FOIA Number: 2007-0143-F

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Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: Domestic Policy Council

Series/Staff Member: Diana Fortuna

Subseries:

OA/ID Number: 12024

FolderID:

Folder Title:
ADAPT [Americans Disabled Attendant Programs Today]

Stack:	Row:	Section:	Shelf:	Position:
S	97	2	10	3

HRSA –
Josh – cash + counseling?
Ruth – will take ogle!!

– Vladek, Shalala
– Employment
– ADA, IDEA
– HRSA?

I ask for accomplishments document
called
Sally Richardson
Michael McMillen

Sally – contract – identific, security → wg takes info
– bias + delink
– UCSF – Mitchell LaPlante
– WG – ASPE
– Bob ADD → ASPE
– ASMB
– ASL
– MC + MA
– Ed? OMB? – yes
– SSA? – yes

Allan Beyman
NCIL
Not DD issue

state share
Fatins RWJ

Step 2 contng on Step 1
Timing → end of yr – prel. options – pilot
Dec.

constituency partners
→ State

Anne calls

Ckg contractor w/ Kafka
Wk – 1st wk Sept.

Sally
410-786-3870

Ruth 302-539-1205-home
(690-6443)

BOB W 690-6590
office

Laura Oliven Silberfarb
09/11/97 11:05:32 AM

Record Type: Record

To: Anne E. Tumlinson/OMB/EOP, Cynthia M. Smith/OMB/EOP, Diana Fortuna/OPD/EOP

cc:
Subject: Personal care

FYI

---------- Forwarded by Laura Oliven Silberfarb/OMB/EOP on 09/11/97 11:05 AM ----------

Daniel J. Chenok
09/11/97 11:00:27 AM

Record Type: Record

To: Laura Oliven Silberfarb/OMB/EOP

cc:
Subject: Personal care

---------- Forwarded by Daniel J. Chenok/OMB/EOP on 09/11/97 11:00 AM ----------

BNA
Daily Report for Executives

No. 176
Thursday September 11, 1997

Regulation, Law & Economics

Medicaid
Final Rule Allows Personal Care Coverage Outside of Patient's Home

A final rule published Sept. 11 expands Medicaid coverage of personal care services to locations outside the home of the beneficiary.

The final rule, effective Nov. 10, implements a provision in the Omnibus Budget Reconciliation Act of 1993 that added section 1905(a)(24) of the Social Security Act. The statute required compliance as of Oct. 1, 1994. A proposed rule was published in March 1996.

According to the Health Care Financing Administration rule, personal care services must be authorized

by a physician in accordance with a plan of treatment or by another state plan, provided by a qualified individual who is not a member of the patient's family, and furnished in a home or other location.

States are not required to pay for personal services under Medicaid, and about 32 states currently pay for the benefit, HCFA said.

In general, Medicaid personal care services include such things as assistance with eating, bathing, dressing, personal hygiene, activities of daily living, bladder and bowel requirements, and taking medications, HCFA said.

States are given the latitude to decide whether personal care services must be authorized by a physician or otherwise authorized in accordance with a service plan approved by the state, HCFA said. States also may determine who is qualified to provide personal care services, as long as they are not a legally responsible relative, HCFA said.

The agency said it would publish a state *Medicaid Manual* instruction addressing the definition and delivery of personal care services.

HCFA said the rule would not have a significant impact on the operations of small rural hospitals, but that the provision would increase Medicaid expenditures by the federal government and states.

The costs, which resulted from adoption of the statute, have been included in the Medicaid budget baseline, HCFA said. Additional costs of the benefit are estimated at $195 million in fiscal 1998 for the federal government, and $145 million for states, according to the rule.

To Cynthia Smith
S-7840
Fr: Diana

HON. NEWT GINGRICH

OF GEORGIA

IN THE HOUSE OF REPRESENTATIVES

Tuesday, June 24, 1997

MR. GINGRICH. Mr. Speaker, I want to introduce today the "Medicaid Community Attendant Services Act of 1997" as part of my commitment to empowering all Americans and to the principles of community based care. This bill allows for choices for persons with disabilities so that individuals can receive the care that is most appropriate for them. Everyone deserves the opportunity to lead a full and independent life and people with disabilities are no exception.

I believe that personal empowerment is essential to the "pursuit of happiness" and believe that this bill will begin a very important debate about long term care in the nation. During the 104th Congress, I submitted for the Congressional Record a statement in support of community-based care based upon the recommendations of a Disabilities Task Force on Disabilities which I appointed in Georgia and the work of advocates for community-based care from around the nation.

The bill I am introducing today is the starting point for the dialogue about the best way to empower persons with disabilities. I am aware that this proposal may have significant cost implications, so I encourage careful consideration and additional input to help ensure a sound policy decision.

H.R. 2020
"Medicaid Community Attendant Services Act of 1997"
105th Congress, 1st Session

The "Medicaid Community Attendant Services Act of 1997" (CASA) would allow for coverage of community-based attendant services under the Medicaid program. Current individuals who are entitled to nursing facility services or intermediate care facility services for the mentally retarded would be given the option of choosing qualified community-based attendant services.

Qualified Services.

Qualified services would be based on an assessment of functional need agreed to by the

individual. This services could be provided in a home or community-based setting, such as a school, workplace, recreation or religious facility, but not an institutional setting. Those services could include backup and emergency attendant services; training on how to select, manage, and dismiss attendants; and health-related tasks performed by unlicensed personal attendants.

Transitional Monies.

For the transition to a community setting, expenditures may include rent and utility deposits, and other basic supplies and necessities for the transition to a home setting. The total amount of transition expenditures and care should not exceed costs had that individual remained in an institutional facility.

A transitional allotment of $2 billion for states would be included beginning in 1998 and phasing out by 2003. The Secretary should give preference to states that do not currently have community-based care programs in place in order to facilitate program development.

State Option.

States would have the option to cover individuals on a sliding scale above an income limitation if it finds that the potential for employment opportunities would be enhanced.

Standards.

The State would be responsible for adopting standards of care with minimum qualifications and requirements. Ongoing monitoring and protections for beneficiaries are included in conjunction with the Secretary. The State is responsible for the development of it transitional program in consultation with State Independent Living Councils and the State Developmental Disabilities Councils, and Councils on Aging.

Reports.

Reports to Congress will be provided on: home health regulations; an individual's assessment on the need for community services; and impact to the State, Federal Government, and beneficiaries of CASA. A task force to look at the financing of long term care services would be developed.

NEWT GINGRICH
Sixth DISTRICT, GEORGIA

THE SPEAKER

WASHINGTON OFFICE
2428 RAYBURN HOUSE OFFICE BLDG
WASHINGTON, DC 20515-1006
(202) 225-4501

3823 Roswell Road
Suite 200
Marietta, GA 30062
(770) 565-0318

Congress of the United States
House of Representatives

VIA FAX

TO: Rush

FROM: Chuck

DATE: 6/25

RE: TASA

TOTAL PAGES: *(including cover)* 3

MESSAGE:

Copy to Cynthia/Diana — See page 3

Can we?

Elena

THE WHITE HOUSE

WASHINGTON

THE PRESIDENT HAS SEEN
6-25-97

June 20, 1997

Copied
Reed
Kagan
Emanuel
COS

'97 JUN

MEMORANDUM FOR THE PRESIDENT

FROM: Bruce Reed
Elena Kagan

SUBJECT: DPC Weekly Report

1. Tobacco -- Review of Settlement: As you know, State Attorneys General and representatives of individual claimants reached an historic agreement with the tobacco industry yesterday, and you called on DPC and HHS to coordinate a thorough public health review of the agreement. To accomplish this review, we have set up a number of interagency working groups to focus on discrete aspects of the agreement. The working groups, which will begin to meet on Monday, will explore questions relating to: (1) FDA jurisdiction and access, advertising, and labeling rules; (2) liability limits and disclosure of documents; (3) use of the funds, including for children's health; (4) environmental tobacco smoke; (5) public education programs; (6) smoking cessation programs and research; (7) the financial structure and capacity of the industry and the size of the agreement's payouts and penalties. We hope to get a complete recommendation to you in a matter of weeks, though working with HHS always takes more time than expected.

2. Housing -- State of the Cities Report: On Monday, you will announce the issuance of HUD's report, "The State of American Cities." The report describes (1) the "decades of decline" leading up to the early 1990s; (2) the significant improvements made by cities since 1993 as a result of the strong economy and your urban policies, including Empowerment Zones, CDFI, and home ownership strategies; (3) the challenges that remain, including job growth disparity between cities and suburbs, increased poverty concentration in central cities, and continued middle-class migration from central cities to suburbs; and (4) the Administration's "Urban Agenda for the Future," a comprehensive plan based on the same empowerment principles, including local control and flexibility, that undergird everything we have done so far.

Building on the report, you will announce three new policies to help America's cities: (1) You will initiate the Officer Next Door program, which will make government-owned homes available for sale at a 50% discount to police officers who agree to live in the communities they patrol; (2) You will announce a 25 basis points reduction in mortgage insurance premiums for first-time buyers who purchase homes in central cities (from 1.75% to 1.50%), which will reduce closing costs by about $200; and (3) You will call for Congress to act on legislation allowing low-income families to take Section 8 assistance in the form of Home Ownership Empowerment Vouchers and announce a new Freddie Mac pilot program that in the interim, will assist 1,000 to 2,000 such families to purchase their own homes.

THE PRESIDENT HAS SEEN
6-25-97

3. AIDS -- Guidelines on HIV Treatment: On Thursday, HHS released guidelines on HIV treatment procedures, which emphasize the effectiveness of early use of protease inhibitors. Both the AIDS community and the medical community praised the guidelines for helping doctors to provide appropriate treatment. As we expected, however, the AIDS community also responded to the guidelines by demanding additional federal funds to ensure that all people with HIV can obtain the recommended treatment. We should expect these demands to increase still further in the coming months. The DPC and OMB are currently reviewing whether to propose additional funding in this area and, if so, what legislative vehicle to use.

4. Welfare -- Legal Immigrant Benefits: Legislation on legal immigrants reported by the Senate Finance Committee this week improved on the House Ways and Means version, but still fails to comport with the budget agreement. As you know, the budget agreement would restore SSI and Medicaid benefits to any legal immigrant in the country on August 23, 1996 who is or becomes disabled. The legislation passed out of House Ways and Means would restore SSI and Medicaid benefits to both the disabled and non-disabled elderly, but only if they were already receiving benefits on that date -- ~~essentially grandfathering~~ those already on the rolls. The House proposal, though protecting 50,000 more people initially than the budget agreement, would protect 75,000 *fewer* people in 2002. The Senate Finance Committee this week passed legislation which would grandfather all those on the rolls on August 23, 1996 *and* allow disabled legal immigrants in the country on that date to apply for SSI until September of this year. This proposal is actually the most expensive of the three, costing $10.4 billion, as compared to the $9.7 billion price tag of the budget agreement and the $9.0 billion cost of the House proposal.

One way to bridge the differences between the budget agreement and the Congressional proposals is to find the money to cover both groups of immigrants -- those in the country on August 23, 1996 who are or become disabled *plus* the non-disabled elderly on the rolls as of that date. Legislation of this kind would cost $11.4 billion. In the letter you sent to Chairman Kasich yesterday, which threatened to veto legislation that does not protect all legal immigrants covered under the budget agreement, you expressed support for this option, stating that "my clear preference would be to assist both disabled and elderly legal immigrants." We have some reason to hope that we can achieve this result, though much more work remains to be done.

5. Welfare -- Welfare-to-Work Plan: The welfare-to-work legislation passed out of the Senate Finance Committee this week, as compared with the House Ways and Means version, favors formula over competitive grants, governors over mayors, and rural areas over cities. Whereas Ways and Means would distribute 50% of the $3 billion by formula and 50% by competition, the Finance Committee would distribute 75% by formula and only 25% by competition. The percentage of formula money flowing to local jurisdictions (including to cities) would be the same under both proposals (75%), but the Finance Committee would send the funds through local welfare offices controlled by the governors instead of, as in the Ways and Means proposal, private industry councils controlled by the mayors. As to competitive funds, the Finance Committee retained Ways and Means' ~~25% set-aside for rural areas~~, but completely eliminated Ways and Means' 65% set-aside for the 100 cities with the most poor people. During

THE PRESIDENT HAS SEEN
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mark-up, the Finance Committee added language to strengthen the anti-displacement provisions of the program.

6. Welfare -- Privatization: There was a major battle in the Finance Committee regarding the chairman's provision to deem the Texas privatization proposal approved and allow up to ten other states to privatize Medicaid, food stamps, and other program operations. Senator Conrad offered a motion to strike the provision. This motion won, with votes from all Democrats and Senators D'Amato and Jeffords. Then, after some back-room wrangling, the chairman's proposal was limited only to Texas, and Senators D'Amato and Jeffords changed their votes. Thus, the Senate bill allows complete privatization of all health and human services programs in Texas, but only in Texas. In the House, the bills reported out by the Agriculture and Commerce committees allow all 50 states to privatize food stamp and Medicaid operations.

7. Welfare -- Employment Prospects of Welfare Recipients: Many economists are now turning their attention to the question of whether there will be enough jobs for welfare recipients who need to go to work. In a draft, not-for-quotation study, former OMB Program Associate Director Isabelle Sawhill and Daniel McMurrer conclude that the economy, if it continues to grow, should produce a sufficient number of jobs to accommodate welfare recipients required to enter the labor force under the new welfare law. This conclusion is based on their estimate that only about 150,000 additional welfare recipients each year will need to go to work under the law. Sawhill and McMurrer arrive at this estimate by showing that most states can meet this year's 25% work participation requirement by counting those already working and claiming credit for caseload reductions from the past several years. The annual 5% increases in work participation rates until 2002 then will require states to find work for 150,000 additional welfare recipients each year.

Sawhill and McMurrer also note that welfare recipients who do find full-time employment should stay above the poverty line with the help of the EITC, the higher minimum wage, and subsidized child care. A mother with two children who earned $10,000 a year in 1996 (slightly less that what a full-time year-round worker would make at $5.15 an hour) also would qualify for $3,556 from the EITC and about $2,400 in Food Stamps. After paying $765 in payroll taxes, the family would have a disposable income of just over $15,000. With child care subsidies, this family's disposable income would stay above the poverty line, but in the absence of such subsidies, out-of-pocket child care expenses would push the family back below poverty.

8. Health -- Congressional Action: The Senate Finance Committee reported out legislation on Medicare and Medicaid this week. The Medicare provisions preserved many of the Administration's priorities including: new plan options, such as preferred provider organizations and provider sponsored organizations; preventive benefits, including mammography expansions and colorectal screening; and traditional provider and beneficiary savings, which when combined with your home health care reallocation, will extend the life of the Medicare trust fund for at least a decade. The Finance Committee legislation also reduced the size of the Medical Savings Account demonstration to 100,000 people. The committee

THE PRESIDENT HAS SEEN
6-25-97

included a number of reforms that expose beneficiaries to new costs, including an income-related deductible, a $5 per visit home care co-payment, and a gradual increase in the Medicare retirement age from 65 to 67. We anticipate, however, that all three of these provisions will be dropped either on the Senate floor or in conference.

The Medicaid provisions include a Disproportionate Share Hospital (DSH) proposal that cuts payments to high DSH states much more significantly than either your original budget proposal or the House Commerce Committee legislation. Though we will try to soften the impact on these states, we are having difficulty attracting much Congressional support for this effort. The Finance Committee also failed to provide the full amount of investments specified in the budget agreement for the District of Columbia, Puerto Rico, and low-income Medicare beneficiary protections. In preliminary conversations, the Republican leadership has indicated some willingness to restore these investments.

9. Crime -- Juvenile Crime Update: Last week, the Senate Judiciary Committee released a new Chairman's mark of its juvenile crime legislation. This version is better than both the original Senate bill and the House-passed bill. The new mark removes provisions that we considered objectionable, such as a death penalty for minors and a mandatory 6-level sentence enhancement for gang activity. The mark, however, still falls short of our Anti-Gang and Youth Violence Act: the mark has no major gun provisions (it neither mandates child safety locks nor extends Brady to violent juveniles); no dedicated prevention funding; insufficient funds for prosecutors and courts; and inadequate protections for juveniles incarcerated in state facilities. The Senate was originally scheduled to mark up the legislation last week, but the session was postponed and no new markup date has been scheduled.

10. Education -- Testing Initiative: Mike Cohen met with Bob Chase last week to discuss NEA support for your national testing initiative. Chase will push for the NEA, at its convention in early July, to repeal existing policy, adopted during the Bush Administration, opposing any federal efforts to develop educational tests. Delegates to the convention almost certainly will approve this proposal, which already has the support of the NEA's Board of Directors. Chase also will introduce a motion specifically supporting our testing initiative if he believes he has the votes to pass it.

11. Disabilities -- ADAPT Protest: As you know, disability advocates have long pushed for Medicaid to cover personal attendant services and to put community-based services on an equal footing with nursing homes. The disability group ADAPT uses disruptive tactics to convey this message. Last November, in the midst of such a disruption, the Office of Public Liaison agreed that you would hold a meeting with ADAPT and other disability groups on this topic in the first quarter of the year. That meeting has just been scheduled for September. This week, ADAPT demonstrated outside Alexis Herman's office to protest our lack of action. ADAPT also is putting pressure on Speaker Gingrich, who committed to ADAPT last year that he would introduce legislation on the subject. The DPC, Public Liaison, and HHS are meeting with ADAPT next Wednesday and are working together on options in advance of that meeting.

Will-Grundy
CENTER for INDEPENDENT LIVING

The Barrier Free Press

Center for Independent Living

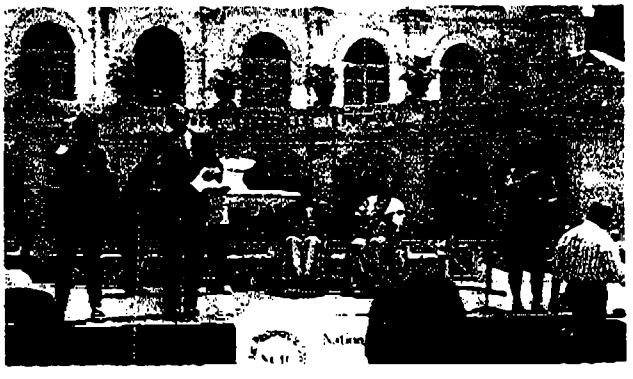
2415-A West Jefferson Street
Joliet, Illinois 60435
(815)729-0162 (815)729-2085 TTY

HOURS: 8:30 A.M - 4:30 p.m
Monday - Friday

SUMMER 1997

CASA Introduced!

Hundreds of people with disabilities, advocates, and friends converged in Washington, D.C. on June 5 to march and rally for the introduction of the Community Attendant Services Act, or CASA. Our message was heard because on June 24 Speaker of the House Newt Gingrich introduced CASA. Briefly, CASA will re-direct money that is now spent in warehousing people with disabilities to in-home assistance. People with disabilities will have the opportunity to live in their own homes, secure real employment, recreate, and enjoy true freedom.



Iowa Sen. Harkin addresses rally.

We thank Speaker Gingrich for his leadership in introducing this most important law. Its passage will not be easy, as the nursing home industry is very powerful both in human and financial resources. However, we have right on our side. We know that existing in an institution of any kind does not promote independence or dignity. The time is NOW to call our Congressmen and Senators in Washington and urge their support of this life-saving bill. We encourage senior citizens to become active in the passage of this bill and eliminate the myth that once one becomes a certain age, one automatically must be institutionalized.

Call today, tomorrow, and every day until CASA is a reality. Join us as we undertake this national effort to "Free Our People."

Details About CASA

On June 24, Speaker of the House Newt Gingrich introduced the "Medicaid Community Attendant Services Act of 1997," or CASA. This bill, when passed,

will re-direct billions of dollars that normally go to institutions such as nursing homes to home-based assistance. People with disabilities will now have a choice of living in their own homes and hiring personal assistants or going into nursing homes or other institutions. Highlights from the bill include:

Qualified Services. Qualified services would be based on an assessment of functional need agreed upon the individual. These services could be provided in a home or community-based setting, such as a school, workplace, or recreation or religious facility, but not an institutional setting. Those services could include backup and emergency attendant services; training on how to select, manage, and dismiss attendants; and health-related tasks performed by unlicensed personal attendants.

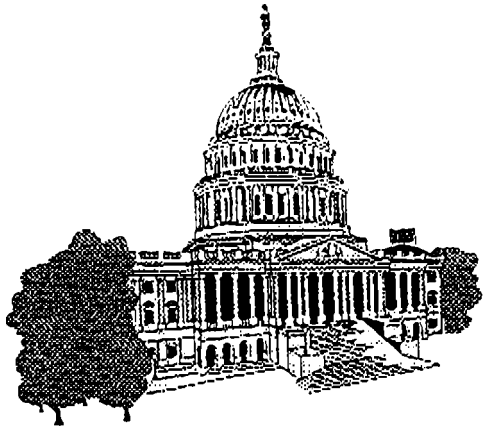
Transitional Monies. For the transition to a community setting, expenditures may include rent and utility deposits and other basic supplies and necessities for the transition to a home setting. The total amount of transition expenditures and care should not exceed costs had that individual remained in an institutional facility. A transitional allotment of $2 billion for states would be included beginning in 1998 and phasing out by 2003. The Secretary should give preference to states that do not currently have community-based care programs in place in order to facilitate program development.

State Option. States would have the option to cover individuals on a sliding scale above an income limitation if findings indicate that the potential for employment opportunities would be enhanced.

Standards. The State would be responsible for adopting standards of care with minimum qualifications and requirements. Ongoing monitoring and protections for beneficiaries are included in conjunction with the Secretary. The State is responsible for the development of a transitional program in consultation with State Independent Living Councils, State Developmental Disabilities Councils, and Councils on Aging.

Reports. Reports to Congress will be provided on: home health regulations; an individual's assessment on the need for community services; and impact to the State, Federal Government, and beneficiaries of CASA. A task force to look at the financing of long term care services would be developed.

In introducing the bill, Speaker Gingrich said, "Everyone deserves the opportunity to lead a full and independent life and people with disabilities are no exception. I believe that personal empowerment is essential to the 'pursuit of happiness' and believe that this bill will begin a very important debate about long term care in the nation." We could not agree more! Help us and advocates nationwide by calling your Congressman and urging his/her support. Congressman Jerry Weller's address is 51 W. Jackson St., Joliet, Il 60432; 815-740-2028; 815-740-2037 fax. Congressman Harris Fawell's address is: 115 W. 55th St., Suite 100, Clarendon Hills, Il 60514; 708-655-2052. Please call, write, and/or visit these Congressmen until CASA is passed. If you need more information, call Rachel at the Center.



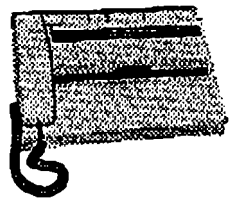
HEALTH CARE FINANCING ADMINISTRATION

Fax

Transmittal Cover Sheet

Center for Medicaid and State Operations
7500 Security Boulevard
Room C5-22-23
Baltimore, Maryland 21244

Phone: (410) 786-3870
Fax: (410) 786-0025



Date: 8/26/97. *Number of Pages (including cover sheet):* 6

Addressee

To: Diana Fortana, 202-456-7431

Organization: Ann Tomlinson Cynthia Smith 202-395-7840

Phone Number:

Fax Number:

From: Sally Richardson

Organization:

Phone Number: 410-786-3870

Comments

Oxford - ILURP - conference
2/1/98 - date certain

1) past accomps - Colorado - home health in home (MA)
- DME - MC
~~(WISCO - PACE - CCE)~~

2) new - contract (30·60·90)
- work gp (Fri)
- Cash + counseling

3) CASA

Date certain: inst → comm. - prob is beds get backfilled
- (also operatl - svcs)
- optional + no backfill? - gaming/CH bed
- neg home

Analysis of ~~ADOPT~~ info - what we know/don't know

DRAFT final - end of tomorrow TJG - 1 TO: physical (vs. assistant)

"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 FY99; $380 million in FY2000; $280 million in FY2001; $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

Relationship between CASA and current law

(To be added)

HCFA Reaction

- We are committed to addressing the imbalance between institutional and community 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.

- We already are working on reviewing the existing Medicaid regulations to examine the institutional bias, and we expect to have this analysis completed by the end of the year. In addition, we are forming a workgroup to examine recommendations about how to reduce the institutional bias and promote home and community based care. This workgroup will establish a partnership with ADAPT, other disability groups, State agencies and other stakeholders to ensure that they are involved and have an opportunity to contribute.

- **Cost:** It is likely that the availability of these services will induce more utilization, so that costs will go up. Compounding the possible cost expansion is the lack of a limitation on paying family members. This has always been thought to increase costs and increases the woodworking effect as recipients begin paying family members for services they have been providing all along.

  On the other hand, there might be some savings from people who are currently receiving more expensive care moving to less expensive caregivers. It seems unlikely, however, that these savings will be enough to offset the new costs. How know ?

- **RWJ "cash and counseling" demonstration**. It would be premature to require coverage of these services before we obtain results from this RWJ "cash and counseling"demonstration. This demonstration is a controlled experimental design to test the impact of providing beneficiaries with the cash value of the benefits to which they are eligible. Beneficiaries will be matched with a counselor to whom they are accountable for how they spend the money. ASPE and HCFA are sharing in the cost of evaluating this demonstration. The results are not likely to be available for another three years. !

- **Lack of protection of beneficiaries' rights**. We are concerned that there are many opportunities for abuse of beneficiaries. For example, who would decide if they were capable of making decisions about their personal attendants? What happens if a beneficiary suddenly became cognitively impaired? What happens if a beneficiary used all of the allotment early in the month and couldn't pay for services later in the month?

- **Inadequate quality standards for personal attendants.** We are concerned that the minimum quality standards would not be sufficient to ensure that beneficiaries are receiving adequate/appropriate care. Moreover, this legislation states that the attendants do not have to be licensed. This raises the issue of a need for references/criminal background checks. There would be no assurance that the money would be used for

intended purposes. Given that the government is footing the bill, it can be argued that there should be adequate accountability rules.

FAX COVER SHEET

OFFICE OF LEGISLATION

Number of Pages: 3 Date: 7/18/97

To: Okinen Fortuna

From: Jennie Barney

Fax: 456-7431

Fax: 202-690-8168

Phone:

Phone:

REMARKS: Here's our list of tasks. I hope you had a nice vacation

HEALTH CARE FINANCING ADMINISTRATION
200 Independence Ave., SW
Room 341-H, Humphrey Building
Washington, DC 20201

DRAFT

ADMINISTRATION MEETING WITH ADAPT

On June 25th, the White House convened a meeting with approximately 10 representatives from ADAPT. Administration participants included Maria Echaveste, Chris Jennings, Diana Fortuna from the White House and Bruce Vladeck, Bob Williams and Mary Harahan from the Department of Health and Human Services. The following is a brief summary of ADAPT's position and the Administration's response.

ADAPT raised four issues:

(1) They requested our support of H.R.2020, the Community Attendant Services Act (CASA).

(2) By 1/1/98, they would like a policy change to allow any individual in a nursing home to have a choice of whether to remain in the nursing home or move into the community.

(3) (A) They asked that we examine all Medicaid regulations and establish a home and community based bias rather than an institutional bias; and

(B) They would like us to de-link the Medicare and Medicaid rules (e.g., home health).

(4) They stressed the importance of consumer empowerment. They argued that control needs to be placed with the recipient of services (e.g., "cash and counseling" demo).

Bruce Vladeck responded that the Administration would:

(1) Contract with an outside researcher to examine: (A) the Medicaid regulations and rules to identify "institutional bias" or excessive reliance on a "medical model;" and (B) de-linkage of the Medicare and Medicaid rules.

(2) Create a workgroup to address issues related to eliminating the institutional bias in Medicaid. One charge of the workgroup would be to brainstorm on the issue of a "date certain" for changing the policy on letting dollars follow the person from a nursing home to a home or community-based setting. An idea raised in the meeting was to explore creating a pilot project to evaluate this idea.

(3) Analyze the new CASA bill introduced by Speaker Gingrich. (We have not had time to properly analyze the bill since it was just introduced on June 24, 1997.) Bruce expressed interest in experimenting with a differential match rate. He suggested the possibility of a demonstration to explore the idea.

(4) Ask HCFA/OACT (John Klemm), Departmental and OMB staff to talk to ADAPT to better understand the type of data they have with respect to cost savings of home and

DRAFT

community based care versus institutional care, and to perhaps collect and analyze this information.

(5) Recommend that HCFA central office staff visit several independent living centers to gain a deeper understanding of what they offer.

(6) As an aside, Bruce Vladeck mentioned that HCFA is close to announcing a new solicitation for consumer directed DME. He did not say when it would be announced or how many States/geographic regions/people it would involve.

Agenda:

1. Maria Echaveste opens

2. Chris Jennings on principles (see attached talking points)

3. We ask Kafka to present

4. Bruce Vladeck presents action items in attached paper

5. Bob Williams and Mary Harahan are prepared to chime in where necessary

6. Maria Echaveste closes by saying we want working group that will include ADAPT to convene the last week in July

We are here today to talk with you about how the federal government can enhance the ability of people with disabilities to live in their communities.

We would like to lay out some specific ideas for you today, and Bruce Vladeck will do that a bit later.

Accomplishments [Don't dwell on this section for more than a few moments!]: We believe we have made some important progress on this issue in the last 4 years, through steps like:

- eliminating the cold bed rule, making it easier for states to do home and community-based waivers;
- HCFA's development of the new cash and counseling demonstration;
- the President's budget proposals to reduce barriers to work for those on SSI/SSDI;
- more recently, our work to keep disabled legal immigrants covered by SSI and Medicaid;
- of course, our unsuccessful attempt to do national health care reform.

Do overview in paper, as follows:
Nevertheless, 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 reaching these goals.

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.

Obviously any progress we make in this area must be made within the framework of the balanced budget agreement -- that is true of all our initiatives.

We appreciate the fact that Speaker Gingrich just yesterday introduced the CASA bill in order to stimulate debate on this issue.

We look forward to studying that bill and particularly want to look further at the cost implications.

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 budget neutral demonstration projects on Consumer-Directed Durable Medical Equipment. The demonstration is designed to test whether coverage of wheelchairs and other DME items can be made more flexible for beneficiaries through use of an organization that would help beneficiaries obtain appropriate assessment, documentation and information about equipment as well as lower prices. 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 on Developmental 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 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) **Establishing a New 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 an 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.

6/25

Oxford/Anberger

1. CASA

2. If in, take $ to go to comm choice 1/98
"Date certain"

merge {
3. Regs - examine inst/over medicalization
- create comm beds
- Academic? BV - ideas; do by contract
4. Delink'g MC from MA - home health elsewhere
}

5. Locus of control - to indiv. - training adjunct on manag'g
calif sem - local hc corps - good vs bad
Use ICC's?

*CO to ICC/ADAPT new folks
*BV re who 7 him

Mike Bob + I

*date certain: pilot BV; sit down w/MA; wk gp
*MA - data exists; just collect
*Und better how progs wk
*3+4 do w/contractor
*OMB + Klemm mtg w/ them
BV fears dumping
↳ ADAPT: MOE
Ann + Mike will talk

WTW - welfare → attendants. already doing in PA; BW - career ladder/wages
→ training of attdts ⇒ more degrees + higher cost; fixed cost world; compromise here
BV - coop Minsky - worker - owned / consumer
Waivers - for fragmented, medicalized

Energy: demo for crit mass of proof that/how saves + cost eff.
*Hace acts mstg...

Denver → stab DME

CASA: loss of hcbs as entitlement / state plan / biggest
demo diff [illegible] match rates } BV

CJ: Help CBO/actuaries understand
MA: Gingrich trying to set up w/acts
State plans w/ SUGs ⇒ Fed costs
Woodwork

BV: All geriatric model - a lot of woodwork
CJ: We can help them w/access?)
VT ↓ nsg h beds
70% success on nsg → comm placement; BV 100% - too conserv.
Also, assisted lvg ctr. - feeder system
Can't wt for cos. to shift to; Cassie - even in comm. [illegible] cos, make people look expensive

mharahan @ OSASPE.DHHS.GOV
08/13/97 10:00:00 AM

Record Type: Record

To: diana fortuna

cc:
Subject: Re: ADAPT et. al -Reply

I don't know whether HCFA is on board since they have not responded. Bob talked to Bruce a couple of weeks ago but I don't think anything has happened. My reading of CASa is that we could not support it because the eligibility is really broad and it still looks like an entitlement to me and the only expenditure ceiling seems to be limited to what you would otherwise spend in nursing homes. It is not even practical to test it in a demo...as it is written...I think we have already done that in Channeling and numerous other demos. we need to focus on the under 65 population and link PAS to employment in my judgment. but more importantly right now we need to have a work group process for engaging adapt and other disability folks in how to expand access to pas and keep people out of institutions when they don't need to be there in a cost effective manner. The best approach frankly is what we developed for health care reform. incidentally we put that in the tobacco hopper but that probably doesn't mean anything.

mharahan @ OSASPE.DHHS.GOV
08/12/97 04:36:00 PM

Record Type: Record

To: diana fortuna

cc:
Subject: ADAPT et. al

Hope you are having a nice summer. Is there something going on that HHS is blissfully unaware of regarding the SEPT 10 meeting between the disability groups and the President? Or do we know the game plan and its just Bob and I who are in the dark. We need some decisions about a strategy...and I think the bottom line here is our willingness to commit some real dollars to a serious demonstration that attempts to test the costs and feasibility of a CASA type proposal for younger disabled persons. I am leaving to go to Spain on Friday and will not be back until the end of the month. If you need something from my office in this regard please call Ruth katz. Do you know that Bob Williams will come to ASPE effective Sept 2??? thanks for letting me worry you. I heard rumors that you might be coming here. Hopefully to do something more fun than hassling people to deal with things they wish to ignore.

105TH CONGRESS
1ST SESSION

H. R. _____

IN THE HOUSE OF REPRESENTATIVES

Mr. GINGRICH introduced the following bill; which was referred to the Committee on _____

A BILL

To amend title XIX of the Social Security Act to provide for coverage of community attendant services under the medicaid program.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Medicaid Community Attendant Services Act of 1997".

SEC. 2. COVERAGE OF COMMUNITY-BASED ATTENDANT SERVICES UNDER THE MEDICAID PROGRAM.

(a) REQUIRING COVERAGE FOR INDIVIDUALS ENTITLED TO NURSING FACILITY SERVICES OR INTERMEDI-

ATE CARE FACILITY SERVICES FOR THE MENTALLY RETARDED.—Section 1902(a)(10)(D) of the Social Security Act (42 U.S.C. 1396a(a)(10)(D)) is amended—

(1) by inserting "(i)" after "(D)", and

(2) by adding at the end the following:

"(ii) subject to section 1932(b), for the inclusion of qualified community-based attendant services for any individual who, under the State plan, is entitled to nursing facility services or intermediate care facility services for the mentally retarded and who requires such services based on functional need (and without regard to age or disability);".

(b) MEDICAID COVERAGE OF COMMUNITY-BASED ATTENDANT SERVICES.—

(1) IN GENERAL.—Title XIX of the Social Security Act, as amended by section 114(a) of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, is amended—

(A) by redesignating section 1932 as section 1933, and

(B) by inserting after section 1931 the following new section:

"COVERAGE OF QUALIFIED COMMUNITY-BASED ATTENDANT SERVICES

"SEC. 1932. (a) QUALIFIED COMMUNITY-BASED ATTENDANT SERVICES DEFINED.—

"(1) IN GENERAL.—In this title, the term 'qualified community-based attendant services' means attendant services (as defined by the Secretary) furnished to an individual—

"(A) 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;

"(B) 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, an intermediate care facility for the mentally retarded, or other institutional facility;

"(C) under either an agency-provider model or other model (as defined in subsection (c)); and

"(D) the furnishing of which is selected, managed, controlled by the individual (as defined by the Secretary).

"(2) SERVICES INCLUDED.—Such term includes—

"(A) backup and emergency attendant services;

"(B) voluntary training on how to select, manage, and dismiss attendants; and

"(C) health-related tasks (as defined by the Secretary) that are assigned to, delegated to, or performed by, unlicensed personal attendants.

"(3) EXCLUDED SERVICES.—Subject to paragraph (4), such term does not include—

"(A) provision of room and board, and

"(B) prevocational, vocational, and supported employment.

"(4) FLEXIBILITY IN TRANSITION TO HOME SETTING.—Under regulations of the Secretary, such 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 required for an individual to make the transition from a nursing facility or intermediate care facility for the mentally retarded to a home setting.

"(b) LIMITATION ON AMOUNTS OF EXPENDITURES AS MEDICAL ASSISTANCE.—

"(1) IN GENERAL.—In carrying out section 1902(a)(10)(D)(ii), a State shall permit an individual who is entitled to medical assistance with respect to nursing facility services or intermediate care facility services for the mentally retarded and who qualifies for the receipt of such services to choose to receive medical assistance for qualified community-based attendant services (rather than medical assistance for such institutional services), in the most integrated setting appropriate to the needs of the individual, so long as the aggregate amount of the Federal expenditures for such individuals in a fiscal year does not exceed the total that would have been expended for such individuals to receive such institutional services in the year plus, subject to subsection (e), the transitional allotment to the State for the fiscal year involved, as determined under paragraph (2)(B).

"(2) TRANSITIONAL ALLOTMENTS.—

"(A) TOTAL AMOUNT.—The total amount of the transitional allotments under this paragraph for—

"(i) fiscal year 1998 is $580,000,000,

"(ii) fiscal year 1999 is $480,000,000,

"(iii) fiscal year 2000 is $380,000,000,

"(iv) fiscal year 2001 is $280,000,000,

"(v) fiscal year 2002 is $180,000,000 and

"(vi) fiscal year 2003 is $100,000,000.

"(B) STATE ALLOTMENTS.—The Secretary shall provide a formula for the distribution of the total amount of the transitional allotments provided in each fiscal year under subparagraph (A) among States. Such formula shall give preference to States that have a relatively higher proportion of long-term care services furnished to individuals in an institutional setting but who have a plan under subsection (e) to significantly reduce such proportion.

"(C) USE OF FUNDS.—Such funds allotted to, but not expended in, a fiscal year to a State are available for expenditure in the succeeding fiscal year.

"(e) DELIVERY MODELS.—For purposes of this section:

"(1) AGENCY-PROVIDER MODEL.—The term 'agency-provider model' means, with respect to the provision of community-based attendant services for an individual, a method of providing such services under which a single entity contracts for the provision of such services.

"(2) OTHER MODEL.—The term 'other model' means a method, other than an agency-provider model, for provision of services. Such a model may include the provision of vouchers, direct cash payments, or use of a fiscal agent to assist in obtaining services.

"(d) QUALITY ASSURANCE.—

"(1) IN GENERAL.—No Federal financial participation shall be available with respect to qualified community-based attendant services furnished under an agency-provider model or other model unless the State establishes and maintains a quality assurance program that is developed after public hearings, that is based on consumer satisfaction, and that, in the case of services furnished under the agency-provider model, meets the following requirements:

"(A) SURVEY AND CERTIFICATION.—The State periodically certifies and surveys such provider-agencies. Such surveys are conducted

on an unannounced basis and average at least 1 a year for each agency-provider.

"(B) STANDARDS.—The State adopts standards for survey and certification that include—

"(i) minimum qualifications and training requirements for provider staff;

"(ii) financial operating standards; and

"(iii) a consumer grievance process.

"(C) MONITORING BOARDS.—The State provides a system that allows for monitoring boards consisting of providers, family members, consumers, and neighbors to advise and assist the State.

"(D) PUBLIC REPORTING.—The State establishes reporting procedures to make available information to the public.

"(E) ONGOING MONITORING.—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.

"(2) PROTECTION OF BENEFICIARIES.—

"(A) IN GENERAL.—The regulations promulgated under section 1930(h)(1) shall apply with respect to the protection of the 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 arrangements services.

"(B) DEVELOPMENT OF ADDITIONAL REGULATIONS.—The Secretary shall develop additional regulations to protect the health, safety, and welfare for individuals receiving qualified community-based attendant services other than under an agency-provider model. Such regulations shall be designed to maximize the consumers' independence and control.

"(C) SANCTIONS.—The provisions of section 1930(h)(2) shall apply to violations of regulations described in subparagraph (A) or (B) in the same manner as they apply to violations of regulations described in section 1930(h)(1).

"(e) TRANSITION PLAN.—

"(1) IN GENERAL.—As a condition for receipt of a transitional allotment under subsection (b)(2), a State shall develop a long-term care services tran-

sition plan that establishes specific action steps and specific timetables to increase the proportion of long-term care services provided under the plan under this title in home and community-based settings, rather than institutional settings.

"(2) PARTICIPATION.—The plan under paragraph (1) shall be developed with major participation by both the State Independent Living Council and the State Developmental Disabilities Council, as well as input from the Councils on Aging.

"(f) ELIGIBILITY.—Effective January 1, 1999, a State may not exercise the option of coverage of individuals under section 1902(a)(10)(A)(ii)(V) without providing coverage under section 1902(a)(10)(A)(ii)(VI).

"(g) REPORT ON IMPACT OF SECTION.—The Secretary shall submit to Congress periodic reports on the impact of this section on beneficiaries, States, and the Federal Government.".

(c) COVERAGE AS MEDICAL ASSISTANCE.—

(1) IN GENERAL.—Section 1905(a) of such Act (42 U.S.C. 1396d) is amended—

(A) by striking "and" at the end of paragraph (24),

(B) by redesignating paragraph (25) as paragraph (26), and

(C) by inserting after paragraph (24) the following new paragraph:

"(25) qualified community-based attendant services (to the extent allowed and as defined in section 1932); and".

(2) ELIGIBILITY CLASSIFICATIONS.—Section 1902(a)(10)(A)(ii)(VI) (42 U.S.C. 1396a(a)(10)(A)(ii)(VI)) is amended by inserting "or qualified community-based attendant services" after "section 1915" each it appears.

(3) CONFORMING AMENDMENTS.—(A) Section 1902(j) of such Act (42 U.S.C. 1396a(j)) is amended by striking "(25)" and inserting "(26)".

(B) Section 1902(a)(10)(C)(iv) of such Act (42 U.S.C. 1396a(a)(10)(C)(iv)) is amended by striking "(24)" and inserting "(25)".

(d) REVIEW OF, AND REPORT ON, REGULATIONS.—The Secretary of Health and Human Services shall review existing regulations under title XIX of the Social Security Act insofar as they regulate the provision of home health services and other services in home and community-based settings. The Secretary shall submit to Congress a report on how excessive utilization of medical services can be reduced under such title by using qualified community-based attendant services.

(e) DEVELOPMENT OF FUNCTIONAL NEEDS ASSESSMENT INSTRUMENT.—The Secretary shall develop a functional needs assessment instrument that assesses an individual's need for qualified community-based attendant services and that may be used in carrying out sections 1902(a)(10)(D)(ii) and 1932 of the Social Security Act.

(f) TASK FORCE ON FINANCING OF LONG-TERM CARE SERVICES.—The Secretary shall establish a task force to examine appropriate methods for financing long-term care services. Such task force shall include significant representation of individuals (and representatives of individuals) who receive such services.

SEC. 3. STATE OPTION FOR ELIGIBILITY FOR INDIVIDUALS.

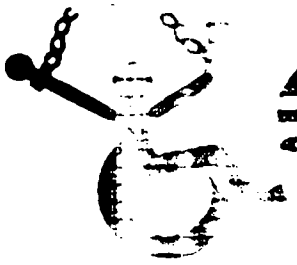
(a) IN GENERAL.—Section 1903(f) of the Social Security Act (42 U.S.C. 1396b(f)) is amended—

(1) in paragraph (4)(C), by inserting "subject to paragraph (5)," after "does not exceed", and

(2) by adding at the end the following:

"(5)(A) A State may waive the income limitation described in paragraph (4)(C) in such cases as the State finds the potential for employment opportunities would be enhanced through the provision of such services.

"(B) In the case of an individual who is made eligible for medical assistance because of subparagraph (A), not-



ADAPT
action news bulletin

cc Anne Tumlinson OMB
Jennie Bonney, HCFA

The Honorable Bill Clinton
President of the United States
1600 Pennsylvania Avenue
Washington, D.C. 20000

July 31, 1997

Dear Mr. President:

ADAPT is anticipating our upcoming meeting on September 10, 1997.

We want this meeting to result in your commitment to direct people in your Administration to take specific policy actions that will give people with disabilities more choices in what services they receive, where they receive those services and how these long term care services are paid for.

Currently over 80% of our public long term care dollars are spent on nursing homes and other institutions with the remaining 20% being split between all community-based programs. The media recently has had a field day bashing fraudulent home care services but the reality is that people with disabilities, old and young, want services delivered in the community in a legal way that allows for the maximum independence of the person to control their services. The medical model of long term care services is as outdated as our welfare system has been. Your Administration must make the same commitment to change our long term care system that you have made to reform welfare. From an economic point of view as well as a human rights perspective this must be done. Change long term care as we know it.

Rhetoric is fine during a campaign but now is the time for dramatic legislative and administrative actions that will result in changes in how people with disabilities receive home and community based attendant services.

ADAPT has had one meeting with members of your Administration in mid June but have had no communication since. Our reason for the first meeting was to lay out the groundwork for the type of proposals

your intention was. The September 10th meeting must not be a photo opt. Your time and our time is too valuable for that type of meeting.

As you know ADAPT has been advocating and has recently got introduced H.R. 2020, Medicaid Community Attendant Services Act of 1997 (MiCASA). Speaker Gingrich introduced the bill and House Minority Leader Richard Gephardt has agreed, as has others, to be a co-sponsor. ADAPT would like your endorsement and the leadership from your Administration to get bi-partisan support for the passage of H.R. 2020 MiCASA and the principles it is based on.

There has been no communication from your office about the agenda. There has been no communication from your office about who will be attending the meeting. There has been no communication about proposals that might be pursued before the meeting.

ADAPT would like to hear from your office by August 15th with the following information: the draft agenda, proposed people attending and possible proposals that you will make during the meeting.

Thank you for your support of disability issues.

Mike Oxford
ADAPT

cc Jennings, Lambrew
Bill White
(Fax to Anne Tumlinson
5-7840
2 pages

HON. NEWT GINGRICH

OF GEORGIA

U.S. HOUSE OF REPRESENTATIVES

Tuesday, June 24, 1997

MR. GINGRICH. Mr. Speaker, I want to introduce today the "Medicaid Community Attendant Services Act of 1997" as part of my commitment to empowering all Americans and to the principles of community based care. This bill allows for choices for persons with disabilities so that individuals can receive the care that is most appropriate for them. Everyone deserves the opportunity to lead a full and independent life and people with disabilities are no exception.

I believe that personal empowerment is essential to the "pursuit of happiness" and believe that this bill will begin a very important debate about long term care in the nation. During the 104th Congress, I submitted for the Congressional Record a statement in support of community-based care based upon the recommendations of a Disabilities Task Force on Disabilities which I appointed in Georgia and the work of advocates for community-based care from around the nation.

The bill I am introducing today is the starting point for the dialogue about the best way to empower persons with disabilities. I am aware that this proposal may have significant cost implications, so I encourage careful consideration and additional input to help ensure a sound policy decision.

H.R. 2020
"Medicaid Community Attendant Services Act of 1997"
105th Congress, 1st Session

The "Medicaid Community Attendant Services Act of 1997" (CASA) would allow for coverage of community-based attendant services under the Medicaid program. Current individuals who are entitled to nursing facility services or intermediate care facility services for the mentally retarded would be given the option of choosing qualified community-based attendant services.

Qualified Services.

Qualified services would be based on an assessment of functional need agreed to by the

individual. This services could be provided in a home or community-based setting, such as a school, workplace, recreation or religious facility, but not an institutional setting. Those services could include backup and emergency attendant services; training on how to select, manage, and dismiss attendants; and health-related tasks performed by unlicensed personal attendants.

Transitional Monies.

For the transition to a community setting, expenditures may include rent and utility deposits, and other basic supplies and necessities for the transition to a home setting. The total amount of transition expenditures and care should not exceed costs had that individual remained in an institutional facility.

A transitional allotment of $2 billion for states would be included beginning in 1998 and phasing out by 2003. The Secretary should give preference to states that do not currently have community-based care programs in place in order to facilitate program development.

State Option.

States would have the option to cover individuals on a sliding scale above an income limitation if it finds that the potential for employment opportunities would be enhanced.

Standards.

The State would be responsible for adopting standards of care with minimum qualifications and requirements. Ongoing monitoring and protections for beneficiaries are included in conjunction with the Secretary. The State is responsible for the development of it transitional program in consultation with State Independent Living Councils and the State Developmental Disabilities Councils, and Councils on Aging.

Reports.

Reports to Congress will be provided on: home health regulations; an individual's assessment on the need for community services; and impact to the State, Federal Government, and beneficiaries of CASA. A task force to look at the financing of long term care services would be developed.

HOMECARE

NATIONAL ASSOCIATION FOR HOME CARE
228 Seventh Street, SE
Washington, DC 20003
202/547-7424, 202/547-3540 fax

MARY SUTHER
CHAIRMAN OF THE BOARD
VAL J. HALAMANDARIS
PRESIDENT

HONORABLE FRANK E. MOSS
SENIOR COUNSEL
STANLEY M. BRAND
GENERAL COUNSEL

MEMORANDUM

June 15, 1997

TO: Members of American Disabled for Attendant Programs Today (ADAPT)

FROM: Val J. Halamandaris, President
Mary Suther, Chair

On behalf of the National Association for Home Care (NAHC), we want to thank you for coming to our offices to bring to our attention issues of critical importance to ADAPT. Together, I am confident that we can address these issues which reflect our mutual concern for those who rely on home and community based services. Our commitment to the consumer is underscored in the opening lines of our mission statement that has been in place since the founding of the organization in 1982:

> NAHC is a professional association representing the interests of Americans who need home care (including acute, long term, and terminal care) and the caregivers who provide them with in-home health and supportive services.

We have made many efforts to ensure a productive relationship between people with disabilities, their families, caregivers and the home care community.

NAHC sits on the steering committee of the National Institute on Consumer Directed Care, sponsored by the National Council on Aging, to foster better collaboration on these issues. We were pleased to cosponsor, with a number of organizations (including the World Institute on Disability, NCOA, and several nursing organizations) a symposium on consumer-directed long term care services. We welcome the opportunity to work with you to make public policy more responsive to the needs of people with disabilities.

HOMECARE

We included advocates for people with disabilities at our conference on home care aide issues in the spring. We would welcome the opportunity to have a presentation by ADAPT members at the 16th Annual Meeting of the National Association for Home Care. The meeting will be held in Boston, October 17-22, 1997. We will work together to determine the best possible time.

NAHC supports the right of consumers to choose the type of care and the caregiver that best suits their needs. We believe that federal policy and regulations should never become so cumbersome as to pose barriers to consumers accessing essential care.

We believe consumers have the right to self-direct their care or choose administration of care by an agency without diminishing quality or quantity of care received. Consumers should be permitted to receive services through a combination of service delivery modes. However, at the same time, NAHC believes that both the consumer and the caregiver have rights. This includes a caregiver's right to compliance with applicable state and federal labor health and safety laws and regulations. It is incumbent on our organizations to make certain that these laws do not create barriers, but maintain the ability to protect caregivers.

Home care and ADAPT have much in common. While we cannot direct the actions of our state affiliates, we will encourage our state home care associations to meet with local ADAPT groups on ways to create consumer driven attendant services.

NAHC has consistently endorsed the following CASA principles, including those which would:

* empower consumers with maximum control to select, manage, and control their attendant services,

* maintain emphasis on community-based, not institutional care,

* base eligibility on functional need, regardless of age and/or disability,

* ensure that needed services are available 24 hours a day, 7 days a week,

* ensure that needed back-up and emergency services are available,

* authorize programs that allow for the development of options, such as vouchers; direct case payments to individual providers, and consumer directed agency models, with appropriate standards and safeguards to ensure quality of care,

* ensure the appropriate delegation of health related tasks,

* make available voluntary training for consumers,

* ensure that personal attendants receive livable wages and benefits, and

HOMECARE

* base attendant services on agreed-upon individualized service plans.

NAHC has longstanding concerns about the imposition of home care copays due to their regressivity and likelihood of creating barriers to needed home care. Certainly, though, creative ideas need to be developed that would allow individuals with disabilities who are not currently eligible for Medicare or Medicaid to more fully access these vital programs. In addition, NAHC believes that individuals in need of home health services should be entitled to the same high quality and standards of care, regardless of their levels of income or source of public funding for their care.

NAHC believes that every effort must be made to avoid unnecessary institutionalization. The National Association for Home Care is proud of our advocacy of home and community based alternatives to institutionalization. NAHC's visibility and credibility on Capitol Hill, with the White House, and throughout the Nation, is linked to its name. Our name will remain the same. Our commitment to ensuring that "home care" is accessible, responsive to consumer needs, and encompasses more than "medically related" services, will continue.

NAHC is already in on-going discussions with a number of beneficiary and disability groups on ways to have home care more available and tailored to individuals with chronic care needs. We look forward to including ADAPT members in these discussions, and including in our discussions the importance of developing transition plans for people with disabilities coming out of institutions.

Thank you again for the opportunity to enter into a more direct dialogue with you on these important issues. We look forward to working toward enactment of these goals and principles.

ANA
AMERICAN NURSES ASSOCIATION

600 MARYLAND AVENUE, SW
SUITE 100 WEST
WASHINGTON, DC 20024-2571
202 651-7000 • FAX 202 651-7001
HTTP://WWW.NURSINGWORLD.ORG

BEVERLY L. MALONE, PHD, RN, FAAN
PRESIDENT

GERI MARULLO, MSN, RN
EXECUTIVE DIRECTOR

June 18, 1997

To Members of ADAPT:

The American Nurses Association (ANA) has long believed that clients are the primary decision makers in matters concerning their own health, treatment, and well-being. The goal of nursing actions is to support and enhance the client's responsibility and self-determination to the greatest extent possible.

The American Nurses Association is cognizant of the difficulties under our current health care system of assuring that all Americans have full access to appropriate health care in all appropriate settings including their homes if they so choose. Until we have a health care system that truly recognizes the health care needs of our citizens, it will be necessary to continue to identify solutions that address the rights and concerns of all consumers, including people with disabilities, while ensuring quality health care.

ANA has been supportive and will continue to be supportive of the principles contained in ADAPT's CASA including:

- control of the consumer, within the parameters state laws and regulations, to select, managed and control their attendant services;
- community-based, not institutional
- eligibility based on function need regardless of age and/or disability
- services available in-home, and other locations;
- services available 24-hour days a day, 7 days a week;
- back up and emergency services must be available;
- program should allow for co-payment/cost sharing for people with higher incomes;
- delivery of services must include options for vouchers, direct cash payment, individual provider model, as well as a consumer directed agenda model;
- health related tasks can be assigned, delegated or done by unlicensed personal attendants in accordance with state licensure and scope of practice laws and regulations;
- voluntary training should be available for consumers;
- personal attendants should receive a livable wage and benefits, and
- attendant services should be based on an agreed upon a individual service plan.

ANA will provide avenues for communicating these concerns through our National organization and State affiliates so that we can continue a productive dialogue and work together toward resolution of these issues. We continue to believe a full resolution will be possible when the nation develops a consensus on health care.

Specifically, I will request to the ANA Board of Directors that they consider:

*a presentation for ADAPT members at the next ANA National Convention; and
*the creation of a task force with ADAPT as a member to work on de-medicalizing home and

parents
- wkg gp-no secy
- homebd
- LTH wkinc

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) **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.

6UD

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:

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[Note: Our understanding was that you wanted to leave some big ticket items for the President to announce at the meeting in September with ADAPT. One option is to mention #4A and and leave the other items -- 4B,C and D -- for the September meeting.]

4. 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:

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.

[Should we include B,C and D?]

B) **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.

what all these?

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.

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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. We will work with Members to have the income cap removed during conference.

6. Clarify Administration's position on homebound definition for home health care. We listened to concerns raised by advocates for people with disabilities that our proposal to restrict access to the Medicare home health benefit would have severe implications for people with disabilities. We changed our position on restricting the definition of homebound status, and supported the removal of the proposal from the House and Senate reconciliation bills.

1- Mazzia

2- Kafka

cold bed/lap - easier to get

1/93 179 waivers - 48

226 - 49

Actions - 205 - new + renewed

Cold bed

checks - wk gp - ADAPT members measures

RWJ cash + e

THE WHITE HOUSE

WASHINGTON

June 16, 1997

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

Dear Michael:

The President will be meeting with leaders of the disability community on September 10, 1997 to discuss issues important to people with disabilities , including personal assistance services. We would like to include representatives of ADAPT in the meeting.

Prior to the meeting with the President, the White House would like to begin a consultative process with ADAPT to discuss 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.

We are ready to begin this process immediately and are waiting for ADAPT to propose dates for the first meeting.

Sincerely,

Maria Echaveste
Assistant to the President
Office of Public Liaison

POTENTIAL AGENDA ITEMS FOR ADAPT MEETING

The following are some ideas for potential agenda items for a meeting with ADAPT.

I. The following are several options that would not require a legislative change.

- **Briefing on HCFA regulation on coverage of Personal Care Services.** HCFA is in the final phases of clearing a regulation on personal care services with OS. The existing regulations do not provide for personal care services furnished in settings other than the recipient's home. They also require supervision by a registered nurse. [ADAPT will like the fact that PCS can be provided outside the home because they want to be integrated into the community; they won't be satisfied because it does not use the words "client-directed."]

  The proposed rule would specify that personal care services are services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, ICF/MR or IMD that are: (1) authorized by a physician in accordance with a plan of treatment; (2) provided by an individual who is qualified to provide such services and who is not a member of the individual's family; and (3) furnished in a home, and if the State chooses, in another location.

- **Create Secretarial Working Group on Personal Attendant Services.** The Secretary would appoint a working group of senior HHS staff, State officials and representatives from the disability community to develop an action plan to promote consumer directed services strategies. The work group would examine a number of options including:

  A. Convening a National Conference on Consumer Directed Services. This conference would bring together experts, States and potential consumer to focus attention on and to recommend solutions for removing the institutional bias in current financing programs and promoting the use of consumer directed services approaches. The work group would:

  --Identify options and a time line for creating a new national demonstration of consumer directed services for which HHS would request $100 million in the FY99 budget and consider seeking external support for from foundations as well.

  --Identify approaches to modifying aspects of nurse practice acts that are barriers to consumer directed services and create model guidelines that promote consumer directed services within a framework that addresses health and safety issues for vulnerable persons.

  B. Creating a plan with States to encourage the participation of welfare recipients in job training and job placement activity intended to expand the supply of qualified personal care attendants.

- **HCFA will provide technical assistance to States to design "client-directed" waiver programs.** HCFA is willing to provide technical assistance to States interested in

designing a "client-directed" Home and Community Based waiver program. HCFA can share the experience of other States who have already gone through this process.

Toward this end, HCFA is drafting a letter to State Medicaid Directors urging them to make appropriate home and community-based services (HCBS) waivers available to all persons currently institutionalized or at risk of institutionalization. The letter notes that a number of States have promoted active consumer participation in their waivers, including needs assessment, service planning, provider recruitment and choice in the oversight of the quality of services furnished. The letter encourages States to continue this effort. [ADAPT wants beneficiaries to have control in hiring, firing and training personal attendants.]

II. The following are several legislative options:

- **Recommend alternative to proposal to convert HCBS waiver to a State Plan option.** The House Commerce Committee dropped this provision due to a CBO cost estimate of $1.6 billion. This provision is not in the latest version of the Senate Finance Committee document. Our actuaries' preliminary estimate is that these options would be budget neutral. [This proposal is aimed at easing the burden on States; ADAPT has not been advocating for this change.]

  Preferred Option: In addition to the current waiver provision, States could choose to provide home and community based services as a State Plan option. There would be a requirement, however, for individual cost-neutrality (i.e., each individual's care under the HCBS benefit would be no more expensive than institutional care for that person) rather than aggregate cost-neutrality. The new State Plan option would retain the same flexibility with regard to targeting of benefits and requirement that persons served have an institutional level of care.

  Alternative: States that have demonstrated satisfactory progress under their approved waivers could choose to convert to the State Plan option. The Secretary would reserve the right to approve or deny a State's request to convert to the State Plan option. If approved, no further action to establish cost-neutrality or periodically seek renewal of the program would be required. It is assumed that the approved number of recipients for the last year of the existing waiver would be inflated by the percentage increase in the State's population age 65 and older (for programs serving aged/disabled) or the general population (for programs serving the MR/DD). In addition, expenditures in the last year of the existing waiver would be inflated by the increase in the Medicare Home Health Input Price Index.

- **Work Incentive for People with Disabilities - Medicaid.** 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 incomes up to 250

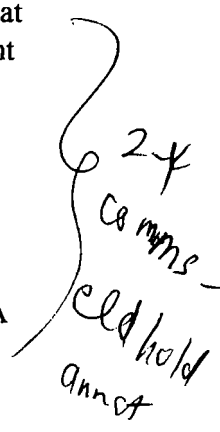
percent of poverty to buy into Medicaid. We will work with Members to have the income cap removed during conference.

- **Discuss Administration's current position on homebound definition for home health care.** We listened to concerns raised by advocates for people with disabilities that our proposal to restrict access to the Medicare home health benefit would have severe implications for people with disabilities. We changed our position on restricting the definition of homebound status, and supported the removal of the proposal from the House and Senate reconciliation bills.

III. HCFA Solicitations

- **HCFA draft solicitation for dually eligible beneficiaries.** 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.

- **HCFA solicitation for Consumer-Directed DME.** 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.



In addition, we would recommend the following with respect to CASA:

- **Recognize CASA as a way to focus discussion.** As a way of responding to ADAPT's advocacy of the CASA proposal, we could state that it is a good point of departure for helping to focus policy discussion around the need for increased access to consumer driven personal assistance. [The White House has proposed the idea of a White House Work Group on Personal Assistance/CASA to vet issues around CASA in preparation for a Fall meeting with ADAPT and the President.]

We recommend that the following item not be on the agenda for discussion:

- **Gunderson legislation**. HCFA has a number of concerns about the Gunderson legislation

and our preliminary recommendation is that we not endorse this approach. Our actuaries believe that a strict budget neutrality provision would be difficult to enforce. We believe that it would be premature to establish this as an optional service before we obtain results from the RWJ demonstration. Furthermore, we are concerned that there are many opportunities for abuse of beneficiaries.

OVERVIEW OF THE HCFA "CONSUMER-DIRECTED DME" CONCEPT

The "Consumer-Directed-DME" initiative would test a prior authorization payment system in combination with enhanced assessment and consumer information and involvement in purchasing decisions.

Current Status: We have recently elicited feedback on the concept from advocacy and industry groups serving people with disabilities and are reviewing their comments and guidance for possible inclusion in the demonstration design.

DME Policy Background: Beneficiaries at a Health Care Financing Administration (HCFA) beneficiary focus group convened last fall in Denver stated that they wanted more flexibility and consumer-control in the purchase and maintenance of durable medical equipment (DME), especially wheelchairs. As a result, HCFA's Office of Research and Demonstrations has developed a demonstration concept in response to this need.

Medicare's definition of DME is regarded by the physically disabled as too restrictive, being limited to equipment which can be used in the home and "necessary on the basis of the individual's medical and physical conditions." Medicare generally does not pay for routine maintenance of equipment, but equipment repairs are covered. In addition, Medicare does not cover equipment used for environmental control or merely for comfort or convenience. As a result, Medicare often does not cover items which beneficiaries with physical disabilities believe are necessary to restore maximal functional independence. Physicians must prescribe DME but often lack the expertise about the specific equipment available as well as the method of documenting medical necessity. Claims are subject to denials after the beneficiary receives the equipment. Beneficiaries who need modified or customized equipment often have unanticipated out-of-pocket costs depending on whether the DME is approved. (Medicaid DME coverage is often less restrictive than Medicare.)

Demonstration Concept: HCFA has developed a demonstration design to test whether coverage of wheelchairs and other DME items can be made more flexible for beneficiaries through use of an organization which would help beneficiaries obtain appropriate assessment, documentation, and information about equipment as well as lower prices. The demonstration sponsor would be expected to obtain volume discounts for beneficiaries using their services. The savings would be used to pay for additional needed equipment beyond the traditional coverage limits. The demonstration is to be budget neutral. The sponsor would also provide information on durability and repair-ability of equipment and assist beneficiaries in maintenance and repair of the equipment.

HCFA would solicit participation only from disability service providers that are consumer-controlled entities, including Centers for Independent Living which are funded under the Rehabilitation Act and administered by the Department of Education. We would seek proposals that include provision of wheelchairs, seating, and other mobility assistive devices such as scooters. If an applicant wants to add additional DME items, this enhancement can be

described in the application.

How the Model Would Work: A physically-disabled beneficiary would have the option of bringing a physician's prescription for a wheelchair to the sponsoring organization. If the sponsor determines that there are insufficient details on the prescription or the beneficiary needs additional assessment, a referral or list of options of potential seating clinics or other professionals to do a detailed assessment will be made available to the beneficiary. The sponsor may provide or arrange these services. The beneficiary would be provided with a list of potentially useful equipment (both equipment known to be Medicare-covered as well as other equipment which might be useful).

Once the prescription has sufficient detail and is signed by a physician, the beneficiary may use the sponsor as the purchasing agent or obtain the equipment from another supplier. The sponsor would send the prescription to the DME Regional Carrier (DMERC), which would conduct the medical review and determine a payment amount based on the amount for covered equipment that would be paid to any other supplier. Once the prior authorized payment level has been determined, the sponsoring organization would assist the beneficiary in selecting and purchasing equipment and then pass on discounts that it obtains to the beneficiary. The beneficiary would be able to use the remaining funds to purchase other needed equipment, which might not be Medicare covered, or for future maintenance. We expect that the sponsor will be able to fund their activities through a fee for acting as the purchasing agent and potentially from providing assessment services, if it elects to provide them. If the beneficiary becomes unhappy with the sponsoring organization, he or she could instead purchase the DME through the traditional method.

In the area(s) selected for the demonstration, the sponsoring organization will have the responsibility for making the availability of its services known to potential sources of referrals of beneficiaries needing DME. The organization would be responsible for establishing linkages with other organizations and providers serving the individuals with physical disabilities including disease-specific organizations such as the Stroke Foundation, Muscular Dystrophy Foundation, or the multiple sclerosis organizations, as well as hospitals, physicians and therapists. In addition, the sponsor will work with Medicaid and Vocational Rehabilitation Programs. As a complement to the demonstration, HCFA would broadly disseminate information about the availability of assessment services under Medicare Part B through a pamphlet in physicians' offices and other sites.

Contacts: Bill Clark, ORD 410-786-1484 Laurie Feinberg, M.D. 202-690-7490

cc Chris J
Nancy-Ann Min
Elena Kagan
Bill White
From Diana Fortuna

NOTE TO: Debbie Chang
DATE: March 10, 1997
FROM: Jennie Bonney
SUBJECT: **Rep. Gunderson's "Personal Attendant Services" bill**

At your request, I've prepared a summary of Rep. Gunderson's "Personal Attendant Services" bill (H.R.4250) from the 104th Congress. Speaker Gingrich was the only cosponsor, and no action was taken on the bill last session. (Rep. Gunderson no longer is a Member of Congress.) I searched the 105th Congress, and there is not a similar bill pending this year.

The bill would allow optional coverage of community-based attendant services under the Medicaid program. It defines "qualified community-based attendant services" as care that meets the following conditions:

- The individuals to whom services are furnished would "select, managed and control" the attended services that are provided;
- Services would be covered only if they are home or community based and not provided in a nursing facility or other institution;
- Eligibility for services would be limited to those with functional need;
- Such services would be available in home and other locations such as school, work, recreation and church;
- Such services would be available on an as-needed basis;
- Backup and emergency attendant services would be available;
- A State could impose copayments and cost-sharing based on the income of the individual and in a manner that is not a disincentive for employment;
- Coverage of services could be effected through any appropriate means including vouchers, direct cash payment, individual provider model, or a consumer-directed agency model;
- Voluntary training should be available to recipients on how to select, manage and dismiss attendants;
- Attendant services provided would be agreed upon by the individual and the attendants;
- Health-related tasks could be performed by unlicensed personal attendants; and
- States would submit periodic reports on the coverage of such services to the Secretary.

Medical assistance for "qualified community-based attendant services" need not be made available in all geographic areas of a State or to all beneficiaries.

Medical assistance for "qualified community-based attendant services" may not be made available by a State unless the State establishes that such services will be budget neutral.

The Secretary of HHS would be required to submit periodic reports to Congress on the impact of this legislation on beneficiaries, States and the Federal Government.

***This bill includes many of the principles advocated by ADAPT -- American Disabled for Attendant Programs Today

*ASPE/HCFA look@this

cc ChrisJ
Bruce Vladeck
(Fax 690-6262)
Nancy-Ann Min
5-7289
From Diana Fortuna

November 4, 1996

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

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

[illegible]

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,

Michael Oxford
National Organizer

June 17, 1997

Dear Missy:

Sorry we missed you. Tell the Speaker "Happy Birthday" for us. Attached is what we think you and the Legislative Council need to finish the draft.

As you are aware, we are in town until June 26, 1997. As agreed upon, we have already called the CBO and left a message. We are still awaiting...

* a draft of the legislation for our review by Friday June 19.

* the status of our recommendations for inclusion in the budget reconciliation.

* a meeting with representatives of the CBO on scoring issues.

* **assurance that the bill will be introduced before noon on June 23.**

Again—sorry we missed you. Hopefully, we can resolve the above issues before close of business on Friday.

Kindest Regards,

ADAPT

fax to Anne Tumlinson
from Diana F
5-7840

6/17/97
ADAPT

Memo
To: Missy Jenkins
From: ADAPT
Re: Points to be incorporated in legislation - The name of the bill shall be "The Community Attendant Services Act" of 1997.

1. The Community Attendant Services Act must establish a priority for home and community based services in all 50 states. Funds must follow the eligible person from the institution to the community. Funding must de-emphasize the existing medical model and reverse the current institutional biases in Titles XVIII and XIX of the Social Security Act.

2. The Community Attendant Services Act shall amend the existing Title XIX of the SSA so that it will combine funds for institutional and community services, and give a priority to home and community based services, e.g., an enriched match to states that emphasizes home and community based services.

A. The Act must integrate the existing fragmented funding streams into a single, coherent long term care system.

B. Each State must assure that its fragmented long term care services shall be integrated into a seamless long term care system.

C. Each State must establish a Transition Task Force to ensure a smooth transition from the existing institutional-medical system to a home and community based system. Said Task Force must include the State Developmental Disability Councils, state Councils on Aging and StateIndependent Living Councils.

D. The Transition from an institutional based system to a home and community based system must be completed by July 26, 2000.

E. Congress shall require HHS to review existing and to promulgate new regulations so that excessive utilization of medical services is eliminated and so that delegation, assignment and performance of health related services may be performed by qualified unlicensed persons.

3. The Community Attendant Services Act must include the following services:

A. Personal care services.

B. Consumer directed health related tasks, i.e., tasks that are assigned or delegated by medical professionals.

C. Household services, e.g., meal preparation, cleaning, etc.

D. Cognitive services, e.g., medication reminders; money management, cuing with ADLs or IADLs.

E. Mobility Services, e.g., driving and escort.

4. The Community Attendant Services Act must contain the following:

A. A delivery system with the following payment options:

1. Direct Pay;
2. Vouchers;

3. Fiscal intermediaries;
4. Consumer directed agency model.

B. Maximum control by the consumer to select, manage and control their services.

C. Home and community based programs must be based on consumer satisfaction instead of medical criteria.

D. Funds must follow the people into the setting of their choice. All services must be provided in the most integrated setting appropriate to the needs of the individual. States are required to offer the person in an institution the full range of home and community based services that both exist or could be developed by a state to achieve this integration. The individual must have a choice in using Title XIX and other public funds for home and community based services rather than be limited to the current institutional only system.

E. Community-based services must be available in every state.

F. Eligibility must be based on functional needs of the consumer, not medical diagnosis, type of disability or age.

1. Establish a functional needs assessment instrument that assesses the need for home and community based services.

G. Home and community based services must be available in home and other locations, including but not limited to school, work, recreation and church.

H. Home and community based services must be available 24 hours a day, 7 days a week.

I. Back up and emergency attendant home and community based services must be available.

J. Eligibility must include persons whose income is three times the SSI level and persons whose income exceeds this amount shall share the costs of services based on a sliding fee scale developed by the Transition Team.

K. Home and community based services must not be a disincentive to employment.

L. Delivery of service must include vouchers, direct cash payment, individual provider model, as well as consumer directed agency model.

M. Consumer control must include the right to select, manage, and train attendants. Voluntary training should be available for recipients on how to select, manage and dismiss attendants Consumer control also includes the right to value independence and community activities over medical advice.

N. Attendants should receive a livable wage and benefits.

O. Attendant home and community based services should be based on a mutually agreed upon individual service plan.

P. Health-related tasks shall be assigned, delegated to and/or performed by unlicensed personal attendants.

Q. A fair hearing system must be composed of people with disabilities to hear their appeals.

4. There shall be established a Task Force to study the financing of the long term care system. This Task Force shall be composed of a majority of people with disabilities.

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.

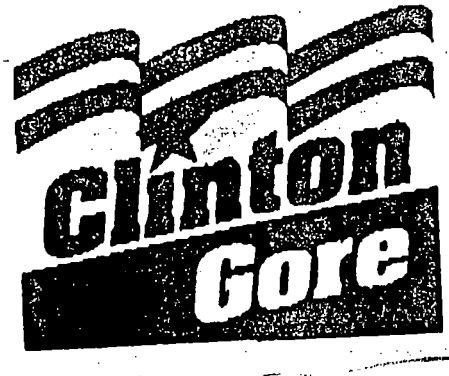
The Administration has been steadfast in its support for community care for people of all ages who have disabilities. We know that most people prefer home and community supports and we are pleased that many states are moving aggressively to use their own funds and federal support to improve the quality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



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

National Campaign Headquarters • P.O. Box 615 • Little Rock, Arkansas 72203 • Telephone (501) 372-1992 • FAX (501) 372-2282

HCFA
MEDICARE • MEDICAID

FAX COVER SHEET

OFFICE OF LEGISLATIVE & INTER-GOVERNMENTAL AFFAIRS

Number of Pages: 4 Date: 6/19/97

To: Erica Edwards From: Jennie Bonney

Fax: 456-7431 Fax: 202 690-8168

Phone: _____ Phone: _____

REMARKS: Please give to Diana + tell her it is a discussion draft for our 10 am. with Bruce tomorrow.

Thanks,

Jennie

HEALTH CARE FINANCING ADMINISTRATION
200 Independence Ave., SW
Room 341-H, Humphrey Building
Washington, DC 20201

POTENTIAL AGENDA ITEMS FOR ADAPT MEETING

The following are some ideas for potential agenda items for a meeting with ADAPT. They are listed in what we believe to be the order of importance to ADAPT.

- **HCFA will provide technical assistance to States to design "client-directed" waiver programs.** HCFA is willing to provide technical assistance to States interested in designing a "client-directed" Home and Community Based waiver program. HCFA can share the experience of other States who have already gone through this process.

  Toward this end, HCFA is drafting a letter to State Medicaid Directors urging them to make appropriate home and community-based services (HCBS) waivers available to all persons currently institutionalized or at risk of institutionalization. The letter notes that a number of States have promoted active consumer participation in their waivers, including needs assessment, service planning, provider recruitment and choice in the oversight of the quality of services furnished. The letter encourages States to continue this effort. [ADAPT wants beneficiaries to have control in hiring, firing and training personal attendants.]

- **Establish a Secretary Work Group on Personal Attendant Services.** The Secretary could appoint a representative six month study group to identify actions that we can undertake under current law. The group could identify and produce a series of quick turn around products on: current best practices and guidelines for States wishing to move to a more consumer driven approach. In addition, the work group could study how to encourage States to use welfare reform to develop personal assistance services worker capacity.

- **Briefing on HCFA regulation on coverage of Personal Care Services.** HCFA is in the final phases of clearing a regulation on personal care services with OS. The existing regulations do not provide for personal care services furnished in settings other than the recipient's home. They also require supervision by a registered nurse. [ADAPT will like the fact that PCS can be provided outside the home because they want to be integrated into the community; they won't be satisfied because it does not use the words "client-directed."]

  The proposed rule would specify that personal care services are services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, ICF/MR or IMD that are: (1) authorized by a physician in accordance with a plan of treatment; (2) provided by an individual who is qualified to provide such services and who is not a member of the individual's family; and (3) furnished in a home, and if the State chooses, in another location.

- **Expand RWJ "Cash and Counseling" Demonstrations.** The Department could encourage RWJ to expand its current "cash and counseling" demonstration. At present, the demonstrations are limited to 4 States. We could encourage that RWJ expand the

number to 10 States. Beneficiaries participating in the RWJ demonstration will be given the cash value of benefits for which they otherwise would be eligible. The beneficiary will be permitted to spend the money on disability related items including personal attendants, assistive technology, transportation, etc. A counselor will be assigned to each participant to account for how the dollars are spent. Evaluations will be conducted at 3 months, 6 months and one year.

- **Briefing on RWJ "Cash and Counseling" Demonstration.** RWJ is funding this demonstration, providing technical assistance and paying for one-half of the evaluation. HCFA/ASPE are funding the other half of the evaluation. It is a controlled experimental design with 2,000 controls and 2,000 in the treatment group in each State. The four States include New York, Arkansas, Florida and New Jersey. Beneficiaries participating in the demonstration will be given the cash value of what they otherwise would be eligible for. The beneficiary will be permitted to spend the money on disability related items including personal attendants, assistive technology, transportation, etc. A counselor will be assigned to each participant to account for how the dollars are spent. Evaluations will be conducted at 3 months, 6 months and one year.

- **Recommend alternative to proposal to convert HCBS waiver to a State Plan option.** The House Commerce Committee dropped this provision due to a CBO cost estimate of $1.6 billion. This provision is not in the latest version of the Senate Finance Committee document. Our actuaries' preliminary estimate is that these options would be budget neutral. [This proposal is aimed at easing the burden on States; ADAPT has not been advocating for this change.]

  Preferred Option: In addition to the current waiver provision, States could choose to provide home and community based services as a State Plan option. There would be a requirement, however, for individual cost-neutrality (i.e., each individual's care under the HCBS benefit would be no more expensive than institutional care for that person) rather than aggregate cost-neutrality. The new State Plan option would retain the same flexibility with regard to targeting of benefits and requirement that persons served have an institutional level of care.

  Why alt? Cost?

  Alternative: States that have demonstrated satisfactory progress under their approved waivers could choose to convert to the State Plan option. The Secretary would reserve the right to approve or deny a State's request to convert to the State Plan option. If approved, no further action to establish cost-neutrality or periodically seek renewal of the program would be required. It is assumed that the approved number of recipients for the last year of the existing waiver would be inflated by the percentage increase in the State's population age 65 and older (for programs serving aged/disabled) or the general population (for programs serving the MR/DD). In addition, expenditures in the last year of the existing waiver would be inflated by the increase in the Medicare Home Health Input Price Index.

- **Discuss Administration's current position on homebound definition for home health care.** We listened to concerns raised by advocates for people with disabilities that our proposal to restrict access to the Medicare home health benefit would have severe implications for people with disabilities. We changed our position on restricting the definition of homebound status, and supported the removal of the proposal from the House and Senate reconciliation bills.

In addition, we would recommend the following with respect to CASA:

- **Recognize CASA as a way to focus discussion.** As a way of responding to ADAPT's advocacy of the CASA proposal, we could state that it is a good point of departure for helping to focus policy discussion around the need for increased access to consumer driven personal assistance. [The White House has proposed the idea of a White House Work Group on Personal Assistance/CASA to vet issues around CASA in preparation for a Fall meeting with ADAPT and the President.]

We recommend that the following item not be on the agenda for discussion:

- **Gunderson legislation**. HCFA has a number of concerns about the Gunderson legislation and our preliminary recommendation is that we not endorse this approach. Our actuaries believe that a strict budget neutrality provision would be difficult to enforce. We believe that it would be premature to establish this as an optional service before we obtain results from the RWJ demonstration. Furthermore, we are concerned that there are many opportunities for abuse of beneficiaries.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

05-Nov-1996 02:27am

Copies to: Carol Rasco
Nancy-Ann Min
Chris Jennings
Bruce Vladeck
From: Diana Fortuna

TO: ADA-LAW

FROM: alec vachon

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). :)

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.

OPRA Agenda

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.

[Contents] [Next]

Home | Conferences & Training | Services | Links

Oxford -
913-233-
4522

FAX NOTE

ADAPT of Texas
1319 Lamar Sq DR #101
Austin, TX 78704
512/442-0252
512/442-0522 fax

Date: [illegible]

To: [illegible] Justin Dart [illegible] MARK SMITH
[illegible] Judy Heumann [illegible] Marca Bristo Paul Marchand

From: ADAPT [illegible]

Total number of pages sent (including cover sheet) 3

If you do not receive all pages call: 512/442-0252

Note: [illegible]

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[illegible]-6218 202-[illegible] 202/[illegible]

202/[illegible]-7507 [illegible]-7662 202/[illegible]-7088

FACSIMILE COVER SHEET
OFFICE OF DISABILITY POLICY

DATE: 8/14/97

TRANSMITTED TO: Diana Fortuna 456-7431 fax

FROM: Thea Spiess

SUBJECT: Letter re HR 2020 (CASA)

NO. OF PAGES (including cover sheet): 3

ADDITIONAL MESSAGE: I've requested copies of the other letter(s) like this one that we've received - I'll fax them when I get them. It is obvious from the requests to "support, co-sponsor" that these letters are also going to congresspeople too.

Office of the Secretary
U.S. Department of Housing and Urban Development
451 7th Street S.W. Room 10234
Washington, DC 20410
Office: (202) 401-7991 Fax: (202) 401-6725

IMPACT Inc.
2735 E. Broadway
Alton, IL 62002

Secretary Andrew Cuomo
Department of Hoiusing and Urban Developmen
451 7th Street
Washington, D.C. 20410

July 16, 1997

Secretary Andrew Cuomo
Department of Housing and Urban Development
451 7th Street
Washington, D.C. 20410

Dear Mr. Cuomo:

I am asking that you formally support, co-sponsor, or otherwise demostrate a willingness to vote for HR 2020. This is the "Medicaid Community Attendant Services Act of 1997."

As a friend of a person with disability, this type of legislation could dramatically effect and improve the quality of life for my friend and others with disabilities. My friend use a personal assistant on a daily basis and this bill would give me a sense of security in knowing that my friend would not be instutionalized if it would be necessary to rely on Medicaid or Medicare for my attendant service.

This bill has been long in coming and I urge your continued support until it is reality and a law. The passage of this bill would allow for individuals to live independently and be a part of the community.

Sincerely,

Amy J. Blough

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