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Disabilities - Public Liaison Meeting

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Disabilities - Public Liaison Meeting

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RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
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Disabilities -
public liaison mtg

Diana —
Thanks for this summary. It looks to me as if we should try to respond somehow to the President's frustration on CASA issues. Would you talk with Nancy-Ann and see if you can figure out something to do in this area? Also, call me re the EO.
Thanks
Elena
cc: Bruce

Meeting with Disability Advocates 9/10/97 -- Summary

ADA: Fred Fay spoke about the importance of the ADA, including funding for enforcement. The President responded that he needs the disability community to help convince Congress that the funding increases we have sought for DOJ and EEOC enforcement are needed. The President also commented that he should talk more about people with disabilities in public settings, and that he did so a lot during prior years' budget fights.

Children's SSI: Paul Marchand of the Arc said the new standard was too strict; that appeal rates are only 44%, which is too low; that the cutoffs are unfairly targeted at kids with mental disorders (85% of the 135,000); that the advocates have good communications with SSA, but SSA should institute a moratorium on further reviews. He cited an anecdote of a child with an IQ of 46 being denied. He noted the variation among states, from Mississippi's denial rate of over 80% to DC's denial rate of under 30%. He noted Arkansas' low rate. He said there is evidence of SSA employees "intimidating" families and threatening the loss of wages if they appeal and lose.

The President responded that he is concerned about the variations among states, and said it raised the question if the differences reflect "political preferences" among states rather than the severity of the disabilities. He said that SSA stated it was legally not possible to do what Daschle/Chafee/etc. wanted -- i.e., recreate the old law via regulation. He said that he has asked SSA to report back to him in 30 days about the concerns Marchand was raising. It was pretty clear that this would focus on the reevaluation process, and not on the standard.

Personal Assistance Services: Gina MacDonald of the National Council of Independent Living spoke about the need for policy changes to make it possible for people to have personal assistants, such as a tax credit. Bob Kafka of ADAPT said political leaders always say they support home and community-based services (HCBS), but that they don't really do so "when the rubber hits the road," and nursing homes continue to eat up 80% of the dollars. He complained that last year in our arguments against the Republican Medicaid proposal, we continually referred to maintaining nursing home protections without referring to the alternative of home and community-based services. He raised our concern about the "woodwork effect" of CASA-type approaches, and said that where there is the political will, solutions can be found, referring to child health and tobacco. He said they were seeking our "endorsement of the principles of CASA."

Mike Oxford of ADAPT said that HCFA has written some good letters to the states on this issue lately, but that always giving states the option was a problem. He said Kansas is quite progressive on HCBS, while Missouri is not and has a long waiting list, and therefore people cross the border to get services. He referred to the "Helen L" Supreme Court case on the "right to services in the most integrated setting," and said we should use that case to move to a "date certain" policy administratively, while CASA is being debated. (Not sure of details on Helen L case; I think it was an ADA case that the Supreme Court chose not to hear.)

The President asked which states are better than others on HCBS. People mentioned Kansas, Colorado, Massachusetts, Illinois, and Pennsylvania, and said they weren't seeking a single model among the states. The President said he believed in this issue, and that the problem is that the dollars don't follow the person, since the entitlement is attached to the services rather than the person. He said that this is not a "human answer" to a person in a nursing home, and that "I'd be furious" if that answer were given to him if he were in that situation, but as President he has a responsibility to live within the budget and deal with CBO scoring of this issue. He said the Administration has been pleading with states to take advantage of options, but they have not responded (by this, I believe he meant our efforts to get congressional approval to turn the HCBS waiver into a state plan amendment). He said he was pleased that the Speaker introduced CASA so that we could have a dialogue. The President said that if some states are successful in moving people from nursing homes to the community in a cost-effective manner, we should get them to tell us how they make it work from a cost perspective.

Bruce Vladeck noted that the HCFA actuaries are talking to ADAPT to learn about state data on cost savings; he noted the regulatory review that HCFA has begun to identify where the institutional biases are; and he said HHS would be seeking sites to test the "date certain" concept, including ensuring consumer protections, saying HHS would work with ADAPT on this "right away." Kafka said ADAPT has a credibility problem in convincing people that this can be done, and noted they need help with NGA in particular. Judy Heumann of the Dept. of Education noted that cost/benefit analyses need to take account of dollars outside of Medicaid, noting that someone who can't get a job because they don't have a personal assistant might go on SSI/SSDI. The President said that if we can show this can be done in a cost effective manner (I think via demonstrations), then we can convince everyone to do this (states, Congress, etc.). Paul Marchand of the Arc noted that only 2 out of 6 New England states still have institutions for the mentally retarded, and that it would be very useful if we could tout this fact, to show there is no need for institutions and that this policy can work. The President said this was a good idea. The President did not mention sending Gingrich a letter or any timetable for the work group. In the briefing prior to the meeting, the President expressed frustration that we didn't have more progress to show on this issue.

IDEA: Nancy Diehl of the Parent Network thanked the President for all he has done on IDEA, but asked him to show his leadership on the budget issue by making it a priority. The President said that disabled children will benefit from America Reads and his other education proposals as much as or more than other children, and noted that funding for IDEA has increased 36% since he has been President. He said that prior to last year he had always asked for more IDEA funding than Congress and that the Republicans are simply trying to put him in a political bind by underfunding Goals 2000 and America Reads and giving the money to IDEA. He said he would do "the best I can by IDEA," but urged the group not to "let them take advantage of us" on this issue. Paul Marchand noted that the disability groups are on record with the Hill as saying they don't want money for IDEA that is taken from other programs, and the President thanked him for that.

Employment: Tony Coelho noted that people with disabilities have a very low rate of unemployment and high dependence on SSI/SSDI; and that the cost of these programs puts a major burden on the federal budget. He said that 50% of those on SSA's rolls are capable of substantial gainful employment (a statistic I have never heard before). Coelho said that all the welfare-to-work incentives we are instituting may hurt the employment prospects of people with disabilities. Coelho praised the Administration for taking the "small but significant" steps of the Medicaid buy-in and the SSA ticket, but said we must "keep it moving" through the executive order on this topic that is now under consideration within the Administration. (Prior to the meeting, I had asked him not to raise the E.O. since it is still being debated internally; he said the community is well aware of the issue, and that he planned to raise it.)

Paul Edwards of the American Council of the Blind spoke about 4 issues: strengthening Section 508 of the Rehab Act; his concern that the FCC has not yet taken action on regulations to implement the accessibility requirements of the Telecommunications Act, and he can't get an explanation on when they will do so or why there is a delay; we must ensure that in the ISTEA reauthorization there is increased funding for public transit; and that the federal government must do a better job as a model employer of people with disabilities. In that regard, Edwards said that the executive order is crucial, and that he had some data that suggested that the employment rate of people with disabilities in the federal government may be dropping rather than rising. Coelho then said we must all be vigilant in making sure that the ISTEA reauthorization does not include any weakening of ADA transportation requirements.

The President said there will be more money for transportation, but it would not necessarily be for mass transit; and so people had to be ready for that fight. He also noted the opportunities that technology is opening up for people to work at home. The President also said the corporate America should take a look at these issues, and that the issues are so complex that maybe "we need to have your committee," referring, I think, to the executive order. He said that if the economy is to continue to perform so positively we need to involve more those outside the mainstream -- the poor and the disabled.

Bob Williams of HHS said many people on TANF are disabled, and Susan Daniels of SSA echoes his concern that it would be bad if welfare reform simply shifted funds from welfare to SSI. The President said he had never made the connection before in his mind between our TANF welfare to work efforts and putting people with disabilities to work. The Vice President said he would follow up aggressively on the information superhighway issue that Edwards raised.

Conclusion: At the end, Marca Bristo of the National Council on Disability praised the President's efforts as being far more than those of his predecessors, and said we "desperately need more from your office." The President said it was a great meeting, and that he valued it because it is so easy for him to get isolated from issues and people; and that he wanted to work with their team and be part of their movement.

Disabilities - public liaison mtg

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

- You will enter the Cabinet Room, walk around the room and greet the participants, and make opening remarks.
- 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.
- You will make remarks after each topic is presented (see attachments).
- After the issue discussion, Tony Coelho and Marca Bristo will thank you.
- 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
Tab 6: Background and Talkers on Supplemental Security Income Eligibility
Tab 7: Background and Talkers on Personal Assistant Services
Tab 8: Background and Talkers on Individuals with Disabilities Education Act
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.

WELCOMING REMARKS

- 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.

- 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.

- 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.

- 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

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

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.

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 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.

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.

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.

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.

EMPLOYMENT OF PEOPLE WITH DISABILITIES

Advocates Who Will Discuss:

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

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.

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Clinton Presidential Records
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Elena Kagan
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FOLDER TITLE:

Disabilities - Public Liaison Meeting

2009-1006-F
db1527

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

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P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
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b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Participants:

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Jenness Roth (Nancy's Attendant)
Paul Edwards
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Joseph Rosenstein (John's Interpreter)
Robert Kafka
Carol A. Jones (Bob's Attendant)
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P6/(b)(6)

Becky Ogle

Disabilities - Public Liaison meeting

Version: September 8 - 10:00 am

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

- 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. Currently, 250 percent of 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. **The Administration originally proposed Medicaid buy-in with no income limit, so this provision should not be over emphasized.**

- 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..

- 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 under freedom of choice waivers..

- 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 but have subsequently been terminated from SSI because of the PRWORA's tighter definition of childhood disability. It should be noted that disability groups perceive the Administration's interpretation of the new SSI definitions for children as overly harsh resulting in large numbers of children losing eligibility.

- 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.

- The Act establishes the Program of All inclusive Care for the Elderly (PACE) as a State plan option under Medicaid to provide comprehensive community-based health and long-term care to eligible individuals over age 55 who would otherwise require nursing care.

- Medicare will now pay at least part of the cost of renting upgraded durable medical equipment (DME). The Act allows DME suppliers to receive Medicare payment for upgraded DME as if it were equipment. Beneficiaries may be billed the difference between the standard rate and the cost for the upgraded equipment.

Personal Care Services Regulation

- 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 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. However, it should be noted that States have been able to provide personal care services under waivers without the regulation, and it has taken DHHS 4 years to finalize the regulation.)**

    - 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.

Home and Community-Based Care Services

- The Health Care Financing Administration continues to support and promote [illegible] 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 © 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.

- 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.

- 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.

- 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.

- 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

- 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. The two studies will consist of a comprehensive review and analysis of Medicaid policies, regulations and statutes which relate to long-term care services to identify:

    - the institutional bias in Medicaid law, regulation, All State Medicaid Directors Letters, and other documents ,
    - requirements that overly promote the medical model in long-term care,
    - identify ways we can promote home and community-based care, and
    - identify to the extent to which Medicare and Medicaid are unnecessarily linked.

  - 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 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 .)**

- 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. This effort is a major research effort on behalf of DHHS. 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.

    - The experimental group members who receive cash payments in lieu of arranged services will be required to account for how they spend the funds. Minimal restrictions will be placed on beneficiaries' use of the cash benefits so long as purchases are related to disability needs. Where the relationship of a planned use of the cash benefit to a disability need is not self-evident, prior approval may be required.

    - 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.

- Each State proposal contains detailed provisions for monitoring the quality of care provided under the demonstrations. Monitoring is provided by the counselors, registered nurses and/or the fiscal intermediaries depending on the State.

- 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) [illegible] 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.

- 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.

- 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.

- 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 in May 1997 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

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

- *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[1], 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.[2]
- Additional costs may also arise to the extent that CASA participants make use of other 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(c) 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.

Disabilities - Public Liaison meeting

Diana Fortuna
09/08/97 10:45:49 AM
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Record Type: Record

To: Elena Kagan/OPD/EOP

cc: Laura Emmett/WHO/EOP
Subject: FYI on POTUS Meeting on Disability on Wed

Bill White of Public Liaison is trying to get OMB to agree to a big increase in ADA enforcement in advance of the budget -- I doubt he'll succeed. The attached talking points were done by Liz Savage at DOJ as a first draft for the meeting; I have some concerns/questions about them that I have to figure out.

We should catch up on the status of this meeting -- I don't know how involved you want to be. The topics are Medicaid home and community-based services, the ADA, IDEA, children's SSI, and employment. Most of the work is centered on Medicaid, and Chris J. and I are having a meeting on that this morning (I mentioned this to Laura). But the other 4 topics also need work; I am pushing for a premeeting on those 4 in addition to the Medicaid meeting we are having this morning.

On the disability executive order, we are meeting on Thursday, by the way, but I don't think it can come up at the President meeting.

---------------------- Forwarded by Diana Fortuna/OPD/EOP on 09/08/97 10:33 AM ---------------------------

William H. White Jr.
09/08/97 10:14:28 AM

Record Type: Record

To: Michael Deich/OMB/EOP

cc: Diana Fortuna/OPD/EOP, Maria Echaveste/WHO/EOP, Mark Hunker/WHO/EOP
Subject: POTUS Meeting - ADA Enforcement

Thanks for listening to my plea this morning. It would make a great impact if the President could state at this Wednesday's disability meeting that we will call for a 19% (which is only $2 million) increase in funding for ADA Enforcement in our FY99 DOJ Budget request. Please see the attached proposed talking points. Thanks.

ADA ENFORCEMENT

o 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.

- o Although we have been quite successful, we all know we have a long way to go. All of you are all too familiar with the backlogs at the Justice Department and the EEOC. We all know that our resources are not sufficient to address the majority of meritorious complaints received.

- o 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.

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

(MICHAEL, THE NEXT TALKING POINT IS THE ONE WE WOULD LIKE TO MAKE STRONGER.)

- o We are considering a proposal to significantly increase ADA enforcement resources in the FY 1999 budget I will submit to Congress early next year. (DOJ*s OMB request calls for a 19% increase ($2,173,000).

- o Members of both houses of Congress have said they will never weaken the ADA. (As Senator Hutchinson (R-AR) recently told a reporter *[P]oliticians see it as political nitroglycerin... They*re afraid to handle it, afraid to touch it.*)

- o By failing to adopt my proposals for very limited increases to already limited enforcement budgets, they have indirectly weakened the law.

- o 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. Obtaining increases for ADA enforcement will require a similar effort.

Disabilities - public liaison meeting

9/8/97 Pre-meet on disability group meetings

Mtg - Wed 11th. 12 advocates at mtg

Pres remarks

J. Dart remarks - mediate

5 topics

1 - ADA

Call MD → DOT budget request - 2m. 19% ↑. ←

2. SSI kids

P. will be asked to ask SSA to review stat interp.

variation from state to state

low appeals rate

what to say

3. Personal assisted service

Concerns at costs + beneficiary protections ↙ consumer safeguards. - Pitch for CASA - (Speaker introduced)

want to know our position

Date certain - anyone in nursing home can get community based services - capped at nursing home rate

(2x # if nursing home beds backfilled)

BVladeck - will conduct state experiments

essentially a deinstitutionalization project

commit to pilot program

} allows exper. make sure protections are there

WH just formed to look at this question.

Welfare-to-work connection?

? to ID other (incremental) next steps

progress report - 90-120 days.

Letter to Gingrich??

Call up G's office - give heads up.

4. IDEA - Congratulations

will come up? Hope not

Have Q+A ready.

Put in P's opening remarks — 5. Employment - maybe run out of time.