryland | Paul<br>Edwards<br>Florida | Marca<br>Bristo<br>Illinois |
|------------------------|----------------------------|------------------------------------|------------------|---------------------------|----------------------------|-----------------------------|

## BACKGROUND ON PARTICIPANTS

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The statesman of the disability rights movement. A lifelong Republican who endorsed the President in a speech last year at the DNC Convention. Topic: Justin will congratulate you for open the meeting on behalf of the community. Will act as moderator and provide opening remarks that will get meeting started properly.

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Pioneer of disability rights movement. Has reverential respect of entire disability community. Chair of Clinton/Gore disability outreach in both '92 and '96. Operates largest disability community computer network. Person with severe physical disability. (Via speaker phone.) Topic: The ADA and FDR Memorial.

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Chair of CCD, an umbrella organization representing 125 disability organizations. Director of government affairs for the ARC, formerly known as the Association for Retarded Citizens. Decades as leading Washington advocate. Topic: Supplemental Security Income eligibility for children.

5. Ms. Gina McDonald  
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Executive Director of Kansas Association for Independent Living. Presidentially appointed member of the National Council on Disability. Note: Gina has a hearing disability, but will be using an assistive listening device. Topic: Personal Assistant Services.

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Parent of a child with a disability. One of the nation's most articulate and respected parent advocates. Topic: Individuals with Disabilities Education Act.

10. Mr. Paul Edwards  
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Miami, Florida

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Treasurer - Speaking for Ourselves  
Plymouth Meeting, Pennsylvania

National leader of people first movement for the rights of people labeled mentally retarded. Articulate. Presidentially appointed member of the National Council on Disability. African-American. Person with mental retardation. Topic: ADA

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Pioneer of the independent and disability rights movement. Appointed by the President in 1993 as Chair of the National Council on Disability. President of Access Living of Metropolitan Chicago.

## TIPS ON TALKING TO PEOPLE WITH DISABILITIES

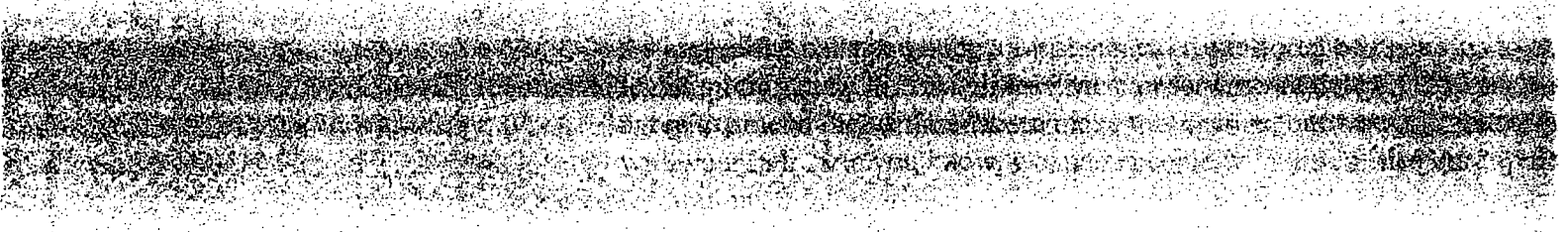
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The Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA, which governs special education) are viewed as virtually sacred by the community. The Administration has been extremely strong in supporting these laws. In 1994, the community was very fearful that the Republican takeover of Congress would lead to attempts to weaken these laws. The threat never materialized into proposed legislation, but the community believes it must be ever-vigilant in defending these laws.



## WELCOMING REMARKS

- o Welcome to the Cabinet Room of the White House.
- o Joining me today are several key members of my Administration, including Maria Echaveste, who directs my Public Liaison Office, Chris Jennings, my senior health care advisor, Administrator Bruce Vladek from HCFA, my friend Tony Coelho from the President's Committee on Employment for People with Disabilities, Judy Heumann from the Department of Education, Marca Bristo from the National Council on Disability, and Bob Williams from HHS.
- o I'm proud of our record of working to increase the independence, inclusion, and empowerment of people with disabilities. (We couldn't have gotten this far without the support of so many of you around this table today.)
- o I understand that people with disabilities are not looking for special treatment, but equal access to the American dream. I understand the importance of integrating disability issues into all policies and programs of the Administration, a task at which both Judy Heumann and Bob Williams have had great success.
- o On the other hand, I recognize how far we have yet to go. Justin can best put it in a historical context for us, but we know that the disability rights movement is still comparatively young. We have a vision of how the world ought to work, but we clearly aren't there yet. I am determined to move ahead.
- o On critical civil rights laws, we have vigorously enforced the ADA, and we have defended it from ignorant and malicious attacks. This year, with the critical assistance of Assistant Secretary Judy Heumann [who is at the meeting] we secured the reauthorization of the IDEA in a manner that reaffirms our nation's commitment to children with disabilities and their parents.
- o On the key issue of health care for people with disabilities, we haven't gotten as far as I would have liked, as you know. But we fought hard and won our fight to preserve the Medicaid guarantee, when it was under attack in 1995 and 1996, a change that would have been so dangerous for people with disabilities, among many others.
- o As part of the balanced budget I just signed, we restored SSI benefits to over 300,000 legal immigrants with disabilities. Most observers predicted that Congress would never agree to amend the welfare law to make this change, but we were able to persuade them with your help. As you know, we made people with disabilities our top priority for restorations.

- o We are moving forward to improve employment prospects for people with disabilities. The balanced budget included a modified version of my proposal to let states offer a Medicaid buy-in for people on SSI who want to return to work. In addition, my proposal to offer a "ticket" to those on SSI or SSDI who are seeking to return to work is under active consideration on the Hill.
- o But I also know there are areas where we can and must do more, and I'm looking forward to a substantive discussion.
- o Before we begin, I want to give special recognition to Fred Fay who is joining us via speaker phone from his home in Concord, Massachusetts, and Becky Ogle, who worked night and day organizing the disability community both in '92 and '96.
- o Justin, why don't you lead us off.

## ADA ENFORCEMENT

### Advocates Who Will Discuss:

- Fred Fay, Chair, DNC Disability Advisory Committee
- Ms. Debbie Robinson, Speaking for Ourselves

### Administration Officials Present:

- Marca Bristo, Chair, National Council on Disability

**Background:** Passed in 1990 with bipartisan support, the ADA provides civil rights protections for persons with disabilities parallel to those established by the Federal government under the Civil Rights Act, in the areas of employment, public accommodations, transportation, and telecommunications. The law is the central achievement of the disability movement.

One emerging concern is that some courts have ruled that people on SSI and SSDI can't sue under the ADA for employment discrimination, because their disability application requires them to assert that they can't work. EEOC and SSA have filed amicus briefs supporting people with disabilities on this issue.

### What Advocates Will Say:

- The ADA is so critical to the disability community. We appreciate your strong support for it. We encourage the Administration to increase its enforcement efforts.

### ADA Talking Points:

- Vigorous enforcement of the Americans with Disabilities Act (ADA) has been a top priority of my Administration. The Justice Department, the EEOC, and other federal agencies have established aggressive enforcement programs. We have emphasized voluntary compliance, but have not been afraid to litigate when entities fail to comply with the law.
- Although we have been quite successful, we all know we have a long way to go. Our resources are not sufficient to address the majority of meritorious complaints received in a timely fashion.
- My budgets have consistently called for an increase for ADA enforcement at the Department of Justice. However, the Congress has failed to approve these increases, which is indirectly weakening the important law.
  - FY 1998: 5% (\$477,000)
  - FY 1997: 3.9% (\$361,000)
- I am committed to significantly increasing ADA enforcement resources in the FY 1999

budget I will submit to Congress early next year. This Administration recognizes additional resources are necessary to strengthen a comprehensive enforcement program that seeks to achieve greater access for persons with disabilities at home, in their communities, and in the workplace. [DOJ's request to OMB calls for a 19% increase of \$2,173,000.]

- The ADA became law because your organizations, both nationally and at the grassroots level, worked together to educate the Congress on why the law was urgently needed. You won because you were well-organized and persistent. I will fight for greater funding, but the only way to make this a reality is if the disability community can make this a priority with the Congress.

## INDIVIDUALS WITH DISABILITIES EDUCATION ACT

### Advocates Who Will Discuss:

- Nancy Diehl, Parent Network on Disability
- John Harper, Student with a Disability

### Administration Officials Present:

- Judy Heumann, Assistant Secretary, Department of Education

**Background:** IDEA was reauthorized in June of this year, after an elaborate bipartisan process led by Senator Lott that reconciled all the competing interests of schools, parents, teachers, and others. IDEA has civil rights protections that give children with disabilities the right to attend school. The Administration has been extremely supportive of the disability community on IDEA. School boards and the unions often view IDEA as an "unfunded mandate" that is a drain on budgets. They point out that federal funds support only 7-8% of the costs of special education, even though the original legislation foresaw federal payments covering 40% of costs. We have fought the "unfunded mandate" interpretation in a number of settings, instead stressing that IDEA is a civil rights law that shouldn't be weakened or tampered with.

However, advocates are upset that we are opposing the Senate's large increases in IDEA funding. The Senate is funding IDEA at the expense of Administration priorities such as Goals 2000 and America Reads. We suggested in a recent SAP that IDEA is adequately funded at our requested level, and that the Senate should redirect funds to Administration priorities. Advocates have misread that SAP to say that we consider IDEA a "low priority program."

The administration was the first to propose a significant increase in IDEA appropriations in the 1997 budget 17%. Congress provided a 34% increase. For 1998 we proposed an inflationary increase (\$129,000,000). While the final figures are not out the House is proposing an increase of more than \$300,000,000 and the Senate is seeking an \$800,000,000 increase.

### What Advocates Will Say:

- Thank you for your leadership on IDEA reauthorization. It is critical to our kids' futures.

### IDEA Talking Points:

- The passage of the IDEA was a tremendous success for the Administration. The bipartisan approach which was used during the reauthorization enabled us to produce a bill which I believe will help to ensure that disabled children across this country have the ability to obtain a quality education that will result in their graduation from high school, ability to pursue higher education and obtain meaningful employment.
- Secretary Riley and his staff worked diligently with all constituencies to ensure that the legislation which was passed maintained strong civil rights protections for children with disabilities. Our principle from the beginning has been that "ALL" children must be able to take advantage and benefit from the educational reforms occurring across this country.

- I have supported increases in funding for IDEA over the past five years while seeking to improve the overall federal investment in education. I very much support the fact that disabled children and adults are increasingly being educated in inclusive settings. I believe this affords our country greater opportunities to ensure that we accept disabled people as being a meaningful part of the fabric of our country.

- As you know I have made education one of my highest priorities. The passage of IDEA was critical to ensure that disabled children will be able to benefit from the other educational programs we have been designing such as the HOPE scholarships, and America Reads.

- Your active support to ensure that this legislation is effectively understood and implemented will be critical.

- The signing of the IDEA at the White House was one of the most important moments in my tenure. We couldn't have done it without you then and we will not be able to do it without you in the future.

## SUPPLEMENTAL SECURITY INCOME ELIGIBILITY FOR CHILDREN

### Advocates Who Will Discuss:

- Paul Marchand, the Arc; Chair, Consortium of Citizens with Disabilities

### Administration Officials Present:

- Susan Daniels, Associate Commissioner for Disability, SSA

**Background:** Last year's welfare reform law set a stricter definition of disability for children's SSI, after unsubstantiated media reports that children faked disabilities to get benefits, and concerns that the program tripled in size since 1989 to one million children. The Administration fought successfully against block granting the program, but ultimately acquiesced to the new definition. The new law explicitly eliminated an eligibility test known as the "IFA" that allowed many children with less severe disabilities to qualify for the program, particularly mental disabilities. Estimates at the time were that 180,000 children would lose benefits.

After the law was signed, a small group of Senators (Conrad, Chafee, Daschle) and advocates alleged that SSA had legal authority to recreate most of the IFA via regulation, cutting off only 35,000 children. SSA ultimately determined that doing so was contrary to congressional intent and the bipartisan understanding at the time. SSA's regulation had modest changes that brought the impact down to 135,000 children.

SSA is now more than half-way through reevaluations of the cases of 270,000 children. <sup>Over</sup> ~~About~~ 100,000 children have lost eligibility to date. The final number of children cut off is expected to be close to SSA's estimate of 135,000. However, advocates allege SSA is discouraging appeals and is not implementing the new standard consistently across the country.

### What Advocates Will Say:

- Your administration chose an unnecessarily tough standard when interpreting Congress's intent to tighten up on this program. SSA should reconsider its position. (Paul Marchand feels strongly that the law discriminated against children with mental retardation.)
- ~~Advocates~~ Advocates and experts have suggested more modest changes to SSA's regulation. SSA should stop the cutoffs to take time to consider and respond to these suggestions.
- In SSA's reviews, disturbing trends have emerged. Few families are appealing SSA's decisions. SSA may be discouraging appeals. There are dramatic differences among states. Mississippi has terminated more than 80% of the cases it has reviewed, while Pennsylvania and California have terminated a little over a third of cases. Instead of rushing to get through this workload, SSA should stop and ensure that families have all the rights and information they are entitled to.

### **SSI Kids Talking Points:**

- I know that Acting Commissioner John Callahan met with a group of advocates (including the Arc) just last week to talk about these issues, and we appreciate your constructive involvement in this critical process.
- I am pleased that, as part of the balanced budget I signed into law, we were able to grandfather Medicaid benefits for all these children, so that none of them will lose health insurance.
- As you know, I did not seek these changes in the children's SSI program, and I fought against the SSI block grant and other proposals that would have been far worse than what we ended up with.
- When the law was enacted, my Administration, acting through the Commissioner of Social Security, examined the evidence and interpreted the law to create a standard that was consistent with her best reading of congressional intent. SSA does not believe that a more liberal interpretation is legally possible.
- I know SSA is committed to ensuring that these reviews are conducted consistently and fairly, and takes this responsibility extremely seriously. Because this issue is so critical, I have asked Commissioner Callahan to report back to me on the concerns you are raising within 30 days.

**Possible Question:** SSA says that our preferred interpretation is not legal, but documents have come to light showing that SSA did consider that option. What do you say about that?

**Answer:** My understanding is that SSA developed the documents you're talking about as part of their process for making a decision on the legal merits, but ultimately came to the conclusion I described earlier.

## PERSONAL ASSISTANT SERVICES

### Advocates Who Will Discuss:

- Gina MacDonald, National Center for Independent Living ("nickel")
- Bob Kafka and Mike Oxford, ADAPT

### Administration Officials Present:

- Bruce Vladeck, HCFA Administrator
- Bob Williams, new Deputy Assistant Secretary for Disability Policy at HHS (has a severe disability; was just promoted from elsewhere in HHS to this job. Bob speaks through a device called a liberator.)

**Background:** ADAPT believes that people with disabilities are "imprisoned" in nursing homes because Medicaid is biased against home and community-based services. Today, states limit these services through waivers that cap the number of participants, while nursing home eligibility is more open-ended.

**CASA:** ADAPT will push for your support of their bill, the Medicaid Community Attendant Services Act. CASA requires states to cover community-based attendant services for those now eligible for nursing home care. It also gives beneficiaries a greater say in how those dollars are spent. Under pressure from ADAPT, Speaker Gingrich introduced CASA in June without endorsing it, instead calling it a "starting point" for an important dialogue and noting it has cost implications. Rep. Gephardt has also signed on as a co-sponsor. ADAPT knows that CASA is unlikely to pass in its current form, but views its introduction as a great victory. (CASA is not the highest priority of other disability groups, some of which have specific reservations about it.)

The Administration has not taken a position on CASA prior to this meeting. We have two major concerns about it. First, although it has a spending cap, CASA would have significant costs. It would require services for as many as one million people who now live at home but are so severely disabled that they could qualify for nursing home care. Further, any nursing home beds vacated by those moving to the community are likely to be filled promptly. Second, giving beneficiaries control of significant Medicaid dollars raises critical questions about quality standards, fraud, and whether Medicaid should pay family members for care.

Although we can't support CASA, we can support CASA's principles while recognizing our serious concerns. In response to a June meeting with ADAPT, HHS just formed a work group to identify next steps, including working with states on demonstrations of these principles. Finally, you can inform the group that you are writing Speaker Gingrich to lay out your position on CASA.

**Date Certain:** Recognizing that CASA raises these concerns, ADAPT is now pushing a more immediate fallback option. Known as the "date certain" concept, it would allow all individuals who are actually in nursing homes as of a certain date to move to community

settings if they wish. While this approach solves some of CASA's problems, it would still cost money since the nursing home beds would be filled by new patients.

**What Advocates Will Say:**

- People with disabilities are dying in nursing homes, and incremental steps are not enough.
- Do you support CASA, the bill introduced by Speaker Gingrich and supported by Rep. Gephardt, that would let people with disabilities live independently in their own homes at a lower cost?
- If you can't support CASA, can't you at least support a "date certain" policy?

**Personal Assistant Services Talking Points:**

- As many of you know, this is an issue that I have cared about for a long time, and I am pleased that we have made the progress we have made.
- My Administration has made it easier than ever for states to get waivers for home and community-based services. About a quarter of a million people are now served in these programs, and HCFA is continuing to push states to make these services available.
- We would have made more progress if health care reform had been enacted, including our proposal for a block grant for these services. More recently, we were rebuffed by Congress in our efforts to further simplify the waiver process.
- Other positive steps we are taking:
  - Under the balanced budget, we just got rid of the old requirement that you can't get certain supported employment services unless you were in an institution.
  - This week, HHS is lifting the requirement that personal care services must be supervised by a nurse, as part of a new rule that allows states to offer these services in the home or locations outside the home, including the workplace.
  - HHS has a number of critical demonstration projects going on.
- Because of a meeting with ADAPT in June, HHS has a new work group that is working with you. By the end of the year, it will complete its policy review to identify provisions that contribute to Medicaid's institutional bias. It will also work with states to develop demonstrations of the principles of CASA, and I have asked them to report to me by the end of February with an action plan.

- I am also asking the work group to examine linking the need for more qualified attendants with state welfare reform work requirements under TANF. Linking the needs of people with disabilities for attendants and the needs of low-income families for jobs seems to be well worth pursuing.
- Although Bruce Vladeck, who has been instrumental in this process as HCFA Administrator, is leaving the Administration shortly, I am pleased that Bob Williams [who is in the room] will play a key role in this process. Bob has just been named Deputy Assistant Secretary at HHS.
- I strongly support the principles of CASA but, as you know, it appears that the bill would have significant costs. In addition, there are unanswered questions about quality, particularly if one were to move quickly toward consumer-directed models that are at this point untested. Nevertheless, I want to send a strong signal that I believe CASA is an excellent vehicle for discussing our mutual goals and allowing us to move forward on them. Therefore, I plan to send a letter to Speaker Gingrich applauding his action in introducing CASA, and seeking to work with him and others on this.
- [If you are pushed on the "date certain" concept:] My understanding is that the date certain concept would also increase Medicaid costs. However, the work group is committed to working with states on demonstrations of this idea, along with others.

## EMPLOYMENT OF PEOPLE WITH DISABILITIES

### Advocates Who Will Discuss:

- Tony Coelho, Chair, President's Committee on Employment of People with Disabilities
- Paul Edwards, American Council of the Blind

### Administration Officials Present:

- Susan Daniels, Associate Commissioner for Disability, SSA

**Background:** ~~In spite of the ADA, the unemployment rate of people with disabilities remains high. It is approximately 75% for people with severe disabilities. While the rate has improved since the passage of the ADA and more improvement is expected, the~~ disability community argues we must focus on barriers to work that prevent people with disabilities from working, ~~particularly those who are on SSI or SSDI. These problems include eventual loss of Medicaid or Medicare if they return to work; higher costs for items like personal assistance services, computer accommodations, and transportation; less than full access to education and to mainstream employment and training programs; as well as continuing discrimination.~~

**Medicaid Buy-in:** The balanced budget included a ~~modified form that will~~ <sup>President's budget proposal in</sup> help people with disabilities work without losing their health care coverage. Today people on SSI who go to work lose Medicaid if their earnings exceed caps that vary by state. Since it is so difficult for people with disabilities to get private insurance, many people who are eligible for SSI "manage" their income to ensure that they keep Medicaid --by stopping work when they hit the caps, or even turning down promotions.

This new state option will allow SSI beneficiaries with disabilities who earn more than these caps to keep Medicaid by contributing to the cost of their coverage as their income rises. The final version included an income cap of 250% of poverty that will limit the usefulness of this proposal in some states.

**SSI Ticket Proposal:** The President's budget included a new "pay for results" strategy to encourage more SSDI and SSI beneficiaries to return to work. Under this pilot proposal, SSDI and SSI beneficiaries could choose their own public or private rehabilitation providers. Providers who successfully assist beneficiaries in leaving the rolls and returning to work would be paid a percentage of the disability benefits saved. These payments would continue only as long as the person remained off the rolls, up to a maximum of five years. Because providers would be rewarded for results rather than for their costs, this should encourage more providers to have a continuing interest in their clients' long term success, which in turn may lead to more beneficiaries returning to work.

Republicans and Democrats on the Hill have put forth similar proposals (Rep. Bunning proposed this concept before we did), so there is hope of action on this soon.

Note: The Administration's appointees with disabilities, led by Tony Coelho, are urging us to issue an executive order that would make this issue a priority and set up a task force to identify further actions to solve this problem. However, it is not appropriate to discuss that issue here since we have not yet made a decision on the executive order within the Administration.

#### **What Advocates Will Say:**

- Tony Coelho: We appreciate the Administration's efforts on this issue, including its proposal that states can offer SSI recipients a "buy-in" to Medicaid as their income rises, as well as its "ticket to independence" proposal. However, more must be done. The most critical area is health care. We also believe that Treasury should seriously consider offering tax credits to people with disabilities, who so often face higher costs.
- Paul Edwards: We are concerned to see the declining rate of employment of people with disabilities in the federal government.
- Paul Edwards: We are concerned about access to the information superhighway for the blind.

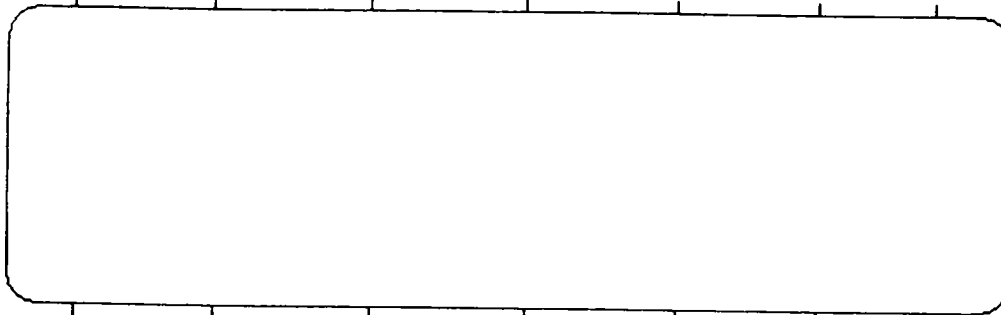
#### **Employment Talking Points:**

- This is clearly the next frontier for people with disabilities. A large and growing number of people with disabilities can work, and want to work. With the help of the ADA and technology advances, society is coming to recognize that being disabled does not mean you can't contribute to our nation's economy. However, people with disabilities face a variety of complex barriers to work.
- That why I'm so pleased that our proposal for a Medicaid buy-in for people with disabilities was accepted by the Congress as part of the balanced budget.
- In addition, I am hopeful that the bipartisan interest in the "ticket" proposal, to increase the number of people with disabilities who can return to work, will lead to legislative action soon.
- Nevertheless, we must do more. My Administration continues to be actively engaged in identifying further steps we can take, as Tony knows.

## Attachment I

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|                             |                       |                      |                          |                             |                            |                      |
|-----------------------------|-----------------------|----------------------|--------------------------|-----------------------------|----------------------------|----------------------|
| Michael<br>Oxford<br>Kansas | Bob<br>Kafka<br>Texas | Justin<br>Dart<br>DC | The<br>Vice<br>President | Nancy<br>Diehl<br>Tennessee | John<br>Harper<br>Illinois | Tony<br>Coelho<br>DC |
|-----------------------------|-----------------------|----------------------|--------------------------|-----------------------------|----------------------------|----------------------|



|                        |                            |                                    |                  |                           |                            |                             |
|------------------------|----------------------------|------------------------------------|------------------|---------------------------|----------------------------|-----------------------------|
| Paul<br>Marchand<br>DC | Gina<br>McDonald<br>Kansas | Debbie<br>Robinson<br>Pennsylvania | The<br>President | Becky<br>Ogle<br>Maryland | Paul<br>Edwards<br>Florida | Marca<br>Bristo<br>Illinois |
|------------------------|----------------------------|------------------------------------|------------------|---------------------------|----------------------------|-----------------------------|

Enforcement guidance in feb 96; amicus briefs in lots of cases; ssa weighed in on dc circuit case, saying shouldn't be estopped; doj filed for them

##### FACSIMILE SHEET #####

**SOCIAL SECURITY ADMINISTRATION**

Office of the Commissioner  
500 E Street, S.W., Suite 850  
Washington, DC 20254

Date: 9-8-97Number of Pages: 5From: Brian D. Coyne  
Chief of StaffTo: Diana Fortuna

Location/Organization: \_\_\_\_\_

Telephone Number: (202) 358-6013

Telephone Number: \_\_\_\_\_

Fax Number: (202) 358-6076

Fax Number: 452-7431

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**Message:**

The Washington, D.C. Office of the Commissioner has relocated effective October 28, 1996. Please note the new address, telephone and fax numbers listed above.

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Background Paper 1 2 Q & A's

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## SSI Kids

Disabled children have been eligible for benefits under the SSI program since its inception in 1974. Children are eligible to receive the same amount as disabled or blind adults. Prior to 1990, the criteria used to determine disability in children was limited to "listed impairments."

Following the 1990 Supreme Court decision in Sullivan v Zebley, the Social Security Administration, in order to fulfill the mandate of the court, revised the disability criteria to pay children with significantly less severe disabilities, adding an "individualized functional assessment" for each child that did not meet the previous criteria. Around the same time, SSA implemented more comprehensive rules for children with mental impairments pursuant to the 1984 Amendments which directed this change. Under both the new rules for mental impairments, and the individualized functional assessment, children's abilities and limitations were assessed in various domains of functioning.

Following these two changes, the number of disabled children on the SSI rolls grew from less than 300,000 in 1989 to about one million in 1996. This growth drew media and Congressional attention. Criticism ranged from complaints that children with marginal disabilities were receiving benefits, to allegations that parents were coaching children to do poorly in school in order to receive benefits.

Although wide-spread evidence of coaching was never found, many teachers were critical of the program, believing that the cash benefits were attractive to parents and provided a disincentive to maximize a child's abilities. The National Commission on Childhood Disability's report in 1995 and other reports at the time, recommended revising the eligibility criteria to be more restrictive so that children with less severe disabilities, such as learning disabilities and mild behavioral problems, would no longer be eligible for benefits.

In 1995, the House of Representatives passed legislation to restrict the number of children receiving SSI benefits. Under their proposal most children would have lost cash benefits, receiving instead non-cash benefits under a block grant program administered by the States. This provision was dropped in favor of an approach that was approved in the Senate and which was included in the Personal Responsibility Act and Work Opportunity Reconciliation Act of 1996.

In this legislation, cash benefits were retained for disabled children under the SSI program, but the disability standard for children was tightened. In particular a new statutory definition of disability for children was enacted, and the individualized functional assessment was eliminated. The rules for mental impairments were largely left intact, with the exception of the deletion of "maladaptive behavior" because of concern that it was weighted too heavily in the criteria.

Under the new statutory definition of disability, a child can be eligible for SSI only if he or she has a medically determinable physical or mental impairment which results in marked and severe functional limitations. In addition, the condition must be expected to last (if it hasn't already) for one year or be expected to end in death. In general, this definition has been interpreted to mean that a child's impairment or impairments must be of "listing level" (or equivalent) severity in order to be considered disabling. In assessing disabilities based on their impact on a child's ability to function, "listing level" severity has been taken to mean, at a minimum, marked limitations in at least two areas of functioning.

Children who had been entitled under the individualized functional assessment or who were entitled based on maladaptive behavior were to be reevaluated to determine if they met the new criteria. Out of the one million children on the rolls, SSA is reviewing the entitlement of approximately 270,000 children.

SSA estimates that about 135,000 children will lose their entitlement to benefits as a result of these reviews. To date, SSA has determined that about 100,000 children do not meet the new standard of disability. These children have full appeal rights to have this decision reviewed and may elect to continue to receive benefits while their case is under appeal. Advocates for disabled children have said that SSA's new rules for children are too strict and do not reflect Congressional intent. However, the statutory language and accompanying Conference report language provide little latitude for a more liberal interpretation of the rules.

Critics argue that SSA could have used a lesser standard than the one that was adopted, which is "marked limitations in two areas of functioning". Critics have suggested that a standard of "one marked and one moderate" would be more appropriate. (Under the individualized functional assessment, a child could qualify with "one marked and one moderate limitation" or with "three moderate limitations.") However, the statutory language specifically invalidated the individualized functional assessment, which used the "one marked/one moderate" standard. Further, the conference report language says that in those areas that involve functioning, no less than two marked limitations would be the standard for qualification.

SSA incorporated several new features into the rules to ensure that children with severe disabilities were not overlooked. The incorporation of these elements reduced the projected number of children whose eligibility would be ended from 185,000 to 135,000. In particular SSA emphasized a step called "functional equivalence" that allows a child with any impairment(s) to qualify based on marked functional limitations in two areas of functioning. SSA also included additional guidance on physical impairments, on chronic and/or episodic impairments and created a new form to document that all steps were completed for each child.

## SSI Kids

Q. Mr. President, there are many problems with the Social Security Administration's review of disabled children under the new eligibility criteria for SSI. In particular, children are being denied due process. Parents are being discouraged from filing appeals when they are told that their children's entitlement will end. There is an unprecedented low appeal rate, 10-15 percent, in this most vulnerable group. And if parents do appeal, the Social Security employees are discouraging them from requesting that benefits be continued while the case is under appeal by insisting that these benefits must be paid back if the child is not found to be entitled. These overpayments are frequently waived.

A. Anyone would be concerned, as I am, that this most vulnerable group be afforded all of their rights. And I want to be sure that the Social Security Administration protects these rights. I understand that parents have 60 days to file an appeal. Of those claims that have completed the 60-day time period, 44 percent of parents have filed an appeal. I believe that previous low estimates did not take into consideration that many parents were still in the appeal period and had not yet taken action to file an appeal. I understand that the Social Security Administration expects that rate to continue and that it is comparable to appeal rates for other types of cases.

Of those parents who have filed for appeal, 63 percent have asked that benefits be continued during the appeal. The Social Security Administration has already taken action to ensure that all employees have clarified instructions for advising parents about benefit continuation to ensure that this option is clearly understood and that parents can make an informed choice on whether or not to elect his option. The Agency is also reviewing these and other issues to ensure that parents and children are protected.

### **Additional Background:**

The Agency is reviewing the appeal rate/benefit continuation allegations to determine if any other actions are needed. In addition, The Agency has agreed to review any egregious cases in its Central Office using a special group of policy experts. The agency is also reviewing a number of other concerns raised by the advocates to ensure that implementation of the new criteria is being done fairly and in accordance with due process procedures.

The Agency has not agreed to place 800 numbers of various legal aid groups in the notices to parents, because some areas, such as Pennsylvania, might have legal support, but other parts of the country do not. Instead, every field office has a list of pro bono legal service agencies in its service area. The notice advises parents that if they need legal assistance to call the local field office.

The Agency has also stated it will investigate any instances in any office where individuals may have been discouraged from appealing and will take quick action to resolve any instances where this may have happened.

## SSI Kids

Q. Mr. President, The Administration has made a mistake. The new rules put into place by the Social Security Administration in February of this year are much too restrictive and thousands of severely disabled children are being cut off from needed SSI benefits. We have been told that the Agency did not have the authority to issue less restrictive criteria. However, we know that as late as January of this year, one month before the new rules were issued, the Social Security Administration was developing rules that would be more lenient. Will you ask the Social Security Administration to review its interpretation of the law?

A. I understand this is a complex legal standard and that the Social Security Administration wrestled with this issue at great length. I know the Agency took a long time developing the new rules and much of that deliberation was to ensure that this issue was given full consideration. I understand there are differing opinions on the interpretation of the statutory language and conference report language. In fact Congressional leaders have voiced different interpretations of Congressional intent. I know the Social Security Administration is reviewing these points carefully in light of the comments they have received and these points will be addressed in the publication of the final rules.

### Additional background:

Critics are suggesting that the Agency establish a standard that was previously used under the individualized functional assessment which was specifically eliminated in the Personal Responsibility and Work Opportunity Act of 1996. Further, the conference language describes a level of severity contemplated by the new law that is significantly more restrictive than previously used under the individualized functional assessment. Given these two facts it would be difficult to establish a standard at the level of severity suggested by the critics. It would be illogical, if not illegal, to reestablish the same standard that was specifically struck by the law.

To help analyze this issue, the Social Security Administration drafted in late Fall a version of the new rules based on the more lenient interpretation as expressed by advocates. This process helped to crystallize the issue and pointed out that the suggested rationale for using the less severe standard was not supported. Various points raised in the draft regulation were subsequently addressed in the regulations that were published.

## AMERICANS WITH DISABILITIES ACT -- SUMMARY

The Americans with Disabilities Act (ADA) provides civil rights protections for persons with disabilities parallel to those established by the Federal government under the Civil Rights Act.

**1. Employment:** The ADA requires employers to make reasonable accommodations to the known physical and mental limitations of a qualified applicant or employee unless that imposes an undue hardship on the employer. Accommodations in most cases can be made at little or no cost, and could include making worksites accessible, modifying equipment or work schedules, providing new devices, restructuring jobs, or providing readers or interpreters.

Administrative enforcement is done by the Equal Employment Opportunity Commission, after which individuals have the right to sue in court; however, compensatory damages are limited to \$300,000 plus back pay.

The ADA excludes people who currently use illegal (?) drugs from its protections, but it does prohibit discrimination against recovering drug addicts and alcoholics and against individuals who have successfully completed rehabilitation.

**2. Transportation:** The ADA requires that individuals with disabilities have access to transportation. All new public buses must be accessible to persons with disabilities. No retrofitting of buses is required. Transit authorities must provide paratransit or other special transportation services to those individuals who cannot use regular bus service. All new rail vehicles and stations must be accessible. Existing rail systems and stations are given specific deadlines by which they must comply with ADA standards.

**3. Public Accommodations:** Public accommodations include all sales and service establishments, as well as educational institutions, recreational facilities, and social service centers. The ADA requires such facilities to make reasonable modifications in policies and procedures, unless those modifications would fundamentally alter the nature of the services provided. All new construction and alterations in public accommodations, as well as in commercial facilities such as office buildings, must be accessible. Retrofitting of existing buildings is only required when "readily achievable." Such facilities may not use eligibility criteria that screen out individuals with disabilities, unless such screens are necessary for their operation.

Individuals can sue for an injunction that requires an accommodation to comply with the ADA. Monetary relief is limited to attorney fees and court costs. Only the Attorney General can seek monetary damages and then only in suits of general public importance.

**4. Telecommunications:** All carriers offering phone service to the general public must provide telecommunications relay service that permit individuals who use non-voice devices the opportunity for communication equivalent to what is provided to other customers. The system must operate 24 hours a day, and users must pay no more than other customers. The Federal Communications Commission is responsible for enforcement.

Week ending 8/30/97

## NATIONAL WORKLOAD STATUS CHILDHOOD REDETERMINATIONS

|                                                                        |             |       |
|------------------------------------------------------------------------|-------------|-------|
| SSI Childhood Recipients                                               | 998,280     |       |
| Original Redetermination Workload                                      | 288,000     |       |
| Continuances Screened Out Before Notices                               | 23,658      |       |
| Total Notices Sent                                                     | 264,342     |       |
| Additional Continuances Screened Out After Notices                     | 4,666       |       |
| Cases Redetermined at <u>Initial Level</u>                             | 206,908     |       |
| Cases Continued                                                        | 85,330      | 41.2% |
| Cases Ceased                                                           | 121,578     | 58.8% |
| Percent of Ceased Cases that Appeal Within 60 Days                     |             | 44.0% |
| Cases Redetermined at <u>Reconsideration Level</u>                     | 2,240       |       |
| Cases Continued                                                        | 1,510       |       |
| Cases Ceased                                                           | 120,000 730 |       |
| Cases Terminated for Non-Disability Reasons                            | 6,624       |       |
| Total Continuances of Cases Decided (Redeterminations Plus Screenouts) | 115,164     | 49.0% |

Note: Early data from appeals are not representative and should not be used for projections.

TABLE 2 - ICR2  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY STATE AGENCY  
CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|-------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| CONNECTICUT           | 294   | 49            | 124             | 19    | 486            | 45.0                   | 580                  | 12           | 2     | 594            | 55.0                  | 1,080          |
| MAINE                 | 68    | 12            | 116             | 0     | 196            | 43.6                   | 245                  | 9            | 0     | 254            | 56.4                  | 450            |
| MASSACHUSETTS         | 1,104 | 257           | 676             | 9     | 2,046          | 49.9                   | 1,796                | 252          | 10    | 2,058          | 50.1                  | 4,104          |
| NEW HAMPSHIRE         | 87    | 7             | 14              | 0     | 108            | 42.0                   | 138                  | 11           | 0     | 149            | 58.0                  | 257            |
| RHODE ISLAND          | 105   | 14            | 93              | 1     | 213            | 30.3                   | 461                  | 28           | 0     | 489            | 69.7                  | 702            |
| VERMONT               | 99    | 47            | 28              | 1     | 175            | 47.6                   | 185                  | 8            | 0     | 193            | 52.4                  | 368            |
| BOSTON REGION         | 1,757 | 386           | 1,051           | 30    | 3,224          | 46.3                   | 3,405                | 320          | 12    | 3,737          | 53.7                  | 6,961          |
| NEW JERSEY            | 1,170 | 462           | 1,070           | 7     | 2,709          | 57.7                   | 1,725                | 259          | 5     | 1,989          | 42.3                  | 4,698          |
| NEW YORK              | 3,615 | 490           | 4,090           | 10    | 8,205          | 37.8                   | 11,354               | 2,144        | 7     | 13,505         | 62.2                  | 21,710         |
| NEW YORK REGION       | 4,785 | 952           | 5,160           | 17    | 10,914         | 41.3                   | 13,079               | 2,403        | 12    | 15,494         | 58.7                  | 26,408         |
| DELAWARE              | 183   | 22            | 20              | 4     | 229            | 53.5                   | 178                  | 18           | 3     | 199            | 46.5                  | 428            |
| DISTRICT OF COLUMBIA  | 206   | 123           | 0               | 6     | 335            | 64.4                   | 184                  | 1            | 0     | 185            | 35.6                  | 520            |
| MARYLAND              | 1,024 | 140           | 92              | 4     | 1,260          | 48.8                   | 1,265                | 49           | 7     | 1,321          | 51.2                  | 2,581          |
| PENNSYLVANIA          | 4,126 | 1,122         | 1,978           | 0     | 7,226          | 61.6                   | 4,296                | 200          | 6     | 4,502          | 38.4                  | 11,728         |
| VIRGINIA              | 2,392 | 354           | 708             | 10    | 3,464          | 49.3                   | 3,337                | 220          | 3     | 3,560          | 50.7                  | 7,024          |
| WEST VIRGINIA         | 524   | 72            | 42              | 0     | 638            | 34.5                   | 1,159                | 50           | 0     | 1,209          | 65.5                  | 1,847          |
| PHILADELPHIA REGION   | 8,455 | 1,833         | 2,840           | 24    | 13,152         | 54.5                   | 10,419               | 538          | 19    | 10,976         | 45.5                  | 24,128         |

TABLE 2 - ICR2  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY STATE AGENCY  
CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS  | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|--------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| ALABAMA               | 1,080  | 122           | 281             | 21    | 1,504          | 28.6                   | 3,512                | 145          | 102   | 3,759          | 71.4                  | 5,263          |
| FLORIDA               | 3,521  | 225           | 1,175           | 33    | 4,954          | 44.2                   | 5,811                | 368          | 80    | 6,259          | 55.8                  | 11,213         |
| GEORGIA               | 946    | 129           | 177             | 2     | 1,254          | 32.0                   | 2,539                | 120          | 1     | 2,660          | 68.0                  | 3,914          |
| KENTUCKY              | 2,210  | 505           | 1,018           | 8     | 3,741          | 57.3                   | 2,674                | 114          | 0     | 2,788          | 42.7                  | 6,529          |
| MISSISSIPPI           | 732    | 146           | 108             | 5     | 991            | 17.4                   | 4,661                | 27           | 3     | 4,691          | 82.6                  | 5,682          |
| NORTH CAROLINA        | 4,376  | 304           | 1,339           | 19    | 6,038          | 57.1                   | 4,182                | 355          | 1     | 4,538          | 42.9                  | 10,576         |
| SOUTH CAROLINA        | 722    | 58            | 264             | 1     | 1,045          | 30.3                   | 2,365                | 39           | 0     | 2,404          | 69.7                  | 3,449          |
| TENNESSEE             | 1,014  | 109           | 102             | 7     | 1,232          | 28.0                   | 3,104                | 36           | 24    | 3,164          | 72.0                  | 4,396          |
| ATLANTA REGION        | 14,601 | 1,598         | 4,464           | 96    | 20,759         | 40.7                   | 28,848               | 1,204        | 211   | 30,263         | 59.3                  | 51,022         |
| ILLINOIS              | 2,580  | 241           | 391             | 2     | 3,214          | 28.1                   | 7,194                | 1,013        | 2     | 8,209          | 71.9                  | 11,423         |
| INDIANA               | 1,269  | 140           | 234             | 15    | 1,658          | 38.7                   | 2,337                | 290          | 4     | 2,631          | 61.3                  | 4,289          |
| MICHIGAN              | 2,876  | 585           | 1,644           | 49    | 5,154          | 58.2                   | 3,682                | 15           | 2     | 3,699          | 41.8                  | 8,853          |
| MINNESOTA             | 842    | 423           | 374             | 2     | 1,641          | 62.4                   | 990                  | 0            | 0     | 990            | 37.6                  | 2,631          |
| OHIO                  | 2,574  | 396           | 291             | 17    | 3,278          | 36.7                   | 5,156                | 493          | 0     | 5,649          | 63.3                  | 8,927          |
| WISCONSIN             | 909    | 423           | 366             | 0     | 1,698          | 37.7                   | 2,553                | 252          | 0     | 2,805          | 62.3                  | 4,503          |
| CHICAGO REGION        | 11,050 | 2,208         | 3,300           | 85    | 16,643         | 41.0                   | 21,912               | 2,063        | 8     | 23,983         | 59.0                  | 40,626         |
| ARKANSAS              | 1,003  | 24            | 121             | 4     | 1,152          | 24.4                   | 3,302                | 270          | 2     | 3,574          | 75.6                  | 4,726          |
| LOUISIANA             | 1,824  | 125           | 518             | 8     | 2,475          | 23.3                   | 7,151                | 995          | 1     | 8,147          | 76.7                  | 10,622         |
| NEW MEXICO            | 162    | 29            | 150             | 2     | 343            | 33.3                   | 638                  | 49           | 0     | 687            | 66.7                  | 1,030          |
| OKLAHOMA              | 261    | 15            | 22              | 0     | 298            | 24.4                   | 885                  | 38           | 0     | 923            | 75.6                  | 1,221          |
| TEXAS                 | 1,723  | 79            | 261             | 18    | 2,081          | 21.4                   | 6,902                | 709          | 18    | 7,629          | 78.6                  | 9,710          |
| DALLAS REGION         | 4,973  | 272           | 1,072           | 32    | 6,349          | 23.2                   | 18,878               | 2,061        | 21    | 20,960         | 76.8                  | 27,309         |

TABLE 2 - ICR2  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY STATE AGENCY  
CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|-------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| -----                 | ----- | -----         | -----           | ----- | -----          | -----                  | -----                | -----        | ----- | -----          | -----                 | -----          |
| IOWA                  | 302   | 20            | 27              | 1     | 350            | 23.2                   | 1,072                | 88           | 0     | 1,160          | 76.8                  | 1,510          |
| KANSAS                | 380   | 41            | 141             | 1     | 563            | 24.2                   | 1,618                | 139          | 3     | 1,760          | 75.8                  | 2,323          |
| MISSOURI              | 1,049 | 178           | 309             | 18    | 1,554          | 27.8                   | 3,639                | 387          | 0     | 4,026          | 72.2                  | 5,580          |
| NEBRASKA              | 191   | 20            | 46              | 0     | 257            | 32.9                   | 515                  | 10           | 0     | 525            | 67.1                  | 782            |
| KANSAS CITY REGION    | 1,922 | 259           | 523             | 20    | 2,724          | 26.7                   | 6,844                | 624          | 3     | 7,471          | 73.3                  | 10,195         |
| COLORADO              | 287   | 240           | 213             | 3     | 743            | 46.0                   | 820                  | 49           | 2     | 871            | 54.0                  | 1,614          |
| MONTANA               | 80    | 6             | 6               | 0     | 92             | 21.5                   | 311                  | 23           | 1     | 335            | 78.5                  | 427            |
| NORTH DAKOTA          | 36    | 3             | 12              | 0     | 51             | 33.8                   | 100                  | 0            | 0     | 100            | 66.2                  | 151            |
| SOUTH DAKOTA          | 118   | 8             | 168             | 2     | 296            | 57.4                   | 194                  | 26           | 0     | 220            | 42.6                  | 516            |
| UTAH                  | 141   | 29            | 60              | 1     | 231            | 40.5                   | 318                  | 20           | 2     | 340            | 59.5                  | 571            |
| WYOMING               | 56    | 20            | 46              | 0     | 122            | 49.0                   | 110                  | 12           | 5     | 127            | 51.0                  | 249            |
| DENVER REGION         | 718   | 306           | 505             | 6     | 1,535          | 43.5                   | 1,853                | 130          | 10    | 1,993          | 56.5                  | 3,528          |
| ARIZONA               | 813   | 67            | 265             | 1     | 1,146          | 59.5                   | 724                  | 55           | 0     | 779            | 40.5                  | 1,925          |
| CALIFORNIA            | 4,140 | 726           | 1,766           | 161   | 6,793          | <del>62.0</del>        | 3,735                | 419          | 16    | 4,170          | 38.0                  | 10,963         |
| HAWAII                | 22    | 22            | 3               | 0     | 47             | 62.7                   | 25                   | 3            | 0     | 28             | 37.3                  | 75             |
| NEVADA                | 192   | 24            | 75              | 4     | 295            | 64.4                   | 124                  | 22           | 17    | 163            | 35.6                  | 458            |
| SAN FRANCISCO REGION  | 5,167 | 839           | 2,109           | 166   | 8,281          | 61.7                   | 4,608                | 499          | 33    | 5,140          | 38.3                  | 13,421         |

TABLE 2 - ICR2  
 INITIAL LEVEL  
 SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
 BASIS OF DETERMINATION BY STATE AGENCY  
 CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS  | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|--------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| ALASKA                | 54     | 4             | 20              | 3     | 81             | 51.9                   | 60                   | 15           | 0     | 75             | 48.1                  | 156            |
| IDAHO                 | 189    | 20            | 224             | 5     | 438            | 43.6                   | 527                  | 38           | 1     | 566            | 56.4                  | 1,004          |
| OREGON                | 269    | 30            | 160             | 18    | 477            | 62.1                   | 252                  | 24           | 15    | 291            | 37.9                  | 768            |
| WASHINGTON            | 418    | 158           | 160             | 17    | 753            | 54.5                   | 592                  | 29           | 8     | 629            | 45.5                  | 1,382          |
| SEATTLE REGION        | 930    | 212           | 564             | 43    | 1,749          | 52.8                   | 1,431                | 106          | 24    | 1,561          | 47.2                  | 3,310          |
| TOTAL                 | 54,358 | 8,865         | 21,588          | 519   | 85,330         | 41.2                   | 111,277              | 9,948        | 353   | 121,578        | 58.8                  | 206,908        |

PREPARED BY: OFFICE OF DISABILITY  
 SOURCE: 1997 SSA-832 FILE

TABLE 4 - ICR4  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY BODY SYSTEM  
CUMULATIVE THROUGH 08/30/97

| BODY SYSTEM           | MEETS  | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | TOTAL   |
|-----------------------|--------|---------------|-----------------|-------|----------------|------------------------|---------------------|--------------|-------|----------------|-----------------------|---------|
| CARDIOVASCULAR        | 94     | 44            | 64              | 5     | 207            | 27.6                   | 508                 | 31           | 3     | 542            | 72.4                  | 749     |
| DIGESTIVE             | 32     | 35            | 67              | 0     | 134            | 38.4                   | 201                 | 13           | 1     | 215            | 61.6                  | 349     |
| ENDOCRINE             | 85     | 48            | 65              | 4     | 202            | 30.2                   | 441                 | 24           | 1     | 466            | 69.8                  | 668     |
| GENITO-URINARY        | 41     | 17            | 33              | 1     | 92             | 32.5                   | 182                 | 9            | 0     | 191            | 67.5                  | 283     |
| GROWTH IMPAIRMENT     | 116    | 21            | 115             | 1     | 253            | 73.3                   | 81                  | 9            | 2     | 92             | 26.7                  | 345     |
| HEMIC AND LYMPHATIC   | 199    | 55            | 26              | 0     | 280            | 55.8                   | 207                 | 15           | 0     | 222            | 44.2                  | 502     |
| IMMUNE DEFICIENCIES   | 84     | 47            | 50              | 0     | 181            | 61.4                   | 100                 | 14           | 0     | 114            | 38.6                  | 295     |
| MENTAL DISORDERS      | 49,410 | 7,231         | 18,773          | 459   | 75,873         | 43.1                   | 94,759              | 5,292        | 263   | 100,314        | 56.9                  | 176,187 |
| MULTIPLE BODY SYSTEMS | 279    | 74            | 112             | 1     | 466            | 75.9                   | 133                 | 14           | 1     | 148            | 24.1                  | 614     |
| MUSCULOSKELETAL       | 319    | 143           | 220             | 6     | 688            | 36.8                   | 1,085               | 95           | 4     | 1,184          | 63.2                  | 1,872   |
| NEOPLASTIC            | 29     | 7             | 12              | 0     | 48             | 40.3                   | 67                  | 4            | 0     | 71             | 59.7                  | 119     |
| NEUROLOGICAL          | 2,392  | 716           | 1,000           | 26    | 4,134          | 59.6                   | 2,622               | 168          | 12    | 2,802          | 40.4                  | 6,936   |
| OTHER                 | 162    | 59            | 218             | 1     | 440            | 4.9                    | 4,579               | 3,911        | 43    | 8,533          | 95.1                  | 8,973   |
| RESPIRATORY           | 347    | 110           | 139             | 7     | 603            | 13.6                   | 3,635               | 184          | 14    | 3,833          | 86.4                  | 4,436   |
| SKIN                  | 14     | 9             | 22              | 0     | 45             | 28.8                   | 102                 | 8            | 1     | 111            | 71.2                  | 156     |
| SPECIAL SENSES/SPEECH | 755    | 249           | 672             | 8     | 1,684          | 38.1                   | 2,575               | 157          | 8     | 2,740          | 61.9                  | 4,424   |
| TOTAL                 | 54,358 | 8,865         | 21,588          | 519   | 85,330         | 41.2                   | 111,277             | 9,948        | 353   | 121,578        | 58.8                  | 206,908 |

PREPARED BY: OFFICE OF DISABILITY  
SOURCE: 1997 SSA-832 FILE

Week ending 8/30/97

## **NATIONAL WORKLOAD STATUS CHILDHOOD REDETERMINATIONS**

|                                                                           |         |       |
|---------------------------------------------------------------------------|---------|-------|
| SSI Childhood Recipients                                                  | 998,280 |       |
| Original Redetermination Workload                                         | 288,000 |       |
| Continuances Screened Out Before Notices                                  | 23,658  |       |
| Total Notices Sent                                                        | 264,342 |       |
| Additional Continuances Screened Out After<br>Notices                     | 4,666   |       |
| Cases Redetermined at Initial Level                                       | 206,908 |       |
| Cases Continued                                                           | 85,330  | 41.2% |
| Cases Ceased                                                              | 121,578 | 58.8% |
| Percent of Ceased Cases that Appeal Within<br>60 Days                     |         | 44.0% |
| Cases Redetermined at Reconsideration Level                               | 2,240   |       |
| Cases Continued                                                           | 1,510   |       |
| Cases Ceased                                                              | 730     |       |
| Cases Terminated for Non-Disability Reasons                               | 6,624   |       |
| Total Continuances of Cases Decided<br>(Redeterminations Plus Screenouts) | 115,164 | 49.0% |

Note: Early data from appeals are not representative and should not be used for projections.

TABLE 2 - ICR2  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY STATE AGENCY  
CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|-------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| CONNECTICUT           | 294   | 49            | 124             | 19    | 486            | 45.0                   | 580                  | 12           | 2     | 594            | 55.0                  | 1,080          |
| MAINE                 | 68    | 12            | 116             | 0     | 196            | 43.6                   | 245                  | 9            | 0     | 254            | 56.4                  | 450            |
| MASSACHUSETTS         | 1,104 | 257           | 676             | 9     | 2,046          | 49.9                   | 1,796                | 252          | 10    | 2,058          | 50.1                  | 4,104          |
| NEW HAMPSHIRE         | 87    | 7             | 14              | 0     | 108            | 42.0                   | 138                  | 11           | 0     | 149            | 58.0                  | 257            |
| RHODE ISLAND          | 105   | 14            | 93              | 1     | 213            | 30.3                   | 461                  | 28           | 0     | 489            | 69.7                  | 702            |
| VERMONT               | 99    | 47            | 28              | 1     | 175            | 47.6                   | 185                  | 8            | 0     | 193            | 52.4                  | 368            |
| BOSTON REGION         | 1,757 | 386           | 1,051           | 30    | 3,224          | 46.3                   | 3,405                | 320          | 12    | 3,737          | 53.7                  | 6,961          |
| NEW JERSEY            | 1,170 | 462           | 1,070           | 7     | 2,709          | 57.7                   | 1,725                | 259          | 5     | 1,989          | 42.3                  | 4,698          |
| NEW YORK              | 3,615 | 490           | 4,090           | 10    | 8,205          | 37.8                   | 11,354               | 2,144        | 7     | 13,505         | 62.2                  | 21,710         |
| NEW YORK REGION       | 4,785 | 952           | 5,160           | 17    | 10,914         | 41.3                   | 13,079               | 2,403        | 12    | 15,494         | 58.7                  | 26,408         |
| DELAWARE              | 183   | 22            | 20              | 4     | 229            | 53.5                   | 178                  | 18           | 3     | 199            | 46.5                  | 428            |
| DISTRICT OF COLUMBIA  | 206   | 123           | 0               | 6     | 335            | 64.4                   | 184                  | 1            | 0     | 185            | 35.6                  | 520            |
| MARYLAND              | 1,024 | 140           | 92              | 4     | 1,260          | 48.8                   | 1,265                | 49           | 7     | 1,321          | 51.2                  | 2,581          |
| PENNSYLVANIA          | 4,126 | 1,122         | 1,978           | 0     | 7,226          | 61.6                   | 4,296                | 200          | 6     | 4,502          | 38.4                  | 11,728         |
| VIRGINIA              | 2,392 | 354           | 708             | 10    | 3,464          | 49.3                   | 3,337                | 220          | 3     | 3,560          | 50.7                  | 7,024          |
| WEST VIRGINIA         | 524   | 72            | 42              | 0     | 638            | 34.5                   | 1,159                | 50           | 0     | 1,209          | 65.5                  | 1,847          |
| PHILADELPHIA REGION   | 8,455 | 1,833         | 2,840           | 24    | 13,152         | 54.5                   | 10,419               | 538          | 19    | 10,976         | 45.5                  | 24,128         |

TABLE 2 - ICR2  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY STATE AGENCY  
CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS  | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|--------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| ALABAMA               | 1,080  | 122           | 281             | 21    | 1,504          | 28.6                   | 3,512                | 145          | 102   | 3,759          | 71.4                  | 5,263          |
| FLORIDA               | 3,521  | 225           | 1,175           | 33    | 4,954          | 44.2                   | 5,811                | 368          | 80    | 6,259          | 55.8                  | 11,213         |
| GEORGIA               | 946    | 129           | 177             | 2     | 1,254          | 32.0                   | 2,539                | 120          | 1     | 2,660          | 68.0                  | 3,914          |
| KENTUCKY              | 2,210  | 505           | 1,018           | 8     | 3,741          | 57.3                   | 2,674                | 114          | 0     | 2,788          | 42.7                  | 6,529          |
| MISSISSIPPI           | 732    | 146           | 108             | 5     | 991            | 17.4                   | 4,661                | 27           | 3     | 4,691          | 82.6                  | 5,682          |
| NORTH CAROLINA        | 4,376  | 304           | 1,339           | 19    | 6,038          | 57.1                   | 4,182                | 355          | 1     | 4,538          | 42.9                  | 10,576         |
| SOUTH CAROLINA        | 722    | 58            | 264             | 1     | 1,045          | 30.3                   | 2,365                | 39           | 0     | 2,404          | 69.7                  | 3,449          |
| TENNESSEE             | 1,014  | 109           | 102             | 7     | 1,232          | 28.0                   | 3,104                | 36           | 24    | 3,164          | 72.0                  | 4,396          |
| ATLANTA REGION        | 14,601 | 1,598         | 4,464           | 96    | 20,759         | 40.7                   | 28,848               | 1,204        | 211   | 30,263         | 59.3                  | 51,022         |
| ILLINOIS              | 2,580  | 241           | 391             | 2     | 3,214          | 28.1                   | 7,194                | 1,013        | 2     | 8,209          | 71.9                  | 11,423         |
| INDIANA               | 1,269  | 140           | 234             | 15    | 1,658          | 38.7                   | 2,337                | 290          | 4     | 2,631          | 61.3                  | 4,289          |
| MICHIGAN              | 2,876  | 585           | 1,644           | 49    | 5,154          | 58.2                   | 3,682                | 15           | 2     | 3,699          | 41.8                  | 8,853          |
| MINNESOTA             | 842    | 423           | 374             | 2     | 1,641          | 62.4                   | 990                  | 0            | 0     | 990            | 37.6                  | 2,631          |
| OHIO                  | 2,574  | 396           | 291             | 17    | 3,278          | 36.7                   | 5,156                | 493          | 0     | 5,649          | 63.3                  | 8,927          |
| WISCONSIN             | 909    | 423           | 366             | 0     | 1,698          | 37.7                   | 2,553                | 252          | 0     | 2,805          | 62.3                  | 4,503          |
| CHICAGO REGION        | 11,050 | 2,208         | 3,300           | 85    | 16,643         | 41.0                   | 21,912               | 2,063        | 8     | 23,983         | 59.0                  | 40,626         |
| ARKANSAS              | 1,003  | 24            | 121             | 4     | 1,152          | 24.4                   | 3,302                | 270          | 2     | 3,574          | 75.6                  | 4,726          |
| LOUISIANA             | 1,824  | 125           | 518             | 8     | 2,475          | 23.3                   | 7,151                | 995          | 1     | 8,147          | 76.7                  | 10,622         |
| NEW MEXICO            | 162    | 29            | 150             | 2     | 343            | 33.3                   | 638                  | 49           | 0     | 687            | 66.7                  | 1,030          |
| OKLAHOMA              | 261    | 15            | 22              | 0     | 298            | 24.4                   | 885                  | 38           | 0     | 923            | 75.6                  | 1,221          |
| TEXAS                 | 1,723  | 79            | 261             | 18    | 2,081          | 21.4                   | 6,902                | 709          | 18    | 7,629          | 78.6                  | 9,710          |
| DALLAS REGION         | 4,973  | 272           | 1,072           | 32    | 6,349          | 23.2                   | 18,878               | 2,061        | 21    | 20,960         | 76.8                  | 27,309         |

TABLE 2 - ICR2  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY STATE AGENCY  
CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|-------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| IOWA                  | 302   | 20            | 27              | 1     | 350            | 23.2                   | 1,072                | 88           | 0     | 1,160          | 76.8                  | 1,510          |
| KANSAS                | 380   | 41            | 141             | 1     | 563            | 24.2                   | 1,618                | 139          | 3     | 1,760          | 75.8                  | 2,323          |
| MISSOURI              | 1,049 | 178           | 309             | 18    | 1,554          | 27.8                   | 3,639                | 387          | 0     | 4,026          | 72.2                  | 5,580          |
| NEBRASKA              | 191   | 20            | 46              | 0     | 257            | 32.9                   | 515                  | 10           | 0     | 525            | 67.1                  | 782            |
| KANSAS CITY REGION    | 1,922 | 259           | 523             | 20    | 2,724          | 26.7                   | 6,844                | 624          | 3     | 7,471          | 73.3                  | 10,195         |
| COLORADO              | 287   | 240           | 213             | 3     | 743            | 46.0                   | 820                  | 49           | 2     | 871            | 54.0                  | 1,614          |
| MONTANA               | 80    | 6             | 6               | 0     | 92             | 21.5                   | 311                  | 23           | 1     | 335            | 78.5                  | 427            |
| NORTH DAKOTA          | 36    | 3             | 12              | 0     | 51             | 33.8                   | 100                  | 0            | 0     | 100            | 66.2                  | 151            |
| SOUTH DAKOTA          | 118   | 8             | 168             | 2     | 296            | 57.4                   | 194                  | 26           | 0     | 220            | 42.6                  | 516            |
| UTAH                  | 141   | 29            | 60              | 1     | 231            | 40.5                   | 318                  | 20           | 2     | 340            | 59.5                  | 571            |
| WYOMING               | 56    | 20            | 46              | 0     | 122            | 49.0                   | 110                  | 12           | 5     | 127            | 51.0                  | 249            |
| DENVER REGION         | 718   | 306           | 505             | 6     | 1,535          | 43.5                   | 1,853                | 130          | 10    | 1,993          | 56.5                  | 3,528          |
| ARIZONA               | 813   | 67            | 265             | 1     | 1,146          | 59.5                   | 724                  | 55           | 0     | 779            | 40.5                  | 1,925          |
| CALIFORNIA            | 4,140 | 726           | 1,766           | 161   | 6,793          | 62.0                   | 3,735                | 419          | 16    | 4,170          | 38.0                  | 10,963         |
| HAWAII                | 22    | 22            | 3               | 0     | 47             | 62.7                   | 25                   | 3            | 0     | 28             | 37.3                  | 75             |
| NEVADA                | 192   | 24            | 75              | 4     | 295            | 64.4                   | 124                  | 22           | 17    | 163            | 35.6                  | 458            |
| SAN FRANCISCO REGION  | 5,167 | 839           | 2,109           | 166   | 8,281          | 61.7                   | 4,608                | 499          | 33    | 5,140          | 38.3                  | 13,421         |

TABLE 2 - ICR2  
 INITIAL LEVEL  
 SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
 BASIS OF DETERMINATION BY STATE AGENCY  
 CUMULATIVE THROUGH 08/30/97

| STATE (DDS)<br>REGION | MEETS  | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST.<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | STATE<br>TOTAL |
|-----------------------|--------|---------------|-----------------|-------|----------------|------------------------|----------------------|--------------|-------|----------------|-----------------------|----------------|
| ALASKA                | 54     | 4             | 20              | 3     | 81             | 51.9                   | 60                   | 15           | 0     | 75             | 48.1                  | 156            |
| IDAHO                 | 189    | 20            | 224             | 5     | 438            | 43.6                   | 527                  | 38           | 1     | 566            | 56.4                  | 1,004          |
| OREGON                | 269    | 30            | 160             | 18    | 477            | 62.1                   | 252                  | 24           | 15    | 291            | 37.9                  | 768            |
| WASHINGTON            | 418    | 158           | 160             | 17    | 753            | 54.5                   | 592                  | 29           | 8     | 629            | 45.5                  | 1,382          |
| SEATTLE REGION        | 930    | 212           | 564             | 43    | 1,749          | 52.8                   | 1,431                | 106          | 24    | 1,561          | 47.2                  | 3,310          |
| TOTAL                 | 54,358 | 8,865         | 21,588          | 519   | 85,330         | 41.2                   | 111,277              | 9,948        | 353   | 121,578        | 58.8                  | 206,908        |

PREPARED BY: OFFICE OF DISABILITY  
 SOURCE: 1997 SSA-832 FILE

TABLE 4 - ICR4  
INITIAL LEVEL  
SSI CHILDHOOD DISABILITY REDETERMINATIONS - MINOR CHILDREN  
BASIS OF DETERMINATION BY BODY SYSTEM  
CUMULATIVE THROUGH 08/30/97

| BODY SYSTEM           | MEETS  | MED<br>EQUALS | FUNC-<br>EQUALS | OTHER | TOTAL<br>CONT. | INIT<br>CONTIN<br>RATE | NOT<br>LIST<br>SEV. | FAIL<br>COOP | OTHER | TOTAL<br>CEASE | INIT<br>CEASE<br>RATE | TOTAL   |
|-----------------------|--------|---------------|-----------------|-------|----------------|------------------------|---------------------|--------------|-------|----------------|-----------------------|---------|
| CARDIOVASCULAR        | 94     | 44            | 64              | 5     | 207            | 27.6                   | 508                 | 31           | 3     | 542            | 72.4                  | 749     |
| DIGESTIVE             | 32     | 35            | 67              | 0     | 134            | 38.4                   | 201                 | 13           | 1     | 215            | 61.6                  | 349     |
| ENDOCRINE             | 85     | 48            | 65              | 4     | 202            | 30.2                   | 441                 | 24           | 1     | 466            | 69.8                  | 668     |
| GENITO-URINARY        | 41     | 17            | 33              | 1     | 92             | 32.5                   | 182                 | 9            | 0     | 191            | 67.5                  | 283     |
| GROWTH IMPAIRMENT     | 116    | 21            | 115             | 1     | 253            | 73.3                   | 81                  | 9            | 2     | 92             | 26.7                  | 345     |
| HEMIC AND LYMPHATIC   | 199    | 55            | 26              | 0     | 280            | 55.8                   | 207                 | 15           | 0     | 222            | 44.2                  | 502     |
| IMMUNE DEFICIENCIES   | 84     | 47            | 50              | 0     | 181            | 61.4                   | 100                 | 14           | 0     | 114            | 38.6                  | 295     |
| MENTAL DISORDERS      | 49,410 | 7,231         | 18,773          | 459   | 75,873         | 43.1                   | 94,759              | 5,292        | 263   | 100,314        | 56.9                  | 176,187 |
| MULTIPLE BODY SYSTEMS | 279    | 74            | 112             | 1     | 466            | 75.9                   | 133                 | 14           | 1     | 148            | 24.1                  | 614     |
| MUSCULOSKELETAL       | 319    | 143           | 220             | 6     | 688            | 36.8                   | 1,085               | 95           | 4     | 1,184          | 63.2                  | 1,872   |
| NEOPLASTIC            | 29     | 7             | 12              | 0     | 48             | 40.3                   | 67                  | 4            | 0     | 71             | 59.7                  | 119     |
| NEUROLOGICAL          | 2,392  | 716           | 1,000           | 26    | 4,134          | 59.6                   | 2,622               | 168          | 12    | 2,802          | 40.4                  | 6,936   |
| OTHER                 | 162    | 59            | 218             | 1     | 440            | 4.9                    | 4,579               | 3,911        | 43    | 8,533          | 95.1                  | 8,973   |
| RESPIRATORY           | 347    | 110           | 139             | 7     | 603            | 13.6                   | 3,635               | 184          | 14    | 3,833          | 86.4                  | 4,436   |
| SKIN                  | 14     | 9             | 22              | 0     | 45             | 28.8                   | 102                 | 8            | 1     | 111            | 71.2                  | 156     |
| SPECIAL SENSES/SPEECH | 755    | 249           | 672             | 8     | 1,684          | 38.1                   | 2,575               | 157          | 8     | 2,740          | 61.9                  | 4,424   |
| TOTAL                 | 54,358 | 8,865         | 21,588          | 519   | 85,330         | 41.2                   | 111,277             | 9,948        | 353   | 121,578        | 58.8                  | 206,908 |

PREPARED BY: OFFICE OF DISABILITY  
SOURCE: 1997 SSA-832 FILE



## **Administration Accomplishments: Home and Community Based Services**

- Huge home and community-based Medicaid waiver program serving 250,000 people. Through these waivers, four states have eliminated MR/DD institutions and moved services to the community. [How to describe how these have expanded since 1993? -- number of people served? Number of waivers? Reduction in number of 18-65 institutionalized population?]
- Administrative changes have greatly simplified these waivers (can we claim expanded?) -- including elimination of the "cold bed" rule and prototype waiver applications.
- HCFA continues to push states to make HCBS available (letters to states in June and July of this year).
- Unsuccessful legislative initiatives by the Administration include the long term care block grant that was part of our health care reform legislation and legislation to further simply the HCBS waiver program by converting it to a state plan amendment.
- The new balanced budget includes a step in the right direction on this issue: individuals no longer need to have been in an institution in order to be eligible for habilitation services (?) under a waiver.
- Other positive items in the balanced budget for people with disabilities include: a modified version of the Administration's proposal to allow states to establish a Medicaid buy-in program for certain people on SSI who are seeking to return to work; limits on managed care for children with disabilities; reinstatement of Medicaid and SSI for disabled legal immigrants who were in the country when the welfare law was signed; and grandfathering Medicaid for children losing SSI as a result of the new disability standard. [These items are all less germane to HCBS.]
- Critical research and demonstrations going on:
  - Cash and counseling demonstration waivers under review from 4 states -- can we talk about these?
  - HCFA will ask Centers for Independent Living to participate in a four site demonstration of a consumer-directed model of purchasing durable medical equipment -- can we talk about this?
  - Small demonstration waiver in Colorado to test providing home health services outside of the home or institution.
  - Research on dual-eligibles highlighted in 1997 research agenda?
  - Rhode Island demo?
  - Wisconsin demo request -- can't talk about it?

**HEALTH CARE FINANCING ADMINISTRATION  
NATIONAL HEADQUARTERS  
7500 Security Boulevard  
Baltimore, MD 21244-1850**



**FACSIMILE TRANSMISSION REQUEST**

**ADDRESSEE:**(Name, Organization, Address) **FROM:** Rena

Diana Fortuna  
Chris Jennings

**OFFICE OF THE ADMINISTRATOR  
C5-26-11-Location  
C5-16-03-Mail Stop**

**Phone:** \_\_\_\_\_ **Phone:** (410) 786-3151 /Fax (410) 786-8060

**TOTAL PAGES:** **ADDRESSEE'S FAX MACHINE NUMBER** **DATE:**  
Cover + 15 202-456-7431 9-4-97

**REMARKS:**

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The attached has just been put into HHS clearance and is being sent to you unofficially.

**DETERMINED TO BE AN ADMINISTRATIVE**

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Cathy Tabor

**AT:** 410-786-3151

(Name)

(Phone)

~~CONFIDENTIAL~~

Version: September 4 - 4:00 pm

**Briefing Materials for the President's Meeting with Disability Groups  
September 10, 1997**

The Clinton Administration has achieved some remarkable milestones toward promoting the agenda of individuals with disabilities to live a full, productive, and independent life. With the help of the disability community this Administration has been able to focus the attention of the country, and the Congress on these important issues. This paper highlights some of those achievements.

**The Balanced Budget Act of 1997**

- o Under section 4733 of the recently enacted Balanced Budget Act, States are permitted to allow certain Supplemental Security Income (SSI) beneficiaries who are disabled and would lose eligibility because of their earnings to purchase Medicaid coverage. Eligibility is extended to SSI beneficiaries whose income is less than 250 percent of the Federal poverty level for the applicable family size. The poverty level for one person is currently a little over \$2,210 per month. States will set premiums based on an income-related sliding scale.
- o The Act in section 4743, also amended the home and community-based waiver program by eliminating the requirement that individuals be discharged from a nursing facility or intermediate care facility for the mentally retarded to be eligible to receive habilitation services under a home and community-based waiver.
- o The Act in section 4701 exempts certain children with disabilities including SSI beneficiaries, and children in foster care from being required to receive care through a managed care entity.
- o The Act in section 5305 reinstates Medicaid eligibility for certain aliens who receive SSI. Medicaid benefits were denied to this group of elderly and disabled aliens in the Personal Responsibility and Work Opportunities Reconciliation Act (PRWORA) of 1996.
- o Similarly, the Act in section 4913 restores Medicaid eligibility to disabled children who were receiving SSI at the time of enactment of the PRWORA of 1996.

**Personal Care Services Regulation**

- o The Personal Care Services Regulation which makes personal care services an optional Medicaid benefit which may be covered under States' Medicaid programs has been signed

DETERMINED TO BE AN ADMINISTRATIVE

MARKING INITIALS: pb DATE: 10/20/17

Final

- to Reg  
- on display  
- published

by the Secretary of Health and Human Services and will be published in the *Federal Register* in the very near future. (\*\*\*) This is clearly a candidate for White House intervention. OMB has had the regulation for 60 days, but is believed to be finalizing their review. The President could announce the date of publication if cleared.)

+ DME Δ/boc

- The regulation permits States to cover personal care services in the home and at the State's additional option, in locations outside the home including the work place.
- Personal care services are services to assist a person with activities of daily living such as assistance with eating, meal preparation, bathing, dressing, personal hygiene, and taking medications. Services may also include activities which are essential to the health and welfare of the beneficiary, such as house keeping chores like bed making, dusting, and vacuuming.
- The regulation removes the requirement that a registered nurse must supervise personal care services, thus reducing the cost, and making the service more flexible to meet the beneficiary's needs.

VS -

### Home and Community-Based Care Services

- o The Health Care Financing Administration continues to support and promote community-based long-term care for the elderly and people with developmental or physical disabilities through the home and community-based waiver program authorized under section 1915 C of the Social Security Act. Currently over 250,000 individuals with disabilities receive a wide array of services from personal assistance to home modifications and assistive devices (to name only a few) under 226 of these programs in 49 States and the District of Columbia. Similar services are provided in Arizona under their 1115 waiver. Through the use of this Medicaid waiver provision, four States have entirely eliminated their large publicly-funded institutions for people with developmental disabilities and replaced them with integrated community services. Most others have significantly phased down reliance on inappropriate institutional care for people with disabilities as a result of the waiver program.
- o Under the Clinton Administration numerous changes have been implemented to simplify the home and community-based waiver application and approval process. One of the most lasting and meaningful changes to promote home and community care and "level the playing field" with institutional care was the elimination of the rule that required States to show that without the waiver an equal number of beds would have to exist in institutions or nursing homes to accommodate those receiving waiver services.
- o In an effort to further simplify the process for receiving certain waivers, HCFA has provided States with a prototype waiver application for individuals with AIDS,

individuals with traumatic brain injury, and medically fragile children to expedite approval of these waivers. States may now establish a 1915 © waiver program for these individuals by filling in the State-specific information, signing, and submitting the prototype waiver application. Waivers submitted without alteration are expeditiously approved by HCFA.

- o On June 27, HCFA released a letter to State Medicaid Directors to encourage them to reduce the size of large providers of residential services under the home and community-based waiver program. To allow maximum flexibility to States in establishing home and community-based waiver programs, HCFA has not establish a formal Federal policy on the number of people who can reside in a group home. However, the Department is concerned that homes serving large populations may not be able to provide an authentic community experience.
- o In an additional letter, dated July 25, HCFA urged all State Medicaid Directors to make available appropriate home and community-based waiver options to all persons who are institutionalized, or at risk of institutionalization. HCFA also firmly stated its belief that, "... an individual has the right to assume risk, commensurate with that person's ability and willingness to assume responsibility for the consequences of that risk."

#### **Research and Demonstration Activities**

- o To honor its commitment to the disability community to move toward the goal of encouraging provision of long-term care services in the community, rather than in institutional settings, HCFA in consultation with leaders of the ADAPT movement has modified its current contract with the University of California, San Francisco, to undertake two related studies.
  - A comprehensive review and analysis of Medicaid regulations and statutes which relate to long-term care services to identify:
    - 1) existing Medicaid regulations which bias long-term care services toward institutional services and away from home and community-based services to determine if alternate interpretations are available to eliminate the bias or if statutory changes are required,
    - 2) requirements which bias services toward a medical model rather than a social model of care, and
    - 3) the extent to which restrictive Medicaid regulations may be linked unnecessarily to Medicare statutes and regulations which are oriented to post acute care.
  - Second, the study will examine gaps in Medicaid statutory and regulatory language

which might limit Medicaid beneficiaries having:

- 1) a choice to elect home and community-based services or institutional services, even if the individuals are currently residing in an institutional setting; and
- 2) a full range of home and community-based services available.

- A project Advisory Committee composed of between 8 and 10 individuals knowledgeable about disabilities as these relate to Medicaid beneficiaries will inform the work of the contractors. Representatives could include individuals from ADAPT, the National Council on Aging, and other relevant groups, as well as health services researchers familiar with disability issues.

- The contractor will make <sup>when</sup> interim reports to the DHHS/OMB work group discussed below at 30, 60, and 90-day intervals after beginning work under the contract. The interim reports will identify policies, regulations, and statutes identified by those dates which need to be addressed by the work group. These interim reports are to expedite action by DHHS to eliminate the institutional bias in Medicaid and to delink Medicare and Medicaid regulations when found to be appropriate.

- The final report will describe all the regulations and statutes which were reviewed, and describe the problem areas identified and the potential areas for change. The final report will include policy recommendations, as well as potential research and demonstration projects.

- o HCFA has established a work group to review the findings of the studies on eliminating the institutional bias in Medicaid and delinking problematic Medicare policies from Medicaid. The work group consists of Health and Human Services staff, and staff from the Office of Management and Budget. The members will consult regularly with a group of "constituency partners" representing the disability community, State agencies, and other appropriate Federal agencies. The work group will work with the advocacy community to identify States which are willing to participate in pilot studies designed to implement the "date certain" concept. We believe these pilots could serve the symbiotic purposes of helping States which have mandates to reduce their institutionalized populations and HCFA's desire to explore identifying the barriers to implementing the "date certain" concept. The "date certain" concept identifies the date on which all individuals who are in institutions on that date will have the option to move into a community-based living arrangement, and receive needed services without the requirement for a waiver. (The "date certain" issue has been identified by representatives of ADAPT as the one step the President could take at this meeting to show real support. ADAPT argues that the "date certain" concept is a win-win concept because by definition it is cost neutral, and does not expand the numbers of people eligible for service. Two versions of the concept proposed by ADAPT are - 1) the

**"date certain" would be the day those eligible could begin to move to the community from institutions, and 2) the "date certain" is the date on which all persons in institutions on that date would be permitted to move to the community when administratively feasible. The first is preferred. The second is considered a "no brainer" by ADAPT. Given the history of deinstitutionalization of the mentally retarded and mentally ill, which has identified the many benefits and the serious risks involved, HCFA is committed to proceeding in a manner which serves to protect the interests of beneficiaries .)**

- o With funding from the Robert Wood Johnson Foundation, four States, Arkansas, Florida, New Jersey, and New York, have developed and submitted to HCFA waiver applications to explore alternative ways to provide consumer-directed personal care services. These waiver applications are currently under review at HCFA. The purpose of these demonstrations would be to provide greater autonomy to consumers of long-term care services by empowering them to purchase the assistance they require to perform their activities of daily living. In order to accomplish this objective, cash allowances (coupled with information services) would be provided directly to persons with disabilities -- enabling them to choose and purchase the services they feel would best meet their needs. These proposed demonstrations are frequently referred to as "Cash and Counseling Demonstrations." Some of the major characteristics of the Cash and Counseling Demonstrations include:

- The experimental model for the demonstration would permit States to allow clients to choose cash payments in lieu of traditional case management services.
- To the fullest extent possible, minimal restrictions would be placed on the use of cash by beneficiaries with disabilities. *logged*
- In addition to purchasing personal assistance services, the waiver would permit States to offer a range of optional supportive services, including, but not limited to: recruitment of workers, screening of workers, training of the consumer and worker, back-up or emergency services, and assistance with tax forms and insurance paperwork.
- The availability of counseling services would be integral to a consumer-directed approach and to this demonstration. At a minimum, counseling involves helping consumers to decide whether to choose the cash option and how they might best spend the money available to them. Counselors should give consumers the facts and options they need to make informed choices for themselves.
- The demonstration would accommodate participation of approximately 9,750 elderly, 7,125 non-elderly individuals with disabilities, and 1,750 children with disabilities. The demonstration is a collaborative effort by representatives of the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for

Planning and Evaluation, the Health Care Financing Administration, the National Program Office at the University of Maryland's Center on Aging, the National Council on Aging, and Mathematica Policy Research (the evaluator).

- o HCFA recently approved an 1115 waiver for Colorado which will permit greater flexibility in defining where Medicaid home health services may be provided. Instead of limiting visits to a beneficiary's place of residence, the demonstration would permit the same types of services to be provided in other settings (e.g., schools, work sites, or day treatment centers). However, the State would not permit reimbursement for any visits which occur in hospitals, nursing homes, or intermediate care facilities for the mentally retarded.
  - The State estimates that between 100 and 200 clients will participate. Demonstration clients will meet Medicaid eligibility requirements. The primary purpose of this demonstration project is to develop and refine the independent care model, and to assist individuals who are capable of directing their own care.
  - Services will be provided under a fee-for-service delivery model for this demonstration project. Demonstration participants will be permitted to choose among participating providers (agencies) within a geographic area. Participation by home health agencies, nurses, and aides will be voluntary. Approximately 10 agencies will be selected to participate in the program. These agencies will be stratified by size and location (rural and urban).
- o HCFA will release a program announcement to Centers for Independent Living (CILs) intended to test a model of consumer-directed durable medical equipment (CD-DME) that covers a range of activities such as assessment and purchasing related to wheelchairs and accessory items. CD-DME sponsors will provide assistive technology information and facilitate consumers' access to expert assessment and care coordination. In partnership with consumers with physical disabilities, sponsors will also more efficiently acquire Medicare-financed DME products and services through a process of prior authorization. Savings accrued from more efficient purchasing will be used to establish beneficiary credit accounts that may be used by beneficiaries to acquire enhanced equipment and/or services not covered by Medicare. Up to four sites are expected to be awarded pre-waiver development grants of approximately \$150,000 each.
- o In their fiscal year 1997 research agenda, HCFA is sponsoring a grants program to foster a more integrated and flexible service delivery system for Medicaid and Medicare dually-eligible beneficiaries by working collaboratively with States and providers to develop more effective systems of care to meet the diverse and complex needs of these beneficiaries.
  - One illustrative model included in the grants announcement was an *Independent Living Model Integrated with Medical Services*, with emphasis on increased consumer direction and control, innovative case management models built around current resource systems for those with disabilities (e.g., Centers for Independent

Living), and new payment approaches that provide increased consumer control and flexibility around key long term care services such as personal assistance services. Discussions with States preparing proposals indicate that several plan to submit proposals targeted to non-elderly beneficiaries with disabilities, with some features of HCFA's illustrative model.

- Twelve proposals were received by the August 29 deadline. HCFA is planning to award approximately six grants of \$150,000 each in October 1997.
- o The State of Wisconsin submitted an application for Medicare and Medicaid demonstration waivers to establish a partnership model of care delivery for under age 65 beneficiaries with physical disabilities and frail elderly beneficiaries who are eligible for Medicare and Medicaid and meet nursing home level of care criteria. The model is similar to the Program of All-inclusive Care for the Elderly (PACE) model in the use of multi-disciplinary care teams, prepaid capitation and the sponsorship by a community-based service provider. The partnership model for people with disabilities would use Centers for Independent Living as the community-based provider. Waiver approval is anticipated this fall with implementation targeted for January 1, 1998. The model is a voluntary enrollment model, and Wisconsin expects to enroll up to 300 individuals at each of three sites. The Wisconsin Partnership model is the first known comprehensive capitated model of service delivery specifically designed for Medicare and Medicaid beneficiaries with physical disabilities.
- o The State of Rhode Island was awarded a HCFA planning grant to design an integrated approach to health/medical care and for life-long community supports for adults with developmental disabilities. Staff from Rhode Island Division of Developmental Disabilities along with Department of Human Services, people with disabilities, service providers, and advocates worked for over 2 years to design this waiver proposal. The planning was completed in July 1996. HCFA is currently reviewing the implementation proposal submitted by the State which will consolidate the current Medicaid and other Federal funding streams into a single coherent funding resource. This will help enable the restructuring and transition of the service system to promote more personally directed supports and services. The program will serve 3,500 beneficiaries statewide.

#### **Status of HCFA Initiatives Announced at the June 25 White House Meeting**

- o Contract to review Medicaid regulations for institutional bias and delink Medicare and Medicaid policy - Covered above.
- o Establish a workgroup to address bias issues - Covered above.
- o Analyze Community Assistant Services Act (CASA) - Analysis attached.

- o Analyze ADAPT's data on cost effectiveness - HCFA's actuaries and the Office of the Assistant Secretary for Planning and Evaluation in DHHS are currently reviewing data provided to them by OMB.
- o HCFA Central Office staff will visit several independent living centers - HCFA's Center for Beneficiary Services (CBS) is to set up visits in collaboration with the Department of Education and ADAPT.
- o Announcement of the Consumer-Directed DME solicitation - CBS plans an early FY 1998 solicitation.

**ATTACHMENT****"MEDICAID COMMUNITY ATTENDANT SERVICES ACT OF 1997" (H.R.2020)****Introduced by Speaker Gingrich on June 24, 1997****Summary of H.R.2020**

**Coverage of "Qualified Community-based Attendant Services."** The bill would require a State Medicaid plan to include qualified community-based attendant services for any individual who is entitled to nursing facilities or intermediate care facilities for the mentally retarded (ICF/MR) and who requires such services based on functional need (without regard to age or disability).

**Individual choice of care setting.** A State would permit an individual who is entitled to Medicaid and qualified for care in a nursing facility or an ICF/MR to choose to receive qualified community-based attendant services in the most integrated setting appropriate to the individual so long as the aggregate amount of Federal expenditures for such individual does not exceed the total that would have been spent in an institution plus the transitional allotment for the State involved.

**Definitions.**

- ◆ **"Qualified Community-based Attendant Services."** A new section is added that defines "qualified community-based attendant services" as attendant services furnished to an individual:

- (1) on an as-needed basis under a plan of service that is based on an assessment of functional need and that is agreed to by the individual;
- (2) in a home or community-based setting, which may include a school, workplace or recreation or religious facility, but does not include a nursing facility, ICF/MR or other institutional facility;
- (3) under either an agency-provider model or other model; and
- (4) the furnishing of which is selected, managed and controlled by the individual (as defined by the Secretary).

The term would include: backup and emergency attendant services; voluntary training on how to select, manage and dismiss attendants; and health-related tasks (as defined by the Secretary) that are assigned to, delegated to, or performed by, unlicensed personal attendants. Excluded services would include: provision of room and board; and prevocational, vocational and supported employment. The Secretary would promulgate regulations that the term may include expenditures for transitional costs such as rent and utility deposits, first months' rent and utilities, bedding, basic kitchen supplies and other necessities.

- ◆ **"Agency-provider model"** means a method of providing community-based services under which a single entity contracts for the provision of such services.
- ◆ **"Other model"** means a method, other than agency-provider, for provision of community-based attendant services. Such a model may include vouchers, direct cash payments or use of a fiscal agent to assist in obtaining services.

**Transition allotments.** Transitional allotments would be provided of: \$580 million in fiscal year (FY) 1998; \$480 million in FY 1999; \$380 million in FY 2000; \$280 million in FY 2001; \$180 million in 2002; and \$100 million in 2003. The Secretary would provide a formula for distribution of the allotment to States.

In order to receive transitional funds, a State would be required to develop a long-term care services transition plan that establishes specific action steps and specific timetables to increase the proportion of long-term care services provided under the plan in home and community based settings, rather than institutional settings. The plan would be developed with "major participation" by both the State Independent Living Council and the State Developmental Disabilities Council, as well as input from Councils on Aging.

**State Quality Assurance Program.** No Federal financial participation would be available with respect to qualified community-based attendant services unless the State establishes and maintains a quality assurance program that is developed after public hearings and that is based on consumer satisfaction. For services furnished under the agency-provider model, they would have to meet the following requirements:

- (1) The State must periodically certify and survey provider agencies on an unannounced basis at least once a year;
- (2) The State adopts standards relating to minimum qualifications and training requirements for provider staff, financial operating standards and a consumer grievance process;
- (3) The State provides a system for monitoring boards consisting of providers, family members, consumers and neighbors to advise and assist the State;
- (4) The State establishes reporting procedures to make available information to the public;
- (5) The State provides ongoing monitoring of the delivery of attendant services and the effect of those services on the health and well-being of each recipient.

The regulations promulgated under section 1930(h)(1) would apply with respect to health, safety and welfare of individuals receiving qualified community-based attendant services in the same manner as they apply to individuals receiving community supported living arrangement services. The Secretary would promulgate additional regulations to protect the health, safety and welfare for individuals receiving qualified community-based attendant services other than under an agency-provider model.

**Secretarial requirements.** The Secretary would be required to submit to Congress periodic reports on the impact of this section on beneficiaries, States and the Federal government.

The Secretary of HHS would be required to review existing Medicaid regulations as they regulate the provision of home health services and other services in home and community-based settings and submit a report to Congress on how excessive utilization of medical services can be reduced by using qualified community-based attendant services.

The Secretary would be required to develop a functional needs assessment instrument that assesses an individual's need for qualified community-based attendant services.

The Secretary would be required to establish a task force to examine appropriate methods for financing long-term care services. The task force would include "significant" representation of individuals (and representatives of individuals) who receive such services.

**Other requirements.** Effective 1/1/99, a State could not elect to cover individuals in a medical institution without also electing to cover individuals who would be eligible for care in a medical institution, but are receiving home and community based care.

The definition of "medical assistance" is amended to add "qualified community-based attendant services" (to the extent allowed and as defined in section 1932).

Each time "section 1915" appears in the eligibility section, the term "or qualified community-based attendant services" is added.

States would have the option of waiving the income limitation in section 1903(f) if the State finds the potential for employment opportunities would be enhanced through the provision of such services. The State may impose a premium based on a sliding scale relating to income.

**Effective Date:** 1/1/98

## **HHS Preliminary Analysis of CASA Bill**

We are committed to addressing the imbalance between institutional and community-based services within the Medicaid program and to promoting consumer-directed home and community based services and personal assistance services. This legislation takes great strides in both these areas. The legislation extends actions of the Clinton Administration achieved through the Balanced Budget Act of 1997, the Personal Care Services Regulation (soon to be published), and Medicaid programmatic actions through the home and community-based care waiver program.

- The Administration supports the bill's concept of providing community attendant care services in locations other than the home.
- We also support the bill's concept of making community-based care an option for those in need of long-term care services.
- The Personal Care Services final regulation, scheduled for publication this week, will contain specific provisions that support expansion of home and community-

based care.

- The regulation removes the requirement for supervision by a registered nurse, reducing the cost and making this a more affordable option for States to elect. The regulation further supports the direction the CASA bill takes in expanding provision of services to locations other than in the home.
- The CASA bill contains provisions that address the provision of high quality services, and controlling the costs in providing all long-term care services which are major concerns of the Department. Recognition of these two concerns in the CASA bill reflects the disability community's understanding of these two important issues. We are doing a number of things to examine these issues in a controlled and deliberate way, and will continue to need the support of the disability community to inform this process.

Despite our strong support for the goals of increased community integration and consumer direction and control for beneficiaries with disabilities, the legislation presents several policy and operational concerns.

## Policy Concerns

### Cost

There are several facets to the cost issue. The bill intends to offer individuals currently residing in institutions the option of receiving personal assistance services in the community. While there might be some savings from people who are currently receiving more expensive care moving to less expensive care givers, we are concerned that these savings will not be enough to offset new costs.

- *Filling of beds* – While services might be provided in the community at a cost equal to, or lower than the institutional cost for a given individual, it is quite likely that the institutional beds will be filled by persons waiting for institutional services, increasing overall costs.

It is difficult to imagine how one might prohibit States from filling beds freed up under this bill. Our experience with the Home and Community Based Waiver program demonstrated the difficulty in constraining State and/or provider behavior in this respect.

- *Transitional Costs* – For States seeking to shift more services to the community and to ultimately close larger institutional settings, there are transitional costs related to covering fixed institutional costs with declining populations that are difficult to resolve in a budget neutral way.
- *Increased Utilization* – It is likely that the availability of personal attendant services will induce more utilization, through the so-called “woodwork effect,” so that overall costs will increase as individuals who would not seek institutional care would seek community care under this new program.

# msh7 92 - now  
lf -60

- *Paying Family Members* -- Compounding the possible cost expansion is the lack of specific language regarding payment to family members for care which could otherwise be furnished without charge. The language should be amended to specify that payment is not available for services furnished by a spouse to a spouse or a parent to a child.

### Cost Limitations

- The bill does have some mechanisms for the State to control costs through a cost neutrality requirement, however, we are unclear how this requirement would be enforced, given the previously identified concerns.
- The bill also permits cost-sharing that could be used to moderate State and Federal spending.

### Actuaries' Concerns

- HCFA actuaries are concerned that even with the limitations on cost in place, implementation of this benefit will result in significant additional spending, above and beyond the \$2 billion transitional pool that is specified in the bill.
- HCFA actuaries question how the limitation on expenditures provided for in CASA is based. Is the limitation based
  - 1) on what is paid under Medicaid for those currently receiving institutional care, or
  - 2) on what would have been paid if all those who receive CASA services instead received institutional care? (Our reading of the bill language would support interpretation 2.)
- Interpretation 1) would implicitly place a limit on who could be served<sup>1</sup>, even though the benefit is envisioned as an entitlement.
- Interpretation 2) would allow all eligible individuals to be served but would result in additional costs to Medicaid if significant numbers of CASA-eligible individuals not now being served by Medicaid in institutions participate in the CASA program.<sup>2</sup>
- Additional costs may also arise to the extent that CASA participants make use of other

<sup>1</sup>As a hypothetical example, suppose Medicaid expenditures for institutional care are \$40 billion, that one-quarter of these costs are shifted to CASA, and that average annual costs for CASA services is \$12,500. (This figure comes from a Kansas program.) Then at most 800,000 total persons (\$10 billion over \$12,500) could be served under CASA without exceeding the expenditure limit.

<sup>2</sup>Data from 1994 the National Health Interview Survey indicate that nearly 1.3 million non-institutionalized individuals have impairments severe enough (3+ ADLs) to be likely to meet CASA criteria, and an estimated 960 thousand of these residents have incomes below the eligibility levels for CASA benefits (300% of SSD).

services (e.g., skilled nursing, therapy) which are not included in the definition of CASA services.

- An operational concern regarding the cost limitation under either interpretation is the difficulty of determining what "would have" been expended as institutional care. Prior experience under demonstrations indicates that such determinations are very problematic in practice.

## **Cash Payments**

The bill identifies that community attendant services could be provided through an agency-based model or an "other" model, with the latter conceivably including vouchers or direct cash payments.

- To date, cash payments have not been authorized in the Medicaid program. There are several issues, ranging from the appropriate amount of Federal oversight to more technical questions such as the possibility that these payments could be considered "income" for purposes of all other Federal and State programs, causing the individual receiving such payments to lose eligibility for services because of their increased "income".
- Although HCFA is interested in exploring well-designed demonstrations to test the effects of these types of models, through demonstrations such as Cash and Counseling, it is premature to support legislation authorizing models such as these absent any understanding of their impact on beneficiaries' health and quality of life, services used, and overall program expenditures.

## **Protection of Beneficiaries' Rights and Quality Standards for Personal Attendants**

We need more information regarding what is meant by the quality standards and beneficiary rights.

## **Exclusion of Institutionalized Individuals**

The legislation excludes payment for services to institutionalized (including those in hospitals) individuals. Over the past several years, we have received complaints from many sources (including ADAPT) that our lack of ability to pay for personal attendants while a person is hospitalized causes hardship for both the provider, the provider agency and the hospital. Reactions from States have been mixed on this issue.

## **Operational Issues**

Many States would face significant capacity issues, including the availability of providers of attendant care, necessary staff training, development of quality oversight mechanisms, development of fiscal agent and other cash or voucher related requirements, as well as funding.

**Room and Board Exclusion**

While this issue is not addressed in the bill language, it will likely be an implementation issue. Similar issues prompted Congress to amend section 1915 © to specifically allow for the payment of the portion of rent and food that can be attributed to the personal care attendant while living in the home of the individual receiving services. It is reasonable to expect that the attendant will have needs and expectations of food and accommodations.

**Distribution of Transitional Funds**

The bill is silent on how transitional funds allocated to a State would then be allocated to individuals. There is some concern that these funds may not be targeted to persons most in need.



**Laura Oliven Silberfarb**

09/08/97 12:01:31 PM

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Record Type: Record

To: Diana Fortuna/OPD/EOP

cc: John F. Morrall III/OMB/EOP, Daniel J. Chenok/OMB/EOP

Subject: personal care services rule

Thanks for your call Diana. We hope to clear the rule today.

The rule makes three significant changes in Medicaid policy:

1. Personal care services may now be provided **without the supervision** of a nurse at the option of the State. Previously, care could be provided by non-nurse personnel, but it still had to be supervised by a nurse. OBRA 93 was silent on the provision. Earlier House and Senate versions required nurse supervision, but these were dropped in conference.
2. Personal care services may be provided **in locations outside of the home**, at the option of the State. Previously, regulations only permitted the personal care services to be provided in the home. This change was in OBRA 1993.
3. Physician may certify the need for the medical equipment on a "case-by case" or as-needed basis. Previous regulation required physicians to certify the need for the medical equipment every 60 days. This is a significant burden reduction for States, physicians and beneficiaries. This was not in legislation and is a policy change by HCFA .

Timothy A. Rosado  
09/09/97 11:24:07 AM

Record Type: Record

To: John A. Gribben/OMB/EOP, Lawrence J. Haas/OMB/EOP  
cc: Diana Fortuna/OPD/EOP, Wayne Upshaw/OMB/EOP, Barry White/OMB/EOP  
Subject: Special Education funding

Even though you did not ask for this, here are some helpful facts and background information on Special Education funding and the CEC Press Release sent over by Diana Fortuna.

Funding. Every budget request of this Administration has provided substantial funding increases for Special Education programs (5.3% for FY 94, 6.0% for FY 95, 3.0% for FY 96, 9.5% for FY 97). The FY 1998 budget request includes a \$174 million, 4.3% increase. Except for FY 97, Congress has funded Special Education below the Administration's requests.

Tax Relief? IDEA does not include specific tax relief provisions as suggested in the Press Release. However, if federal funding exceeds a **\$4.1 billion level**, local education agencies have the ability, under certain conditions, to reduce local special education contributions by 20% (reduce local effort). Theoretically, that 20% reduction could lead to local tax relief. The Administration's budget request of \$4.2 billion is above the trigger.

The Press Release seems to imply that the trigger actually occurs at \$4.9 billion. This is wrong -- the trigger is at the \$4.1 billion level described above. At \$4.9 billion, a different funding distribution formula kicks-in having nothing to do with maintenance of effort for local education agencies.

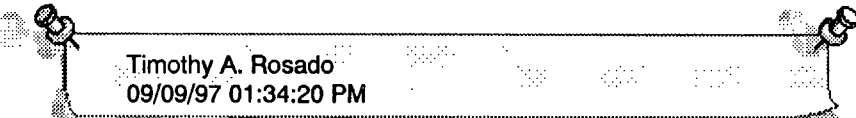
ED position. The \$4.1 billion trigger provision was not pushed by the Department of Education during the reauthorization process and was not included in its proposed bill. Nevertheless, of course, ED eventually agreed to the provision.

Interest Groups. Local school boards and school special education administrators have a strong interest in this provision and local special education funding issues. CEC, in particular, has fairly vocal school administrators group that is associated with the organization.

Base \$4.0b

|      | <u>Adm</u> | <u>House</u> | <u>Senate</u> |
|------|------------|--------------|---------------|
| FY98 | \$174 m    | +300         | +900          |
|      | 4.3%       | 8%           | 23%           |

infl (2.6%)



Timothy A. Rosado  
09/09/97 01:34:20 PM

Record Type: Record

To: Diana Fortuna/OPD/EOP

cc:

Subject: Re: Special Education funding 

If she is talking about more than Special Education Account programs, that's one thing. If she is talking just about Special Education Account programs, the paragraph should probably read:

"NOTE: The Administration was the first to propose a significant increase in appropriations for Special Education programs in the FY 1997 budget -- 9.5 %. Congress eventually provided a 24% increase. For FY 1998, the Administration proposed another 4.3% increase (\$174 million), which is above inflation. Congress has not finalized the Special Education budget; the House proposes a 7.7% increase (\$300 million), while the Senate is proposing a heftier 23% (\$922 million) increase. Both the House and Senate, however, cut other Administration priorities below the budget request."

If the disability groups, themselves, are talking about just Special Education Account programs, it is probably best to use the above paragraph. You may want to run the numbers by Judy Heuman to see what she says.

1. **Are Special Education programs of the Individuals with Disability Education Act (IDEA) a low priority for the Administration given language included the Statement of Administration Policy (SAP) on the House and Senate Labor-HHS appropriations bills?**

Answer. Absolutely not. On the contrary, Special Education funding has and always will be a high priority for this Administration. The Administration's budget request includes a \$175 million, 4.3% increase for Special Education programs over FY 1997. However, the SAP articulates the need to balance scarce federal resources by requesting significant funding increases to other critical need areas.

2. **What is the Administration's record with respect to Special Education funding against Congress' record?**

Answer. For the first three budgets of this Administration, Congress funded Special Education programs at levels less than proposed by the Administration. Only recently has the Congress come around to match or exceed the Administration's requests. Because of the leadership of the President, Special Education funding has risen \$1.1 billion, a 36% increase during this Administration. The Administration proposes another significant funding increase for FY 1998.

3. **Does the Administration oppose funding increases above the funding increases for Special Education programs provided in the budget request?**

Answer. The Administration will work closely with the Congress to ensure a balanced education funding bill that makes new investments in a broad range of important education programs, including Special Education programs. In FY 1997, the Administration helped the Congress find such a balance when the final appropriations bill included an increase above the request for Special Education.

4. **Is the Administration thwarting local tax relief because of its budget request for Special Education programs?**

Answer. Absolutely not. On the contrary, the Administration's budget request is large enough to allow the IDEA trigger to kick-in, which allows local education agencies, under certain conditions, to reduce their special education funding effort (which could lead to local tax relief). This trigger kicks in at \$4.1 billion. The Administration's budget request for Special Education programs is \$4.2 billion.

5. **Does the Administration lack commitment to IDEA because the House and Senate proposed larger funding increases?**

Answer. Absolutely not. IDEA legislation is about much more than funding levels. The Administration worked long and hard with the disability community, the Congress, parents and schools, to construct a reauthorization bill which would ensure that children with disabilities receive a quality education. We think that this has been accomplished, and the Administration's funding request will complement this effort.

01/07/1997 07:42 038381292 0-13-80 3:39AM NATIONAL 7038203660- 7038381292 # 2

cc Elena Kagan  
Mike Cohen  
Bill Kincaid  
Barry White 5.7752  
Larry Haas, OMB  
Diana

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| Fax # 456-6218         |  | Fax #            |              |

## Press Release

For Immediate Release  
Revised

Contact: Lynda Voyles  
703-264-9478 (O)  
703-455-1007 (H)

# President Clinton Short Changes Special Education

## Undermines Tax Relief for Special Education Costs

RESTON, VA, SEPTEMBER 8, 1997--Despite public statements supporting children with disabilities, President Clinton is giving the education of such children short shrift in his funding recommendations. In his 1998 proposal, the president requested \$4.2 billion for special education, compared to \$4.35 billion proposed by the House and \$4.95 billion by the Senate.

In addition, the president's Office of Management and Budget, in a September 2 Statement of Administration Policy, "strongly urge[d]" the Senate to reduce its proposal for "lower priority" programs--which includes special education. The administration says these programs would be "adequately funded" at the administration-requested level.

President Clinton's funding recommendations contrast sharply with statements he made during his campaign and signing of the Individuals with Disabilities Education Act of 1997 (IDEA). In response to CEC questions about funding, he said, "I know how much IDEA means to millions of students with disabilities and their parents...I am committed to maintaining IDEA so that every American student with a disability will receive excellent educational opportunities."

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## President Shortchanges Special Education, Pg. 2

In sharp contrast to the president's goal of ensuring that all children can read by the end of the fourth grade, he requested only a 4.5 percent increase in the Part B program for children with disabilities -- *barely enough to cover inflation*. House members proposed a 7.7 percent increase for this program, and the Senate acknowledged the cost of implementing IDEA with its 27 percent increase. Children who have difficulty learning to read due to a disability need teachers and programs that meet their learning needs. In order to meet the overall objective of "America Reads," IDEA is essential to the needs of the 10 percent of children with challenges such as blindness, learning disability, or other impairment.

"While The Council for Exceptional Children appreciates the President Clinton's commitment to education in general," said Joseph Ballard, CEC's Director of Public Policy, "we regret that he does not appear to be as sensitive to the needs of children with disabilities, nor the needs of taxpayers for relief, as do members of Congress on this particular issue."

The newly reauthorized IDEA would, for the first time, offer local tax relief from the cost of educating children with disabilities. These provisions were championed by school boards, administrators, and parents, as well as special education oriented organizations such as CEC. For tax relief to be triggered, IDEA must be funded above \$4.9 billion. By proposing a lower figure, the president denies local tax relief.

The Council for Exceptional Children, the largest professional association for special educators, works to improve the educational success of students with disabilities and/or gifts and talents. CEC represents members serving more than 5 million students with disabilities and 2.5 million gifted students in the United States.

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EXECUTIVE OFFICE OF THE PRESIDENT  
OFFICE OF MANAGEMENT AND BUDGET  
WASHINGTON, D.C. 20503

September 2, 1997  
(Senate Floor)

## STATEMENT OF ADMINISTRATION POLICY

(THIS STATEMENT HAS BEEN COORDINATED BY OMB WITH THE CONCERNED AGENCIES.)

**S. 1061 – DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES APPROPRIATIONS BILL, FY 1998**

(Sponsors: Stevens (R), Alaska; Specter (R), Pennsylvania)

This Statement of Administration Policy provides the Administration's views on S. 1061, the Departments of Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill, FY 1998, as reported by the Senate Appropriations Committee.

The Committee has developed a bill that provides requested funding for many of the Administration's priorities. We are pleased that the Committee has fully funded Bilingual and Immigrant Education, School to Work, and Education Technology Programs. The Administration is also pleased that the Committee has limited the number of appropriations riders, consistent with the terms of the Bipartisan Budget Agreement. The Senate is urged to continue this practice. As discussed below, the Administration will seek restoration of certain of the Committee's reductions.

The Administration is committed to working with the Senate to identify reductions in the bill in order to find offsets for the restoration of funds that the Administration seeks. For example, the Committee bill provides nearly \$1.5 billion more than the President has requested for three dozen authorities in the Department of Education, while cutting the President's request by almost \$2 billion. Similar reallocations are made in other sections of the bill. We strongly urge the Senate to reduce funding for lower priority programs, or for programs that would be adequately funded at the requested level, and to redirect funding to programs of higher priority, particularly those specified in the Bipartisan Budget Agreement, as noted below.

Unfortunately, the Administration understands that a number of controversial amendments may be offered, such as an amendment to halt the President's national testing initiative, an amendment to prohibit the use of funds in the Act for supervising the Teamster's election, an amendment to enable states to privatize the administration of public assistance programs, and another amendment to provide that welfare recipients in workfare can be paid at rates below the minimum wage. In addition, a number of these proposals, as well as certain provisions of the Committee bill, such as the lack of funding for the President's America Reads Challenge, are contrary to the Bipartisan Budget Agreement. If such policies were adopted, particularly in light of other concerns raised in this Statement of Administration Policy, the President's senior advisers would be forced to recommend that the President veto the bill.

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Ronnie Blumenthal

Downsized govt

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**United States  
Office of  
Personnel  
Management**

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**OFFICE OF THE DIRECTOR  
1900 E STREET, NW., ROOM 5H09  
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Number of Pages

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FAX Number: (202) 606-2183

Remarks

AS Discussed with Leigh Shein

**WARNING:** Many Fax machines produce copies on thermal paper. The image produced is highly unstable and will deteriorate significantly in a few years. It should be copied on a plain paper copier prior to filing.

- The Office of Personnel Management (OPM) tracks and publishes civilian Federal workforce statistics, including statistics on the employment of people with disabilities.
- Annually, Federal agencies report both hiring plans for people with disabilities for the upcoming year and previous year's accomplishments to the Equal Employment Opportunity Commission.
- OPM will review more Federal civilian labor force data to look for reasons why Federal employment of people with disabilities showed a slight decline in 1996. (Possible reasons: voluntary retirements, buyouts, rehiring of Federal workers displaced in reductions in force.)

### **Federal Hiring Options**

Federal agencies can use special hiring authorities when considering certain people with disabilities (those who have severe physical, cognitive, or emotional disability). These authorities provide a unique opportunity to demonstrate the potential to successfully perform the essential duties of a position in the Government, with and without, workplace reasonable accommodation.

There are additional special hiring authorities for certain categories of disabled veterans.

## Hiring and Employment Data for People With Disabilities

### HIRING DATA

|                      | <u>FY 1995</u> | <u>FY 1996</u> | <u>Difference</u> | <u>% Change</u> |
|----------------------|----------------|----------------|-------------------|-----------------|
| Total Hires          | 46,286         | 41,148         | - 5,138           | -11.1%          |
| Total Disabled Hires | 2,798          | 2,255          | - 543             | -19.4%          |
| Pct of Total         | 6.0%           | 5.5%           |                   |                 |

|                    | <u>FY 1995</u> | <u>FY 1996</u> | <u>Difference</u> | <u>% Change</u> |
|--------------------|----------------|----------------|-------------------|-----------------|
| FTP Hires          | 229,363        | 200,915        | -28,448           | -12.4%          |
| FTP Disabled Hires | 12,993         | 10,943         | -2,050            | -15.8%          |
| Pct of FTP         | 5.7%           | 5.4%           |                   |                 |

### EMPLOYMENT DATA

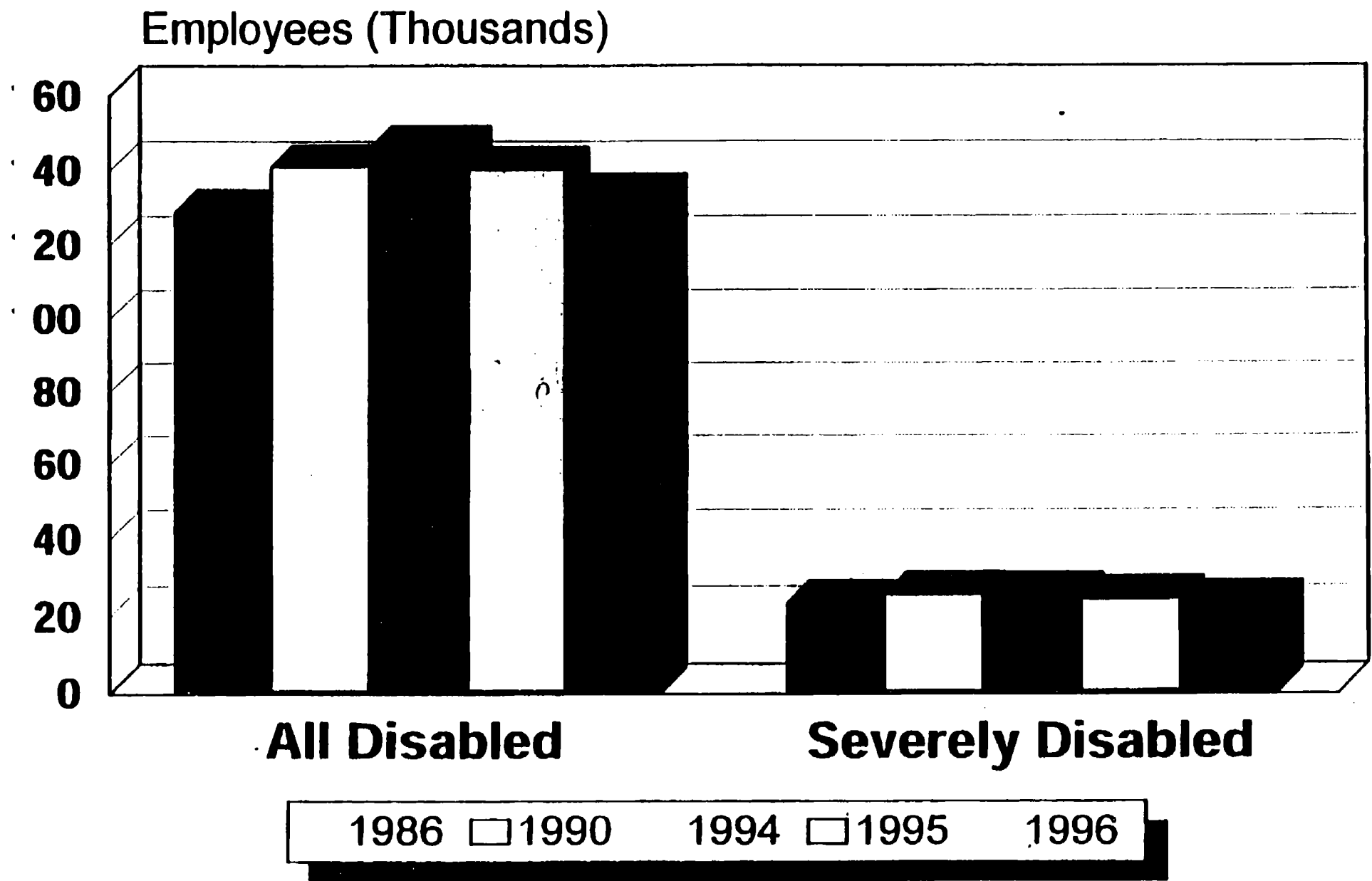
|                  | <u>Sept 1994</u> | <u>Sept 1996</u> | <u>Difference</u> | <u>% Change</u> |
|------------------|------------------|------------------|-------------------|-----------------|
| Total Exec Br.   | 2,043,449        | 1,890,406        | -153,043          | -7.5%           |
| Disabled Exec Br | 145,105          | 132,344          | -12,761           | -8.8%           |
| Pct of Total     | 7.4%             | 7.3%             |                   |                 |

|                  | <u>Sept 1996</u> | <u>March 1997</u> | <u>Difference</u> | <u>% Change</u> |
|------------------|------------------|-------------------|-------------------|-----------------|
| Total Exec Br.   | 1,890,406        | 1,851,835         | -38,571           | -2.0%           |
| Disabled Exec Br | 132,344          | 129,801           | - 2,543           | -1.9%           |
| Pct of Total     | 7.3%             | 7.0%              |                   |                 |

Source: U.S. Office of Personnel Management

# Executive Branch Employment of Workers with Disabilities

## 1986 - 1996



# Executive Branch Employment of Workers with Disabilities

1986 - 1996

|                                  | 1986           | 1990           | 1994           | 1995           | 1996           |
|----------------------------------|----------------|----------------|----------------|----------------|----------------|
| <b>Workers with Disabilities</b> | <b>128,123</b> | <b>140,169</b> | <b>145,105</b> | <b>139,525</b> | <b>132,344</b> |
| <i>% of total Workforce</i>      | 6.6            | 6.9            | 7.4            | 7.4            | 7.3            |
| <b>Severely Disabled *</b>       | <b>22,424</b>  | <b>24,619</b>  | <b>24,560</b>  | <b>23,619</b>  | <b>22,277</b>  |
| <i>% of total Workforce</i>      | 1.2            | 1.2            | 1.3            | 1.3            | 1.2            |

\* As designated by the Equal Employment Opportunity Commission (EEOC).

Source: Central Personnel Data File, Executive Branch (non-Postal) agencies only. (202) 606-1990 OWI@OPM.GOV



# AMERICAN COUNCIL OF THE BLIND

1155 15th Street, N.W. • Suite 720 • Washington, DC 20005  
Telephone (202) 467-5081 • Fax (202) 467-5085

Oral O. Miller, J.D.  
Executive Director

TO: President Clinton

FROM: Members of the American Council of the Blind

SUBJECT: Ensuring Access to Telecommunications Technology and Services

## Background

The Telecommunications Act of 1996 included landmark disability access provisions which require that new telecommunications equipment and services be designed so that people with disabilities can independently use the equipment or service. The disability access requirements are contained in Section 255 of the Telecommunications Act. Congress recognized that individuals with disabilities need improved access to gain an equal opportunity to benefit from the revolutionary changes taking place in telecommunications technology. Under Section 255, manufacturers of telecommunications equipment are required to ensure that such equipment is designed, developed, and fabricated to be accessible to and usable by individuals with disabilities, if readily achievable. Likewise, providers of telecommunications services must ensure that their services are accessible to and usable by individuals with disabilities, if readily achievable. If a telecommunications device or service cannot be made directly accessible to individuals with disabilities, Section 255 requires compatibility with assistive technology commonly used by individuals with disabilities, if readily achievable.

The Federal Communications Commission (FCC) is responsible for implementing and enforcing these requirements. Unfortunately, the FCC has not yet taken action to ensure that the straightforward and future-oriented disability access provisions will be implemented by the telecommunications industry -- both manufacturers and service providers.

It is necessary for the administration to ensure that the FCC takes action to implement the clear mandate contained in the Telecommunications Act by establishing the "rules of the road" for disability access. In addition, clear rules are needed to ensure that all covered manufacturers and service providers will compete on a level playing field. These rules should also cover a broad range of telecommunications services, including enhanced services, user interfaces, and software now commonly included in telecommunications products. Clear and comprehensive rules will ensure that accessibility for individuals with disabilities becomes the priority envisioned by Congress when it enacted the disability access requirements. Further delay by the FCC will do harm to consumers and industry alike.

## **Why is telecommunications access important to people who are blind or visually impaired?**

Today, access to telecommunications products and services means access to education and employment. New technology and services that are inaccessible to people who are blind or visually impaired are rapidly being deployed, thereby excluding millions of visually impaired workers from the work force and creating barriers to learning throughout the classrooms and libraries across America. Examples include:

- \* Telecommunications software that relies on visual displays, graphic icons, or interactive "point and click" menus;
- \* Personal communication devices using touch-screen or pen-based input mechanisms;
- \* Television and cable set top box systems that are operated with "point and click," remote control, and on-screen interactive menus that provide the user with only visual feedback, and;
- \* Telephones and fax machines with video menus, or flat panel key pads, with no alternative access options.

The Telecommunications Act of 1996 also contained important provisions which could dramatically improve access to television and other video programs for people who are blind or visually impaired. [Video description (also known as audio description) refers to a means of making television, movies and other video programming accessible through verbal (audio) descriptions of key visual elements which are inserted into natural pauses between the program's dialogue, without interfering with the original audio of a program or movie. The narration enhances understanding and enjoyment of a video program by providing verbal descriptions of essential visual elements such as settings, action, comparative size, gestures, body language, scene changes, graphics, subtitles, and costumes.]

Despite a mandate to "ensure the accessibility of video programming to persons with visual impairments" contained in Sec. 713 of the Telecommunications Act, the Federal Communications Commission has chosen to focus its rule making on video programming accessibility via closed captioning. Although Congress required the FCC to examine "appropriate methods and schedules for phasing video descriptions into the marketplace ...," the Commission's study failed to adequately address these issues. Accordingly, to date, no further progress has been made to realize video programming access through video descriptions for blind or visually impaired persons as contemplated by Congress.

### **Action Requested**

The American Council of the Blind respectfully requests that the Administration ensure that the FCC takes action to create an equal opportunity for people who are blind or visually impaired to access the new frontier of telecommunications products and services.

### **For further information contact:**

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# **THE INFORMATION SUPERHIGHWAY AND THE BLIND AND VISUALLY IMPAIRED**

by

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Over the past decade, people who are blind have enjoyed a new renaissance in terms of information access. This has been chiefly due to the widespread availability of adaptive technology such as synthesized speech, electro-mechanical braille, and screen magnification systems. The online world has also offered much to persons with vision impairments, but developments in the Information Super Highway and the Internet pose grave dangers to the current level of information access for persons who are blind or visually impaired.

## **THE CURRENT STATE OF THE ART**

Personal computers equipped with speech, braille, and magnification adaptive hardware and software have brought a golden age of information access to persons with vision impairments. Talking computers can be used to write, edit, and access electronic documents. Braille devices can be used to either display copy in electro-mechanical form or print hard copy braille from almost any word processing text file. Magnification hardware and software can enlarge text and display it in a comfortable mode for the user. Electronic reading machines can scan printed books and other text into a personal computer, allowing near instant access to information. Computers equipped with adaptive technology and modems can access computer-based bulletin boards, online services, and the vast Internet to send and receive information in an accessible format. For our purposes, we shall use the term accessible to indicate material and electronic equipment that can be utilized independently by persons who are blind or visually impaired.

Currently, blind persons using adapted personal computers can use the Internet for many important functions: electronic mail, file transfers, accessing document archives, etc. Electronic mail is an empowering technology for persons with vision impairments. This is due to the fact that an individual can use a personal computer equipped with adaptive technologies to independently send and receive electronic mail messages. Online archives

of text and computer software can also be accessed by blind persons using these adaptive systems, and an environment has been created that allows near instant access to this information. In the past, blind people used readers to record this information, or transcribers to translate it into braille, a time consuming process to say the least. On average, it can take weeks or months to transcribe a printed book into audio or braille format, a labor intensive and highly skilled process, with these delays often resulting in lost jobs, incomplete school assignments, and more than a little frustration.

## THE PROPOSED INTERNET AND POTENTIAL PROBLEMS

The new Information Super Highway may become a barrier to accessible information, if proper procedures are not undertaken immediately. We will attempt to highlight some of the major potential problems in this section.

Graphics based menus and user-interfaces, if not properly adapted, can create an insurmountable barrier for the blind community. Current adaptive technology works chiefly with text-based systems, although there are a few graphics-based access technologies emerging. Each graphical user interface requires its own access technology, forcing blind computer users to use different and complex tools for each graphical user interface.

The storage of data as images, not text, presents another potential barrier for blind computer users. Current adaptive systems rely on ASCII-based text to perform reading functions. Documents stored as graphics images cannot be read by current adaptive hardware and software, and are thus inaccessible to blind users. This could prove to be a very difficult problem for people who are blind as graphics-based documents are expected to be in widespread use in everything from office correspondence to graphical electronic mail systems.

Interactive video systems distributed on the Internet also pose serious problems of access for persons who are blind and visually impaired, unless alternative display methods are enacted. These systems include, but are not limited to, document delivery systems, electronic shopping, online encyclopedias, etc.

Another disturbing trend is that of public information terminals or kiosks. These dedicated computer terminals, connected to the Internet, can pose grave dangers for blind users in their current conceived form. These information terminals are expected to rely heavily on graphics to display information to the user, and will also rely on touch-screen technology, both difficult for persons who are blind or visually impaired to access. These public access terminals, by their widespread nature, could pose a serious threat to information access for blind people, as they will be used for building directories, airline reservations, search and retrieval systems, and are expected to be as commonplace as public telephones.

Access to the printed word has always been a chief stumbling block for persons who are blind or visually impaired, witness the term "print handicapped" often being used to describe the visually impaired. As graphical user interfaces become more common, and spread to document delivery systems, blind people are in danger of losing access to stored electronic

information, which has been relatively accessible up to this point. The blindness community is in danger of losing information access as software manuals, office correspondence, and other printed materials migrate to graphics based systems. Steps must be taken to assure that adaptive technology can access documents created and distributed on the Internet.

Another danger is the merger of the cable television system with the Internet. Companies are beginning to offer information and other services that can be accessed using a standard cable television decoder, with the information displayed on standard television equipment. Unfortunately, this arrangement would prevent blind and visually impaired people from accessing the information, as adaptive technology cannot presently operate in this environment.

The expense of accessing the information superhighway is expected to be significantly higher for persons with disabilities than those without disabilities. The initial cost of the access technology required to turn a standard personal computer into an information retrieval device with either speech, braille, or magnified output can run as high as five to ten thousand dollars, depending on the exact nature of the equipment required. In addition, due to the relative slowness of using these alternative output devices, charging by the hour or by the minute (rather than by the amount of information retrieved or accessed) places the disabled person at a distinct financial disadvantage. Sensible pricing structures to take these important facts into account should be supported.

### SOME POSSIBLE SOLUTIONS

We need a series of laws and regulations to establish minimum guidelines, and specific regulations, for information technology so that both the hardware and the user interface software will be accessible to all disabilities. In simple terms, we need an Americans with Disabilities Act (ADA) for technology products and services, where product is defined as any device interfaced to the Information Super Highway. The disabled population need interoperability among user interface options, not just interoperability among applications. an example of this might be a blind person using speech, a deaf/blind person using a braille device, a motor disabled person using a puff switch, while a non-disabled individual employs a touch-screen. this adaptive interoperability is no less do-able than interoperability among applications, but has received little attention. Some other solutions include, but are not limited to, the inclusion of persons who are blind or visually impaired in the creation, testing, and debugging process of new products. Open ended systems should be created that can interface with adaptive hardware and software devices. Where applicable, mainstream devices should have built in access features, or be able to easily interface with adaptive devices. User interfaces must become standardized, and easier to use, and customizable for the individual needs of each end user. Documentation and training materials must be provided in accessible formats. Mainstream and adaptive vendors should work together to create products that are accessible from the design stage to final production.

Access to the superhighway by persons who are blind or visually impaired must be as fast and efficient as that enjoyed by non-disabled users. Overall, success should be measured by useability and accessibility. Successful access is defined as receiving visual information through other means, including (but not limited to) speech output, braille output, or

enlarged output. We encourage our national leaders to champion this cause, as it is a just one. Inaccessible computers and information results in lost jobs, with individuals unable to realize their full potential. We must create a world where information can be accessed by every American, according to their abilities not their limitations.

## COMMUNICATIONS ISSUES FOR PEOPLE WITH DISABILITIES

- I think that new information and communications technologies have the potential to improve the quality of life and independence for people with disabilities. Technologies that convert text to speech –for example --could give people who are blind access to the rapidly expanding universe of online information.
- But if these technologies are not designed from the beginning to be accessible, then people with disabilities will not be full participants in the Information Society.
- One of the projects my Administration has promoted is making the World Wide Web more accessible for people with disabilities. We are working with industry so that they will adopt standards that will provide ■ curbcuts for the information highway. ■
- If there are other steps we should be taking in this area, please let us know and we will be happy to follow up with you.