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Background on ADAPT [American Disabled for Attendant Programs Today] Meeting 6/25/97

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June 24, 1997

TO: MARIA ECHAVESTE
FROM: BILL WHITE - OPL
SUBJECT: BACKGROUND ON ADAPT MEETING

DATE/TIME: Wednesday, June 25, 1997
3:00 - 4:00 PM

LOCATION: OEOB - Room 180

PURPOSE: To attempt to begin a dialogue on personal assistant services with ADAPT.

OUTLINE:	Welcome & Opening	Maria Echaveste
	Introductory Remarks	Chris Jennings
	CASA Overview	Michael Oxford ADAPT
	Administration Proposals	Administrator Bruce Vladek Health Care Financing Admin.
	Close & Next Steps	Maria Echaveste

BACKGROUND: ADAPT is a grassroots civil rights organization that is committed to changing the long term services system. They believe that the current system confines 2 million people with disabilities in nursing homes. ADAPT wants health dollars redirected so that people with disabilities, with the assistance of personal attendants, can live independently within their communities. While ADAPT claims their proposal will save money, HHS disagrees and is concerned with the enormous risk of abuse in such a system. The nursing home industry would also object.

ADAPT is in DC (June 14 - 26) to push for a national attendant services

② money at follow up - transformation - to unreal call ③ get some DC / central folks out visiting

program. Famous for their acts of civil disobedience, this week ADAPT has "visited" the Department of Labor, Transportation, the Greyhound Bus Company (b/c of inaccessible buses) and Gingrich's office. Gingrich, at ADAPT's urging, has introduced legislation (HR 2020, a.k.a. the CASA Bill) on this issue on Monday, June 23rd. HHS is in the process of reviewing this legislation.

Michael Oxford

① Dumping up support for HR 2020 - will want Administration to support

In your introduction, you should set a tone about how this process must work if it is to be productive. You should recognize that although we failed to get a meeting in the first quarter (as we stated), it wasn't for lack of trying. (Like the first term, you are coordinating policy level discussions with the President and key constituency groups, including the disability community.) You need to make clear that the meeting with the President on September 10 is not ADAPT's meeting, but the President's meeting with leaders of the disability community to discuss issues important to people with disabilities, including personal assistance services. We would like to include representatives of ADAPT in that meeting. (In jest, you might say that because ADAPT has not responded "in writing" to your letter of June 16 inviting them to participate, your not sure if they plan to attend!) You should state that our discussions should be about the future, not the past; and focus on substance, and not posturing.

② policy change by 11/1/98 - folks already in position be given choice - budget neutral, maintenance of effort, how do you protect people from being dumped

use consumer protection folks - quality, checkers

After your opening comments, you will introduce Chris Jennings (the President's senior health policy advisor and Deputy Assistant to the President for Domestic Policy). Chris will talk about the importance of the issue, review the Administration's accomplishments, state that the Administration recognizes that more needs to be done, and that we look forward to their ideas.

① Mike will want Rodolfo's ASAP will get back to Michael Oxford

You will then invite ADAPT member Mike Oxford to make a presentation. HCFA Administrator Bruce Vladek will respond to ADAPT and present a number of policy initiatives aimed at addressing the issue (attached).

One of the proposals will be to create a working group to develop action plan to expand access to consumer directed personnel assistance services, which would include a representative from ADAPT. You should close the by announcing the next step, which would be the first meeting of the working group. You should propose to ADAPT the dates of July 28-31 for the first meeting.

⑦ we want to develop a career ladder and a living wage so people stay

Finally, keep in mind that while this may not be your most fun meeting here at the White House, it may be your most memorable. P.S. Don't forget to bring your cutters if they decide to chain themselves in room 180.

③ examine all eggs in Medicaid basket - where there is bias vs - a home care (is there someone now to look at this doing by contract) ④ delinking rules of Medicare to Medicaid to eliminate bias against

⑤ Empowering service delivery - who gets control of our people ready community and economic development issue - locus of control ⑥ we go to work recipients, here's # and there are needs

PARTICIPANTS:

✓ Cassie James	ADAPT
✓ Andres Pete Duran	ADAPT
✓ Michael Oxford	ADAPT
✓ Michael Auberger	ADAPT
✓ Kevin Grivine	ADAPT
Linda Anthony	ADAPT
✓ Kathleen Kliemann	ADAPT - PA
✓ Pamela Burkley	ADAPT
Barbara Toomer	ADAPT
Kevin Burrison	ADAPT

Prob Williams - Common

Comments from Bruce Vladek

worker owned corporation in Bronx -

Kathleen Kleinmann - says the waivers have become a problem because it is now fragmented

Cassie James - developing opptys for disabled to also become providers - cheaper than special - maybe cheaper -

Quality of life is improved, leading to better health care

→ Consumer - Demonstration

Reaction to CASH - HR 2020

Chris Jennings → need more accurate needs so you can better estimate costs, to make case this will work

Demonstrations are needed to get real estimates
Average model - in people's heads is an elderly person who would come out of "woodwork" to take advantage of benefits but those issues aren't necessarily solved for disabled

Assignment for ADAPT

Collection of data do help pressing issues

OMB
CBO → John Cle

parent
- wkg gp-nose
- homebd
- Lth wk inc

PROPOSAL FOR DISCUSSION WITH ADAPT

I. 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 public 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 that impede people with disabilities from participating in the work force.**

II. Action Steps

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 person's 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. Work with States on HCFA solicitations for consumer-directed DME and for dually eligible beneficiaries:

- ◆ HCFA is preparing an initiative that would solicit applications from Centers for Independent Living to develop and implement demonstration projects on Consumer-Directed Durable Medical Equipment. The demonstration will establish service delivery models to facilitate beneficiary access to wheeled mobility equipment through partnerships with sponsoring organizations. Sponsors would facilitate the provision of assistive technology information, assessment and case management activities, prior authorization of equipment, beneficiary credit accounts for increased equipment purchasing flexibility, and other activities as may be approved. State Medicaid and other payor participation also will be encouraged. HCFA anticipates the release of a special solicitation in the near future.

- ◆ HCFA has released a solicitation to States and other interested parties that would work collaboratively with States to develop more effective strategies to meet the diverse and complex needs of the dually eligible Medicare and Medicaid beneficiaries. The solicitation, entitled "Reforming Service Delivery for Dually Eligible Beneficiaries," seeks applications that foster a more integrated and flexible service delivery systems and strengthens Federal and State capabilities to address the problems and challenges that confront these beneficiaries. The closing date for applications has been extended until August 29, 1997.

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. Create a Working Group to Develop Action Plan to Expand Access to Consumer Directed Personnel Assistance Services. A work group would be appointed 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:

- ✓ A) **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.
- B) *major* **Establishing a New National Demonstration Program to Operationalize the 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 costs.
- ✓ C) **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.

✓ D) **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

5. **Advocate for Administration's 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. The Administration recently wrote a letter to Senator Trent Lott urging inclusion of the President's proposal that would not limit eligibility for this program to people whose earnings are below 250 percent of poverty. We will continue to work with Members to have the income cap removed during conference.

THE WHITE HOUSE
WASHINGTON

June 16, 1997

Michael Oxford
ADAPT
P.O. Box 9598
Denver, CO 80209

Dear Michael:

The President has scheduled a meeting with leaders of the disability community for September 10, 1997 to discuss issues important to people with disabilities, including personal assistance services. We would like to include representatives of ADAPT in that meeting.

As you know, the Office of Public Liaison has been actively pursuing the scheduling of a meeting between the President and leaders of the disability community. Prior to the meeting with the President, the White House will continue its consultative process with ADAPT and, in particular, begin a policy discussion regarding the issue of personal assistance services. The Administration will be represented by the White House Office of Public Liaison, Domestic Policy Council, National Economic Council, and the Department of Health and Human Services during the policy discussions with ADAPT.

We are ready to begin the substantive policy discussions immediately and are waiting for ADAPT to propose dates for the first meeting. Please contact Bill White at (202) 456-7032 to coordinate the first meeting.

Sincerely,

A handwritten signature in black ink, appearing to read 'Maria Echaveste', with a long horizontal flourish extending to the right.

Maria Echaveste
Assistant to the President
Office of Public Liaison

Date: 06/18/97 Time: 09:13

bDisabilities Group Protests at DOL; Gains Meeting with Clinton

To: National Desk, Health Care Writer
Contact: Mike Auberger, 202-289-5959,
Jennifer Burnett, 202-842-4466, or
Joe Ehman, 202-842-4466, all of the American Disabled
for Attendant Programs Today

WASHINGTON, June 18 /U.S. Newswire/ -- Members of a national disability rights organization, ADAPT, held a protest at the Department of Labor, forcing the White House to keep its promise made November 1996.

Three hundred members of ADAPT occupied the building while ADAPT representatives negotiated with White House staff, forcing a meeting with the president scheduled for Sept. 10.

The protest was a result of a Clinton Administration promise. In November 1996 a letter was sent to ADAPT by Assistant to the President Alexis Herman, promising a meeting between ADAPT and the president in the first quarter of 1997. The meeting never took place. Alexis Herman is now Secretary of Labor, and ADAPT went to her office to demand accountability for the promise.

The protest caused an immediate reaction from the president's office. The current Assistant to the President Maria Eschaveste and ADAPT member Bob Kafka negotiated an agreement over the telephone. She then faxed a confirmation to ADAPT at the Department of Labor, verifying that the White House Office of Public Liaison had not only arranged the meeting with the president but would also coordinate a policy meeting on Wednesday, June 25. This policy meeting will include Secretary of Health and Human Services Donna Shalala, the heads of Domestic Policy Council, National Economic Council, the Office of Public Liaison and ADAPT.

In a letter to ADAPT dated June 16, Echaveste wrote, "We are ready to begin substantive policy discussions immediately and are waiting for ADAPT to propose dates for the first meeting."

ADAPT is in Washington to support the passage of CASA, The Community Attendant Services Act, which is expected to be introduced next week by Speaker of the House Newt Gingrich. This legislation will redirect Medicaid's long term care funding from nursing homes to home and community-based services. It will allow people to live in their own homes by providing services in the community instead of in nursing homes and other institutions.

ADAPT spent the afternoon surrounding the Bus Terminal stopping buses in downtown D.C., sending a message to Greyhound that access is a civil right. Last year Greyhound maneuvered a delay in the development of ADA regulations regarding over the road coaches. With this delay in place, Greyhound is planning to purchase new inaccessible buses.

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/U.S. Newswire 202-347-2770/
APNP-06-18-97 0929EDT

**ASPE/HCEA looh@this*

November 4, 1996

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

*cc Chr3J
Bruce Vladeck
(fax 690-6262)
Nancy Ann Min
5-728
From Diana Fortuna*

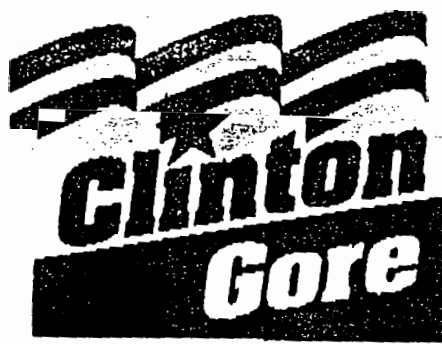
Dear Michael:

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



Statement of Governor Clinton on Personal Assistance Services

I support efforts to make affordable personal assistance services available to Americans with disabilities. We must ensure that all people have the opportunity to live independent lives. People who have disabilities and have a need for personal assistance services should have maximum control over the care they receive. Personal assistance services must be consumer-driven -- they must meet the needs and desires of the user, not the dictates of the supplier.

I believe that personal assistance services are of the utmost importance. I understand that every person has different needs. For this reason, I believe that every individual has a right to personal care.

I believe that personal assistance services should be provided by a wide range of qualified individuals. In my proposal for a National Service Trust Fund, I have suggested that young men and women who go to college can pay for their education by spending two years working in jobs which serve our community -- teaching our children, policing our streets, rebuilding our infrastructure. Employment in personal assistance services should be an option in this program, and I hope thousands of men and women choose it. This is only one of many ways in which we can expand the scope of available services.

Personal assistance services should be a part of any comprehensive health care reform plan. For this reason, I intend to appoint a task force, including individuals with disabilities, on the role of personal assistance services and long term care in health care reform. I have promised to submit a reform package to Congress in the first 100 days of my Administration. The task force will submit recommendations on reform in that time period.

It is time for America to realize that silence on issues of concern to people with disabilities is as damaging as prejudice. As President, I will work with individuals with disabilities to empower people to live independently. I will bring people together and make this plan a reality.

October 16, 1992



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

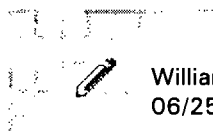
Washington DC - ADAPT HAS 20/20 VISION!! A bill, HR 2020, the Medicaid Community Attendant Services Act, also known as CASA, was introduced today by Speaker of the House Newt Gingrich.

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.

HR 2020 will forever change the way America views disabled people. For the first time, all Americans with disabilities will truly be free to pursue the American dream.

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