DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Care Financing Administration

Center for Medicaid and State Operations
7500 Security Boulevard
Baltimore, MD 21244-1850

Dear State Medicaid Director:

In the Americans with Disabilities Act (ADA), Congress provided that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." 42 U.S.C. § 12101(a)(8). Title II of the ADA further provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity, or be the subject of discrimination by any such entity." 42 U.S.C. § 12132. Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

We have summarized below three Medicaid cases related to the ADA to make you aware of recent trends involving Medicaid and the ADA.

In L.C. & E.W. v. Olmstead, patients in a State psychiatric hospital in Georgia challenged their placement in an institutional setting rather than in a community-based treatment program. The United States Court of Appeals for the Eleventh Circuit held that placement in an institutional setting appeared to violate the ADA because it constituted a segregated setting, and remanded the case for a determination of whether community placements could be made without fundamentally altering the State's programs. The court emphasized that a community placement could be required as a "reasonable accommodation" to the needs of disabled individuals, and that denial of community placements could not be justified simply by the State's fiscal concerns. However, the court recognized that the ADA does not necessarily require a State to serve everyone in the community but that decisions regarding services and where they are to be provided must be made based on whether community-based placement is appropriate for a particular individual in addition to whether such placement would fundamentally alter the program.

In Helen L. v. DiDario, a Medicaid nursing home resident who was paralyzed from the waist down sought services from a State-funded attendant care program which would allow her to receive services in her own home where she could reside with her children. The United States Court of Appeals for the Third Circuit held that the State's failure to provide services in the "most integrated setting appropriate" to this individual who was paralyzed from the waist down violated the ADA, and found that provision of attendant care would not fundamentally alter any State program because it was already within the scope of an existing State program. The Supreme Court declined to hear an appeal in this matter; thus, the Court of Appeals decision is final.

In Easley v. Snider, a lawsuit, filed by representatives of persons with disabilities deemed to be incapable of controlling their own legal and financial affairs, challenged a requirement that beneficiaries of their State's attendant care program must be mentally alert. The Third Circuit found that, because the essential nature of the program was to foster independence for individuals limited only by physical disabilities, inclusion of individuals incapable of controlling their own legal and financial affairs in the program would constitute a fundamental alteration of the program and was not required by the ADA. This is a final decision.

While these decisions are only binding in the affected circuits, the Attorney General has indicated that under the ADA States have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. Reasonable steps should be taken if the treating professional determines that an individual living in a facility could live in the community with the right mix of support services to enable them to do so. The Department of Justice recently reiterated that ADA's "most integrated setting" standard applies to States, including State Medicaid programs.

States were required to do a self-evaluation to ensure that their policies, practices and procedures promote, rather than hinder integration. This self-evaluation should have included consideration of the ADA's integration requirement. To the extent that any State Medicaid program has not fully completed its self-evaluation process, it should do so now, in conjunction with the disability community and its representatives to ensure that policies, practices and procedures meet the requirements of the ADA. We recognize that ADA issues are being clarified through administrative and judicial interpretations on a continual basis. We will provide you with additional guidance concerning ADA compliance as it becomes available.

I urge you also, as we approach the July 26 anniversary of the ADA, to strive to meet its objectives by continuing to develop home and community-based service options for persons with disabilities to live in integrated settings.

If you have any questions concerning this letter or require technical assistance, please contact Mary Jean Duckett at (410) 786-3294.

Sincerely,

Sally K. Richardson

Sally K. Richardson
Director

cc: All HCFA Regional Administrators

All HCFA Associate Regional Administrators
for Medicaid and State Operations

Disability File

CENTER ON DISABILITY AND HEALTH
1522 K Street, N.W., Suite 800
Washington, D.C. 20005
Telephone: (202) 842-4408
FAX: (202) 842-2402

Facsimile Transmittal Form

Date: May 6, 1998

Receiver's FAX#: 456-5557

To: Rosemary Ciotti / Chris Jennings

Company: White House

Department: Health Advisor

Number of pages: (including cover sheet) 5

From: Bob Gross

Description and Message: Chris - Your assistance would be much appreciated on this critical civil rights issue that cuts to the heart of the Patients Bill of Rights. Please call back this afternoon.

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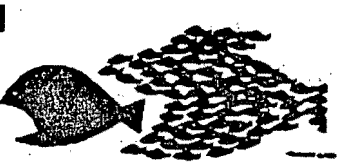

May 6, 1998

Dear National Allies of the Plaintiffs in the DeSario Case,

The attached sign-on letter from 34 original national organizations was delivered to Secretary Shalala's office on April 24th, right in the middle of a Department of Health and Human Services (HHS) strategy meeting to decide how to respond to the DeSario case. That decision of the Second Circuit Court of Appeals explicitly authorized rationing of **all** health care, and even the imposition of a "death sentence" for Medicaid recipients with rare, unusual, or costly treatment needs.

Despite several weeks of urging the Administration to take a stand in the DeSario case, and to explain how the court misconstrued the Department's position about the use of *exclusive* lists of covered treatments, HHS continues to refuse to become involved with the currently pending request for rehearing and reconsideration in that case. Even though the three-judge panel in the DeSario case relied heavily on the Secretary's position, the Secretary is acting as if its asking the Court for an extension of time to submit a clarification of its actual position (because the court might have gotten it wrong) would have no effect.

Instead, HHS officials are planning over the next 4-8 weeks to: (1) conduct a **legal review** of the implications of the Medicaid statute and federal civil rights laws under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act; (2) survey **durable medical equipment (DME) coverage criteria** in Medicaid programs around the country; and (3) develop **policy options** that could take the form of Medicaid regulations or policy guidelines to remove unwarranted obstacles to appropriate **DME coverage**. While this is a good start that we have contributed to through our original sign-on letter to Secretary Shalala, the Department would leave in place the dangerous implications of the DeSario decision, with its imposition of a "death sentence" for persons needing other kinds of treatment, such as surgery, physical therapy, etc.

It is crucial that we intensify our efforts to remind the Administration that its continuing silence and failure to support the plaintiffs in the DeSario case makes a mockery of external review on the basis of medical necessity, consumer participation in decision-making, and the commitment to quality care in the Patients' Bill of Rights. These principles were adopted by the Advisory Commission on Consumer Protection and Quality in the Health Care Industry, which was co-chaired by Secretary Shalala, and strongly endorsed by President Clinton.

But the courts will not wait for HHS to decide on its position in the DeSario case. Courts continue to decide cases as they arise. The next case involving issues related to DeSario currently is pending at the U.S. Court of Appeals for the Fifth Circuit. That case, known as Fred C., involves a single adult Texas Medicaid recipient who needs an augmentative communication

device in order to speak. In this case, the Texas Medicaid program has conceded that Fred C. is a Medicaid recipient who is "homebound" and therefore eligible to receive durable medical equipment, and that the augmentative communication device is "medically necessary" for him. Moreover, Texas already covers augmentative communication devices for children, but refuses to cover them for adults.

The position of the Department of Health and Human Services in the Fred C. case will be actually a revealing "litmus test" for the Department's seriousness of purpose in conducting the DeSario policy review. At stake, in both the DeSario and Fred C. cases, is whether Medicaid provides an individualized right to medically necessary treatment within covered categories of service, and whether the focus of the Medicaid decision-making must be on the medical facts. Supporting the plaintiff in Fred C. would be an important intermediate step in the direction of supporting the crucial right to an individualized determination on the basis of medical necessity since: (1) almost every state Medicaid program already covers augmentative communication (AAC) devices, as has been reported in L. Golinker, "Speaking Up in Court," 8 *Team Rehab Report* 19 (February 1997), (2) the distinction Texas draws between children and adults was not common practice among states before Fred C., and the trend is toward eliminating this distinction, (3) in every final court decision issued to date the Medicaid programs were ordered to cover AAC devices, Meyers (1985)(8th Circuit Court of Appeals); Myers (1995) (Mississippi); Fred C. (1996 and 1997) (Texas); Hunter (1996) (Florida); and (4) HCFA has already issued policy letters stating that AAC devices can be covered under any of the 3 services the courts found in these cases to require AAC device coverage.

The political struggle for health care has clearly shifted from the legislature to the courts, and the executive branch has yet to decide whether it will side with the critical right of low income patients with disabilities to receive medically necessary treatment within covered service categories under the Medicaid program. Our unified voice on these issues can help remind the Administration where its values are-- not only for the Medicaid program but for the Medicare program and private insurance as well.

Five additional national organizations have signed the Shalala letter since the previous deadline of April 24th. There is still time to urge other national organizations to sign on to the Shalala letter in the next few days to encourage the Secretary to support the plaintiffs' petition for a rehearing of the Desario case, and to clarify as soon as possible the requirements which Medicaid programs must use in determining coverage policy. Depending on the Department's reaction to the Fred C. case, it may be necessary to circulate a new sign-on letter to encourage the Department to file an amicus brief in the Fred C. case that affirms the right to receive medically necessary treatment within covered service categories. I will keep you apprised of the Department's response to these critical civil rights issues in the DeSario and Fred C. cases. Thank you for recognizing the importance of protecting the rights of Medicaid recipients with disabilities, thus strengthening the right of all consumers to medically necessary treatments.

Sincerely,

Bob Griss

Bob Griss

April 24, 1998

The Honorable Donna E. Shalala
Secretary
Department of Health and Human Services
615-F Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

The recent legal decision in the DeSario V. Thomas case has enormous negative implications for the ability of health care consumers to obtain medically necessary or appropriate health care. The following organizations strongly urge the Department of Health and Human Services to support the request for rehearing before the full Second Circuit Court of Appeals and to clarify its position on these critical issues.

The decision of the three-judge Second Circuit Court panel to reverse an earlier federal district court ruling would allow state Medicaid programs to use "exclusive lists" for durable medical equipment and other services. The decision also allows those lists to be constructed through a cost-benefit analysis approach that takes into account the needs of the population as a whole, not the needs of the individual patient. This decision, if it is allowed to stand, will mean that patients whose medical requirements are different from the average may not receive needed services. It also will mean that health care professionals will be limited in their ability to prescribe the best treatment for their patients. According to this latest ruling, Medicaid beneficiaries whose treatment needs are denied because of the use of "exclusive lists" should "look for other sources of assistance."

Increasingly, public and private health insurance programs are using lists for durable medical equipment, prescription drugs and other services. While those lists can serve a useful purpose, there must be discretion to prescribe covered services not on those lists if medically necessary or appropriate for a specific patient. The ability to get medically necessary covered services not included on those lists must not depend upon the financial ability of patients. The three-judge panel ruling in the DeSario case undermines this important consumer protection concept, setting a precedent not just for other state Medicaid programs but potentially for the health care system as a whole.

Again, we ask that you act to support the petition for rehearing of the DeSario case. In addition, we hope you will clarify the Administration's position that the appropriate use of lists requires an exception procedure for medically necessary or appropriate services and that discrimination on the basis of health diagnosis or the cost of treatment is not acceptable. Thank you for taking our views into account. We hope to hear from you shortly on this issue.

In the few days since this letter has circulated, it has been endorsed by the following diverse list of 34 national organizations, as of April 24th:

AIDS Action Council
American Congress of Community Supports and Employment Services
American Federation of State and County Municipal Employees (AFSCME)
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Brain Injury Association
Center on Disability and Health
Consumer Coalition for Quality Health Care
Consumer Federation of America
Consumers Union
Epilepsy Foundation
Families USA
Friends Committee on National Legislation
Lutheran Office for Governmental Affairs of the Evangelical Lutheran Church in America
National Association for the Advancement of Orthotics and Prosthetics
National Association of Developmental Disabilities Councils
National Association of People with AIDS
National Association of Social Workers
National Council on the Aging
National Council of Senior Citizens
National Easter Seal Society
National Mental Health Association
National Osteoporosis Foundation
National Senior Citizens Law Center
National Therapeutic Recreation Society
Network: A National Catholic Social Justice Lobby
Paralyzed Veterans of America
Research Institute for Independent Living
Service Employees International Union (SEIU)
Summit Health Coalition
The Arc of the United States
Unitarian Universalist Service Committee
United Cerebral Palsy Associations
Universal Health Care Action Network

Additional sign-on's since April 24th:

Alzheimers Association
Catholic Charities USA
National Association of Area Agencies on Aging
National Health Council
Neighbor to Neighbor

HR 3433 IH

Just ADLs - gets short-term set to last 12mo / Death WORK.

May Resurface as part of Archer tax Bill

Uses CL. Disability IMPAIRMENT-Related 50% <10,000 [versus itemized deduction]

105th CONGRESS

2d Session

H. R. 3433

To amend the Social Security Act to establish a Ticket to Work and Self-Sufficiency Program in the Social Security Administration to provide beneficiaries with disabilities meaningful opportunities to return to work and to extend Medicare coverage for such beneficiaries, and to amend the Internal Revenue Code of 1986 to provide a tax credit for impairment-related work expenses.

Scoring 2+4P — Deduction NO Double Dipping 5-year $1.1.56.

IN THE HOUSE OF REPRESENTATIVES

March 11, 1998

Mr. BUNNING (for himself and Mrs. KENNELLY of Connecticut) introduced the following bill; which was referred to the Committee on Ways and Means

---

A BILL

To amend the Social Security Act to establish a Ticket to Work and Self-Sufficiency Program in the Social Security Administration to provide beneficiaries with disabilities meaningful opportunities to return to work and to extend Medicare coverage for such beneficiaries, and to amend the Internal Revenue Code of 1986 to provide a tax credit for impairment-related work expenses.

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 'Ticket to Work and Self-Sufficiency Act of 1998'.

SEC. 2. THE TICKET TO WORK AND SELF-SUFFICIENCY PROGRAM.

(a) IN GENERAL- Part A of title XI of the Social Security Act (42 U.S.C. 1301 et seq.) is amended by adding at the end the following new section:

'THE TICKET TO WORK AND SELF-SUFFICIENCY PROGRAM

'SEC. 1147. (a) IN GENERAL- The Commissioner of Social Security shall establish a Ticket to Work and Self-Sufficiency Program, under which a disabled beneficiary may use a ticket to work and self-sufficiency issued by the Commissioner in accordance with this section to obtain

VARIOUS RELATED DOCUMENTS

further legislative action with respect to the amendments made by subsection (a), taking into account experience derived from efforts to achieve full implementation of the Ticket to Work and Self Sufficiency Program under section 1147 of the Social Security Act.

SEC. 4. CREDIT FOR IMPAIRMENT-RELATED WORK EXPENSES OF HANDICAPPED INDIVIDUALS.

(a) IN GENERAL- Subpart A of part IV of subchapter A of chapter 1 of the Internal Revenue Code of 1986 (relating to nonrefundable personal credits) is amended by inserting after section 25A the following new section:

`SEC. 25B. IMPAIRMENT-RELATED WORK EXPENSES OF HANDICAPPED INDIVIDUALS.

`(a) ALLOWANCE OF CREDIT- In the case of a handicapped individual, there shall be allowed as a credit against the tax imposed by this chapter for the taxable year an amount equal to 50 percent of the impairment-related work expenses which are paid or incurred by the taxpayer during the taxable year.

`(b) MAXIMUM CREDIT- The credit allowed by subsection (a) with respect to the expenses of each handicapped individual shall not exceed $5,000 for the taxable year.

`(c) DEFINITIONS- For purposes of this section--

`(1) HANDICAPPED INDIVIDUAL- The term `handicapped individual' has the meaning given such term by section 190(b)(3).

`(2) IMPAIRMENT-RELATED WORK EXPENSES- The term `impairment-related work expenses' means expenses--

`(A) of a handicapped individual for attendant care services at the individual's place of employment and other expenses in connection with such place of employment which are necessary for such individual to be able to work, and

`(B) with respect to which a deduction is allowable under section 162 (determined without regard to this section).

`(d) SPECIAL RULES-

`(1) DENIAL OF DOUBLE BENEFIT- The amount of impairment-related work expenses which is allowable as a deduction under section 162 (determined without regard to this paragraph) for the taxable year shall be reduced by the amount of credit allowed under this section for such year.

`(2) ELECTION TO HAVE SECTION NOT APPLY- No credit shall be allowed under subsection (a) for the taxable year if the taxpayer elects to not have this section apply for such year.'

(b) CLERICAL AMENDMENT- The table of sections for such subpart A is amended by inserting

after the item relating to section 25A the following new item:

'Sec. 25B. Impairment-related work expenses of handicapped individuals.'

(c) EFFECTIVE DATE- The amendments made by this section shall apply to taxable years beginning after December 31, 1997.

END

H.R.3600

Health Security Act (Introduced in the House)

p>

SEC. 7901. CREDIT FOR COST OF PERSONAL ASSISTANCE SERVICES REQUIRED BY EMPLOYED INDIVIDUALS.

(a) IN GENERAL- Subpart A of part IV of subchapter A of chapter 1 (relating to nonrefundable personal credits) is amended by inserting after section 23 the following new section:

`SEC. 24. COST OF PERSONAL ASSISTANCE SERVICES REQUIRED BY EMPLOYED INDIVIDUALS.

`(a) ALLOWANCE OF CREDIT-

`(1) IN GENERAL- In the case of an eligible individual, there shall be allowed as a credit against the tax imposed by this chapter for the taxable year an amount equal to the applicable percentage of the personal assistance expenses paid or incurred by the taxpayer during such taxable year.

`(2) APPLICABLE PERCENTAGE- For purposes of paragraph (1), the term `applicable percentage' means 50 percent reduced (but not below zero) by 10 percentage points for each $5,000 by which the modified adjusted gross income (as defined in section 59B(d)(2)) of the taxpayer for the taxable year exceeds $45,000. In the case of a married individual filing a separate return, the preceding sentence shall be applied by substituting `$2,500' for `$5,000' and `$22,500' for `$45,000'.

`(b) LIMITATION- The amount of personal assistance expenses incurred for the benefit of an individual which may be taken into account under subsection (a) for the taxable year shall not exceed the lesser of--

`(1) $15,000, or

`(2) such individual's earned income (as defined in section 32(c)(2)) for the taxable year.

In the case of a joint return, the amount under the preceding sentence shall be determined separately for each spouse.

`(c) ELIGIBLE INDIVIDUAL- For purposes of this section, the term `eligible individual' means any individual (other than a nonresident alien) who, by reason of any medically determinable physical impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months, is unable to engage in any

substantial gainful activity without personal assistance services appropriate to carry out activities of daily living. An individual shall not be treated as an eligible individual unless such individual furnishes such proof thereof (in such form and manner, and at such times) as the Secretary may require.

`(d) OTHER DEFINITIONS- For purposes of this section--

`(1) PERSONAL ASSISTANCE EXPENSES- The term `personal assistance expenses' means expenses for--

`(A) personal assistance services appropriate to carry out activities of daily living in or outside the home,

`(B) homemaker/chore services incidental to the provision of such personal assistance services,

`(C) in the case of an individual with a cognitive impairment, assistance with life skills,

`(D) communication services,

`(E) work-related support services,

`(F) coordination of services described in this paragraph,

`(G) assistive technology and devises, including assessment of the need for particular technology and devices and training of family members, and

`(H) modifications to the principal place of abode of the individual to the extent the expenses for such modifications would (but for subsection (e)(2)) be expenses for medical care (as defined by section 213) of such individual.

`(2) ACTIVITIES OF DAILY LIVING- The term `activities of daily living' means the activities referred to in section 213(g)(3).

`(e) SPECIAL RULES-

`(1) PAYMENTS TO RELATED PERSONS- No credit shall be allowed under this section for any amount paid by the taxpayer to any person who is related (within the meaning of section 267 or 707(b)) to the taxpayer.

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1 the lower of the actual charge or the fee schedule
2 established under section 1848.
3 (b) BLOOD GLUCOSE MONITORS FOR INDIVIDUALS WITH DIABETES.—
4 (1) INCLUDING ALL MONITORS AS DURABLE MEDICAL
5 EQUIPMENT.—Section 1861(n) (42 U.S.C. 1395x(n)) is amended
6 by inserting before the semicolon the following: ", and
7 includes blood glucose monitors for individuals with
8 diabetes without regard to whether the individual has type I
9 or type II diabetes or to the individual's use of insulin
10 (as determined under standards established by the Secretary
11 in consultation with the American Diabetes Association);".
12 (2) 10 PERCENT REDUCTION IN PAYMENTS FOR TESTING
13 STRIPS.—Section 1834(a)(2)(B)(iv) (42 U.S.C. 1395m(a)(2)) is
14 amended by adding before the period the following: "(reduced
15 by 10 percent, in the case of a blood glucose testing strip
16 furnished after 1997 for an individual with diabetes)".
17 (c) EFFECTIVE DATE.—The amendments made by subsections (a)
18 and (b) apply to items and services furnished on or after January
19 1, 1998.
20 **SEC. 11246. RESPITE BENEFIT.**
21 (a) ENTITLEMENT.—Section 1832(a)(2) (42 U.S.C. 1395k(a)(2))
22 is amended by—
23 (1) striking "and" at the end of subparagraph (I),

1 (2) striking the period at the end of subparagraph (J)
2 and inserting "; and", and
3 (3) inserting after subparagraph (J) the following new
4 subparagraph:
5 "(K) respite services for no more than 32 hours
6 each year.".
7 (b) CONDITIONS AND LIMITATIONS ON PAYMENT.—
8 (1) PAYMENT RATE.—Section 1833(a)(2) (42 U.S.C.
9 13951(a)(2)) is amended—
10 (A) by striking "and" at the end of subparagraph
11 (E),
12 (B) by adding "and" at the end of subparagraph
13 (F), and
14 (C) by adding after subparagraph (F) the
15 following:
16 "(G)(i) with respect to respite services, payment
17 shall be made at a rate equal to $7.50 per hour for
18 1998 and at a rate to be determined by the Secretary in
19 subsequent years(but the percentage increase for any
20 year may not exceed that increase in the Consumer Price
21 Index for All Urban Consumers (United States city
22 average.)), and
23 "(ii) notwithstanding any provisions of section
24 1861(v), in the case of respite services furnished by a
25 home health agency (or other organization designated by

1 the Secretary pursuant to regulations), payment to the
2 agency or other organization for respite services may
3 not exceed 110 percent of the hourly respite allowance
4 times the number of hours of respite for which the
5 agency authorizes payment.".
6 (2) CONDITIONS OF PAYMENT.—Section 1835(a)(2) (42
7 U.S.C. 1395n(a)(2)) is amended by—
8 (A) striking "and" at the end of subparagraph (E),
9 (B) striking the period at the end of subparagraph
10 (F) and inserting "; and", and
11 (C) inserting after subparagraph (F) the following
12 new subparagraph:
13 "(G) In the case of respite services, the
14 individual for whom payment is claimed is impaired due
15 to irreversible dementia (the individual has scored
16 three or more errors on the Short Portable Mental
17 Status Questionnaire) and either needs assistance in at
18 least one out of five activities of daily living
19 (bathing, dressing, transferring, toileting, and
20 eating) or in at least one out of four instrumental
21 activities of daily living (meal preparation,
22 medication management, money management, and
23 telephoning), or needs constant supervision because of
24 one or more behavioral problems, as defined by the
25 Secretary.".

1 (3) FAMILY DESIGNATION OF RESPITE SERVICES PROVIDER AND
2 CARE GIVER.—Section 1835(a)(2) (42 U.S.C. 1395n(a)(2)) is
3 amended by—
4 (A) by adding at the end the following new
5 sentences: "In the case of respite services that are
6 the subject of the certification described in
7 subparagraph (G), the entity or individual providing
8 the care for which respite is sought shall designate a
9 respite services caregiver either through a home health
10 agency or (if the Secretary designates other
11 organizations to provide or arrange for such services)
12 other organization. The agency or organization shall
13 determine the amount of respite entitlement remaining
14 in the calendar year and inform the entity or
15 individual of the extent to which respite services may
16 be authorized. When services have been provided, the
17 entity or individual shall inform the agency or
18 organization, which then shall pay the caregiver.
19 Where additional payment is made on behalf of the
20 beneficiary, the agency or organization shall assure
21 that the entity or individual is informed of the limits
22 applicable to payments for such services. Payment may
23 not be made under this title for respite services if
24 the per-hour charge to the patient for care by respite

1 aides exceeds by more than two dollars the hourly rates
2 established under this title."
3 (c) DEFINITIONS.—Section 1861 (42 U.S.C. 1395x) is amended—
4 (1) in subsection (m)—
5 (A) by striking "and" at the end of paragraph (6);
6 (B) by adding "and" at the end of paragraph (7);
7 and
8 (C) by inserting after paragraph (7) the
9 following:
10 "(8) respite services as described in subsection
11 (pp);",
12 (2) in subsection (o)—
13 (A) by striking "and" at the end of paragraph (6);
14 (B) by adding "and" at the end of paragraph (7);
15 and
16 (C) by inserting after paragraph (7) the
17 following:
18 "(8) agrees to provide or arrange for respite services
19 as described in subsection (pp);", and
20 (3) by adding after subsection (oo) as added by section
21 11245 (a)(2) of this Act the following:
22 "Respite Services; Respite Aides; Respite Providers
23 "(pp)(1) The term 'respite services' means temporary care
24 provided to individuals who meet the requirements of section
25 1835(a)(2) for the purposes of ensuring periodic time-off for co-

1 resident primary informal caregivers. Although respite providers
2 may provide assistance with personal care or household
3 maintenance activities, their primary function is to provide
4 protective supervision for persons with Alzheimer's and related
5 dementias whose memory, orientation, judgment, and reasoning
6 abilities have become so impaired that, for safety's sake, they
7 require the constant attention or close physical proximity of
8 another person at all or almost all hours of the day or night.
9 "(2) The term 'respite aides' means individuals who have
10 been designated by the Secretary as qualified to act as
11 caregivers for purposes of providing the services described in
12 paragraph (1). Respite aides may be nurse aides who meet the
13 requirements of section 1819(b)(5), home health aides who meet
14 the requirements of section 1891(a)(3), or other individuals
15 licensed by the State or recognized by the Secretary as having
16 the skills necessary to provide those services.
17 "(3) The term 'respite providers' means organizations
18 identified by the Secretary in regulations as qualified to
19 provide or arrange for respite services under this title. The
20 Secretary may establish by regulation requirements for respite
21 providers that the Secretary determines appropriate.".
22 (d) EFFECTIVE DATE.—The amendments made by this section
23 apply to services furnished after fiscal year 1997.

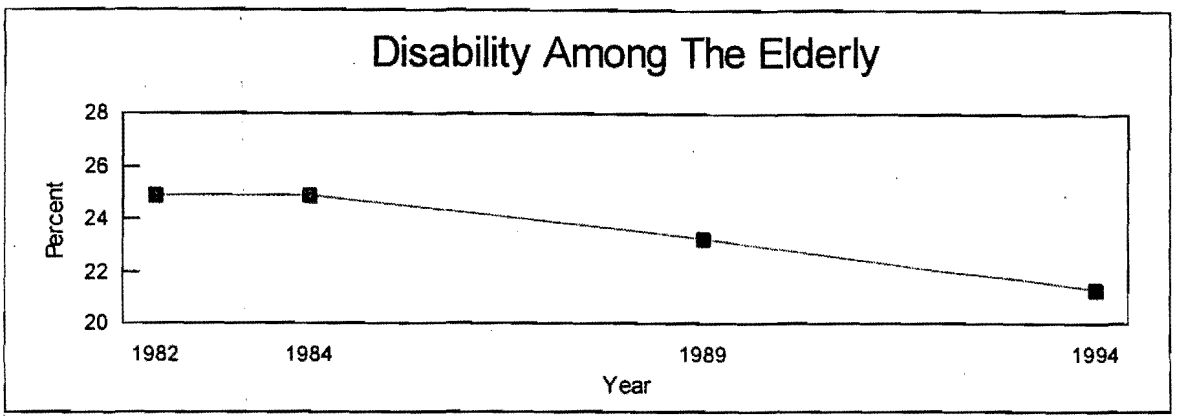
24 **Subpart C—Other Provisions**

Implications of Changing Disability Among the Elderly

David M. Cutler
Professor of Economics, Harvard University

Background Fact: Rates of disability among the elderly have fallen substantially over time.

- Over the past 15 years, disability among the elderly has fallen by about 25 percent.
- Disability is falling in other countries too, although generally by a smaller amount.
- There is widespread agreement that the elderly are healthier than they used to be.



Implication 1: Medicare and Medicaid financing will be dramatically affected.

- Declines in disability at or near current rates would *reduce* Medicare and Medicaid relative to baseline -- by 25 percent or more by the middle of next century.
  - The disabled spend 7 times the non-disabled on Medicare, and even more on Medicaid.
  - This can contribute to solving (some say "solve") the Medicare financing problem. I believe more changes will be needed.
  - Current Medicare forecasts do not do a good job with these changes.
- There are two vital research questions stemming from these findings:
  1. Is disability being *eliminated* or just *delayed*? The implications for Medicare and Medicaid spending, are very different in the two scenarios.
  2. Why are disability rates falling? Disability reductions resulting from increased Medicare spending will have smaller gains to the government than disability reductions not associated with increased medical costs.
     - Some of the changes result from increased medical spending (e.g., cardiovascular treatment; hip replacements) while others result from non-medical factors (e.g., smoking; less manual labor; elevators).
     - It may be that the easy changes have already been made and only the hard ones are left (although smoking seems "easy").

Implication 2: Social Security will be affected as well.

- The potential for the elderly to contribute more meaningfully to society at older ages (active life expectancy) is increasing.
  - This inclines many researchers to support increasing retirement ages.
- Disability insurance claims will likely fall.
  - Although some disability (more so in other countries) is just disguised unemployment.

Implication 3: Private relationships will change.

- Employers will adjust to more productive older workers.
- The need for formal and informal long-term care will decline.
  - This is particularly true as more men reach older ages. Three-quarters of elderly nursing home residents are women.
- Health among the oldest old may increase to levels currently experienced only by the younger old.

Implication 4: Assessments of the value of medical research may be too low.

- Eliminating disability might increase people's health by $500,000 per person or more, on top of increases in longevity.
  - This is based on my own calculations – it's not a "generally accepted number", but it's not unreasonable.
- Improved health is the most important economic change of the 20th century and promises to be the most important change in the next century as well.
  - This is true even if it means increased medical spending.

Disability Reduction Trk

11/98 Draft Language Regarding Medical Research
For Inclusion in the Final Report of the Bipartisan Commission on the Future of Medicare

Recommendation: *The Commission recommends that Congress undertake additional review of the relationship between the federal investment in medical research and resulting savings to the Medicare system, based on preliminary data showing that research outcomes improve the health of and reduce the demand for health care services by Medicare beneficiaries.*

Background: Part of the solution to Medicare solvency should include a strategic look at reducing the need and demand for health care services among Medicare beneficiaries. Demand may be reduced by the utilization of medical innovations that produce more efficient treatments, or the means to effectively prevent or postpone chronic age-related diseases. The goal should be a healthier, more productive and independent population of older Americans, thus reducing some of the need and demand for chronic care services and significantly improving the quality of life of America's elderly.

The most expensive beneficiaries of federal health insurance are chronically disabled seniors who require continuing medical, institutional or at-home care. The Health Care Financing Administration reports that just 11% of the highest cost users account for over 75% of all Medicare reimbursements. Even a small improvement in reducing disability rates among this group would have significant impact on restraining demand and modifying total costs to the Medicare program. In fact, demographers are tracking a steady reduction in disability rates among American aged 80 and over. Studies show that the percentage of disabled seniors today is 20.5%, down from 25.2% in 1982, representing an annual decline of 1.3%. This trend translates into Medicare savings of several billion dollars.

Medical research has produced many of the innovations that have lessened disability in the elderly. In the past few years alone, hundreds of new treatments have been put to use which have dramatically reduced the need for chronic care in the elderly population. Surgical hip and knee replacements, laser-assisted cataract removal, hormonal replacement therapy, antibiotics rather than surgery for peptic ulcers, a simple aspirin a day for cardiovascular health, along with a reduction in smoking, are some of the reasons for the current improvement in health status of older Americans. In the next five to ten years, research will contribute additional innovations which could allow us to postpone the onset of chronic disability from age-related diseases such as diabetes, stroke, and Alzheimer's Disease. Success in a delay strategy for age-related diseases could realize savings to Medicare far greater than proposals that seek only to reduce availability of services or raise costs.

Accelerating the pace of medical discovery requires an infusion of new resources to raise the success rate of research grant applications at the National Institutes of Health as rapidly as possible. Congress is moving towards doubling the NIH budget over a five-

year period but has yet to designate a long-term funding source to supplement annual appropriations. Since Medicare will benefit greatly from a growing investment in medical research -- a coordinated NIH effort to stimulate research in delaying dementia and frailty, for example, could be a part of national strategy for balancing the Medicare accounts – its resources should be considered. What is needed is additional study of the linkage of medical research to declining disability rates as well as efforts to model cost-savings to the Medicare system. The Commission strongly encourages Congress to conduct further review of this issue as a critical part of any long-term solvency plan for the Medicare program.

The Medicaid Purchase Plan is a statewide opportunity for people with disabilities who are working to get the vital health supports through a Medicaid "buy-in." Participants who are working or returning to work are able to earn more, save more and maintain access to health care.

WHY DOES WISCONSIN NEED WAIVERS NOW?

Wisconsin is currently helping nearly 1,000 people with disabilities pursue their employment goals through *Wisconsin Pathways to Independence* and the *Medicaid Purchase Plan*.

Over the past year, Wisconsin has submitted two waiver requests to the Social Security Administration:

- Submitted October, 1999: SSI Waiver
- Submitted June, 2000: SSDI Waiver

Wisconsin needs these federal waivers in order to maximize consumer participation in return-to-work programs for people with disabilities. People with disabilities need these waivers in order to maximize their earnings potential and minimize the risk of returning to work.

- **Federal waivers are integral to the success of both programs.** Wisconsin cannot fully test the *Pathways* intervention without removing income-related disincentives to work. People with disabilities need these waivers if they are to increase their work effort beyond the range of existing work incentives and make full use of the critical health care supports offered by the *Medicaid Purchase Plan*.

- **Consumer and advocate expectations are high.** *Pathways* provides services to people with disabilities in twenty sites across the state. Project participants were recruited, in part, based on the Social Security Administration's professed desire to test alternate benefits systems in the form of federal waivers. Continued enrollment in the *Pathways* intervention—and subsequent participation in the Medicaid buy-in—will be a far greater challenge without the approval of federal waivers.

- **Research results are stunted by limited enrollment numbers.** Delays in enrollment due to the lack of federal waivers may significantly reduce the number of project enrollments and, hence, the strength of conclusions drawn from the data available at the end of the grant period vital toward informing future policy redesign.

Wisconsin has designed the necessary infrastructure to put federal waivers in place now. These waivers will enable participants to maximize participation and earnings potential in *Wisconsin Pathways to Independence* and, subsequently, the *Medicaid Purchase Plan*.

Summary of SSDI Waiver

Waiver was submitted to the Social Security Administration on 6/26/00

	Current Policy	Waiver Request	Rationale
Waiver Eligibility		Participant increases earnings: $75 – 125/ mo.	Targets the waiver to individuals who have increased earnings.
Make Work Pay	Benefit Reduction- $1 for $1 when earnings are above $700/month	When earnings exceed $700/month, reduce DI benefits $65 + ¼ based on all earnings	Replaces an income cliff with a sliding scale reduction of benefits when someone is working. Matches SSI waiver for greater continuity.
Waiver Participants No Worse Off As a Result of Participation	Continuing Disability Reviews (CDR's) may be conducted at 1, 3 or 7 year intervals or can be triggered anytime by other factors (e.g. work).	Suspend all Continuing Disability reviews except for those in which medical improvement is expected	Increases the incentives to work by removing the fear that working will jeopardize one's disability status.
	Trial Work Period (9 month work incentive) in which an individual can test his or her ability to work.	Stop the clock on the trial work period during the demonstration (i.e. if an individual comes into the waiver having used 3 of the 9 months, then they leave the waiver with 3 of 9 months used).	Allows individuals to use this work incentive after the demonstration so they are not negatively effected as a result of participating.
	Extended Period of Eligibility for Cash Benefits (36 month work incentive)	Stop the clock on the extended period of eligibility during the demonstration so it is available to the individual after the demonstration.	Allows individuals to use this work incentive after the demonstration so they are not negatively effected as a result of participating.
	Continued Medicare coverage for up to 7.75 years.	Stop the clock on the period of continued Medicare coverage during the demonstration so it is available to the individual after the demonstration.	Allows individuals to use this work incentive after the demonstration so they are not negatively effected as a result of participating.

WISCONSIN PATHWAYS TO INDEPENDENCE

SSI Waiver : May 15, 2000

Goals	Current System	Proposed SSI Waiver*
Target the Waiver*		• **Increase:** range $75-125 per month • **Minimum:** Authority for range $0-500 per month **(Initial: $0)**
Make Work Pay	• Earnings above $65, $1 of SSI cash benefit reduced for every $2 earnings.	• Earnings above $65, $1 of SSI cash benefit reduced for every $4 earnings.
Save For the Future	• Assets must be under $2000	• Save up to 50% of earnings per year above $2000 in a designated account not to exceed $8000 per year.
Suspend Disability Reviews	• Work and earnings triggers a review of disability status.	• Suspend disability reviews except for individuals in which medically improvement is expected.
Remove Penalties Of Employment-Related Unearned Income	• Unearned income above $20 is used to reduce the SSI benefit $1 for every $1 of income.	• Certain types of unearned income would be counted as earned income for purposes of calculating the SSI cash benefit (i.e. would reduce the SSI benefit by $1 for $4 instead of $1 for $1).

* The proposed SSI waiver represents the Department's best estimate of the SSI waiver elements; however, these elements may change as the waiver is routed at the Social Security Administration and the Office of Management and Budget for review and approval.

Peter A. Weissman

01/12/99 03:27:37 PM

Record Type: Record

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

cc:

Subject: TIME_ SENSITIVE QUESTIONS

Amy Goldstein (wash post) has the following questions:

1: how many disabled people of working age could work if they had the right support?

2: breakdown of the money for the education component- how does the $35 million break down among the different components.

3: information on the tax credits

she also has some health related questions for Chris.

334-7119

1. * NOT KNOWN - BUT WE DO KNOW FROM

2.

October 22, 2000

Chris:

For your information we have sent the enclosed message to more than 4,000 leaders of the disability community in every state and major urban center.

We love you. Lead on.

Justin and Yoshiko

Paul: We love you! Lead on!

JUSTIN DART, JR.
907 6TH STREET, SW, APT. 516C
WASHINGTON, DC 20024
202-488-7684

Justin and Yoshiko

COPY

Election 2000

AMERICA NEEDS YOUR LEADERSHIP

I vote Gore. You vote your conscience. We unite to defend democracy and make it real in every life.

October 15, 2000 Paul

Dear Colleague in Justice:

THE COMING ELECTIONS ARE LIFE OR DEATH FOR DISABILITY RIGHTS AND DEMOCRACY. A powerful minority attacks ADA, IDEA and the American Dream. They threaten to repeal Abraham Lincoln democracy and take us back to states' rights and privilege for the few.

THE NEXT PRESIDENT WILL APPOINT THE SUPREME COURT JUSTICES and sign the laws that will determine the future of our lives and of our democracy.

I SUPPORT AL GORE. As he has stated, he is not history's first perfect leader, but I believe that his record on disability rights and democracy is very much better than that of Governor Bush and his far right supporters.

ON THE TENTH ANNIVERSARY OF THE AMERICANS WITH DISABILITIES ACT, GOVERNOR BUSH said "I strongly support the ADA," – and certainly he has said and done other good things. But the overall record is profoundly disturbing. During his term as governor, Texas opposed our ADA rights in the Olmstead case and declined to support the constitutionality of the ADA in the historic Garrett case. The official Texas Republican platform, under Governor Bush, calls for a devastating amendment to the ADA that would exclude millions of people with disabilities from protection. When seventeen Texas advocates gathered this year on the public sidewalk outside the Governor's Mansion to request a policy meeting, they were arrested.

Get into politics as if your life depended on it. It does.

CLINTON-GORE HAVE LED AMERICA TO ITS GREATEST economy and quality of life. They have supported people with disabilities. They have defended our rights under ADA, IDEA, Medicaid and Medicare. They have supported us on universal health care, the Patients' Bill of Rights, the FDR Memorial, the Work Incentives Improvement Act, Real Choice Systems Change Grants, Hate Crimes, and accessible technology, accessible communications and accessible transportation. They have met with us, they have listened to us. They have empowered us in the executive branch as never before.

AMERICA STILL HAS PROMISES TO KEEP. Clinton-Gore have not solved, could not have solved, all of the centuries old problems of people with disabilities. Millions of us are still unemployed and underemployed. Millions of us are still imprisoned in institutions, nursing homes and back rooms. We must pass MiCASSA and complete the whole spectrum of liberation and empowerment.

I BELIEVE AL GORE IS THE CANDIDATE who will lead us in our battle for equality and who will fight to defend democracy against the forces of retreat. That is why I am an Abraham Lincoln, Teddy Roosevelt Republican for Al Gore.

WHATEVER VOTE YOUR CONSCIENCE DICTATES, AMERICA NEEDS YOUR LEADERSHIP in the closing days of this historic campaign. America needs your strong voice – in whatever party – for the values I know we share: lives of love, choices, productivity and dignity for all.

LET US JOIN TOGETHER, Republicans, Democrats, independents. Let us embrace each other in reverence for individual human life. Let us reach out to all in our communities and urge them to vote for democracy on November 7th. Win or lose in any particular election, let us go forward in passionate solidarity for however long it takes to fulfill the Dream: America for all.

I appreciate you! I love you! Lead on!

Together, we shall overcome.

Justin and Yoshiko

Justin Dart, Jr.

"Nothing about us without us"
Clinton-Gore score on empowerment

THE FOUNDATION OF RIGHTS IS EMPOWERMENT. Rights cannot be handed down. You have to participate in government. You have to be at the policy table.

RELATIVE TO ADMINISTRATIONS PAST, CLINTON-GORE HAVE MADE STRONG CONTRIBUTIONS in the area of empowerment. The President and Vice President have met with us several times. Members of their staff have met with us hundreds of times. They have appointed an astounding number of distinguished disability rights leaders to their administration: **Judy Heumann, Marca Bristo, Tony Coelho, Becky Ogle, Bob Williams, Paul Miller, John Lancaster, Jonathan Young, Bob Boorstin, Liz Savage, Gina McDonald, Michael Winter, Fred Schroeder, Deidre Davis, Debbie Robinson, Bonnie O'Day, Rae Unzicker, John Kemp, Kate Seelman, Susan Daniels, Howard Moses, Marilyn Golden, Hughey Walker, Kate Wolters, Yerker Andersson, Audrey McCrimon, Lilliam Rangel-Diaz, Shirley Ryan, Ela Yazzie-King, June Kailes, Pat Cannon** and many more.

ON SEPTEMBER 10TH, 1997, REPRESENTATIVES OF MAJOR DISABILITY CONSTITUENCIES MET WITH BILL CLINTON AND AL GORE in the Cabinet Room of the White House. The President and VP took notes and dialogued with every participant on policy. There were other such meetings, including one last July 25th with the Vice President and rights leaders, but no photos in our drawer. Rights participants in the pictured meeting included: **Debbie Robinson**, Speaking for Ourselves; **Paul Marchand**, CCD; **Bob Kafka**, **Mike Oxford**, ADAPT; **Becky Ogle**, **Fred Fay**, Justice for All; **Justin Dart**, Justice for All and speaking for people with psychiatric disabilities; **Gina McDonald**, NCIL; **Paul Edwards**, American Council of the Blind; **Nancy Diehl**, National Parent Network; **Tony Coelho**, PCEPD; **Marca Bristo**, NCD; **John Harper**, student leader, advocate for persons with deafness; **Judy Heumann**, Assistant Secretary of Education; **Bob Williams**, Deputy Assistant Secretary, HHS; **Susan Daniels**, Associate Commissioner, SSA - and there were numerous high level staff of the President. **Serving in the administration or sitting at the policy table cannot solve all of your problems, but it is an indispensable step on the journey to equality.**

NCIL

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Michael Oxford
Topeka, Kansas

Region VIII
Nancy Conklin
Grand Junction, Colorado

Region IX
Kent Mickelson
Belmont, California

Region X
Kelly Buckland
Boise, Idaho

Executive Director
Anne-Marie Hughey

FACSIMILE

TO: Chris Jennings

FAX: 202-456-5557

FROM: Bryon McDonald

DATE: July 16, 1998

NUMBER OF PAGES (Including Cover) 3

COMMENT:

NOT JUST RESPONDING TO CHANGE, BUT LEADING IT.

PRIORITY GRASSROOTS TARGETS - Contact Info

Senator William Roth (R-DE) Voice 202-224-2441
Doug Badger, Voice 202-224-2708 (Asst. Chief of Staff)

Senator Larry Craig (R-ID) Voice 202-224-2752

Senator Don Nickles (R-OK) Voice 202-224-5754

Senator Trent Lott (R-MS), Majority Leader, Voice 202-224-6253

Senator Frank Lautenberg (D-NJ) Voice 202-224-4744
Senate Budget Com. Paul Seltman, Voice 202-224-7436

Senator Christopher J. Dodd (D-CT) Voice 202-224-2823
Jim Fenton, staff, same phone

ADMINISTRATION
* Chris Jennings
White House Domestic Policy Council
Voice 202-456-5560
FAX 202-456-5557
Erskine
~~Irskin~~ Bowles
White House Chief of Staff
Voice 202-456-6798
FAX 202-456-2883
John Podesta
Deputy Chief of Staff
Voice 202-456-2459

OMB

* Donna Shalela,
Commissioner, HHS
202-690-7000
Deputy to Commissioner, Voice # 202-690-7431

GRASSROOTS QUESTIONS CHECKLIST:
(All questions don't fit all calls.)

1. Do you have the print materials you need?

2. Do you have email and what is it?_____

3. There are two jobs to do, can you work on either or both:
   Contact Senate offices yourself to ask for cosponsors.
   Outreach to your community and state to do likewise.

4. Send personal stories to your Senators.

5. State Governors. Call your state Governor's Commission, Committee or Advisory Panel on Employment and Disability. Tell them you want the governor to talk to your state US senators and write to Senators Jeffords and Kennedy in support of S.1858.

6. Call Chris Jennings at the White House Domestic Policy Counsel, Phone: 202-456-5560--FAX-202-456-5557. Speak to him personally. Message: S.1858 is both ticket ***and*** continuous healthcare after employment, support passage of this bill this year. Thanks for your work on this so far.

7.

8.

7/15/98

Disability FG

DRAFT: Health Options: Return To Work (Kennedy-Jeffords)

Administrative proposal

- **Aggressively promote Medicaid buy-in option**. This new policy allows states to let people with disabilities, regardless of whether they receive SSI or SSDI, buy into Medicaid, subject to an earned income limit of 250 percent of poverty and unearned and assets limits. Participants would receive the full Medicaid benefits package offered in the state. The President could ask or direct HHS to publish additional guidance, to work with the Governors and state Medicaid directors to encourage them to take this option, and take other actions that would encourage states to adopt this new option.

Legislative proposal (In process of developing with Kennedy and Jeffords staff)

- **Make Medicaid buy-in option more accessible to people who work**. Several provisions of BBA limit its ability to help people with disabilities returning to work.

  - Lift 250 percent cap on earned income and limits on unearned income and assets

  - Allow states to cover additional people with disabilities who do not meet the SSA standard (e.g., working people with AIDS)

- **Create incentives for states to take the Medicaid buy-in option**. Savings in SSI and SSDI resulting from people leaving these programs could be used to provide grants to states to encourage their participation in this Medicaid option. Depending on amount of funds available, three types of grants could be given:

  - **Planning grants**. To provide an immediate incentive for states to take this option, states that submit a short description of their plans could receive a grant (the same amount for all states) to develop state plan amendments. States must consult with the disability community in this planning process. [$50,000-100,000 per state in 1999 and 2000]

  - **Infrastructure and outreach grants**. States that submit a state plan amendment could receive a grant for infrastructure development and education about the new option. This grant could be based on the number of people with two or more limitations on ADLs. [Allocate a fixed amount of funds; one-time only grant]

  - **Performance grants**. States could receive an annual grant based on the number of people leaving SSI and SSDI for work and other outcomes measures This grant would serve as a way to share with states the savings to SSA resulting from people leaving SSI and SSDI for work. [Allocate a fixed amount of funds; ~~one-time only~~ grant]

- **Allow people leaving SSDI program to continue Medicare coverage**. Currently, a person who was on SSDI but who returns to work may continue free Medicare coverage (paying Part B premium only) for up to 39 months. At that point, they may buy into Medicare at full cost. This policy would extend Medicare coverage of the Part A premium indefinitely (rough CBO cost estimate of $300 million over 5 years). NOTE: OMB has not yet decided if they would oppose or support this policy.

Dudsing File

Dear Center Director,

The Health Care Financing Administration (HCFA) is inviting all Centers for Independent Living to apply for a cooperative agreement entitled the "Consumer-Directed Durable Medical Equipment (CD-DME) Demonstration for Medicare Beneficiaries with Physical Disabilities." Enclosed is the application package describing the elements that should be included in your proposal to HCFA. The application is due to HCFA by July 15, 1998. It is planned that four awards will be announced for this cooperative agreement in the Fall of 1998.

In addition to the HCFA application requirements, all candidates are to submit a copy of the fiscal year 1997 704 Annual Performance Report, Part II, as sent to the U.S. Department of Education, Rehabilitation Services Administration, Independent Living Branch.

For further information and questions concerning the enclosed application package, please contact Mr. Richard Getrost, Project Officer (HCFA) at telephone number 410-786-3211. If you need assistance regarding the submission of a 704 Annual Performance Report, please contact Ms. Merri Pearson (Department of Education) at telephone number 202-205-8484, or by TDD at 202-205-8243.

We welcome your application to this demonstration project.

Sincerely,

Nancy-Ann Min DeParle
Administrator

Enclosure

FACT SHEET

TOPIC

Consumer-Directed Durable Medical Equipment (CD-DME) Demonstration Project

BACKGROUND

HCFA is releasing a Program Announcement for a Consumer Directed Durable Medical Equipment (CD-DME) demonstration for Medicare beneficiaries with physical disabilities to all Centers for Independent Living (CILs). The demonstration will test a model of CD-DME that covers a range of activities such as assessment and purchasing related to wheelchairs and accessory items. The CILs will implement the CD-DME model. The U.S. Department of Education, Independent Living Branch (OSERS) is a programmatic partner in the demonstration.

The CILs will have the responsibility of providing assistive technology information and facilitating consumers' access to expert assessment and care management. Coordination of the CIL sponsors with State agencies such as Medicaid and Vocational Rehabilitation Services will be encouraged. In partnership with consumers with physical disabilities, these CIL sponsors will more effectively acquire Medicare-financed products and services through a prior authorization claims process administered by one DME Regional Carrier (DMERC) for the demonstration.

Four CIL sites are expected to be awarded pre-implementation developmental funds of approximately $150,000 in Fall 1998. During the 12 month pre-implementation period (year 1), the sponsors will be required to prepare a workplan and operational protocol, Medicare waivers will be requested, and contractual relationships will be worked out with the designated DMERC. Medicare waivers will be granted for a three year period to provide demonstration services to the beneficiaries who elect to participate in the demonstration project. The demonstration does not involve any changes in Medicare coverage of DME. Medical coverage policies regarding medical necessity will be retained. The demonstration design will maintain budget neutrality.

Consumer direction is key to the proposed demonstration project: (1) sponsoring organizations have governance requirements to assure that people with disabilities not only guide the agencies as board members, but are active as employees and consumer advocates; (2) the implementation of a system of prior authorization of payment for medically necessary equipment is intended to accommodate benefit flexibility in the acquired equipment; and (3) prior authorization and beneficiary credit accounts are intended to enable beneficiaries, in partnership with the CIL sponsors, to negotiate with suppliers over equipment prices, features, warranties, maintenance and 24-hour availability of repair services for wheelchairs and related accessories. Savings accrued by more efficient purchasing will be used to acquire additional equipment and services.

FOR FURTHER INFORMATION

Mr. Richard Getrost, Project Officer (telephone: 410-786-3211) may be contacted with any questions concerning the demonstration. Applications for the CD-DME demonstration program announcement are due COB, Wednesday, July 15, 1998.

05/10/96 FRI 08:12 FAX 202 205 8106 DEPT OF HEALTH AND HUMAN SERVICES

WASHINGTON, D.C. 20201

Executive Secretariat

FACSIMILE

PLEASE NOTIFY OR HAND-CARRY THIS TRANSMISSION TO THE FOLLOWING PERSON AS SOON AS POSSIBLE:

Name: CHRIS JENNINGS

Address:

Message: PER DISCUSSION —

NOTE: LETTER IS NOT DATED — I'll PUSH HCFA TO GET THE OTHERS DONE TODAY.

Telephone: Office: FAX: 456-5557

Number Of Pages Being Transmitted (Including This One)

FROM: SEAN DONOHUE

FAX NUMBER:

OFFICE NUMBER: 205-8806

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

The Honorable George Pataki
Office of the Governor
The Capitol
Albany, NY 12224

Dear Governor Pataki:

I am writing about a critical opportunity for your State to provide real assistance to many people living with disabilities who want to work. Millions of Americans with disabilities are part of our daily workforce. Many others would like work but are concerned if they do they will lose the Medicaid coverage they need for health and long-term care services.

Existing law provides for continued Medicaid coverage for working individuals with disabilities with incomes above the specified income standards. However, these provisions include limits on the amount of income an individual can earn and still remain eligible.

Fortunately, section 4733 of the Balanced Budget Act of 1997 allows States to provide Medicaid coverage to working individuals with disabilities who, because of their earnings, cannot qualify for Medicaid under other statutory provisions. Section 4733 allows States to provide Medicaid coverage to these individuals by creating a new optional categorically needy eligibility group. If a State chooses to cover this group, working individuals with disabilities can become eligible for Medicaid if:

- they are in a family whose net income is less than 250 percent of the federal poverty level for a family of the size involved; and

- except for their earned income, they would be considered to be receiving SSI benefits.

Section 4733 also allows States to require eligible individuals to pay premiums or other cost-sharing charges set on a sliding scale based on income. The amount of the premium or cost-sharing to be paid, if any, is within each State's discretion. In order to be eligible for this benefit, an individual must meet the Social Security SSI disability requirements.

I urge you to give serious consideration to covering this group of Americans under your State's Medicaid program. This coverage can help provide the safety net that individuals with disabilities need to help them to work and lead independent lives.

The Department of Health and Human Services and the Health Care Financing Administration (HCFA) are prepared to assist you in covering these individuals. I have asked HCFA Central and Regional Office staff to be as helpful as possible in both responding to your inquiries and providing technical assistance. If you or your staff have any questions or need assistance, please contact the HCFA Regional Administrator responsible for your State.

Sincerely,

Donna E. Shalala

DRAFT
Possibly Released

Dear Governor:

I am writing about a critical opportunity for your State to provide real help to many disabled individuals who want to work, but who are afraid that if they do, they will no longer be eligible for the Medicaid benefits they need to live in the community -- a choice no one should face.

On April 22, 1998, the Presidential Task Force on Employment of Adults with Disabilities met for the first time in Washington, DC. This task force, created by President Clinton, is charged with the responsibility of finding ways to increase the rate of employment of disabled adults to a level as close as possible to the general population. This goal, if reached, will benefit everyone, not just the disabled individuals who want to work. Instead of having to depend solely on government benefits, disabled individuals who work will become productive citizens, contributing to our nation's well-being.

However, disabled individuals who want to work face many obstacles. One of the biggest is the threat of losing benefits they need to make the transition to productive jobs. If they obtain jobs and earn too much, their incomes can make them ineligible for Medicaid just when they need it most.

Section 1619 of the Social Security Act provides for continued Medicaid coverage for working disabled individuals with incomes above the specified income standards. However, these provisions have relatively low limits on the amount of income an individual can earn and still remain eligible.

Fortunately, a provision (section 4733) of the Balanced Budget Act of 1997 (BBA) enables States to provide Medicaid to disabled working individuals who, because of relatively high earnings, cannot qualify for Medicaid under one of the other statutory provisions. Section 4733 of the BBA allows States to provide Medicaid to these individuals by creating a new optional categorically needy eligibility group. If a State chooses to cover this group, individuals can become eligible for Medicaid if:

- they are in a family whose income is less than 250 percent of the federal poverty level for a family of the size involved; and

- except for their earned income, they would be considered to be receiving SSI benefits.

Section 4733 also provides that States can require eligible individuals to pay premiums or other cost-sharing charges, set on a sliding scale based on income, as the State may determine. The amount of the premium or other cost-sharing to be paid, if any, is entirely within each State's discretion.

In order to be eligible for this new benefit, an individual must meet the Social Security SSI disability requirements. However, now for the first time young people and others with disabilities who want to go to work and need Medicaid can work and receive Medicaid without going on to the Social Security rolls. We believe this is an approach that makes tremendous sense for workers with disabilities, your State and our Nation.

I urge you to seriously consider covering this group under your State's Medicaid program. This coverage can help provide the safety net that disabled individuals need to allow them to work and become productive citizens.

Another section (section 4743) of the BBA removes the requirement under home and community-based services waivers that Medicaid funds for supported employment services be used only for individuals with developmental disabilities who had a prior history of institutionalization. Under this section, you can now choose to use Medicaid to provide supported employment services to such individuals regardless of whether they ever were institutionalized or not. I urge you to seriously consider making this simple but important change to your State plan as well.

The Department and the Health Care Financing Administration (HCFA) are prepared to assist you in covering this new eligibility group. I know that a number of States are also interested in the possibility of seeking Medicaid waivers to address the health care and long-term care coverage needs of workers with disabilities and I have asked HCFA Central and Regional Office staff to be as helpful as possible in both responding to your inquiries and providing technical assistance. If you have any questions, or need assistance, please contact the HCFA Regional Administrator responsible for your State.

Sincerely,

Donna Shalala
Secretary

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FAX TRANSMISSION

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING & EVALUATION
OFFICE OF DISABILITY, AGING & LONG-TERM CARE POLICY
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To: Chris Jennings, Diana Fortuna, Jean Lambert — **Date:** 5-5-98

Fax #: 456-3557, 456-7431, ~~456-7431~~ — **Pages:** 21 **, including this cover**

From: Bob Williams

Michele Adler	☐	**John Drabek**	☐	**Maria Martino**	☐
Kathleen Bond	☐	**Andreas Frank**	☐	**Bill Marton**	☐
Floyd Brown	☐	**Mary Harahan**	☐	**Tammy Bailey**	☐
Robert Clark	☐	**Jennie Harvell**	☐	**Brenda Veazey**	☐
John Cutler	☐	**Ruth Katz**	☐	_____ **(Other)**	☐
Pamela Doty	☐	**Gavin Kennedy**	☐		

COMMENTS: Please deliver to individuals listed above.

Thank you

for Chris Jennings, Jeanne Lambrew & Diana Fortuna from Bob Williams. The CASA testimony before it was cut due to time constraints. Background info for meeting w/ NCIL + CCD on Fri. May 15.

INTRODUCTION

We are pleased to be here today to talk about the President's commitment to expanding and promoting consumer-directed home and community-based services so people with disabilities can live their lives to the fullest potential. It is consistent with our views about the basic rights of all Americans to control and direct their own lives. It is consistent with our strong and rigorous support for equal rights for people with disabilities, as articulated in the Americans with Disabilities Act.

Like everyone here today, the Administration feels strongly about empowering people with disabilities -- including children, working age adults, and older people who need help with basic daily activities -- and their families, by increasing their independence and quality of life. One of the best ways to do this is to provide opportunities for individuals to choose to decrease their reliance on nursing homes, by increasing their options to choose self-directed personal assistance in home and community-based settings.

We will use our time today to discuss our multi-faceted approach to achieving these goals, recognizing that while we won't achieve our goals all at once, we can be aggressive about making real progress toward them. We would like to explain the Administration's commitment to this issue and the activities currently taking place with an HHS work group on home and community-based services. And we would like to discuss our broader strategy, which includes legislative, regulatory, research/demonstration, and other activities.

THE ADMINISTRATION'S COMMITMENT

In May of 1995, after a series of meetings with individuals from the disability community, Secretary Shalala issued a set of principles supporting home and community-based care. She reaffirmed her support for emphasizing home and community-based care services and offering consumers the maximum amount of choice, control and flexibility in how these services are organized and delivered. Since that time, HCFA has increased its technical assistance to States to assist them in developing home and community-based waiver programs and other options to foster care in the community. We continue to be guided by these principles.

This past September, the President and Vice President met with a group of disability community representatives and Federal officials, including Bruce Vladeck, then Administrator of HCFA and Bob Williams, Deputy Assistant Secretary for Planning and Evaluation, to discuss how to move forward on the community's highest priorities. The President has a longstanding interest in addressing the challenges facing people with disabilities who need long term care services and this Administration has a continuing commitment to increase the availability of home and community based personal assistance services. At that meeting, the President expressed appreciation that the Community Attendant Services Act (CASA) bill had been introduced by the Speaker, noting that it will help focus attention on the expansion of home and community based care. He was particularly pleased that it would enable us to have a discussion about how to move more toward a system where "the money can follow the person," no matter in what setting he or she chooses to receive the

services needed. Finally, he noted that a lot of the activity and decision-making regarding home and community-based care and personal assistance services (PAS) is happening in the States. He stressed the importance of enlisting the help of those States that are moving in the right direction, to provide leadership in educating and helping others who are not so far along.

HHS WORK GROUP

As a result of the meeting with the President, and in an effort to pull together all our activities in this area, Bob Williams, HHS's Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, and Sally Richardson were asked to co-chair a work group on home and community based services. The goals of that work group, which began meeting in September, are to review all available information and make recommendations about how to reduce the institutional bias in Medicaid long-term care services and spending and promote home and community-based care. Specifically, we are working to:

- Identify and address the "institutional bias" in the Medicaid program -- so fewer people are forced to move into nursing homes because it is the only way they can get long term care services;

- Provide more program opportunities for consumers and their families to choose the setting in which long term care services are received, with increased flexibility for the "money to follow the person," as opposed to the payment determining the setting in which a person receives services; and,

- Promote consumer direction of home and community based/personal assistance services.

Our work group members include HHS and other Administration officials interested in the issue, as well as an expanded group of "constituency partners" -- representatives of consumer groups, providers, and State agencies -- with whom we consult to ensure that the work group's activities and products take a variety of perspectives into account. The work group is moving ahead on a number of fronts.

Overcoming Institutional Bias

We are exploring a range of demonstration strategies, including opportunities we can offer States to modify their Medicaid programs and try some new ways of helping people who want to and are able to live in the community. We are happy to announce that we will soon be asking States to submit proposals to begin to develop a research design to identify individuals who could successfully move out of nursing homes into the community and to develop the services that would be needed to support these individuals in the community. This solicitation is in response to the commitment made by President Clinton to this issue and the Congressional directive in the FY 1998 Labor/HHS Appropriations Bill. We believe that we will be able to fund research in 3 to 5 States.

Another component of this work involves using HCFA data to improve our understanding of the numbers and characteristics of nursing home residents who may be good candidates for moving back to the community and what they would need in the way of supports. We will then be better able to help the States design strategies that succeed when these individuals attempt to move into the community.

We are also developing strategies to address the President's charge that States should learn from each other how to support and promote home and community based services under 1915(c) Medicaid waivers. Some States are much further along than others in developing innovative and cost-effective service delivery models for home and community-based services. Staff have been talking to a wide range of experts in the aging, disability, and long-term care fields in order to hear what they have learned. We have gotten positive feedback from a growing number of States about the value of developing a "State to State" technical assistance strategy.

We learned from our constituency partners that some States are not fully aware of the flexibility available to them under current regulations. Therefore, we want to clarify some of the things that States can do right now to reduce the institutional bias. We are planning to produce a primer on Medicaid that explains to State officials and consumers what is already available under Medicaid's personal care option, home and community-based waivers, as well as other Medicaid services. This primer will be clearly Stated, so readers can understand what is allowable within the existing framework of Medicaid. The primer will also include some examples of States that have used the flexibility of Medicaid to do some excellent work in reducing nursing home use and increasing community supports.

Finally, last year's CASA bill required a study of the "institutional bias" in the Medicaid program. HHS commissioned an independent contractor -- the University of California at San Francisco -- to conduct such a study. A few weeks ago we received the contractor's draft report. Let me note that this report has already been reviewed by a Blue Ribbon Panel on Personal Assistance Services that includes many consumers with disabilities and other Medicaid and personal assistance services experts.

The report reviews the Medicaid statute and regulations, as well as policy guidance from HCFA, and offers a series of policy options to address the "institutional bias" in Medicaid. The majority of the recommendations would involve statutory changes and many of these changes would involve significant new costs. We are now developing a list of potential regulatory and policy changes on which we can take some more immediate action, while we continue to review long-term legislative options.

ADVISORY COMMISSION'S CONSUMER BILL OF RIGHTS

We understand that a high priority for individuals with disabilities is to ensure that consumer protections are in place that assure access to specialists, continuity of care, and internal and external appeal rights when health plans make decisions that are disputed by its enrollees.

As you know, the President endorsed the Consumer Bill of Rights and Responsibilities, recommended by his Advisory Commission on Consumer Protection and Quality in the Health Care Industry, and challenged Congress to make these important rights apply to consumers of all health plans. The Bill of Rights included important protections such as access to specialists for individuals with chronic care needs, for example: (1) traditional care for consumers who are undergoing a course of treatment for a chronic or disabling condition (or who are in the second or third trimester of pregnancy) at the time they involuntarily change health plans or at a time when a provider is terminated by a plan, and (2) a fair and efficient internal and external appeals process for resolving differences with their health plans and health care providers.

On February 20th, the President directed HHS, as well as other Executive Branch agencies, to bring their programs into compliance with the Consumer Bill of Rights. This Department reviewed the Medicare and Medicaid programs for compliance with the Consumer Bill of Rights. Based on our review, the President praised the Department for how far along these two programs were in complying with the Consumer Bill of Rights and he directed us to bring the two programs into virtual compliance as quickly as possible. The President is extremely committed to making the Consumer Bill of Rights real for all Americans.

EXPANDED SETTINGS & ELIGIBILITY FOR RECEIVING SERVICES (LEGISLATION)

On the legislative front, we were pleased that Congress included in the BBA our proposal for a new State option to allow certain workers with disabilities the ability to purchase Medicaid. Losing health coverage can devaState anyone. Losing health care and personal assistance services is even more devastating for some people with disabilities -- to the point where they are afraid to even try to work, because if they lose SSI or SSDI eligibility, and thus health care, they lose their life line. The new BBA provision should enable many individuals to make a real transition to work. Two days ago, we mailed to State Medicaid Directors a letter that revised the definition of income for the purpose of calculating the eligibility standard under this provision. Under our revised definition, States will determine eligibility based on income net of income disregards.

Also included in the BBA was our proposal to allow States to include prevocational, supported employment, and educational services for all home and community-based services waiver recipients with developmental disabilities. Before this provision was enacted, only those who were formerly institutionalized could receive these services through a home and community-based services waiver.

Finally, the BBA establishes a new type of service provider called Program of All-Inclusive Care For the Elderly (PACE). States may elect to provide PACE program services to individuals who are

Medicare and Medicaid eligible and are enrolled in a PACE program agreement. PACE provides for a coordinated set of services to frail elderly individuals living in the community.

EXPANDING SETTINGS & ELIGIBILITY FOR RECEIVING SERVICES (REGULATION & POLICY)

On the regulatory and policy fronts, this Administration has been very supportive of expansions in home and community based services under the Medicaid 1915(c) waivers. All States are now operating at least one and sometimes several home and community based waivers. Many provide additional supports with other Medicaid services as well. Thirteen States provide attendant care under their home and community-based waiver programs, while thirty-nine States provide personal care under their home and community-based waiver programs. The waiver program has flourished and grown under President Clinton's leadership, and currently there are 226 approved home and community-based waiver programs. We expect the program to continue to expand at an even greater pace as we work with States to find new ways to promote the use of existing services in States that have not provided them yet. In July of 1997, the State Medicaid Directors a letter that promoted the use of Medicaid home and community-based waivers.

We also recently issued revised regulations to increase the responsiveness of the Medicaid personal care option to better meet the needs of people with disabilities. There are currently 31 States providing personal services under their State plans. Individuals are now permitted to receive services both in the home, and outside the home. The new regulation eliminates the requirement that a registered nurse must supervise personal care services, thus reducing cost and making the service more consumer responsive and less "medicalized."

Consumer-Directed Purchasing

Our home and community based care and PAS research agenda is a key part of efforts to help ourselves, and help States and consumers, to find out what works, for whom, how well, and at what cost.

We are promoting our home and community based services agenda by working with States to develop and implement Medicaid demonstrations under the 1115 authority of the Social Security Act. Some focus on the integration of acute and long term care, such as the projects underway in Minnesota and the District of Columbia. Others, such as the newly-approved Colorado home health demonstration address different aspects. Colorado's demonstration will permit home health services to be provided in settings other than the home, such as schools, work sites, or day treatment centers. Wisconsin and Rhode Island have applied for 1115 waivers to serve beneficiaries under age 65 with physical disabilities and adults with developmental disabilities respectively. Four States working with the Robert Wood Johnson Foundation have applied for 1115 waivers to offer consumers cash allowances and counseling to purchase their own attendant services. We are currently reviewing

these waivers and expect to complete our review shortly. We are very interested in finding new ways of doing business in Medicaid and encourage States to bring us their ideas and proposals.

CONCLUSION

We believe it is critically important to continue to develop models both at the State and Federal level that support and encourage the move from reliance on institutional care to a broader array of consumer-directed home and community-based services.

We embrace these goals and will continue to work toward them. The challenge, of course, is to balance our goal of providing more flexibility and choice for people with disabilities, with the need to ensure that any legislation is affordable. Preliminary cost estimates raise the very real questions about whether the balance has yet been achieved. However, we remain committed to working together with you and other interested parties to craft an affordable, consumer-responsive system, that takes advantage of and promotes flexibility in our current programs, to help people obtain and keep the help they need to live as independently as possible.

In conclusion, we would like for all of us to remember that people with disabilities are a very diverse group of individuals. They are children, working-age adults, and the elderly. They have developmental disabilities, emotional or cognitive disabilities, and physical disabilities. This is not a group of people for which a "one solution fits all" answer is appropriate. These individuals need more opportunities, more choices on where and how they are to receive services. Nursing homes, intermediate care facilities for the mentally retarded should be available, but home and community based services must also be available. We cannot afford to have any bias in service delivery.

DRAFT 4/21 -- For 4/22 Task Force Meeting on Returning Individuals to Work

DRAFT Outline for the Administrator's Talking Points

INTRODUCTION

- As Secretary Shalala said, access to health care and long term care can be crucial to job access for persons with disabilities. At HCFA we are mindful of the critical role that our programs, Medicare and Medicaid, can play in providing this essential link for persons with disabilities.

- HCFA has been pursuing a number of activities aimed generally at increasing consumer choice, independence and quality of life for all persons with disability. I will focus my discussion today on those that we see as being of most benefit to disabled individuals who want to work.

- Our work has encompassed legislative, regulatory, research/demonstration, and other activities.

LEGISLATIVE - BBA

- On the legislative front, HCFA has been working with the States to implement the new provision in the Balanced Budget Act that gives States new authority to allow working individuals with disabilities with incomes up to 250% of the federal poverty level to buy into Medicaid.

- We've interpreted the income threshold based on net family income. This means that an individual with an income of $40,000 can qualify to buy into the full array of Medicaid services.

- We believe the new BBA working disabled provision will provide an even greater opportunity for workers with disabilities to maintain health coverage by expanding and simplifying States' abilities to allow individuals with disabilities to return to work and maintain their Medicaid coverage.

- As the Secretary has promiseded, HCFA and the Department of Health and Human Services will do everything they can to encourage States to adopt this optional provision because it is so important to achieving our goal of helping people who want work and can work, to work, by providing that critical link to affordable health care.

- We will immediately engage the States about this matter by meeting with State Medicaid Directors and by writing to the Governors. We will facilitate the sharing of best practices

in this area among States.

REGULATORY -

- We know that the availability of Personal Care Services is also a critical element in enabling a person to work. Personal Care Services are an optional service under Medicaid. At last count, 31 States do offer this optional service.

- This past September the Department published a regulation on personal care services under Medicaid to provide more flexibility to States to encourage the expansion of this option.

- This final rule gives States the option to expand the availability of personal care services by allowing services to be provided outside the home. In addition, the regulation removed the requirement that registered nurses supervise the provision of personal care services.

- Other States provide personal care services through Home and Community Based Services Waivers -- which I'll discuss in a minute.

- As a result, almost all States provide personal care services under their Medicaid programs and these services can now go outside the home -- including into employment settings.

RESEARCH/DEMONSTRATIONS

- One of the crucial tasks currently before HCFA and the Department is to determine why the existing tools we have to encourage individuals to go back to work are not being used.

- We need much better information on what motivates individuals to return to work, as well as what services these individuals need in order to stay working.

- Our research and demonstration agenda in this area will provide us with more data and information to help us better understand the health care needs of and obstacles faced by working individuals with disabilities.

- Specifically, let me mention 4 demonstrations whose results and evaluations will help us plan future activities:

  1. **cash & counseling**
     - this demonstration will test the concept of providing cash to individuals and allowing them to choose and purchase the personal assistance services they need.
     - information and counseling will be provided to assist consumers to make

informed choices

+ FL, NY, NJ, AK are the States that will be testing this concept

2. **"date certain"**

+ HCFA is sponsoring a grants program to assist States to develop mechanisms to work with individuals and their families prior to admission to an institution to consider community-based alternatives and/or mechanisms to transition individuals currently in institutions to the community if that is their choice.
+ the objective of this program is to identify and remedy barriers to community-based care.
+ community based alternatives can include services which will assist individuals to return to work (e.g., prevocational and supported employment services)
+ we expect to issue the grant solicitation before summer and to award grants to 3-5 States in September

3. **Consumer-Directed DME Purchasing -- Medicare**

+ In Medicare, we will be releasing a Program Annoncement for a demonstration of consumer-directed choice and purchase of durable medical equipment, such as wheelchairs.
+ Having the right equipment can facilitate a person's ability to perform activities of daily living, including work.
+ Centers for Independent Living (CIL) will be partners in the demonstration.
+ We expect to award developmental funds to four CILs this fall.

4. **Dual Eligibles Demonstrations**

+ This past month, HCFA awarded 4 grants to 3 States to help improve care for low income Medicare beneficiaries who are also eligible for Medicaid.
+ Projects are being funded in Florida, Wisconsin and Maryland to address the needs of these "dually eligible" beneficiaries.
+ These grants will help us learn how to better coordinate care between Medicare and Medicaid, help disabled beneficiaries move from nursing homes into the community, and target needs of people likely to become dually eligible as they use up their own assets on medical care.

- Also, as the Secretary mentioned, we are providing technical assistance to States, like Wisconsin, that are interested in exploring options and developing concepts around the goal of employing persons with disabilities. We are seeing a growing interest in this area.

OTHER ACTIVITIES

Home and Community-Based Waivers

- The Medicaid program has evolved to better meet the needs of the disabled population, particularly with respect to the provision of home and community based services.

- States are taking advantage of the home and community based waivers under Medicaid -- 1915(c) waivers -- to explore innovative approaches to delivering long term care in community or home settings.

- Some time ago, we made it easier for States to obtain these waivers by eliminating the long-standing "cold bed" rule. This had been a test of whether the state maintained sufficient bed capacity in its institutions to serve those who would be on the waiver in case the waiver failed.

- In 1995, Secretary Shalala issued a set of principles supporting home and community-based care. She reaffirmed her support for emphasizing home and community-based care services and offering consumers the maximum amount of choice, control and flexibility in how these services are organized and delivered.

- Since that time HCFA has actively promoted these waivers, increased its technical assistance to States and developed streamlined waiver applications to facilitate States' efforts to provide more home and community-based care in lieu of institutionalization.

- We have seen a substantial growth in the number of waivers requested and approved. We now have 226 approved and many States have multiple waivers. Thirteen states provide attendant care in their waiver; 39 states provide personal care services in their waiver; and 21 states provide pprevocational and supported employment services to enable persons to enter the workforce.

- Keeping people out of institutions is certainly a step along the route to better serving those individuals who want to be employed. These waivers are an important tool in our arsenal.

Home and Community Based Services Workgroup

- Before closing, I'd like to mention one other activity that is underway and will help inform the future debate about what activities we need to undertake to move us further down this road. I'm referring to the Home and Community-Based Services Workgroup.

- This past Fall, the President met with Representatives from ADAPT to discuss increasing access to home and community based services, including personal care services under Medicaid.

- Secretary Shalala established a workgroup in response to the President's meeting with

ADAPT to address specific issues regarding home and community based services.

- This workgroup is chaired by Bob Williams from ASPE and Sally Richardson, Director of HCFA's Center for Medicaid and State Operations. I'd like to ask Sally to stand so that all of you can see her. I must tell you that it is she, not I, that is owed the credit for much of the activity that has taken place, and is taking place, in HCFA with regard to the subject we're discussing today. Thank you Sally.

- The purpose of the Department workgroup is to consider all available information and make recommendations about how to reduce the institutional bias and promote home and community-based services under the Medicaid program.

- In addition to HHS offices and agencies, other Federal agencies and our constituency partners, including advocacy organizations, are involved in providing input on various issues addressed by the workgroup.

- The Department contracted with the University of California at San Francisco to study "institutional bias" in the Medicaid program. A final report is due by May 1 following review by an Advisory Group comprised of persons with disabilities, as well as, other disability experts. As we review the recommendations of the contractor, I'm sure we will be able to incorporate many of them into our future planning efforts.

- As I mentioned, we will soon release a solicitation seeking State proposals to test the "date certain" concept of moving persons from institutions to the community. The work on that proposal has emanated from this workgroup.

- We also are currently planning to contract for development of a "primer" on Medicaid for individuals with disabilities, detailing what States can do under current law and provide examples to help States better use the options they currently have available to them.

- In summary, I would say that we have been and will continue trying to facilitate States' leadership in expanding home and community-based supports and consumer-directed personal assistance services.

- In closing, I think you can see that we have a multi-faceted approach to achieving our goals. While we recognize that we won't achieve our goals all at once, we can be aggressive about making real progress toward them.

Draft Talking Points for Peggy Hamburg's April 22 Presentation to the Presidential Task Force on Employment of Adults with Disabilities

- I am Margaret Hamburg, Assistant Secretary for Planning and Evaluation in HHS.

  - I am honored to appear here today, as you undertake the important challenge of increasing work opportunities for people with disabilities.

  - My office provides analysis and advice to Secretary Shalala on the policy challenges facing the Department of Health and Human Services. Bob Williams, my Deputy Assistant Secretary for Disability, Aging, and Long-Term Care has helped me keep our disability research and policy work moving steadily forward, and focused on the important issues of the day.

  - We know this Task Force will address health and long-term care supports for people with disabilities who want to work. Without access to this coverage, many people with disabilities would be unable to live in the community at all, much less participate in the work force. We hope our presentations on this panel can help inform this effort.

  - In fact, as Secretary Shalala told us earlier, the fear of losing health coverage is a great concern to many people with disabilities who want to work. As most of you here know all too well, giving up SSI and SSDI benefits to go to work can also mean losing health coverage.

- The work of this task force is important to HHS.

  - We know that people with disabilities want to work -- they tell us so in survey after survey;

- Yet, over 70% of people with disabilities are not even in the work force at all, and this is simply unacceptable;

- I know that few people with disabilities use the work incentives now available, and even fewer are actually able to leave the rolls and go to work each year -- my colleagues at SSA tell me that fewer than 8500 of the over 4.4 million people on SSDI and only about 300 of the 3.3 million on SSI leave the rolls each year; and

- Also, I understand that there is concern that too many young people with severe disabilities leave school and go directly onto the SSI rolls because they think there is no way they will ever be able to do real work.

♦ I will use the analytical and policy strength of my office to shed light on these problems and help craft solutions.

♦ This morning I will briefly summarize a few key issues about people with disabilities that I think are particularly relevant to your deliberations.

♦ Let's start by taking a look at what current research tells us about working age adults with disabilities -- by functional status, employment rates, and some health issues like insurance coverage and health care utilization.

Disability Characteristics

♦ **[Show slide #1]** First, I want to show you the prevalence of disability in the population. As you can see, one in five working age adults, 30 million Americans between the ages of 18 and 65, have a disability.

- A relatively small proportion of the working age population, 4 percent, or 6 million, are disabled enough to meet the disability

TALKING POINTS -- PERSONAL ASSISTANCE SERVICES

- **The Clinton Administration has a strong commitment to and has made enormous progress in reducing unnecessary nursing home use and promoting and expanding home and community based services.** For example:

  - Streamlined HCBS waiver application/approval process; in 1997 waiver spending grew by 44%, while nursing home spending only grew by 4.8%;

  - Secretary Shalala issued strong principles on long-term care in 1995, reinforcing our commitment to home and community based care; and

  - Issued revised regulations for Medicaid personal care that will allow much more flexibility and consumer direction.

- **The President and Vice President met with disability groups in September 1997 to discuss PAS and other issues. As a result, HHS established a Home and Community Based Services Work Group, co-chaired by Bob Williams and Sally Richardson.** The general goals of the group are to study and make recommendations about how to reduce the institutional bias in Medicaid long-term care spending and service delivery to promote home and community-based care, with a particular emphasis on consumer directed services.

- **The HCBS Work Group has been very active and accomplished a great deal, and is launching a number of new initiatives and reforms that we expect to bear fruit in the coming months.** Among the accomplishments:

  - ***Contracted with University of California at San Francisco to conduct an independent study of the institutional bias in Medicaid.*** The draft study was reviewed by the Blue Ribbon Panel on PAS, and will be available in final form in the next few weeks. The report contains 75 policy recommendations on Medicaid personal care services, home and community-based waiver services, and home health services. Options can be grouped into four categories: (1) those requiring statutory change, (2) those requiring regulatory change, (3) those which can be accomplished through issuance of guidelines, and (4) those which necessitate a study or convening of a panel of experts on an issue. Roughly 13 recommendations require statutory change, 32 require regulatory change, 13 can be accomplished through manual guidelines, and 42 recommendations require a study or convening of a panel of experts. It is important to note that about one quarter of the recommendations presented by the UCSF team as needed regulatory or statutory, or policy changes are, in fact, things that are already allowable under the Medicaid program. Further, many states are already using Medicaid to offer services that the UCSF team suggests HHS ought to allow them to offer.

A major recommendation was that personal care services should be a mandatory Medicaid service, like nursing home care. While 34 states already provide personal care, and most of the others do so under HCBS waivers, the Administration and Congress are not likely to add new, unfunded Medicaid mandates to Title XIX. However, the Work Group is stepping up technical assistance for states and consumers to ensure that states make maximum use of current flexibility to provide personal care under Medicaid.

The report also includes a series of recommendations to clarify that personal care and home and community based waiver services: can be delivered by live-in caregivers; should not be restricted to in-home supports; should be used to provide respite for caregivers; should be more consumer directed; and several similar options.

Because many of these recommendations are, in fact, policies that are already in place, and many states already use personal care and waivers to provide these services, the ***State Medicaid Manual transmittal*** on the new personal care regulations will be expanded to clarify that these activities are, indeed, permissible (and have been for a long time). ***The SMM transmittal will be completed and sent out in the Fall.***

- ***Also, the Work Group is continuing to review the UCSF study,*** to determine what additional actions can be taken. The focus will be on recommendations which increase program flexibility without increasing program costs and, especially, those which can be accomplished through the issuance of guidelines.

- ***Contracting for Primer on Medicaid home and community based services***. The UCSF report is a strong indicator that many people are unaware of the flexibility that already exists in Medicaid, and current practices in many states. The **Primer** will explain in clear language all that **is** allowable under the Medicaid long-term care program. It will discuss what flexibility States have under the personal care services option (for example, States can implement consumer-directed personal care services programs) and the HCB waiver program and provide examples of what other States have done. As the Primer is developed, it will be reviewed by consumers and state officials, to ensure that it meets its goals of being easily understood and useful to people in the field. The Work Group expects to disseminate the Primer to states, consumers, providers, and other interested parties by the end of the year. It will include specific suggestions for states, targeted at expanding home and community based services and reducing unnecessary nursing home use. Concrete examples of state innovations will be described.

- ***Continuing to move ahead on the Cash and Counseling demonstration***, to test the possibility of providing consumers with more control over their own PAS by giving them cash, vouchers, or similar vehicles, plus counseling, so they can hire, train, and manage their own service providers.

- ***Conducting a durable medical equipment demonstration*** in collaboration with independent living centers to allow more flexibility in purchasing and budgeting for assistive devices. The announcement seeking proposals for this demonstration was made public in the first week of May.

- ***Recommending legislative change to allow home and community based services to be a state plan option, instead of a waiver.*** The Administration recommended this last year, and will continue to do so.

- ***Drafted announcement for "date certain demonstration."*** HHS is finalizing a solicitation for a grants program to assist States to develop mechanisms to work with individuals and their families prior to admission to a nursing facility to consider community-based alternatives and/or to develop mechanisms to transition individuals currently in nursing facilities to the community if that is their choice. Grant awards will be made by September 30.

- ***Establishing a technical assistance focus, through a contract, to disseminate information and assist states and consumers in efforts to promote the use of home and community based services and consumer directed PAS.*** HHS will award a contract by August to provide assistance and information on model practices and ways to expand and promote home and community based services and minimize reliance on nursing homes. The technical assistance will be provided in the form of written materials, conferences and forums, electronic communications, and other means. HCFA technical assistance to states which are trying to expand HCBS and consumer directed care will continue.

    - One particular focus of the technical assistance efforts will be to ensure that ***information about the Helen L. case is disseminated widely.*** The goal will be to inform states and consumers about the implications of the Third Circuit Court decision that Title II of the ADA requires PAS to be provided in the most integrated setting, and identify activities to raise ADA issues about home and community based services throughout the country.

- ***Contracting for an analysis of the MDS, to increase knowledge about nursing home residents' characteristics,*** to enable states and the federal government to better target efforts to move people out of nursing homes.

- ***The Work Group has completed a study of programs that train people on the welfare rolls to become PAS providers.*** Work Group members reviewed training programs and developed a list of critical elements of good training programs to prepare welfare workers to be PAS providers. This study will be distributed widely in June. It is currently under review by the Work Group. In the Fall, the Work Group is planning to hold a small meeting of experts in PAS and welfare to discuss future activities.

- ***The Work Group has also been involved in a number of other activities:***
  - disseminating information from an extensive series of interviews with consumers;
  - disseminating to all HCFA regional waiver coordinators and state waiver staff a HCBS waiver manual developed by the Atlanta regional staff;
  - posting on the Internet and otherwise disseminating a series of reports on maximizing consumer direction in personal assistance services;
  - completing the "Mentoring Project," in which states that are farther along in home and community based care "mentor" states that are not as far ahead;
  - finalizing a study of the California In Home Services and Supports program and disseminating the results; and
  - stepping up an already active research agenda on HCBS.

TALKING POINTS -- RETURN TO WORK

- **In March, the President signed an Executive Order on Employment of People with Disabilities.** People with disabilities report that the fear of losing essential health and long-term care services covered under Medicare and Medicaid, is an important factor in preventing them from leaving the federal income support programs (Supplemental Security Income and Social Security Disability Income) and trying to work. HHS is conducting research on what types of incentives could have a significant impact on helping these individuals enter the work force.

  - ***The Secretary of HHS has written to each of the Governors to inform them of the new provision under the BBA,*** which allows states to offer Medicaid services to people with disabilities who are able to work and earn more than the currently allowed limits. This will enable people with disabilities to earn middle income salaries, but retain the health and long term care they need.

    - **WE NEED YOUR HELP** in publicizing the availability of this new Medicaid option, and encouraging states to include it in their Medicaid state plans.

  - ***The Administration supported and Congress enacted a provision that allows HCBS waivers to provide supported employment to all participants with mental retardation or mental illness,*** not just those recipients who were formerly institutionalized. A number of states have already picked up on this, and HHS will provide technical assistance to other states who want to do so.

  - ***HHS has a solid research agenda underway.*** A recent HHS study conducted with SSA reviewed the research on the link between health care coverage and the decision to work. While few empirical studies were identified, the available evidence suggests that health care access is one important factor in the decision to seek work. Another recently completed study confirmed that at least some Section 1619 participants deliberately restrain their earnings so they can keep Medicaid. HHS is also looking at the impact of Medicaid expansions in Tennessee and Oregon to determine whether improved health care access led to greater numbers of people with disabilities entering the work force. Finally, at Secretary Shalala's request, Bob Williams' office is initiating a new research study to examine why some people with disabilities are able to successfully enter the work force and/or use existing work incentives while others are not.

  - ***Independent living centers and other consumer service organizations need to fill an important void: they must familiarize themselves with the current work incentives for SSI and SSDI recipients, find out how they work and how to access them, and help consumers use the work incentives.*** On average, fewer than one percent of SSI and SSDI recipients use the work incentives that are currently available.

The Patients' Bill of Rights Takes Provides Important New Protections For People with Disabilities

I. Rights Most Important for People with Disabilities

Access to Specialists: This provision is extremely important for people with disabilities because it assures consumers with complex or serious medical conditions access to to the specialists they need.

Consumers with ongoing health needs often require regular access to physicians and other health care professionals who are trained to address their special needs. This is particularly true for those consumers who have some type of disabling or terminal condition. In such cases, the traditional "gatekeeper" approach used by some health plans can be an impediment to access to quality care. Consumers with complex or serious medical conditions who require frequent speciality care should have direct access to a qualified specialist of their choice within a plan's network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan.

Continuity of Care: providing access to continuity of care for consumers who are undergoing a course of treatment for a chronic or disabling condition.

Patients' who are undergoing an extensive course of treatment at the time they join a new health plan should be able to see their current providers for a period of 90 days. Sudden interruption of care can compromise the quality of care and patient outcomes, particularly for those with ongoing, speciality care. Consumers who are undergoing a course of treatment for a chronic or disabling condition at the time they involuntarily change health plans or at a time when a provider is terminated by a plan for other than cause should be able to continue seeing their current speciality providers up to 90 days.

Prohibiting disclosure of financial incentives. Requiring providers to disclose any incentives, financial or otherwise -- that might influence their decisions. It is particularly important for people with chronic, ongoing, and often more expensive care to ensure that they be aware of any financial incentives that may be influencing their health providers. (The Democratic legislation goes further than the Quality Commission as it forbids any financial incentives, rather than just requiring health plans from requiring it).

Prohibiting "gag clauses" which restrict health care providers' ability to communicate with and advise patients about medically necessary options;

Assurance that Patients are Respected and Not Discriminated Against, including discrimination in the delivery of health care services consistent with the benefits covered in their policy based on mental or physical disability, race, gender, ethnicity, and sexual orientation.

Medical Privacy which assures that individually identifiable medical information is not disseminated and that also provides consumers the right to review, copy and request amendments to their own medical records. This right is particularly important for consumers who feel they have medical conditions that are particularly sensitive.

Grievance and Appeals Processes for consumers to resolve their differences with their health plans and health care providers -- including an internal and external appeals process. This assures when patients' do not get the care they need, they have a fair, objective place for consumers to address their grievances.

II. Other Issues to Address

- **Bringing Federal Government into compliance.** This is particularly important for the millions of people with disabilities in the Medicare and Medicaid program.

- **Legislative Strategy -- Need for their action on the Hill**

6)

Draft Presentation

- Thank Secretary Shalala, Peggy, Nancy Ann for their important work in this area.

  Also like to thank Tony Coehlo and Marca Bristo for their work with the National Council on Disability and the many others in this audience whose dedication and persistence in looking at how to create cost effective work incentives.

- Presentation: Discuss two policy priorities of the President's:

  - Ensuring access to health care for people leaving SSI and SSDI for work.

  - Patient Bill of Rights, which will provide important protections for people with disabilities, and

Proposals to Provide Increased Access to Health Insurance for People with Disabilities

- As early speakers note, the current system does contain disincentives for returning to work — specifically the loss of Medicaid or Medicare coverage.

  - Health insurance is vitally important to all Americans, and has been a top priority for the President since the day he took office. But this is particularly true for people with disabilities. As Peggy showed, people with disabilities have higher health care costs that, without insurance, are devastating.

  - These higher costs also make private coverage inaccessible for many. While some of the barriers to private insurance — preexisting condition exclusions — were eliminated in HIPAA, premiums can still be prohibitively expensive.

- For these reasons, the President supported the Medicaid buy-in provision that got passed in the Balanced Budget Act, although Congress added the 250 percent of poverty income ceiling.

- Before discussing new legislative solutions, I would like to take this opportunity to discuss why the Medicaid buy-in goes to improving access to health insurance for people with disabilities.

- As Nancy Ann described earlier, the Medicaid buy-in offers;

  - The full Medicaid benefit package to

  - People with disabilities meeting:
    SSI disability, unearned income, and assets tests
    With net income below 250 percent of poverty

- Allowing people to buy the full Medicaid benefits package is important because employer-based insurance is not available to all employees — particularly for new workers or part-time workers. For those who do have access to private insurance, Medicaid can serve as a "wrap around" to cover those benefits that private insurance does not cover.

- The buy-in also covers a fairly large group of people with disabilities. It covers:

  - People leaving SSI for work with income below 250 percent of poverty

  - People leaving SSDI after the Trial Working Period, if they meeting the 250 percent of poverty and SSI nonearned income and assets tests

- It also covers people who have not received SSI or SSDI but who meet the eligibility criteria — thus making it possible for some not to enter into these programs at all.

- So, the buy-in goes a long way, but there may be some gaps, including:

  - Those people with disabilities whose income exceeds 250 percent of poverty or

  - Some SSDI beneficiaries who have more than SSI-allowed assets or whose cash benefit exceeds the SSI unearned income standard.

- The Jeffords-Kennedy "Work Incentives Improvement Act" is intended, in part, to address these gaps and other concerns about the current system. It:

  - Allows people to buy a limited Medicaid benefit package — drugs and personal assistance services — through a sliding scale premium. There is a higher Federal match for expenditures for these services, and it

  - Allows SSDI people to buy into Medicare with subsidized premiums.

  Since it does not have upper income limits, it makes virtually all people leaving SSI or SSDI eligible.

- Because we have not yet seen the analysis of state participation, how many individuals will participation, and Federal Medicare, Medicaid and Social Security costs, we do not yet have an official position on this bill.

- However, I'd like to suggest that we can, administratively, work with state to make the current Medicaid buy-in provide the needed access to the full range of benefits that people with disabilities need. For example:

  - States could use Section 1902(r)(2) to make the SSI tests for the buy-in less stringent, or

  - States could use the 1115 waiver authority to, in a budget neutral way, expand coverage beyond 250 percent of poverty.

- As Nancy Ann indicated, we are committed to working with you and working with states to make these options a reality.

- And, if they don't work, we are open to working on other administrative or legislative options to encourage work for people with disabilities, recognizing budgetary constraints.

Patient Bill of Rights

- What it is

- What it means to people with disabilities

DRAFT 4/21 -- For 4/22

Task Force Meeting on Returning Individuals to Work

DRAFT -- Administrator's Talking Points

INTRODUCTION

I'm pleased to be here today to talk about HCFA's ongoing efforts to improve access to health care for people with disabilities. As Secretary Shalala said, access to health and long term care can be crucial for people with disabilities who want to work. At HCFA we are mindful of the critical role that our programs, Medicare and Medicaid, can play in providing this essential link to the workforce for people with disabilities.

HCFA has been pursuing a number of activities aimed at increasing consumer choice, independence, and quality of life for all persons with disability. I will focus today on those activities that we see as being of most benefit to disabled individuals who want to work. We have made progress on three fronts: through legislation, regulations, and research and demonstrations.

LEGISLATION - BBA

On the legislative front, HCFA has been working with the States to implement the new provision in the Balanced Budget Act that permits States to allow working individuals with disabilities with incomes up to 250% of the federal poverty level to buy into Medicaid. We've interpreted this income threshold based on net family income. This means that an individual who earns $40,000 can qualify to buy into the full array of Medicaid services.

We believe this new BBA provision will provide an even greater opportunity for workers with disabilities to maintain health coverage by expanding and simplifying States' ability to allow individuals with disabilities to return to work and maintain their Medicaid coverage.

As the Secretary has promised, HCFA and the Department of Health and Human Services will do everything they can to encourage States to adopt this optional provision. We believe this provision is an important link to achieving our goal of helping people who want to work and can work, to work, by providing affordable health care.

We plan to immediately engage the States to build support for this new option. We will be meeting with State Medicaid Directors in the near future and plan to write to each of the Governors to explain the value of this new option. We are also planning to help States share the best practices in this area.

REGULATIONS -

We know that the availability of Personal Care Services is also a critical element in enabling people with disabilities to work. Personal Care Services are an optional service under Medicaid. At last count, 31 States do offer this optional service.

This past September the Department published a regulation on personal care services under Medicaid to provide more flexibility to States to encourage the expansion of this option. This final rule gives States the option to expand the availability of personal care services by allowing services to be provided outside the home. In addition, the regulation removed the

requirement that registered nurses supervise the provision of personal care services.

In addition to the personal care service option, States also provide personal care services through Home and Community Based Services Waivers -- which I'll discuss more in a few minutes.

Through this combination of approaches, almost all States provide personal care services under their Medicaid programs and these services can now go outside the home -- including into employment settings.

RESEARCH/DEMONSTRATIONS

As Peggy mentioned earlier, one of the crucial tasks that we face today is to determine why the existing tools we have to encourage individuals to go back to work are not being used.

Our research and demonstration agenda will help provide us with more data and information to help us understand the health care needs of and obstacles faced by working individuals with disabilities.

Specifically, I'd like to mention 4 demonstrations whose results and evaluations will help us plan future activities:

Cash & Counseling Demonstration

The first project is called "cash and counseling." This demonstration will test the concept of providing cash to individuals and allowing them to choose and purchase the personal assistance services they need.

Information and counseling will be provided to assist consumers to make informed choices. We have been working with Florida, New York, New Jersey, and Arkansas to develop this concept. We are working very hard to complete the development of this important demonstration and hope to have it operating very soon.

"Date Certain" Demonstration

The second project is called the "date certain" demonstration. HCFA is sponsoring a grants program to help States to develop ways to work with individuals and their families to consider community-based alternatives to institutional care. These alternatives should be available prior to admission to an institution or to allow individuals currently in institutions to transition to the community if that is their choice. We expect to issue the grant solicitation before the summer and to award grants to 3 to 5 States in September.

Consumer-Directed DME Purchasing -- Medicare

In Medicare, we will be releasing a Program Announcement for a demonstration of consumer-directed choice and purchase of durable medical equipment, such as wheelchairs.

Having the right equipment can facilitate a person's ability to perform all activities of daily living, including work.

Centers for Independent Living will be our partners in this demonstration. We expect to award developmental funds to four centers this fall.

Dual Eligibles Demonstrations

This past month, HCFA awarded 4 grants to 3 States to help improve care for low income Medicare beneficiaries who are also eligible for Medicaid, so-called "dual eligibles."

Projects are being funded in Florida, Wisconsin and Maryland to address the needs of these "dually eligible" beneficiaries.

These grants will help us learn how to better coordinate care between Medicare and Medicaid, help disabled beneficiaries move from nursing homes into the community, and target needs of people likely to become dually eligible as they use up their own assets on medical care.

Also, as the Secretary mentioned, we are providing technical assistance to a number of States that are interested in exploring options and developing concepts around the goal of employing persons with disabilities. We are seeing a growing interest in this area.

HOME AND COMMUNITY BASED WAIVERS

In addition to our research and demonstration waivers, we have also made great progress granting State home and community-based waivers, as I mentioned earlier.

States are taking advantage of the home and community based waivers under Medicaid to explore innovative approaches to delivering long term care in community or home settings.

A few years ago, we made a significant change to our rules to make it easier for States to obtain these waivers by eliminating the long-standing "cold bed" rule.

In 1995, Secretary Shalala issued a set of principles supporting home and community-based care. She reaffirmed her support for emphasizing home and community-based care services and offering consumers the maximum amount of choice, control and flexibility in how these services are organized and delivered.

Since that time HCFA has actively promoted these waivers, increased its technical assistance to States and developed streamlined waiver applications to facilitate States' efforts to provide more home and community-based care in lieu of institutionalization.

We have seen a substantial growth in the number of waivers requested and approved. We now have 226 approved and many States have multiple waivers. Thirteen states provide attendant

care in their waiver; 39 states provide personal care services in their waiver; and 21 states provide prevocational and supported employment services to enable persons to enter the workforce.

Before closing, I'd like to mention one other activity that is underway -- the Department's Home and Community-Based Services Workgroup.

This past Fall, the President met with representatives from the disability community to discuss increasing access to home and community based services, including personal care services under Medicaid.

Secretary Shalala established a workgroup in response to the President's meeting which is chaired by Bob Williams from ASPE and Sally Richardson, Director of HCFA's Center for Medicaid and State Operations. I'd like to ask Sally to stand so that all of you can see her. I must tell you that it is she, not I, that is HCFA's expert with regard to the subject we're discussing today. Thank you Sally.

The purpose of the workgroup is to consider all available information and make recommendations about how to reduce the institutional bias and promote home and community-based services under the Medicaid program. In addition to HHS offices and agencies, other Federal agencies and our constituency partners, including advocacy organizations, are closely involved.

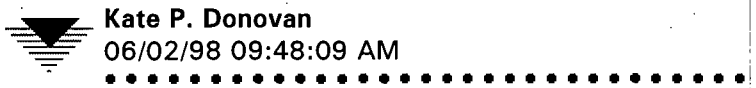
The Department contracted with the University of California at San Francisco to study "institutional bias" in the Medicaid program. A final report is due by May 1. As we review the recommendations, I'm sure we will be able to incorporate many of them into our efforts.

We also are currently planning to contract for development of a "primer" on Medicaid for individuals with disabilities, detailing what States can do under current law and provide examples to help States better use the options they currently have available to them.

Summary

We have been and will continue to promote and encourage States' leadership in expanding home and community-based supports and consumer-directed personal assistance services. While we recognize that we won't be able to achieve our goals all at once, we can be aggressive about making real progress toward them. I think you can see that we have a multi-faceted approach to achieving our goals.

Disability & Bunning Bill



Kate P. Donovan
06/02/98 09:48:09 AM

Record Type: Record

To: Christopher C. Jennings/OPD/EOP, Sarah A. Bianchi/OPD/EOP

cc:
Subject: Draft SAP on HR 3433

Please review the draft SAP on HR 3433, Ticket to Work and Self-Sufficiency Act of 1998 and let me know by 3pm today, Tuesday, if you have any problems (let me know if you want a hard copy - I would be happy to walk one down). The bill is on tomorrow's House schedule. Thanks.

DRAFT - NOT FOR RELEASE

June 1, 1998
(House)

H.R. 3433 - Ticket to Work and Self-Sufficiency Act of 1998
Rep. Bunning (R) KY and 26 cosponsors

The Administration supports H.R. 3433, and is pleased that the House is taking action on the critical issue of making it possible for more people with disabilities to return to or enter the workforce. H.R. 3433 would implement a Presidential initiative to increase flexibility and choice for individuals with disabilities who seek services to help them successfully return to work. This is an Administration priority, as reflected in the President's March 13th Executive Order that established a task force of Federal agencies to identify additional actions required to increase the employment of adults with disabilities.

The Administration will work in the Senate to technically amend the bill to ensure that Federal conflict of interest laws will be clearly and uniformly applied to all members of the proposed Ticket to Work and Self-Sufficiency Advisory Panel. In addition, the bill would impose modest costs on the Medicare Trust Funds. The Administration prefers that the Trust Funds be made whole.

Pay-As-You-Go

H.R. 3433 would affect direct spending and receipts; therefore, it is subject to the pay-as-you-go requirement of the Omnibus Budget Reconciliation Act of 1990. The Office of Management and Budget's scoring estimate for the bill is under development.

* * * * * * *

(Do Not Distribute Outside the Executive Office of the President)

This Statement of Administration Policy (SAP) was developed by the Legislative Reference Division (Haskins) in consultation with Associate Director Mendelson, HLTH (Clendenin/ Miller/Tumlinson), HR (Chow/Cianci/Green), OIRA (Oliven), and BASD (Lind/Bavier). The Social Security Administration (Coyne), the Departments of Education (Hansen) and Health and Human Services (M. Hash, Deputy Administrator for HCFA), and the Office of Government Ethics (Cook) as well as the Domestic Policy Council (Fortuna) concur with this position. The Office of Personnel Management (Wolf) had no objection. The Departments of Justice (Jones), Labor (Morin), and the Treasury (Dorsey), the General Services Administration (Simms), the National Council on Disability (Imparato), and the Office of National Drug Control Policy (Riviat) as well as the National Economic Council (E. Parker) had no comment.

Note: Chris Jennings (per J. Lambrew) does not concur with the second and third sentences of the second paragraph of the SAP regarding the Medicare Trust Funds. We recommend that OMB policy officials consult with Chris Jennings prior to the release of the SAP.

OMB/LA Clearance: _____

Administration Position

To date, the Administration has not taken a formal position on H.R. 3433, but SSA has informally advised Congress that it "is pleased with the spirit and intent" of the bill's "ticket"-related provisions.

Background

Need for Legislation

In part due to rapid program growth in the early 1990s, there has been increased focus on ways to encourage adult Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries to enter or return to the workplace. Although there are work incentives for SSDI and SSI beneficiaries, in FY 1997 less than one half of 1 percent (7,000) became ineligible for benefits because they returned to work. Many assert that SSDI and SSI recipients' fear of losing cash benefits and corresponding Medicare and/or Medicaid benefits provide a disincentive for them to seek employment. In addition, many argue that inadequate access to vocational rehabilitation (VR) services is a barrier to disability recipients returning to work.

Currently, SSA does not provide VR services to SSDI and SSI recipients directly. Instead, it refers approximately 10 percent of new recipients determined to be good VR candidates to the Federal-State VR program administered by the Department of Education. Of the SSDI and SSI recipients referred annually to the VR program, only 10 percent actually obtain VR services and many of these do not return to work.

Legislative Proposals

To increase the number of disability beneficiaries undergoing VR and returning to work, SSA transmitted to Congress the "Ticket to Independence Act" on June 30, 1997. The draft bill would authorize the "Ticket to Independence" project to test the concept of allowing SSDI and SSI beneficiaries to choose their own public or private VR providers. Participating providers would be paid a percentage of the disability benefits saved as a result of beneficiaries returning to work for a specified period of time. A similar proposal was included in the President's FY 1999 Budget.

On March 11, 1998, H.R. 3433, the "Ticket to Work and Self-Sufficiency Act of 1998," was introduced by Representatives Bunning and Kennelly. H.R. 3433 includes provisions similar to the Administration's proposal. Unlike the Administration's proposal, however, it would extend Medicare coverage for SSDI beneficiaries for two years beyond the current-law eligibility period of 39 months after the trial work period.

Major Provisions of H.R. 3433

The following summarizes the major provisions of H.R. 3433.

Ticket To Work and Self-Sufficiency Program

Under current law, individuals with disabilities applying for or awarded SSDI or SSI benefits may be referred by SSA to State VR agencies for rehabilitation services. SSA reimburses a State VR agency for services provided to a disabled beneficiary after the individual engages in work (substantial gainful activity) for nine months.

H.R. 3433 would create the "Ticket to Work and Self-Sufficiency Program," which would revamp the current VR system. The bill would authorize SSA to provide SSDI and SSI recipients with a "ticket" which they could use to obtain services of their choosing from an "employment network" of single or multiple providers, including State VR agencies, to assist them in finding permanent employment. The disability beneficiary and employment network would create a work plan with employment goals and identify the services needed to achieve them.

The bill would authorize SSA to make payments to an employment network through either an "outcome" or "milestone" system. The employment network would chose the system under which it would be reimbursed.

For each month that disability benefits were not payable due to an individual's earnings -- though not longer than 60 months -- the outcome payment system would give the employment network up to 40 percent of the average monthly benefit for the individuals participating in the SSDI or SSI programs. The milestone payment system would provide interim payments to an employment network based on the achievement of one or more milestones related to a SSDI or SSI beneficiary's permanent employment. Under the milestone payment system, the total amount payable to an employment network would be less than that payable under the outcome payment system for a beneficiary who returns to work permanently. H.R. 3433 would authorize appropriations and transfers from the Social Security Trust Fund for this purpose.

The bill would require SSA to prescribe regulations to carry out the Ticket Program. In addition, it would require SSA to: (1) evaluate the program for effectiveness and cost and (2) ensure that disputes between disability beneficiaries and employment networks are resolved.

H.R. 3433 would enable SSA to contract with program managers (one or more private- or public-sector organizations with VR expertise) to assist in administering the Ticket Program. Program managers would identify and recommend employment network providers to SSA and ensure that disability beneficiaries have adequate access to desired services.

Ticket to Work and Self-Sufficiency Advisory Panel

H.R. 3433 would create the Ticket to Work and Self-Sufficiency Advisory Panel. The six member panel would be appointed within 90 days of enactment. Two members, who could not be of the same political party, would be appointed by the President. The remaining four members would be appointed by Congress. (The Majority and Minority leadership each would appoint two members.) The panel would advise the SSA Commissioner and report to the Congress on the Ticket Program implementation and evaluations.

Demonstration Project Authority

H.R. 3433 would extend SSA's authority to conduct demonstration projects, until June 10, 2001, to test alternative approaches to providing disability benefits. In addition, the bill would require SSA to test the effects of a one dollar reduction in benefits for each two dollars of earnings, above a defined threshold, that a SSDI recipient receives.

Extended Medicare Coverage

Under current law, SSDI beneficiaries are eligible to receive Medicare as well as disability benefits through a trial work period. After completing the trial work period, however, beneficiaries' Medicare benefits may continue for 39 months. H.R. 3433 would extend Ticket Program participants' eligibility for Medicare benefits an additional two years. The extended Medicare coverage would expire seven years after the bill's enactment and parallel the phase in of the Ticket Program.

Benefits to Prisoners

Under current law, prisoners are prohibited from receiving Social Security (OASDI) benefits while they are incarcerated after conviction of any crime punishable by imprisonment of more than one year. Federal, State, county or local prisons are required to make available the name and Social Security numbers of any person so convicted and incarcerated. H.R. 3433 would allow SSA to provide incentive payments to correctional institutions for reporting the imprisonment of SSDI beneficiaries, mirroring current law for SSI beneficiaries. In addition, the bill would prohibit prisoners from receiving OASDI benefits after a conviction punishable by any criminal offense.

Clergy Enrollment in Social Security

Current law provides the clergy with Social Security coverage as self-employed workers unless an exemption is filed within a specified period during which compensation is received. To receive this exemption, the clergy member must notify his or her religious order stating opposition to the acceptance of Social Security benefits on religious principles. If elected, the exemption from Social Security benefits cannot be revoked.

H.R. 3433 would create a two year "open season," beginning January 1, 1999, for members of the clergy who initially obtained an exemption from Social Security coverage to obtain coverage. The decision to elect Social Security coverage would be irreversible. Under the

bill, clergy electing coverage would be subject to self-employment taxes and subsequent earnings would be credited towards Social Security and Medicare benefits.

Pay-As-You-Go Scoring

H.R. 3433 would affect direct spending and receipts; therefore, it is subject to the pay-as-you-go requirement of the Omnibus Budget Reconciliation Act of 1990. The Office of Management and Budget's scoring estimate for the bill is under development. The Congressional Budget Office (CBO) estimates that H.R. 3433 would decrease direct spending by $1 million in FY 1999 and a total of $24 million during FYs 1999-2003. CBO estimates that H.R. 3433 would not significantly affect receipts in FY 1999. CBO, however, estimates that the bill would increase receipts by a total of $4 million during FYs 1999-2003. (Note: The bill would result in some costs to the Medicare Trust Funds, but overall the bill would be a paygo saver.)

LEGISLATIVE REFERENCE DIVISION DRAFT
June 1, 1998 - 5:10 p.m.

DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Care Financing Administration

Center for Medicaid and State Operations
7500 Security Boulevard
Baltimore, MD 21244-1850

File Disability

Dear State Medicaid Director:

In the Americans with Disabilities Act (ADA), Congress provided that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." 42 U.S.C. § 12101(a)(8). Title II of the ADA further provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity, or be the subject of discrimination by any such entity." 42 U.S.C. § 12132. Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

We have summarized below three Medicaid cases related to the ADA to make you aware of recent trends involving Medicaid and the ADA.

In L.C. & E.W. v. Olmstead, patients in a State psychiatric hospital in Georgia challenged their placement in an institutional setting rather than in a community-based treatment program. The United States Court of Appeals for the Eleventh Circuit held that placement in an institutional setting appeared to violate the ADA because it constituted a segregated setting, and remanded the case for a determination of whether community placements could be made without fundamentally altering the State's programs. The court emphasized that a community placement could be required as a "reasonable accommodation" to the needs of disabled individuals, and that denial of community placements could not be justified simply by the State's fiscal concerns. However, the court recognized that the ADA does not necessarily require a State to serve everyone in the community but that decisions regarding services and where they are to be provided must be made based on whether community-based placement is appropriate for a particular individual in addition to whether such placement would fundamentally alter the program.

In Helen L. v. DiDario, a Medicaid nursing home resident who was paralyzed from the waist down sought services from a State-funded attendant care program which would allow her to receive services in her own home where she could reside with her children. The United States Court of Appeals for the Third Circuit held that the State's failure to provide services in the "most integrated setting appropriate" to this individual who was paralyzed from the waist down violated the ADA, and found that provision of attendant care would not fundamentally alter any State program because it was already within the scope of an existing State program. The Supreme Court declined to hear an appeal in this matter; thus, the Court of Appeals decision is final.

In Easley v. Snider, a lawsuit, filed by representatives of persons with disabilities deemed to be incapable of controlling their own legal and financial affairs, challenged a requirement that beneficiaries of their State's attendant care program must be mentally alert. The Third Circuit found that, because the essential nature of the program was to foster independence for individuals limited only by physical disabilities, inclusion of individuals incapable of controlling their own legal and financial affairs in the program would constitute a fundamental alteration of the program and was not required by the ADA. This is a final decision.

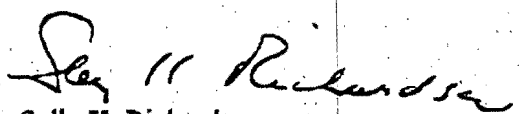
While these decisions are only binding in the affected circuits, the Attorney General has indicated that under the ADA States have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. Reasonable steps should be taken if the treating professional determines that an individual living in a facility could live in the community with the right mix of support services to enable them to do so. The Department of Justice recently reiterated that ADA's "most integrated setting" standard applies to States, including State Medicaid programs.

States were required to do a self-evaluation to ensure that their policies, practices and procedures promote, rather than hinder integration. This self-evaluation should have included consideration of the ADA's integration requirement. To the extent that any State Medicaid program has not fully completed its self-evaluation process, it should do so now, in conjunction with the disability community and its representatives to ensure that policies, practices and procedures meet the requirements of the ADA. We recognize that ADA issues are being clarified through administrative and judicial interpretations on a continual basis. We will provide you with additional guidance concerning ADA compliance as it becomes available.

I urge you also, as we approach the July 26 anniversary of the ADA, to strive to meet its objectives by continuing to develop home and community-based service options for persons with disabilities to live in integrated settings.

If you have any questions concerning this letter or require technical assistance, please contact Mary Jean Duckett at (410) 786-3294.

Sincerely,



Sally K. Richardson
Director

cc: All HCFA Regional Administrators

All HCFA Associate Regional Administrators
for Medicaid and State Operations

Lee Partridge
American Public Human Services Association

Joy Wilson
National Conference of State Legislatures

Jennifer Baxendell
National Governors' Association

Version: September 8 - 10:00 am

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

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

The Balanced Budget Act of 1997

- Under section 4733 of the recently enacted Balanced Budget Act, States are permitted to allow certain Supplemental Security Income (SSI) beneficiaries who are disabled and would lose eligibility because of their earnings to purchase Medicaid coverage. Eligibility is extended to SSI beneficiaries whose income is less than 250 percent of the Federal poverty level for the applicable family size. Currently, 250 percent of the poverty level for one person is currently a little over $2,210 per month. States will set premiums based on an income-related sliding scale. **The Administration originally proposed Medicaid buy-in with no income limit, so this provision should not be over emphasized.**

- The Act in section 4743, also amended the home and community-based waiver program by eliminating the requirement that individuals be discharged from a nursing facility or intermediate care facility for the mentally retarded to be eligible to receive habilitation services under a home and community-based waiver.

- The Act in section 4701 exempts certain children with disabilities including SSI beneficiaries, and children in foster care from being required to receive care through a managed care entity under freedom of choice waivers..

- The Act in section 5305 reinstates Medicaid eligibility for certain aliens who receive SSI. Medicaid benefits were denied to this group of elderly and disabled aliens in the Personal Responsibility and Work Opportunities Reconciliation Act (PRWORA) of 1996 but have subsequently been terminated from SSI because of the PRWORA's tighter definition of childhood disability. It should be noted that disability groups perceive the Administration's interpretation of the new SSI definitions for children as overly harsh resulting in large numbers of children losing eligibility.

- Similarly, the Act in section 4913 restores Medicaid eligibility to disabled children who were receiving SSI at the time of enactment of the PRWORA of 1996.

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

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

Personal Care Services Regulation

- The Personal Care Services Regulation which makes personal care services an optional Medicaid benefit which may be covered under States' Medicaid programs has been signed by the Secretary of Health and Human Services and will be published in the *Federal Register* in the very near future. **(***This is clearly a candidate for White House intervention. OMB has had the regulation for 60 days, but is believed to be finalizing their review. The President could announce the date of publication if cleared. However, it should be noted that States have been able to provide personal care services under waivers without the regulation, and it has taken DHHS 4 years to finalize the regulation.)**

  - The regulation permits States to cover personal care services in the home and at the State's additional option, in locations outside the home including the work place.

  - Personal care services are services to assist a person with activities of daily living such as assistance with eating, meal preparation, bathing, dressing, personal hygiene, and taking medications. Services may also include activities which are essential to the health and welfare of the beneficiary, such as house keeping chores like bed making, dusting, and vacuuming.

  - The regulation removes the requirement that a registered nurse must supervise personal care services, thus reducing the cost, and making the service more flexible to meet the beneficiary's needs.

Home and Community-Based Care Services

- The Health Care Financing Administration continues to support and promote community- based long-term care for the elderly and people with developmental or physical disabilities through the home and community-based waiver program authorized under section 1915 © of the Social Security Act. Currently over

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250,000 individuals with disabilities receive a wide array of services from personal assistance to home modifications and assistive devices (to name only a few) under 226 of these programs in 49 States and the District of Columbia. Similar services are provided in Arizona under their 1115 waiver. Through the use of this Medicaid waiver provision, four States have entirely eliminated their large publicly-funded institutions for people with developmental disabilities and replaced them with integrated community services. Most others have significantly phased down reliance on inappropriate institutional care for people with disabilities as a result of the waiver program.

- Under the Clinton Administration numerous changes have been implemented to simplify the home and community-based waiver application and approval process. One of the most lasting and meaningful changes to promote home and community care and "level the playing field" with institutional care was the elimination of the rule that required States to show that without the waiver an equal number of beds would have to exist in institutions or nursing homes to accommodate those receiving waiver services.

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

- On June 27, HCFA released a letter to State Medicaid Directors to encourage them to reduce the size of large providers of residential services under the home and community-based waiver program. To allow maximum flexibility to States in establishing home and community-based waiver programs, HCFA has not establish a formal Federal policy on the number of people who can reside in a group home. However, the Department is concerned that homes serving large populations may not be able to provide an authentic community experience.

- In an additional letter, dated July 25, HCFA urged all State Medicaid Directors to make available appropriate home and community-based waiver options to all persons who are institutionalized, or at risk of institutionalization. HCFA also firmly stated its belief that, ". . . an individual has the right to assume risk, commensurate with that person's ability and willingness to assume responsibility for the consequences of that risk."

Research and Demonstration Activities

- To honor its commitment to the disability community to move toward the goal of encouraging provision of long-term care services in the community, rather than in

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institutional settings, HCFA in consultation with leaders of the ADAPT movement has modified its current contract with the University of California, San Francisco, to undertake two related studies. The two studies will consist of a comprehensive review and analysis of Medicaid policies, regulations and statutes which relate to long-term care services to identify:

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

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

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

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

o HCFA has established a work group to review the findings of the studies on eliminating the institutional bias in Medicaid and delinking problematic Medicare policies from Medicaid. The work group consists of Health and Human Services staff, and staff from the Office of Management and Budget. The members will consult regularly with a group of "constituency partners" representing the disability community, State agencies, and other appropriate Federal agencies. The work group will work with the advocacy community to identify States which are willing to participate in pilot studies designed to implement the " date certain" concept. We believe these pilots could serve the symbiotic purposes of helping States which have mandates to reduce their institutionalized populations and HCFA's desire to explore identifying the barriers to implementing the

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"date certain" concept. The "date certain" concept identifies the date on which all individuals who are in institutions on that date will have the option to move into a community-based living arrangement, and receive needed services without the requirement for a waiver. **(The "date certain" issue has been identified by representatives of ADAPT as the one step the President could take at this meeting to show real support. ADAPT argues that the "date certain" concept is a win-win concept because by definition it is cost neutral, and does not expand the numbers of people eligible for service. Two versions of the concept proposed by ADAPT are - 1) the "date certain" would be the day those eligible could begin to move to the community from institutions, and 2) the "date certain" is the date on which all persons in institutions on that date would be permitted to move to the community when administratively feasible. The first is preferred. The second is considered a "no brainer" by ADAPT. Given the history of deinstitutionalization of the mentally retarded and mentally ill, which has identified the many benefits and the serious risks involved, HCFA is committed to proceeding in a manner which serves to protect the interests of beneficiaries .)**

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

- The experimental model for the demonstration would permit States to allow clients to choose cash payments in lieu of traditional case management services.

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

- In addition to purchasing personal assistance services, the waiver would permit States to offer a range of optional supportive services, including, but not limited to: recruitment of workers, screening of workers, training of the consumer and worker, back-up or emergency services, and assistance with tax forms and

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insurance paperwork.

- The availability of counseling services would be integral to a consumer-directed approach and to this demonstration. At a minimum, counseling involves helping consumers to decide whether to choose the cash option and how they might best spend the money available to them. Counselors should give consumers the facts and options they need to make informed choices for themselves.

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

- The demonstration would accommodate participation of approximately 9,750 elderly, 7,125 non-elderly individuals with disabilities, and 1,750 children with disabilities. The demonstration is a collaborative effort by representatives of the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation, the Health Care Financing Administration, the National Program Office at the University of Maryland's Center on Aging, the National Council on Aging, and Mathematica Policy Research (the evaluator).

o HCFA recently approved an 1115 waiver for Colorado which will permit greater flexibility in defining where Medicaid home health services may be provided. Instead of limiting visits to a beneficiary's place of residence, the demonstration would permit the same types of services to be provided in other settings (e.g., schools, work sites, or day treatment centers). However, the State would not permit reimbursement for any visits which occur in hospitals, nursing homes, or intermediate care facilities for the mentally retarded.

- The State estimates that between 100 and 200 clients will participate. Demonstration clients will meet Medicaid eligibility requirements. The primary purpose of this demonstration project is to develop and refine the independent care model, and to assist individuals who are capable of directing their own care.

- Services will be provided under a fee-for-service delivery model for this demonstration project. Demonstration participants will be permitted to choose among participating providers (agencies) within a geographic area. Participation by home health agencies, nurses, and aides will be voluntary. Approximately 10 agencies will be selected to participate in the program. These agencies will be stratified by size and location (rural and urban).

o HCFA will release a program announcement to Centers for Independent Living (CILs) intended to test a model of consumer-directed durable medical equipment (CD-DME) that covers a range of activities such as assessment and purchasing related to wheelchairs and accessory items. CD-DME sponsors will provide assistive technology information and facilitate consumers' access to expert assessment and care coordination. In partnership

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with consumers with physical disabilities, sponsors will also more efficiently acquire Medicare-financed DME products and services through a process of prior authorization. Savings accrued from more efficient purchasing will be used to establish beneficiary credit accounts that may be used by beneficiaries to acquire enhanced equipment and/or services not covered by Medicare. Up to four sites are expected to be awarded pre-waiver development grants of approximately $150,000 each.

o In their fiscal year 1997 research agenda, HCFA is sponsoring a grants program to foster a more integrated and flexible service delivery system for Medicaid and Medicare dually-eligible beneficiaries by working collaboratively with States and providers to develop more effective systems of care to meet the diverse and complex needs of these beneficiaries.

- One illustrative model included in the grants announcement was an ***Independent Living Model Integrated with Medical Services***, with emphasis on increased consumer direction and control, innovative case management models built around current resource systems for those with disabilities (e.g., Centers for Independent Living), and new payment approaches that provide increased consumer control and flexibility around key long term care services such as personal assistance services. Discussions with States preparing proposals indicate that several plan to submit proposals targeted to non-elderly beneficiaries with disabilities, with some features of HCFA's illustrative model.

- Twelve proposals were received by the August 29 deadline. HCFA is planning to award approximately six grants of $150,000 each in October 1997.

o The State of Wisconsin submitted an application for Medicare and Medicaid demonstration waivers to establish a partnership model of care delivery for under age 65 beneficiaries with physical disabilities and frail elderly beneficiaries who are eligible for Medicare and Medicaid and meet nursing home level of care criteria. The model is similar to the Program of All-inclusive Care for the Elderly (PACE) model in the use of multi-disciplinary care teams, prepaid capitation and the sponsorship by a community-based service provider. The partnership model for people with disabilities would use Centers for Independent Living a s the community-based provider. Waiver approval is anticipated this fall with implementation targeted for January 1, 1998. The model is a voluntary enrollment model, and Wisconsin expects to enroll up to 300 individuals at each of three sites. The Wisconsin Partnership model is the first known comprehensive capitated model of service delivery specifically designed for Medicare and Medicaid beneficiaries with physical disabilities.

o The State of Rhode Island was awarded a HCFA planning grant to design an integrated approach to health/medical care and for life-long community supports for adults with developmental disabilities. Staff from Rhode Island Division of Developmental Disabilities along with Department of Human Services, people with disabilities, service providers, and

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advocates worked for over 2 years to design this waiver proposal. The planning was completed in July 1996. HCFA is currently reviewing the implementation proposal submitted by the State in May 1997 which will consolidate the current Medicaid and other Federal funding streams into a single coherent funding resource. This will help enable the restructuring and transition of the service system to promote more personally directed supports and services. The program will serve 3,500 beneficiaries statewide.

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

- Contract to review Medicaid regulations for institutional bias and delink Medicare and Medicaid policy - Covered above.

- Establish a workgroup to address bias issues - Covered above.

- Analyze Community Assistant Services Act (CASA) - Analysis attached.

- Analyze ADAPT's data on cost effectiveness - HCFA's actuaries and the Office of the Assistant Secretary for Planning and Evaluation in DHHS are currently reviewing data provided to them by OMB.

- HCFA Central Office staff will visit several independent living centers - HCFA's Center for Beneficiary Services (CBS) is to set up visits in collaboration with the Department of Education and ADAPT.

- Announcement of the Consumer-Directed DME solicitation - CBS plans an early FY 1998 solicitation.

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ATTACHMENT

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

Summary of H.R.2020

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

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

Definitions.

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

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

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

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- **"Agency-provider model"** means a method of providing community-based services under which a single entity contracts for the provision of such services.

- **"Other model"** means a method, other than agency-provider, for provision of community-based attendant services. Such a model may include vouchers, direct cash payments or use of a fiscal agent to assist in obtaining services.

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

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

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

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

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

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

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

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

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

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

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

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

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

Effective Date: 1/1/98

HHS Preliminary Analysis of CASA Bill

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

- The Administration supports the bill's concept of providing community attendant care services in locations other than the home.

- We also support the bill's concept of making community-based care an option for those in need of long-term care services.

  - The Personal Care Services final regulation, scheduled for publication this week, will contain specific provisions that support expansion of home and

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community-based care.

- The regulation removes the requirement for supervision by a registered nurse, reducing the cost and making this a more affordable option for States to elect. The regulation further supports the direction the CASA bill takes in expanding provision of services to locations other than in the home.

- The CASA bill contains provisions that address the provision of high quality services, and controlling the costs in providing all long-term care services which are major concerns of the Department. Recognition of these two concerns in the CASA bill reflects the disability community's understanding of these two important issues. We are doing a number of things to examine these issues in a controlled and deliberate way, and will continue to need the support of the disability community to inform this process.

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

Policy Concerns

Cost

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

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

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

- *Transitional Costs* -- For States seeking to shift more services to the community and to ultimately close larger institutional settings, there are transitional costs related to covering fixed institutional costs with declining populations that are difficult to resolve in a budget neutral way.

- *Increased Utilization* -- It is likely that the availability of personal attendant services will induce more utilization, through the so-called "woodwork effect," so that overall costs will increase as individuals who would not seek institutional care would seek community care

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under this new program.

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

Cost Limitations

- The bill does have some mechanisms for the State to control costs through a cost neutrality requirement, however, we are unclear how this requirement would be enforced, given the previously identified concerns.

- The bill also permits cost-sharing that could be used to moderate State and Federal spending.

Actuaries' Concerns

- HCFA actuaries are concerned that even with the limitations on cost in place, implementation of this benefit will result in **significant additional spending, above and beyond the $2 billion transitional pool that is specified in the bill.**

- HCFA actuaries question how the limitation on expenditures provided for in CASA is based. Is the limitation based

  1) on what is paid under Medicaid for those currently receiving institutional care, or

  2) on what would have been paid if all those who receive CASA services instead received institutional care? (Our reading of the bill language would support interpretation 2.)

- Interpretation 1) would implicitly place a limit on who could be served1, even though the benefit is envisioned as an entitlement.

- Interpretation 2) would allow all eligible individuals to be served but would result in additional costs to Medicaid if significant numbers of CASA-eligible individuals not now being served by Medicaid in institutions participate in the CASA program.2

- Additional costs may also arise to the extent that CASA participants make use of other services (e.g., skilled nursing, therapy) which are not included in the definition of CASA services.

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

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Cash Payments

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

- To date, cash payments have not been authorized in the Medicaid program. There are several issues, ranging from the appropriate amount of Federal oversight to more technical questions such as the possibility that these payments could be considered "income" for purposes of all other Federal and State programs, causing the individual receiving such payments to lose eligibility for services because of their increased "income".

- Although HCFA is interested in exploring well-designed demonstrations to test the effects of these types of models, through demonstrations such as Cash and Counseling, it is premature to support legislation authorizing models such as these absent any understanding of their impact on beneficiaries' health and quality of life, services used, and overall program expenditures.

Protection of Beneficiaries' Rights and Quality Standards for Personal Attendants

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

Exclusion of Institutionalized Individuals

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

Operational Issues

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

Room and Board Exclusion

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

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Distribution of Transitional Funds

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

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