

**NLWJC - Kagan**

**DPC - Box 012 - Folder 021**

**Disabilities - CASA**

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Diana Fortuna 03/10/98 11:21:10 AM

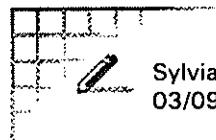
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Record Type: Record

To: Sylvia M. Mathews/WHO/EOP  
cc: Elena Kagan/OPD/EOP, Christopher C. Jennings/OPD/EOP, William H. White Jr./WHO/EOP  
bcc:  
Subject: Re: Upcoming hearing on disability issue 

We are pushing HHS on who will testify now, so we'll see.

Sylvia M. Mathews



Sylvia M. Mathews  
03/09/98 08:49:46 PM

Record Type: Record

To: Diana Fortuna/OPD/EOP  
cc: Elena Kagan/OPD/EOP, Christopher C. Jennings/OPD/EOP, William H. White Jr./WHO/EOP  
bcc:  
Subject: Re: Upcoming hearing on disability issue 

Do you think that we need to push HHS on their choice of testifier?  
Diana Fortuna

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Diana Fortuna 03/09/98 02:43:35 PM

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Record Type: Record

To: Sylvia M. Mathews/WHO/EOP  
cc: Elena Kagan/OPD/EOP, Christopher C. Jennings/OPD/EOP, William H. White Jr./WHO/EOP  
Subject: Upcoming hearing on disability issue

Last September, the President met with disability groups to discuss several issues, including their desire to see Medicaid changed so that services at home and in the community are on an equal footing with nursing home services. The groups sought his endorsement of a bill known as CASA that does so, which has a price tag of \$10-20 billion. The President didn't commit to endorse the bill, but he spoke articulately in the meeting about the problem. You may recall that in the briefing before the meeting the President appreciated the fact that such a change is very difficult to make without spending billions of dollars, but he also expressed some frustration that we didn't have more of an answer or alternative for the groups. Since then, HHS has had a work group making slow progress on the issue, preparing demonstration projects and the like.

This Thursday, there is a hearing in the House on CASA. Gingrich may appear on the first panel

(the community persuaded him to introduce the bill, although he declined to endorse it) along with Dick Gephardt, who is a cosponsor. The Administration has been asked to testify on the second panel. There are two issues:

1. We would like to send a letter from the President to Gingrich this week, outlining what progress we have made in this area and commending him for introducing CASA as a good vehicle to begin a discussion of this important issue. It states that he can not endorse the bill in full in its current form, but that we would like to have a dialogue with the Congress on this issue. However, OMB may object to sending the letter.

2. HHS currently plans to have Medicaid director Sally Richardson testify for the Administration. We hear from Administration appointees with disabilities like Marca Bristo and Bob Williams that disability groups will take offense that Shalala or Nancy-Ann Min are not testifying.

We are trying to work this out, but thought you would want to be aware given the President's interest.

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Diana Fortuna

03/11/98 05:04:34

PM

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Record Type: Record

To: Elena Kagan/OPD/EOP

cc: Laura Emmett/WHO/EOP

Subject: FYI, here's the outcome on the CASA hearing tomorrow

1. Chris negotiated with HHS that Peggy Hamburg (new ASPE Assistant Secretary) will testify with Sally Richardson. Nancy-Ann was allegedly not available due to other hearings. This isn't too bad, although Peggy is unknown to the disability community.

2. Josh Gotbaum objected at the last minute to the letter we wanted to send to Gingrich from the President outlining what we've done in this area that walked a kind of wormy line on CASA (share the goals, premature to endorse in full because of questions and complexity, cost is an issue). He believes we should soft-pedal the President's involvement in this issue because it's such a loser. Chris and I don't agree, but we agreed to drop it for today because we were having an even bigger argument with Josh....

3. Josh initially wanted Peggy/Sally's testimony to explicitly say we "can't support" CASA because of its huge cost, which would have been a major problem because no one (Gingrich, Gephardt) is saying that -- everyone is walking the funny line of embracing the goals but neither endorsing nor opposing it outright -- and we would just be pointlessly shooting ourselves in the foot for no reason, since the legislation is not going anywhere anyway. We talked him out of it and agreed on fuzzy language that doesn't reference CASA specifically, embraces the general goals, mentions cost as an issue.

The hearing is not technically on CASA, but on home and community-based services for people with disabilities. HHS's testimony is pretty strong recounting all the things they are doing in this area. No hostile questions are expected since the subcommittee is doing this largely because of pressure from ADAPT.

Anyway, this is OK for today, but Chris and I will continue to push the Gingrich letter with OMB. Josh seems pretty hostile to this issue.

Diana Fortuna

03/04/98 12:48:17

PM

Record Type: Record

To: Christopher C. Jennings/OPD/EOP, Jeanne Lambrew/OPD/EOP, Elena Kagan/OPD/EOP

cc: Laura Emmett/WHO/EOP

Subject: Hearing on CASA/ADAPT issue

There is a hearing in the House on the CASA bill next Thursday, March 12th. This is the bill being pushed by ADAPT, the disability advocates, that would make home and community-based services, including personal assistance services, mandatory under Medicaid. It has a price tag of about \$12 billion.

I am trying to get details, but the rumor I have heard is that Gingrich and Gephardt will be on the first panel. Gingrich introduced the bill, but does not endorse it. Gephardt is a co-sponsor. The second panel is supposed to be an Administration witness. I hear HCFA wants to send Sally Richardson; disability groups will be mad that it isn't Shalala or Min. Then a 3rd expert panel.

We are finishing up a letter from the President to Gingrich on the legislation that details Administration actions on this issue, praises CASA's goals, notes its costs, declines to endorse it, and says we should work together on the issue. I hope we can issue it in the few days before the hearing.

Elena/Laura: Andy Imparato/Marca Bristo of the National Council on Disability may be calling you on this, supposedly with ideas on what the Administration could say. I am trying to figure out what they think.

## Home and Community-based Services

### What We Can Say:

- Record of Past Accomplishments (see attached)
- Personal Care Reg to be published this week
  - how to describe in pithy way
- New Work Group formed to study issue
  - Contract to review Medicaid regs for institutional bias now underway -- pursuant to ADAPT meeting in June
  - Report in 90 days? to whom?
- Position on CASA:
  - Support principles, but have cost and beneficiary concerns
  - Can we write a letter stating this, similar to Gingrich position? to whom?
- Position on "Date Certain" (they will push on this)
  - Once again budget issue, but we will look at in demo context???

## 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?

**SUMMARY AND TALKING POINTS ON CASA  
(Community Attendant Service Act of 1997:H.R.2020)  
FOR PRESIDENTS MEETING WITH DISABILITY GROUPS**

**BILL SUMMARY**

H.R. 2020 mandates that states provide "community based attendant services" as a matter of choice to persons of all ages residing in institutions and individuals living in the community who would be eligible to receive institutional services based on functional need. Community based attendant services are to be defined by the Secretary, provided in home and community-based settings, and include emergency and back-up attendant services, training on how to manage attendants, and health related tasks by unlicensed attendants. Services are to be provided on an "as needed basis" under a plan of care based on an assessment of functional need. Such services could be provided by agencies or be directed and managed by the consumer. In the latter case, direct cash payments, vouchers and payments to family members would be allowed. Matching Federal medical assistance payments and unmatched "transitional allotments" to increase the availability of home and community-based settings are available to states. The Secretary is to distribute two billion dollars in transitional allotments across states with approved plans over six years with preference given to states with higher proportions of institutionalized individuals. Quality assurance is based on consumer satisfaction. Agency providers are subject to survey and certification and other requirements. The Secretary is required to develop additional health and safety standards that maximize consumer independence and control.

States would be able to limit the amount, duration, and scope of services but could not limit freedom of choice, state wideness or comparability.

## **TALKING POINTS ON CASA FOR PRESIDENT'S MEETING WITH DISABILITY GROUPS**

- ◆ The Administration fully supports the basic goals of CASA, including:
  - addressing the “institutional bias” in the Medicaid program;
  - enabling consumers and their families to choose the setting in which long term care services are received; and
  - promoting consumer direction of home and community based/personal assistance services.
  
- ◆ The Administration has actively supported these goals in a variety of ways:
  - The recently enacted Balanced Budget Act includes a Medicaid buy-in for certain SSI beneficiaries with disabilities who want to work. It also allows home and community based waiver participants to receive supported employment and related services regardless of prior institutionalization. Small victories...but progress nonetheless.
  - I am particularly proud of the commitment we have made to working with the states to streamline the home and community based waiver program. Under this program over 250,000 people now receive the services they need in home and community based settings.
  - I am also happy to announce that we have approved a new Medicaid Personal Care Services regulation which allows states to cover personal care services in the home or in locations outside the home including the work place and removes the requirement that a registered nurse supervise personal care services.
  - The work that HHS is now engaged in with the Robert Wood Johnson Foundation is also significant. Over a year ago HHS and the Foundation joined together to design a research experiment called the “Cash and Counseling Demonstration.” The demonstration will test the cost effectiveness of providing Medicaid beneficiaries with significant disabilities the choice of receiving cash allowances to purchase needed assistance in lieu of receiving agency directed care. Waivers for the demonstration have just been submitted to HCFA and are under review. When implemented, the demonstration is expected to enroll almost 10,000 older persons, 7,000 working age adults and over 1,700 children with disabilities in four states.

- ◆ While these are important accomplishments, I recognize that we need to do more.
  - Based on a meeting that Dr. Vladeck had with some of you in June, HCFA has recently initiated a comprehensive review of Medicaid policy to identify provisions which contribute to the program's institutional bias and to the perpetuation of medical rather than social models of care. He has also ordered an examination of the extent to which Medicaid may need to be "delinked" from Medicare to promote consumer directed services. This review will be completed by the end of the year.
  - In addition, the Department of Health and Human Services has now established a home and community-based services working group of senior staff from across the department to develop options for eliminating the institutional bias in Medicaid, promoting consumer directed home and community based services and reducing unnecessary "medicalization" of long-term care services. An important part of the work of this group will be to explore ways to deinstitutionalize by a "date certain" nursing home residents who want to live in the community.
  - I am also asking the work group to examine options for linking the need for increasing the supply of qualified attendants with the work requirements of state welfare reform under TANF. Linking the needs of people with physical disabilities for attendants and the needs of low-income families for jobs seems to be well worth pursuing.
  - The work group will actively engage partners from the states and disability and aging communities. The group will be chaired by Bob Williams, my new Deputy Assistant Secretary for Disability, Aging and Long-Term Care Policy and by Sally Richardson, HCFA's head of Medicaid and State Operations. I have asked them to report to me by the end of February with an action plan.
- ◆ Now I would like to talk to you briefly about the CASA Legislation, which was introduced early in the summer and which many of you support. The goals are important ones, and I am pleased that you now have a vehicle which will allow them to be discussed and debated. I support the basic goals of CASA... but I also have some serious concerns about its potential consequences, particularly in regard to creating a new entitlement, to the cost consequences of expanding the eligible pool of recipients of community based care, the prematurity of opening up Medicaid to permit cash payments prior to understanding the cost effectiveness of this approach, and to some of the quality provisions. (Probably makes sense for Bruce to do the more detailed discussion and then turn it back at the end??)
  - CASA mandates that all states include community-based services in their Medicaid plans. The Administration has repeatedly gone on record in favor of state flexibility and no new mandates under Medicaid.

- **CASA eligibility criteria would entitle all people who currently live in nursing facilities or ICFs/MR , and those who live in the community but meet the criteria for institutional services to receive community-based attendant services or other models of support such as vouchers or cash. Our preliminary estimates suggest that almost one million people now living in the community may meet CASA's eligibility criteria. This is in addition to the potentially large number of persons now in institutions who may also choose CASA services.**
  - **While the architects of CASA have made some important strides in trying to address cost control issues, far larger numbers of people are likely to opt for CASA services than are currently receiving long-term care services today. The result would be a substantial increase in Federal and state costs.**
  - **Although the bill includes a cost neutrality provision, it appears to tie cost neutrality to what it would cost if the states were to actually serve all eligible individuals in an institution--not to what states are spending or plan to spend on the much smaller number of people who currently receive institutional services.**
  - **The cost containment provisions of CASA are inadequate in today's budget and political climate.**
  - **CASA also contains important provisions that address the need to assure high quality services. But these provisions also raise concerns. For example, the bill would require greater federal regulatory and enforcement requirements for agency provided services than what is now required in our home and community-based waiver program. At the same time, there are only minimal quality assurance and beneficiary protections for consumer directed services models. While we strongly support such models of service delivery, we believe that much more attention needs to be paid to quality concerns.**
  - **I also understand that there is not yet consensus in the disability community about CASA. Some groups believe it is cast too narrowly and should be decoupled from eligibility for institutional care. Others are concerned that the bill's benefits may not be responsive to the needs of certain populations. Some may also be concerned about the latitude given to the Federal Government and to states to define the benefits and the amount, duration and scope of the benefits to be offered.**
- ◆ **Nevertheless, CASA offers us a good platform for discussing our mutual interests and goals. I expect we will be doing much more of this in the months ahead. I believe that one basis for making progress is to experiment with a number of options for addressing the imbalance in Medicaid between community- based and institutional services, and for promoting an expanded array of consumer driven community services and an improved community services infrastructure. I am confident that the steps we are now taking are**

moving us in the right direction.

November 4, 1996

Mr. Michael Oxford  
ADAPT  
835 800 East Road  
Lawrence, Kansas 66047

cc Chris J  
Bruce Kladek  
(Fax 690-6262)  
Nancy - Ann Min  
5-728  
From Diana Fortuna

Dear Michael:

The President is proud of his record on disability rights issues. President Clinton's administration has continued to build policies based on the three simple creeds: inclusion, independence, and empowerment. Last year the President vetoed legislation that would have eliminated the Medicaid guarantee of health care and independence so important to individuals with disabilities. His administration has vigorously enforced the Americans With Disabilities Act, the Individuals With Disabilities Education Act, and other civil rights laws.

To this end we will convene a meeting with the President, ADAPT, and other disability rights leaders to discuss what we can do together to further our efforts on such issues as personal attendant, home and community bases services, and other issues that are important to people with disabilities. Provided the President is re-elected, we will convene this meeting in the first quarter of next year. I will be in touch with you directly to discuss the appropriate arrangements for this meeting.

Sincerely

Alexis Herman.  
Assistant to the President / Director of Public Liaison



# ADAPT

## FREE OUR PEOPLE

The President of the United States  
The White House  
1600 Pennsylvania Avenue, NW  
Washington, D.C. 20500

December 20, 1996

My Dear Mr. President:

Congratulations on your re-election. Beginning in early 1997, your administration will need to address major issues confronting the growing and active disability community. Perhaps the most major will be long term care services.

ADAPT anticipates a productive meeting with you and your staff to discuss the critical issues surrounding the delivery and funding of long term services.

This meeting should produce a plan of action that enhances home and community attendant services. Designating timelines and people accountable for results will be critical to this plan, indeed, to any restructure of the current institutionally biased long term care system. This plan's funding component should redirect and redistribute the federal funding that forces people with disabilities, old and young, into nursing homes and other institutions.

Your leadership will be essential in persuading Congress to tackle the controversial institutional, medical-model bias in the Medicaid program. People with disabilities, regardless of age or type of disability, rely on the Medicaid program for the support services necessary to live as independently as possible. Yet, as you know, these very services often act as barriers to independence. The disability community will enthusiastically support reform of this system.

As you may have heard, while in Atlanta ADAPT met with Speaker Gingrich on this same matter. The Speaker, though cagey in the past, made concrete, written commitments (see enclosed) as to how and by when he will work with ADAPT toward the reform of the Medicaid program and passage of ADAPT's proposed long term services legislation CASA, the Community Attendant Services Act. It is deeply troubling to us that the Speaker will make such a commitment to us, but your administration has yet to do so. We hope this meeting will remedy this disturbing situation.

Alexis Herman's November 4, 1996 memo states you will meet with ADAPT and other disability groups in the 1st quarter of 1997 (see enclosed).

ADAPT recommends representatives from the following national organizations representing people with disabilities be also be invited to the meeting: National Council on Independent Living, Disability Rights Action Coalition on Housing, Not Dead Yet, TASH and the American Association of People with Disabilities. This is a good mix of organizations your administration has worked with in the past and which represent people with disabilities throughout the United States. ADAPT will send you a list of people from these organization who will make the meeting substantive and productive.

Please let us know by January 6, 1997 exactly when and where the meeting will be held.

**FREE OUR PEOPLE!**

Thank you for your support,

A handwritten signature in black ink, appearing to read "Mike Oxford", with a long horizontal flourish extending to the right.

Michael Oxford  
National Organizer



A Monthly Publication of The Ohio Private Residential Association June, 1996

## COMMUNITY ATTENDANT SERVICES ACT

The Community Attendant Services Act (CASA) was drafted by the American Disabled for Attendant Programs Today (ADAPT) in May 1995 to establish a national program of community-based attendant services for people with disabilities, regardless of age or disability. The bill would redirect long-term care dollars and redesign regulations to encourage community-based attendant services instead of institutional services. It would require states to develop community-based attendant service programs that conform to the following principles:

1. Program must ensure maximum control by the consumers to select, manage, and control their attendant services.
2. Attendant services must be community-based.
3. Eligibility must be based on functional needs, not medical diagnosis, type of disability or age.
4. Services must be available in home and other locations including, but not limited to, school, work, recreation and church.
5. Services must be available 24 hours a day, 7 days a week.
6. Back-up and emergency attendant services must be available.
7. Program must allow for co-pay/cost sharing for people with higher incomes. Services should not be a disincentive to employment.
8. Delivery of services must include vouchers, direct cash payment, individual provider model, as well as consumer directed agency model.
9. Voluntary training should be available for recipients on how to select, manage and dismiss attendants.
10. Attendants should receive a livable wage and benefits.
11. Attendant services should be based on a mutually agreed-upon individual service plan.
12. Health-related tasks can be delegated to, or be done by, unlicensed personnel.

Each state would be required to develop a program of Attendant Services which:

1. Describes the services which could be provided by an unlicensed person to a person with a disability; and
2. Establishes minimum standards for attendant service programs; and
3. Provides for a comprehensive assessment of attendant services needs; and
4. Requires the development of an Individual Service Plan by both the consumer and a representative of the state agency.

The bill also requires that states specify how they will ensure and monitor the quality of services and how each state should develop a State Plan of Attendant Services based on the aforementioned principles.

### Funding

The bill would require the federal government to redirect 25% of the current Medicaid budget now used for nursing home payments for the development of this national attendant services program and a combination of dollars now spent on attendant type services in Title XIX home health, ICFs/MR and personal care option will be used for the development of the state programs created as a result of this Act.

The state match for community-based attendant services would be ten percentage points less than the state Medicaid match for institutional programs with each state receiving a proportional share of these funds based on a percentage of state population requiring attendant services.

The draft bill is currently awaiting legislative sponsorship and a commitment from House Speaker Gingrich to allow the bill to be introduced in the House. ADAPT is continuing its efforts to find sponsors and get the bill introduced.

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104TH CONGRESS  
2D SESSION

# H. R. 4250

To amend title XIX of the Social Security Act to permit a State the option of covering community-based attendant services under the Medicaid program.

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## IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 27, 1996

Mr. GUNDERSON (for himself and Mr. GINGRICH) introduced the following bill; which was referred to the Committee on Commerce

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## A BILL

To amend title XIX of the Social Security Act to permit a State the option of covering community-based attendant services under the Medicaid program.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. OPTIONAL COVERAGE OF COMMUNITY-BASED**  
4 **ATTENDANT SERVICES UNDER THE MEDIC-**  
5 **AID PROGRAM.**

6 (a) COVERAGE.—

7 (1) IN GENERAL.—Section 1905 of the Social  
8 Security Act (42 U.S.C. 1396d) is amended—

9 (A) in subsection (a)—

1 (i) by striking "and" at the end of  
2 paragraph (24),

3 (ii) by redesignating paragraph (25)  
4 as paragraph (26), and

5 (iii) by inserting after paragraph (24)  
6 the following new paragraph:

7 "(25) subject to subsection (t)(3), qualified  
8 community-based attendant services (as defined in  
9 subsection (t)(1)); and"; and

10 (B) by adding at the end the following new  
11 subsection:

12 "(t)(1) The term 'qualified community-based attend-  
13 ant services' means community-based attendant services  
14 furnished to individuals under a plan of care if all the fol-  
15 lowing conditions are met:

16 "(A) The individuals to whom the services are  
17 furnished select, manage, and control the attendant  
18 services to be provided.

19 "(B) Attendant services would be covered only  
20 if they are home or community-based and are not  
21 provided in a nursing facility or other institutional  
22 facility.

23 "(C) Eligibility for such coverage would be lim-  
24 ited to those who required such services based on  
25 functional need.

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1           “(D) Such services would be available in home  
2           and in other locations, including school, work, recre-  
3           ation and church.

4           “(E) Such services would be available on an as-  
5           needed basis.

6           “(F) Backup and emergency attendant services  
7           would be available.

8           “(G) Notwithstanding section 1916, a State  
9           may impose copayments and cost-sharing for individ-  
10          uals for attendant services based on the income of  
11          individuals involved and in a manner so as not to be  
12          a disincentive for employment.

13          “(H) Coverage of services could be effected  
14          through any appropriate means, which may include  
15          through provision of vouchers to eligible individuals,  
16          through direct cash payment, through an individual  
17          provider model, or through a consumer-directed,  
18          agency model.

19          “(I) Voluntary training should be available to  
20          recipients on how to select, manage, and dismiss at-  
21          tendants.

22          “(J) The particular attendant services to be  
23          covered for an eligible individual would be based on  
24          a service delivery plan that is agreed upon by the in-  
25          dividual and the attendants.

1           “(K) Health-related tasks included within such  
2           services could be delegated to (or performed by) un-  
3           licensed personal attendants.

4           “(L) The State provides for the periodic sub-  
5           mission to the Secretary of reports on the coverage  
6           of such services under this subsection.

7           “(2) Medical assistance for qualified community-  
8           based attendant services need not be made available in all  
9           geographic areas of a State or to all beneficiaries, notwith-  
10          standing anything to the contrary in section 1902(a)(1)  
11          or section 1902(a)(10)(B).

12          “(3) Medical assistance for qualified community-  
13          based attendant services may not be made available by a  
14          State under section 1905(a)(25) unless the State estab-  
15          lishes that the provision of medical assistance with respect  
16          to such services will not increase the Federal payments  
17          made under this title above the level of such payments  
18          if such medical assistance under such section had not been  
19          provided.”

20                 (2) CONFORMING AMENDMENTS.—(A) Section  
21                 1902(j) (42 U.S.C. 1396a(j)) is amended by striking  
22                 “(25)” and inserting “(26)”.

23                 (B) Section 1902(a)(10)(C)(iv) (42 U.S.C.  
24                 1396a(a)(10)(C)(iv)) is amended by striking “(24)”  
25                 and inserting “(25)”.

1 (b) EFFECTIVE DATE.—The amendments made by  
2 subsection (a) shall apply to services furnished on or after  
3 the date of the enactment of this Act.

4 (c) REPORTS TO CONGRESS.—The Secretary of Sec-  
5 retary of Health and Human Services shall submit to Con-  
6 gress periodic reports on the impact of the amendments  
7 made by this section on medicaid beneficiaries, States, and  
8 the Federal Government.

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“(24)”

EXECUTIVE OFFICE OF THE PRESIDENT

05-Nov-1996 02:27am

*Copies to: Carol Rasco  
Nancy-Ann Min  
Chris Jennings  
Bruce Vladeck*

TO: ADA-LAW  
FROM: alec vachon

*From: Diana Fortuna*

SUBJECT: ADAPT Wins Agreement with Speaker Gingrich

Congratulations to ADAPT! Today, ADAPT reported that it worked out a deal with Speaker Gingrich to will introduce legislation in early 1997 which will change the future of long term care services in America. Full ADAPT press release is below.

I give ADAPT huge credit. ADAPT hammered out a specific promise, with a specific timeline, with specific Gingrich staff named to work out the deal. That's smart bargaining.

Now for the political message: For Gingrich to produce, he will need to be Speaker again (VOTE REPUBLICAN FOR HOUSE AND SENATE), and could be really helped by a Republican President (VOTE DOLE). :)

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ADAPT Action News Bulletin

For Immediate Release  
November 3, 1996

For more information, contact:  
Mike Auberger (404) 659-2727  
Mark Johnson (404) 350-7490

On Sunday, November 3, 30 representatives of ADAPT (American Disabled for Attendant Programs Today) and Speaker of the House Newt Gingrich hammered out an agreement whereby Gingrich will introduce legislation in early 1997 which will change the future of long term care services in America.

Written in his own hand, Gingrich's commitment to introduce the Community Attendant Services Act (CASA) came after three years of dogged efforts by thousands of ADAPT activists across this country. This agreement lays out a strategy which will establish national and state legislative committees with ADAPT representatives, including an initial meeting before Thanksgiving; designate staff in Washington and Georgia to coordinate the development and passage of this legislation; and see the legislation introduced in January with Congressional hearings to follow in February and March. The Speaker also indicated he would involve the Governors' Association, the Congressional Budget Office, and the appropriate House and Senate committees. Gingrich committed to seek final passage of CASA and its enactment into law prior to the end of the first session of the 105th Congress. "Until this legislation becomes reality," reminded Stephanie Thomas, ADAPT Texas organizer, "ADAPT will remain guardedly optimistic. Newt has broken promises to ADAPT before - we hope this time is different and we expect him to keep his word."

Currently, Medicaid policy mandates States to provide nursing home care to America's older and disabled citizens, but does nothing to guarantee them equal access to home and community based services. CASA promises

that guarantee.

While Gingrich met with representatives from 30 states, hundreds of other ADAPT members marched to, and gathered in, Atlanta's Olympic Centennial Park to remember the thousands of persons who die prematurely every year in American nursing homes.

British singer/songwriter Johnny Crescendo began the memorial with a song written for his friend who died in a nursing home. He was followed by Justin Dart, Chair of the World Congress on Disability held in conjunction with the 1996 Paralympics, and former Chair, under Presidents Reagan and Bush, of the President's Committee for Employment of Persons with Disabilities. Dart indicted America for counting the "deaths of whales, spotted owls and butterflies," while not counting the deaths of persons forced into nursing homes as a result of the current institutional bias in Medicaid.

After the memorial, ADAPT National Organizer, Mike Auberger termed the ADAPT-Gingrich agreement "...an historic meeting which will ultimately create the Emancipation Proclamation for persons with disabilities."

\*\*\*\*\*

American Disabled for Attendant Programs Today

We're ADAPT.

We're back.

Get used to it.

**DATE:** May 15, 1996

**FROM:** Administrator

**SUBJECT:** Promotion of Home and Community-Based Services in the Most Integrated Setting

**TO:** Regional Administrator  
Regions I - X

Attached is a copy of a statement issued by Secretary Donna Shalala supporting the principles of home and community care, consumer choice, and self determination. As you know, the Health Care Financing Administration strongly advocates consumer choice in determining utilization of long term services and supports in the most integrated setting possible.

Please share the Secretary's statement with the states in your region. Consistent with this direction, I encourage you to assist the states in the development and implementation of home and community-based services. I am asking Central Office staff to work closely with you to provide any technical assistance you or the states need to stimulate the development and improvement of waivers to maximize customer choice and allow states flexibility to administer such programs.

Over the past year, we have initiated dialogue with consumer advocacy groups across the country, including Americans Disabled for Attendant Programs Today (ADAPT), Family Voices, United Cerebral Palsy, and many others. This initiative has resulted in the identification of many issues concerning individuals with disabilities. Many of these issues have been resolved through discussions between the involved consumers, the Regional Offices and appropriate state agencies. In several states, new waivers have been developed as a result of these discussions. I have requested Paul Mendelsohn of the Office of Beneficiary Relations (410-786-3213) and Mary Clarkson of the Medicaid Bureau (410-786-5918) to coordinate this activity for me. Mr. Mendelsohn and Ms. Clarkson will work closely with staff from Region VIII, which is the regional office focal point for the ADAPT Initiative.

This Agency and Department are committed to providing every opportunity possible to maximize customer choices in the long term care arena. I appreciate your attention, support, and cooperation.

Bruce C. Vladeck

Attachment

**STATEMENT BY HHS SECRETARY DONNA E. SHALALA****SUPPORTING THE PRINCIPLES OF HOME AND COMMUNITY CARE  
AND CONSUMER CHOICE AND SELF-DETERMINATION**

I want to take this opportunity to reaffirm our support for the principles of emphasizing home and community based services and offering consumers the maximum amount of choice, control, and flexibility in how those services are organized and delivered. Specifically, we support the principles of:

- promoting greater control for consumers to select, manage, and direct their own personal attendant services;
- expanding community-based, non-institutional supports;
- promoting the use of functional assessments to determine eligibility for home and community based services;
- offering opportunities for states to: (a) provide services in both in-home and out-of-home locations; (b) provide services at any time during the day or night; and (c) offer back-up and emergency services;
- experimenting with alternative ways to finance services (such as vouchers and direct cash payments) in addition to the traditional agency-based model;
- encouraging the use of alternative providers, including informal providers such as friends and relatives;
- developing new ways to help consumers train and manage their attendants;
- demonstrating a commitment to the quality of life of the people who provide attendant care; and
- encouraging the use of agreed-upon individualized plans for attendant care.

The Administration has been steadfast in its support for community care for people of all ages who have disabilities. We know that most people prefer home and community supports and we are pleased that many states are moving aggressively to use their own funds and federal support to improve the quality of life of people who use these supports and those who provide them.

We also recognize that the vast majority of home and community care today is provided by family members and friends. They are there because they choose to be there to support their loved ones. But they need some support and reinforcement. One of the key ways government can help families is to offer some relief, in the form of home and community based services.

Working with the Governors and with consumers and advocacy groups, we have made a number of key regulatory changes over the past two years that demonstrate our strong view about offering incentives for states to expand community based care. Despite grave threats of erosion of the fundamental structure of the Medicare and Medicaid programs, we continue to pursue ways to encourage this movement.

The Department of Health and Human Services is also pursuing an ambitious research and demonstration agenda to find imaginative, new ways to maximize consumer choice and self determination. Many of the elements of this research agenda will have the immediate result of helping many people receive the supports they need. We will, for example, look at new ways to help consumers hire, train and manage their attendants, at alternative providers, and experiment with offering consumers cash instead of services.

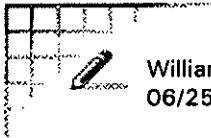
I take great pride in being part of an Administration that promotes these basic principles. I am pleased that we have made so much headway in moving toward their realization, although I recognize that we still have much work to do. I continue to appreciate the opportunity to work with the disability community as we work toward our common goals.

▶ **Diana Fortuna**  
06/25/97 01:36:00 PM  
.....

Record Type: Record

To: Elena Kagan/OPD/EOP, Cynthia A. Rice/OPD/EOP  
cc:  
Subject: Background on CASA from ADAPT

----- Forwarded by Diana Fortuna/OPD/EOP on 06/25/97 01:36 PM -----

 William H. White Jr.  
06/25/97 01:34:13 PM

Record Type: Record

To: See the distribution list at the bottom of this message  
cc:  
Subject: Background on CASA from ADAPT

**FOR IMMEDIATE RELEASE**  
June 23, 1997

Contact: Mike Auberger/Bob Kafka (202) 289-5959  
Joe Ehman (202) 842-4466  
Missy Jenkins, aide to Newt Gingrich (202) 225-4501  
Washington DC - ADAPT HAS 20/20 VISION!! A bill, HR 2020, the Medicaid, Community Attendant Services Act, also known as CASA, was introduced today by Speaker of the House Newt Gingrich.  
HR 2020 states that any individual who is entitled to nursing home or other institutional services will now have the choice where and how these services are provided. The vision of OUR HOMES NOT NURSING HOMES will finally become a reality for many of the two million Americans currently residing in nursing homes.

HR 2020 will clearly free disabled and elderly people by the thousands from nursing homes and other institutions. Currently, the United States spends 80% of Medicaid dollars in nursing homes. HR 2020 will allow the money to follow the individual into the community. "This historic legislation is consistent with America's goal of empowerment and liberty for all-including disabled people," said Mike Auberger, ADAPT organizer. Attendant services provided in disabled peoples' homes include help with dressing, bathing, eating, toileting, and ventilator care. There is no known medical reason why these services have to be provided in an institutional setting. With HR 2020, the consumer will control the delivery of these everyday services.

▶ **Diana Fortuna**  
06/16/97 05:57:53 PM  
.....

Record Type: Record

To: Maria Echaveste/WHO/EOP, William H. White Jr./WHO/EOP  
cc: Christopher C. Jennings/OPD/EOP, Elena Kagan/OPD/EOP, Jeanne Lambrew/OPD/EOP  
Subject: FYI: good ideas from Bob Williams of HHS on this ADAPT issue

I really think we should consider taking up Bob's suggestions on ADAPT. He is plugged in and very constructive on these things. (I am sure Bob does not agree with ADAPT that you have not been responsive, Bill.)

----- Forwarded by Diana Fortuna/OPD/EOP on 06/16/97 05:53 PM -----



**bwilliams @ acf.dhhs.gov**  
06/16/97 04:32:00 PM

Record Type: Record

To: Diana Fortuna  
cc:  
Subject: Re: Re: ADAPT's Friday, the 13th letter

Forwarded to: internet[fortuna\_d@a1.eop.gov]  
cc:  
Comments by: Bob Williams@ADD.OC@ACF.WDC  
Comments:

Three suggestions which could either be carried out individually or in succession:

o The White House response should be followed up with a call from Maria to demonstrate our earnestness. She would undoubtedly take flack about the White House and Bill's lack of responsiveness, timing, etc., but hopefully after that she could begin the conversation again. For whatever reason, this has become a personality contest and it needs to be put on a new track.

o You all might want to think about asking Justin to do some fence mending as well. I do not know if he would be willing or effective if he agreed to play such a role but think it is worth a conversation.

o Apart from the response, you all might consider issuing a statement to the disability community essentially providing specifics on the process to be followed from here on out. That puts the White House on record with the wider community and takes some of the power and focus away from ADAPT and its June 13th letter.

Disabilities - CAA

To: Chris Jennings, Jeanne Lambrew, Anne Tumlinson

From: Diana Fortuna 

cc: Elena Kagan, Bill White

Here is Bob Williams and Mary Harahan's first shot at a sheet for the ADAPT meeting. What I don't know is whether they propose to unveil all of this on Wednesday, or keep some in our hip pocket -- and what we would think of that.

Please look this over and let me know what you think. I think we need a conference call on this on Tuesday p.m.

To: <bwilliams@ACF.DHHS.GOV>  
Cc:  
Bcc:  
From: MARY HARAHAH <mharahan@OSASPE.DHHS.GOV>  
Subject: adapt  
Date: Monday, June 23, 1997 12:35:31 EDT  
Attach: ADAPT2.WPD, Headers.822  
Certify: N  
Forwarded by: Bob Williams@ADD.OC@ACF.WDC

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Forwarded to: internet[Bruce Vladeck@internet]  
fax[Diana Fortuna, 9-456-7028]  
internet[fortuna\_d@a1.eop.gov]  
cc:  
Forwarded date: Monday, June 23, 1997 15:56:57 EDT  
Comments by: Bob Williams@ADD.OC@ACF.WDC  
Comments:

I am both emailing and faxing a copy of the attachment to you. Mary and I worked on it together and believe it puts our best foot forward. She has already discussed it with Debbie and will be adding a section regarding HCFA's new initiative with independent living centers around the acquisition of DME. Let Mary or I know what you think of this draft. Thanks!

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[Original Message]

<WP Attachment Enclosed>

--> ATTACHMENT: ADAPT2.WPD <--

## PROPOSAL FOR DISCUSSION WITH ADAPT

**Overview.** The Administration recognizes that we must make greater efforts to support the ability of people with disabilities to live in the community and to engage in productive activity in accordance with their individual choices and circumstances. To that end we will work over the next two years to identify and reduce the barriers and disincentives in our health care financing programs to living in the community and engaging in socially productive activity including employment. Specifically, we will continue and expand our efforts to:

- **Reduce the institutional bias and where appropriate the medical orientation of current Medicaid long-term care financing;**
- **Promote consumer directed services for individuals with disabilities who want and need them;**
- **Expand the supply of well-trained personal attendants;**
- **Remove other barriers in our health care financing programs which impede people with disabilities from participating in the work force.**

In pursuit of these goals, we will take the following actions:

1. **Expedite final rule making for the HCFA regulation on the coverage of personal care services.** This rule will permit personal care to be provided in settings other than a persons' own home at state option, and without the supervision of a registered nurse as long as authorized by a physician in accordance with a plan of treatment.

This new rule will remove some of the key barriers to consumer directed services within the Medicaid personal care option.

2. **Create Secretarial Working Group to Develop Action Plan to Expand Access to Consumer Directed Personnel Assistance Services.** The Secretary would appoint a working group of senior HHS staff, State Officials and representatives from the disability community, with participation from OMB and the White House to develop an action plan for expanding and promoting consumer directed services strategies. The work group would consider a number of options including:

- **Convening a National Conference on Consumer Directed Services.** The conference would bring together people with disabilities, State officials, federal policy makers and technical experts to draw attention to the current institutional emphasis of Medicaid long-term care financing, identify barriers to consumer directed services and to recommend strategies for promoting consumer directed services strategies in public financing programs.
- **Establishing a New National Demonstration Program to Operationalize the**

JUN-23-1997 15:39 FROM ADD

TO

94567431 P.04

**Principals of CASA.** The new demonstration would be directed at working age adults with disabilities who require attendant services and would be implemented as a 6-10 states experiment with a rigorous evaluation design to test impacts on consumer economic and social self-sufficiency, satisfaction and and on costs.

- **Encouraging the Removal of Barriers to Consumer Directed Services in Nurse Practice Acts.** HCFA, AOA, and ADD would work with the disability community and states to identify barriers within Nurse Practice Acts that inhibit the use of consumer directed services and strategies for overcoming these barriers including the creation and implementation of model guidelines that support consumer directed services within a framework that addresses health and safety issues for vulnerable persons.
  - **Expanding the Supply of Personal Care Attendants in Conjunction with State Welfare Reform Strategies.** In partnership with States, ACF and HCFA with the Office of the Secretary would support the development of job training and placement programs which encourage welfare recipients to become personal care attendants.
- 3. Plan and Implement a New Technical Assistance Strategy to Support State Programs of Consumer Directed Services.** HCFA, the Administration on Aging and the Administration for Development Disabilities will develop a new technical assistance program to help states design and implement consumer directed services approaches under the Medicaid personal care option, the Home and Community based waiver program and the Older Americans Act Title III programs. As an initial step, HCFA is drafting a letter to State Medicaid Directors urging them to make home and community-based services (HCBS) waivers available to all persons currently institutionalized or at risk of institutionalization and requesting them to consider incorporating consumer directed services principals into their programs.
- 4. Work Incentive for People with Disabilities.** The President proposed a work incentive to encourage SSI beneficiaries to return to work. The President's proposal would allow States to permit SSI beneficiaries to buy into Medicaid after they exceed the 1619 income threshold. The Senate Finance Committee bill has included a provision to give States the option of permitting SSI beneficiaries with income up to 250 percent of poverty to buy into Medicaid. We will work with Member to have the income cap removed during conference.

▶ **Diana Fortuna**  
05/30/97 09:04:06 AM  
.....

Record Type: Record

To: William H. White Jr./WHO/EOP  
cc: See the distribution list at the bottom of this message  
bcc:  
Subject: Re: ADAPT 

I think Bill's idea is a sound one, if not an especially appealing one. We made this commitment, and letting it drift will lead to a mess sooner or later.

William H. White Jr.

  07:58:52 PM

Record Type: Record

To: See the distribution list at the bottom of this message  
cc: Maria Echaveste/WHO/EOP, PALMIERI\_J @ A1 @ CD @ LNGTWY, Cheryl M. Carter/WHO/EOP, Craig T. Smith/WHO/EOP  
Subject: ADAPT

Our ADAPT friends are coming to DC in mid-June. They are pressing for a meeting with the President on home and community based services (The CASA Bill), and are threatening civil disobedience. We originally committed in writing to doing a meeting with the President during the first quarter of this year. They are also pressing Gingrich.

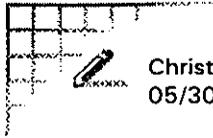
Because of the President's schedule, we may be months away from doing such a meeting.

I'd like to deflect their ire by offering to set-up a consultative process for ADAPT and senior White House policy staff (that's you folks) over the next few months, hear them out, and work to determine whether we can support their legislation (or some version of it). We would offer a meeting with the President at the conclusion of the process (possibly in September). I think they may accept this approach if we were able to commit to a specific day or week for a meeting with the POTUS.

Please give me your feedback.

Message Sent To: \_\_\_\_\_

Disabilities - CABA



Christopher C. Jennings  
05/30/97 11:08:03 AM

Record Type: Record

To: Diana Fortuna/OPD/EOP

cc: See the distribution list at the bottom of this message

Subject: Re: ADAPT

I love these meetings. I only wonder if, as important as we all are, that we might want to entice Bruce, Gene, and/or Frank to come -- if it becomes clear we do not adequately fit the bill.

cj

Message Copied To:

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William H. White Jr./WHO/EOP  
Elena Kagan/OPD/EOP  
Nancy A. Min/OMB/EOP  
Jeanne Lambrew/OPD/EOP  
Sarah A. Bianchi/OMB/EOP  
Maria Echaveste/WHO/EOP  
palmieri\_j @ a1 @ cd @ lngtwy  
Cheryl M. Carter/WHO/EOP  
Craig T. Smith/WHO/EOP



**FORTUNA D @ A1**  
03/11/97 08:22:00 PM

Record Type: Record

To: BVLadeck @ hcfa.gov@INET@LNGTWY, kking @ hcfa.gov@INET@LNGTWY, dchang @ hcfa.gov@INET@LNGTWY

cc: See the distribution list at the bottom of this message

Subject: CASA Act

As you know, we have this outstanding meeting with ADAPT and other disability groups on home and community-based services and other disability issues. ADAPT is certain to want to talk about the CASA bill, and so we need HCFA's analysis of it.

I'm not sure that the bill as introduced (by Gunderson, I think?) is as extreme as earlier summaries I had seen. We would be particularly interested in cost implications. Could you get us something in the next week?

Message Copied To:

Christopher C. Jennings  
Jeanne Lambrew  
William H. White Jr.  
Nancy A. Min  
Elena Kagan

*Disability -  
CASA*