



MAR 30 REC'D

**PARALYZED VETERANS
OF AMERICA**

Chartered by the Congress
of the United States

March 23, 1994

The Honorable Carol H. Rasco, M.S.
Assistant to the President for
Domestic Policy
The White House
Washington, DC 20500

Dear Ms. Rasco:

We are now in the final stages of completing the proceedings from
the National Conference on Economic Consequences of Disabilities.

Accordingly, we would like for you to submit a picture of
yourself by April 1st, to accompany your Keynote Address at the
conference. A black and white or color photo will be acceptable.
Please note that this picture will not be returned unless
otherwise requested.

Feel free to contact me at (202) 416-7657 if you have any
questions.

Sincerely,

Joan E. Napier
Administrative Assistant
Research and Education

✓ Photo sent
Mar. 30, 1994
to Joan E. Napier
by: Pat Roman

*National
Head Injury
Foundation, Inc.*



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*Serving People
with Traumatic
Brain Injury*

Promoting Prevention

103D CONGRESS
1ST SESSION

H. R. 3121

To amend the Public Health Service Act to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 22, 1993

Mr. SLATTERY (for himself, Mr. GREENWOOD, Mr. PALLONE, and Mr. QUILLEN) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury, and for other purposes.

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

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the "Traumatic Brain
5 Injury Act of 1993".

6 **SEC. 2. FINDINGS AND PURPOSE.**

7 (a) **FINDINGS.**—Congress finds that—

1 (1) the incidence of head injury in the United
2 States is increasing, with over 2,000,000 head inju-
3 ries per year resulting from automobile crashes,
4 sports, recreational activities, assaults, violence and
5 other falls and incidents;

6 (2) a majority of all head injuries are caused by
7 motor vehicle accidents;

8 (3) individuals between the ages of 15 and 24
9 are at greatest risk for sustaining head injuries;

10 (4) of the individuals who sustain head injuries
11 each year, approximately 500,000 require hos-
12 pitalization, and 75,000 to 100,000 of such individ-
13 uals die within hours of the injury;

14 (5) of the individuals who survive head injuries
15 each year, approximately 70,000 to 90,000 will suf-
16 fer irreversible debilitating loss of function, 5,000
17 will develop epilepsy as a result of the injury, and
18 2,000 will exist in a coma;

19 (6) a significant number of individuals with
20 traumatic brain injury are not easily restored to so-
21 ciety and require years of rehabilitation, medical fol-
22 low-up and integrated community services, which are
23 costly and frequently not readily available;

24 (7) individuals sustaining traumatic brain in-
25 jury require coordinated and specialized services, in-

1 including post-injury supervised programs facilitating
2 reentry into the community;

3 (8) many health and social service agencies,
4 both public and private, overlook, exclude or inad-
5 equately serve individuals surviving traumatic brain
6 injury;

7 (9) society bears an economic cost of approxi-
8 mately \$25,000,000,000 per year for the direct and
9 indirect costs of traumatic brain injury, which in-
10 clude medical treatment, rehabilitative and support
11 services and lost income;

12 (10) a program to develop national standards
13 for helmets used by bicyclists and others is needed;
14 and

15 (11) a national plan to provide services for indi-
16 viduals surviving traumatic brain injuries and their
17 families is needed.

18 (b) PURPOSE.—It is the purpose of this Act to—

19 (1) facilitate the conduct of research and the
20 collection and compiling of accurate statistical data
21 on traumatic brain injury;

22 (2) raise public awareness concerning the risks
23 and consequences of such injuries and the distinct
24 needs of individuals (and their families) following
25 survival from traumatic brain injury;

1 (3) provide the public with all necessary and
2 relevant information about the prevention of trau-
3 matic brain injury, in order for individuals to make
4 informed and educated safety decisions;

5 (4) promote the creation of innovative programs
6 and policies to prevent traumatic brain injury and to
7 rehabilitate those individuals who have survived such
8 injuries;

9 (5) designate a Federal agency to oversee and
10 promote projects relating to the prevention of, and
11 rehabilitation from, traumatic brain injury;

12 (6) create State advisory boards to coordinate
13 citizen participation in community programs dealing
14 with traumatic brain injury;

15 (7) create a registry to advance epidemiologic
16 research on such trauma;

17 (8) establish standards for the marketing of
18 brain injury services;

19 (9) require the Secretary to publish various re-
20 ports concerning the activities of the Department of
21 Health and Human Services in this area, including
22 an annual review of relevant activities; and

23 (10) provide for the initiation of a program to
24 establish national standards for helmets used by
25 bicyclists and others.

1 **SEC. 3. AMENDMENT TO PUBLIC HEALTH SERVICE ACT.**

2 Title XII of the Public Health Service Act (42 U.S.C.
3 300d et seq.) is amended—

4 (1) by redesignating parts C through F as parts
5 D through G, respectively; and

6 (2) by inserting after part B the following new
7 part:

8 "PART C—TRAUMATIC BRAIN INJURY

9 "SEC. 1225. DEFINITIONS.

10 "As used in this part:

11 "(1) ADMINISTRATOR.—The term 'Adminis-
12 trator' means the Administrator of the Agency for
13 Health Care Policy and Research.

14 "(2) DIRECTOR.—The term 'Director' means
15 the Director of the Centers for Disease Control and
16 Prevention.

17 "(3) TRAUMATIC BRAIN INJURY.—The term
18 'traumatic brain injury' means an acquired injury to
19 the brain caused by an external physical force. Such
20 term does not include brain dysfunction caused by
21 congenital or degenerative disorders, nor does such
22 term include birth trauma. Such term is synonymous
23 with the term 'head injury'.

1 **"SEC. 1225A. AGENCY FOR HEALTH CARE POLICY AND RE-**
2 **SEARCH STUDY OF EFFECTIVENESS OF TRAU-**
3 **MATIC BRAIN INJURY INTERVENTIONS.**

4 **"(a) IN GENERAL.—**The Secretary, acting through
5 the Administrator, shall conduct a study concerning trau-
6 matic brain injury.

7 **"(b) MAJOR FINDINGS.—**The study conducted under
8 subsection (a) shall seek to—

9 **"(1) identify common therapeutic interventions**
10 **which are used for the rehabilitation of individuals**
11 **with traumatic brain injuries, and shall include an**
12 **analysis of—**

13 **"(A) the effectiveness of each such inter-**
14 **vention in improving the functioning of individ-**
15 **uals with brain injuries; and**

16 **"(B) the comparative effectiveness of inter-**
17 **ventions employed in the course of rehabilita-**
18 **tion of individuals with brain injuries to achieve**
19 **the same or similar clinical outcome; and**

20 **"(2) develop practice guidelines for the rehabili-**
21 **tation of traumatic brain injury.**

22 **"(c) REPORTING REQUIREMENTS.—**Not later than 4
23 years after the date of enactment of this part, the Sec-
24 retary shall prepare and submit to the appropriate com-
25 mittees of Congress, a report containing the results of the
26 studies conducted under this section.

1 “(d) AUTHORIZATION OF APPROPRIATION.—There
2 are authorized to be appropriated to carry out this section,
3 \$2,000,000 for fiscal year 1994, and such sums as may
4 be necessary for each of the fiscal years 1995 through
5 1996.

6 **“SEC. 1225B. CENTERS FOR DISEASE CONTROL AND PRE-**
7 **VENTION STUDY OF TRAUMATIC BRAIN IN-**
8 **JURY OCCURRENCE.**

9 “(a) IN GENERAL.—The Secretary, acting through
10 the Director, and in cooperation with other Public Health
11 Service agencies as may be necessary, shall conduct stud-
12 ies concerning traumatic brain injury, and shall establish
13 a reporting system under subsection (b).

14 “(b) REPORTING SYSTEM.—To assist in data and in-
15 formation gathering, the Director shall establish a uniform
16 reporting system under which hospitals, State and local
17 health-related agencies will report to the Director on
18 matters including—

19 “(1) the occurrence of traumatic brain injuries;
20 and

21 “(2) the health insurance status of individuals
22 with traumatic brain injury.

23 The reporting system should be established to permit the
24 Director to make an accurate assessment of resource
25 needs and long term outcomes.

1 “(c) SURVEY AND COOPERATIVE AGREEMENTS.—

2 “(1) SURVEY.—The Director shall determine
3 which Federal, State, local or other entities collect
4 data on traumatic brain injury and the means by
5 which such entities collect such data.

6 “(2) COOPERATIVE AGREEMENTS.—The Direc-
7 tor may enter into cooperative agreements with
8 other agencies, and provide assistance to other enti-
9 ties with responsibility for data collection, to estab-
10 lish traumatic brain injury as a specific reportable
11 condition in existing and future reporting systems.
12 Any data systems established in conjunction with
13 such agencies should be compatible with other such
14 data systems.

15 “(d) MAJOR FINDINGS OF STUDIES.—The studies
16 conducted under subsection (a) shall seek to—

17 “(1) determine the major causes of traumatic
18 brain injury;

19 “(2) determine the preventive efforts that are
20 being used by States and non-profit agencies to re-
21 duce the occurrence of such injuries;

22 “(3) determine the number of individuals sur-
23 viving traumatic brain injuries, and the cost of
24 treatment and other related costs;

1 “(4) develop a uniform reporting system to fa-
2 cilitate the reporting to the Centers for Disease Con-
3 trol and Prevention concerning the occurrence of
4 traumatic brain injury;

5 “(5) identify States and localities that have ap-
6 proved mandated helmet use laws for bicyclist;

7 “(6) identify States and localities that have im-
8 plemented unique approaches to encouraging bicycle
9 helmet use;

10 “(7) determine the health insurance status of
11 individuals with traumatic brain injury; and

12 “(8) initiate a program of prevention research
13 to develop effective prevention of traumatic brain in-
14 jury.

15 “(e) REPORTING REQUIREMENTS.—Not later than 4
16 years after the date of enactment of this part, the Sec-
17 retary shall prepare and submit to the appropriate com-
18 mittees of Congress, a report containing the results of the
19 studies conducted under this section.

20 “(f) BIENNIAL REPORT.—The Secretary shall bienni-
21 ally prepare a report containing recommendations for the
22 prevention of traumatic brain injuries. The report shall
23 also identify States that have mandated helmet laws for
24 bicyclists, as well as States that have unique bicycle hel-

1 met-use promotion programs in place. Such reports shall
2 be disseminated to State health officers.

3 “(g) AUTHORIZATION OF APPROPRIATION.—There
4 are authorized to be appropriated to carry out this section,
5 \$2,000,000 for fiscal year 1994, and such sums as may
6 be necessary for each of the fiscal years 1995 through
7 1996.

8 **“SEC. 1225C. SPECIAL PREVENTION PROJECTS.**

9 “(a) IN GENERAL.—The Secretary shall cooperate
10 with, and may provide assistance to, public and private
11 nonprofit entities to reduce the incidence of traumatic
12 brain injury through the establishment and effectuation
13 of prevention projects. In carrying out this section, the
14 Secretary may award grants to State and local entities,
15 and to public or non-profit private entities, to support—

16 “(1) special prevention and public awareness
17 initiative projects;

18 “(2) model traumatic brain injury prevention,
19 research and support programs;

20 “(3) projects that study the service needs of in-
21 dividuals with traumatic brain injury; and

22 “(4) projects involving grants for services co-
23 ordination.

24 “(b) REQUIREMENTS.—To be eligible to receive as-
25 sistance under subsection (a), an entity shall—

1 “(1) prepare and submit to the Secretary an
2 application, at such time, in such manner, and con-
3 taining such information as the Secretary may re-
4 quire; and

5 “(2) provide assurances to the Secretary that
6 any preventive measures implemented under a pre-
7 vention project funded under this section may
8 include—

9 “(A) behavioral and environmental tech-
10 niques, as well as educational and responsible-
11 use programs;

12 “(B) the use of innovative and proven
13 model prevention approaches;

14 “(C) the promotion of activities that will
15 minimize brain injury risk in athletes (such as
16 the use of head protection gear); and

17 “(D) the improvement of community-level
18 access to data-base systems to assist in design-
19 ing, developing, and implementing traumatic
20 brain injury prevention programs.

21 “(c) RESTRICTION ON USE OF FUNDS.—A grant
22 under subsection (a) may not be expended to engage in
23 advocacy regarding Federal, State, or local laws.

24 “(d) RULE OF CONSTRUCTION.—The Secretary may
25 not require that, as a condition of the receipt of a grant

1 under subsection (a), a State have in effect a law regard-
2 ing the use of helmets while operating motorcycles.

3 “(e) **AUTHORIZATION OF APPROPRIATIONS.**—There
4 are authorized to be appropriated to carry out this section,
5 \$4,000,000 for fiscal year 1994, and such sums as may
6 be necessary for each of the fiscal years 1995 and 1996.

7 **“SEC. 1225D. BASIC AND APPLIED RESEARCH.**

8 “(a) **IN GENERAL.**—The Secretary, acting through
9 the Director of the National Institutes of Health, may pro-
10 vide assistance to public and private nonprofit entities to
11 support the conduct of basic and applied research concern-
12 ing traumatic brain injury, especially with respect to the
13 biomechanics of brain injury, the molecular and cellular
14 characteristics of primary and secondary injury to the
15 brain and the development of improved experimental brain
16 injury models.

17 “(b) **SPECIFIC RESEARCH.**—Research to be con-
18 ducted with assistance provided under subsection (a) shall
19 be determined by the Secretary, prior to the provision of
20 such assistance, to contribute to the strategies that will
21 limit primary and secondary mechanical, biochemical and
22 metabolic insults to the brain and minimize the extent,
23 severity and progression of resulting dysfunctions. In im-
24 plementing this section the Secretary shall emphasize—

1 “(1) the development of new methods and mo-
2 dalities for the more effective diagnosis, measure-
3 ment of degree of injury, post-injury monitoring and
4 prognostic assessment of head injury for acute,
5 subacute and later phases of care;

6 “(2) the development, modification and evalua-
7 tion of therapies that retard, prevent or reverse
8 brain damage after acute head injury, that arrest
9 further deterioration following injury and that pro-
10 vide the restitution of function for individuals with
11 long-term injuries;

12 “(3) the integration of basic research into clini-
13 cal care settings;

14 “(4) the development of a continuum of care
15 from acute care through rehabilitation, designed, to
16 the extent practicable, to integrate rehabilitation and
17 long-term outcome evaluation with acute care re-
18 search;

19 “(5) the development of programs that increase
20 the participation of academic centers of excellence in
21 head injury treatment and rehabilitation research
22 and training; and

23 “(6) the conduct of national consensus con-
24 ferences on managing head injury and related reha-

1 bilitation concerns, the findings of which shall be
2 published.

3 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
4 are authorized to be appropriated to carry out this section,
5 \$5,000,000 for fiscal year 1994, and such sums as may
6 be necessary for each of the fiscal years 1995 and 1996.

7 **“SEC. 1225E. STATEWIDE PROGRAM FOR TRAUMATIC BRAIN**
8 **INJURY.**

9 “(a) GRANTS.—The Secretary shall award grants to
10 States for the establishment of programs related to trau-
11 matic brain injury. Such programs shall include State ad-
12 visory boards, patient advocacy and service coordination
13 systems, and State registries concerning individuals af-
14 fected by traumatic brain injuries. Services may also be
15 provided under this section, within the limits of service
16 availability, to individuals whose deficits are not due to
17 traumatic brain injury. To be eligible for such services,
18 such individuals should be comparable to traumatic brain
19 injury patients in regard to the range of services needed,
20 the severity and duration of deficits, and the etiology of
21 their deficits being due to a nonprogressive and non-
22 recurring disorder.

23 “(b) GENERAL ELIGIBILITY REQUIREMENTS.—To be
24 eligible to receive a grant under subsection (a), a State
25 shall—

1 “(1) prepare and submit to the Secretary an
2 application, at such time, in such manner, and con-
3 taining such information as the Secretary may re-
4 quire;

5 “(2) provide assurances that it will prepare and
6 submit to the Secretary reports describing the activi-
7 ties undertaken under the State system established
8 under the grant; and

9 “(3) provide for the establishment of a State-
10 wide program that includes a State registry for trau-
11 matic brain injury information, a program of patient
12 advocacy and service coordination, and a State advi-
13 sory board with respect to activities under this
14 section.

15 “(c) SPECIFIC PROGRAM REQUIREMENTS.—

16 “(1) STATE REGISTRY.—To be eligible to re-
17 ceive a grant under subsection (a), a State shall—

18 “(A)(i) establish and maintain, through
19 the utilization of procedures to ensure privacy
20 and maintain the confidentiality of information,
21 which are acceptable to the Secretary, a central
22 registry of persons who sustain traumatic brain
23 injury in order to—

24 “(I) collect information to facilitate
25 the development of injury prevention,

1 treatment, and rehabilitation programs;
2 and

3 “(II) report data to the Director on
4 an annual basis for State reporting re-
5 quirements; and

6 “(ii) a violation of such privacy and con-
7 fidentiality procedures or the unauthorized use
8 of such information may result in a loss of sup-
9 port under this section; and

10 “(B) provide summary registry data or
11 data that is not personally identifiable to public
12 and private entities to conduct studies using
13 data collected by the traumatic brain injury
14 registry established under subparagraph (A),
15 for which the coordinator may charge a fee for
16 all expenses associated with the provision of
17 data or data analysis.

18 “(2) ADVOCACY AND SERVICE COORDINA-
19 TION.—To be eligible to receive a grant under sub-
20 section (a), a State shall—

21 “(A) designate a State coordinator for
22 traumatic brain injuries who—

23 “(i) shall establish policies and stand-
24 ards for coordinating services within the

1 State for individuals with traumatic brain
2 injury;

3 “(ii) may contract with qualified agen-
4 cies or employ staff to provide services
5 under this section on a statewide basis to
6 eligible individuals;

7 “(iii) shall be responsible for a pro-
8 gram of activities related to preventing and
9 reducing the rate of traumatic brain inju-
10 ries in the State; and

11 “(iv) shall, after consultation with the
12 State advisory board established under
13 paragraph (3), establish standards regard-
14 ing the marketing of services (by hospitals
15 and other providers) to traumatic brain in-
16 jury patients or family members, dissemi-
17 nate the standards to case management
18 programs, and furnish information on such
19 standards to individuals who sustain trau-
20 matic brain injuries (and the family mem-
21 bers of such individuals) at the earliest ap-
22 propriate opportunity after the individual
23 has sustained the injury (such standards to
24 include (at a minimum) a rule prohibiting
25 payments under a case management pro-

1 gram under this section for referring pa-
2 tients);

3 “(B) provide assurances that a protection
4 and advocacy system established under this sec-
5 tion will—

6 “(i) provide legal, administrative and
7 other appropriate remedies or approaches
8 to ensure the protection of, and advocacy
9 for, the rights of individuals with trau-
10 matic brain injury within the State who
11 are or may be eligible for treatment, serv-
12 ices, or rehabilitation;

13 “(ii) provide information and referral
14 to programs and services addressing the
15 needs of individuals with traumatic brain
16 injuries; and

17 “(iii) provide for the investigation of
18 incidents of abuse and neglect of individ-
19 uals with traumatic brain injuries when in-
20 cidents are reported for the provision of
21 excessive or unnecessary services or other
22 complaints relating to the care of such in-
23 dividuals, and payment for the referral of
24 patients;

1 “(C) ensure the provision to persons with
2 traumatic brain injury of information regarding
3 appropriate public or private agencies that pro-
4 vide rehabilitative services so that injured per-
5 sons or individuals responsible for such persons
6 may obtain needed service to alleviate injuries
7 and avoid secondary problems; and

8 “(D) for purposes of identifying the serv-
9 ices required to prevent the institutionalization
10 or to minimize the need for residential rehabili-
11 tation in the case of traumatic brain injuries,
12 establish a services coordination program that
13 shall—

14 “(i) provide for the initial assessment
15 of the individual’s need for traumatic brain
16 injury services;

17 “(ii) provide for the reassessment of
18 each patient at regular intervals to deter-
19 mine the extent of each patient’s progress,
20 to ascertain whether a patient is being
21 kept too long in a given setting or provided
22 services inappropriately, or to determine
23 whether the patient would be better served
24 by other services or in another setting;

1 “(iii) prepare a treatment plan for
2 each individual requiring services coordina-
3 tion, within an appropriate period after the
4 individual sustains the injury, based on a
5 consultation with the individual (other
6 than an individual who is comatose in
7 which case consultation shall be with a
8 person with legal responsibility over such
9 individual) and any person named by the
10 individual (preparation of the plan may be
11 delayed based on a certification, including
12 a brief explanation of the reason for the
13 delay, by a physician attesting that such a
14 delay is in the individual’s best interests
15 with a copy of the treatment plan and any
16 modifications to the plan being presented
17 to the individual or the individual’s legal
18 representative);

19 “(iv) ensure that each individual’s
20 treatment plan is regularly updated (based
21 on consultation with the individual and the
22 person responsible for the injured individ-
23 ual) with data and information about
24 treatments and services provided, as well
25 as specific measures of the individual’s

1 current performance or activity relative to
2 goals previously established;

3 “(v) assist the individual in obtaining
4 services necessary to allow the individual to
5 remain in the community;

6 “(vi) coordinate home care services
7 with other services;

8 “(vii) ensure appropriate, accessible,
9 and cost-effective services;

10 “(viii) assist the individual with prob-
11 lems related to the provision of home care
12 services;

13 “(ix) ensure the quality of home care
14 services;

15 “(x) assess the individual’s need for
16 and level of home care services at appro-
17 priate intervals during the course of the in-
18 dividual’s treatment under the program;
19 and

20 “(xi) explore efforts to include serv-
21 ices coordination provisions under the
22 State’s medicaid program under section
23 1931 of the Social Security Act.

24 “(3) STATE ADVISORY BOARD.—

1 “(A) IN GENERAL.—To be eligible to re-
2 ceive a grant under subsection (a), a State shall
3 establish an advisory board within the appro-
4 priate health department of the State or within
5 another department as designated by the chief
6 executive officer of the State.

7 “(B) FUNCTIONS.—An advisory board es-
8 tablished under subparagraph (A) shall be cog-
9 nizant of findings and concerns of Federal,
10 State and local agencies, citizens groups, and
11 private industry (such as insurance, health care,
12 automobile, and other industry entities). Such
13 advisory boards shall encourage citizen partici-
14 pation through the establishment of public
15 hearings and other types of community out-
16 reach programs.

17 “(C) COMPOSITION.—An advisory board
18 established under subparagraph (A) shall be
19 composed of—

20 “(i) representatives of—

21 “(I) the corresponding State
22 agencies involved;

23 “(II) public and nonprofit private
24 health related organizations;

1 “(III) other disability advisory or
2 planning groups within the State;

3 “(IV) members of an organiza-
4 tion or foundation representing trau-
5 matic brain injury survivors in that
6 State; and

7 “(V) injury control programs at
8 the State or local level if such pro-
9 grams exist; and

10 “(ii) a substantial number of individ-
11 uals who are survivors of traumatic brain
12 injury, or the family members of such indi-
13 viduals.

14 “(d) REPORT.—Not later than 2 years after the date
15 of enactment of this part, the Secretary shall prepare and
16 submit to the appropriate committees of Congress a report
17 concerning the findings and results of the programs estab-
18 lished under this section, including measures of outcomes
19 and consumer and surrogate satisfaction.

20 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
21 are authorized to be appropriated to carry out this section,
22 \$27,000,000 for fiscal year 1994, and such sums as may
23 be necessary for each of the fiscal years 1995 and 1996.”.

1 **SEC. 4. NATIONAL HEAD INJURY AWARENESS MONTH.**

2 The month of October, 1993, is hereby designated as
3 “National Head Injury Month” and the President is re-
4 quested to issue a proclamation calling on the people of
5 the United States to observe such month with appropriate
6 ceremonies and activities.

7 **SEC. 5. EFFECTIVE DATE.**

8 This Act shall become effective on October 1, 1993.

○

POLITICAL APPOINTMENTS OF PERSONS WITH DISABILITIES

The White House

- MICHELA ALIOTO (CA) -- Special Assistant, Domestic Policy Office, Office of the Vice-President/The White House
- BOB BOORSTIN -- Special Assistant to the President, Policy Coordination/The White House
- JOHN CRESSMAN (NJ) -- Deputy Director, Office of Administration/The White House
- BONNIE DEANE -- Director, Science, Technology and Infrastructure Division (Human Capital) National Economic Council/The White House
- CHRISTINE MALOY (DC) -- Special Assistant, Visitor's Office/The White House
- PAUL STEVEN MILLER (CA) -- Director, Disability Outreach and Search Manager, Office of Presidential Personnel/The White House
- PHILLIP WEINTRAUB (DC) -- Mail Analysis Clerk, Presidential Correspondence/The White House

Department of Agriculture

- MICHAEL DERIAN -- Confidential Assistant to the Administrator of Agricultural Research Service/Department of Agriculture

Department of Education

- JUDY HEUMANN (CA) -- Assistant Secretary, Office of Special Education and Rehabilitation Services/Department of Education
- HOWARD MOSES (DC) -- Deputy Assistant Secretary, Office of Special Education and Rehabilitation Services/Department of Education
- PATRICIA PARISI (NY) -- Special Assistant/Department of Education

- BOBBY SIMPSON (ARK) -- Commissioner, Rehabilitation Services Administration/Department of Education

Department of Health and Human Services

- FERNANDO TORRES-GIL (CA) -- Commissioner on Aging, Administration on Aging/Department of Health and Human Services
- BOB WILLIAMS (DC) -- Commissioner, Administration on Developmental Disabilities/Department of Health and Human Services

Department of Housing and Urban Development

- THEA SPIRES (ME) -- Fair Housing/Department of Housing and Urban Development
- DONALD THOMPSON (DC) -- Confidential Assistant

Department of Justice

- ELEANOR ACHESON (MA) -- Assistant Attorney General for the Office of Policy Development/Department of Justice
- RICHARD SCHIFFRIN (FLA) -- Deputy Assistant Attorney General, Office of Legal Counsel/Department of Justice
- MICHAEL TECKLENBERG (SC/DC) -- Special Assistant, Assistant Attorney General, Anti-Trust Division/Department of Justice

Department of State

- JANET ALLEM -- Deputy Chief of Staff/Agency for International Development

Department of Veterans Affairs

- JESSE BROWN -- Secretary of the Department of Veterans Affairs
- ROBERT JONES -- (AMVETS)

BOARDS AND COMMISSIONS

National Council on Disability

- MARCA BRISTO (ILL)
- BONNIE O'DAY (MA)
- HUGHEY WALKER (SC)
- KATE PEW WOLTERS (MI)
- MICHELE ALIOTO (CA)

Commission on Presidential Scholars

- NANCY VERDERBER (MO)

Commission on White House Fellowships

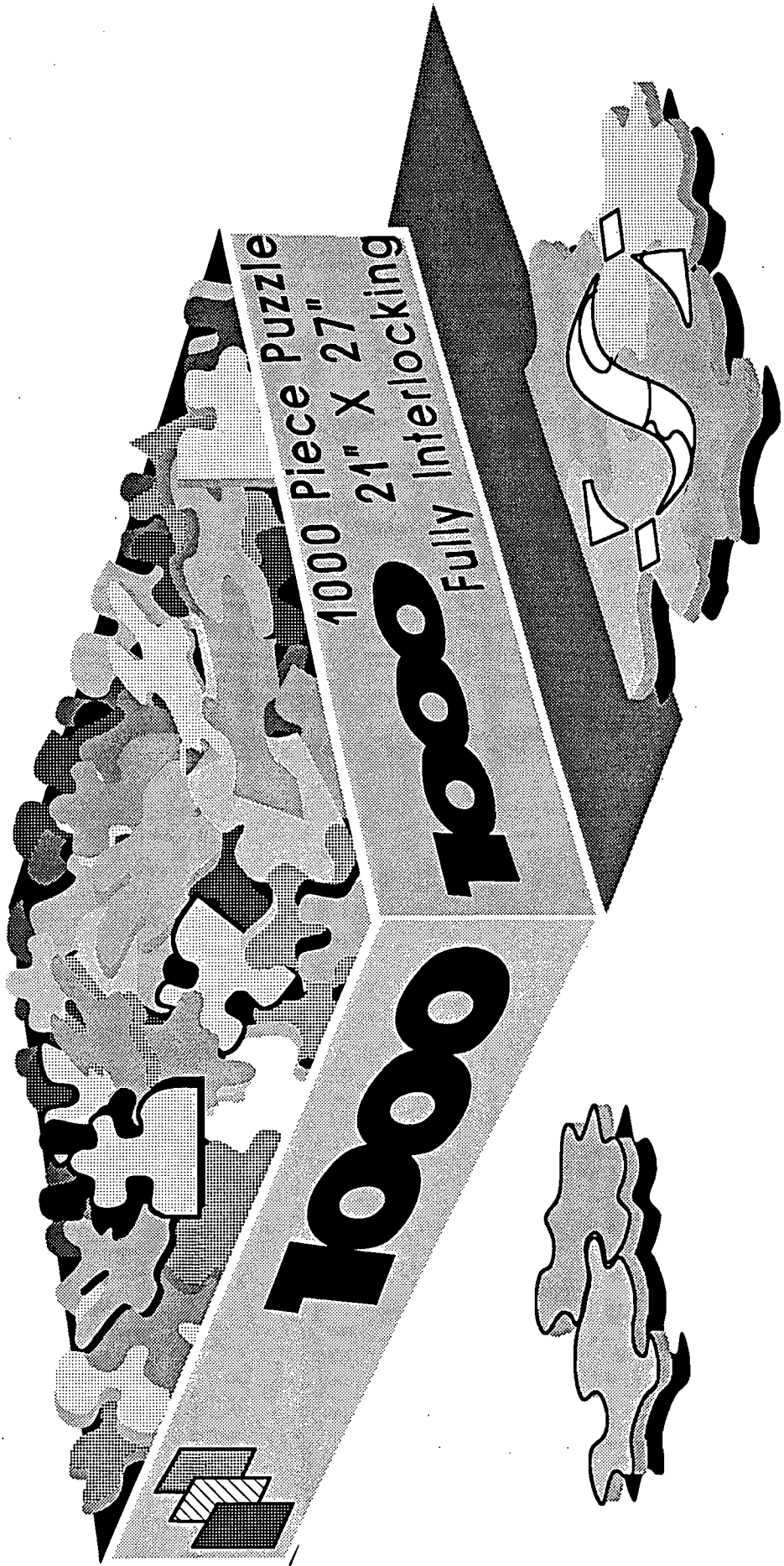
- MAX STARKLOFF (MO)

Lifetime Costs of Communication and Related Disabilities

**Allen E. Boysen, Ph.D. and Robert T. Wertz, Ph.D.
Department of Veterans Affairs**

*Paper Presented to
The National Conference on
Economic Consequences of Disabilities*

Washington, DC, September 29, 1993



1000 Piece Puzzle

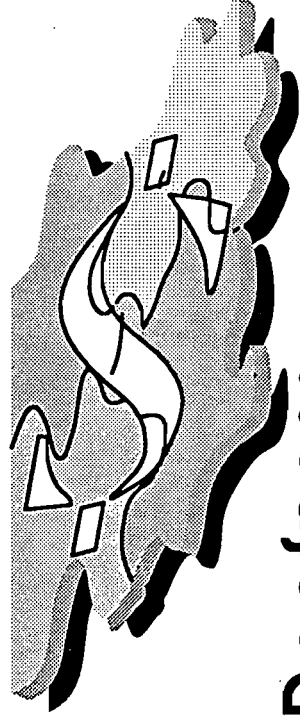
21" X 27"

Fully Interlocking

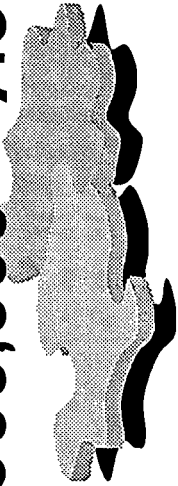
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Prevalence and Cost of Communicative Disorders



	<u>Estimated Cases</u>	<u>Cost of Illness</u>
Deafness	1,800,000	1.8 Billion
Partial Deafness	11,600,000	11.6 Billion
Speech Disorders	8,375,000	9.0 Billion
Language Disorders	6,600,000	7.53 Billion



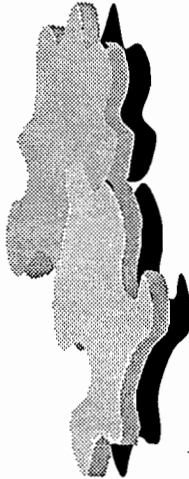


Focus

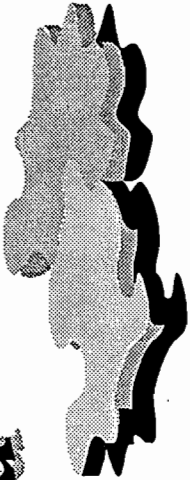
What we know - Costs

How to assess the unknown

Work that needs to be done



Communication and Related Disorders



Voice

Hearing

Speech

Balance

Language

Swallowing



Causes of Communication and Related Disorders in Adults

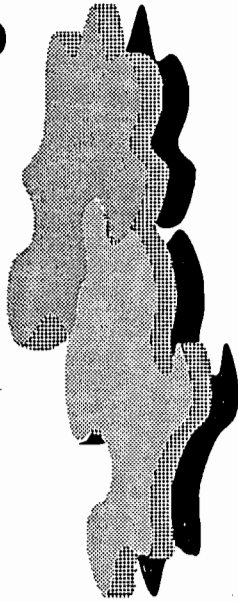
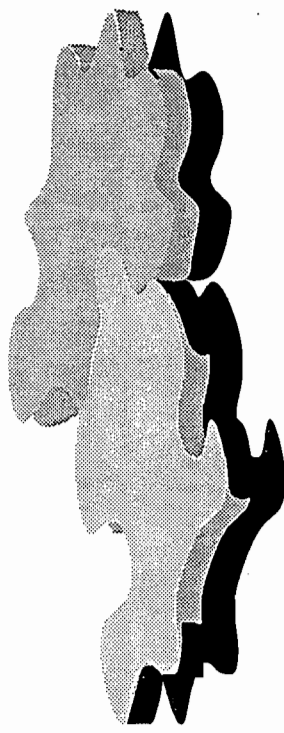
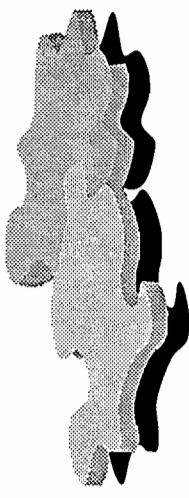
Neurologic Disease

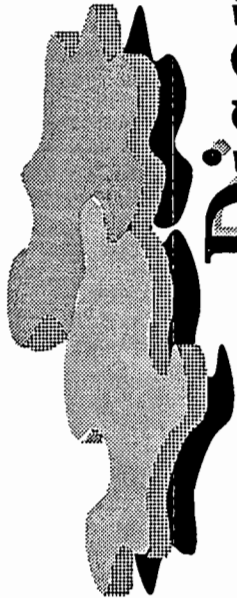
Stroke

Trauma

Cancer

Aging





Costs

Disorders of the Brain

Dementia

113 Billion

Stroke

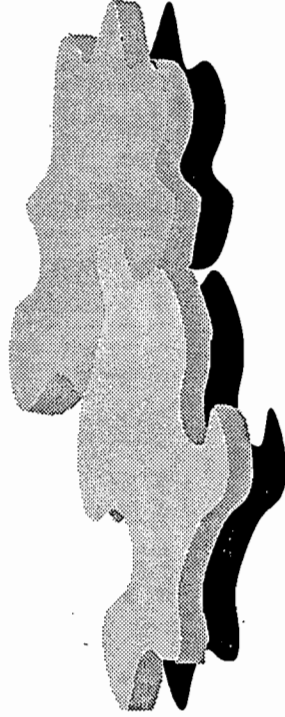
17.9 Billion

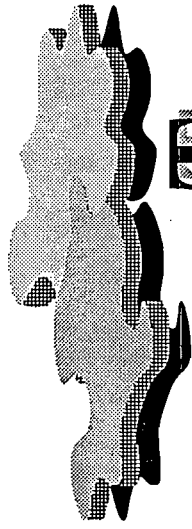
Head Injury

7.6 Billion

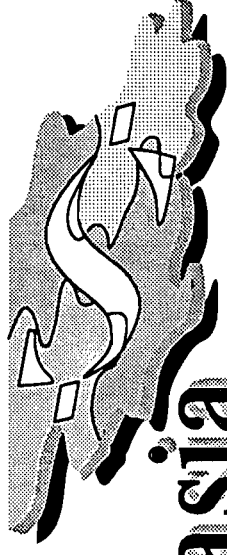
Multiple Sclerosis

7.5 Billion

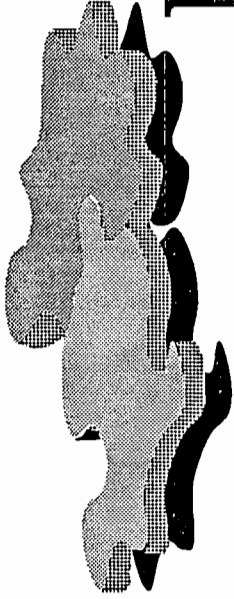




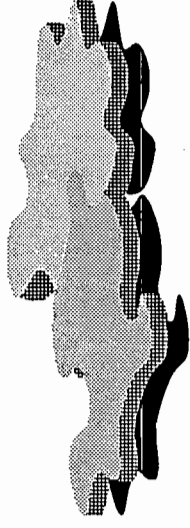
Costs Treatment of Aphasia



Study	Treatment		Efficacy	Cost/ Patient
	Hours	Duration		
Wertz et al. (1981)	6	44 Months	+	\$17,000
Wertz et al. (1986)	8	12 Weeks	+	6,000
Lincoln et al. (1984)	2	24 Weeks	=	3,000



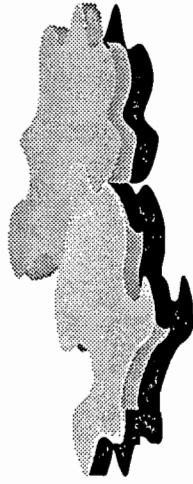
Costs Hearing Loss



Management	Mean	Range
▪ Hearing Aids		
National	\$ 700	\$ 400-2,000
Veterans Affairs	225	180-350
▪ Assitive Listening Devices		100-1,200
▪ Cochlear Implant	30,000	
▪ Interpreter	100,000	



Effects of Intervention on Costs



<u>Effect</u>	<u>Cost Effect</u>
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Intervention	+
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Discovery	+
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Substitution	-
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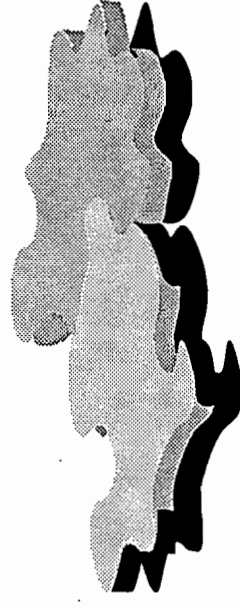
Health	-
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Productivity	-
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Quality of Life Costs

- Loss of wages and health insurance
- Dependency on family
- Augmentative communication devices
- Low self esteem, isolation, etc.



Need for Data

Need

Approach

Determine current costs

National information system

Valid outcome measures

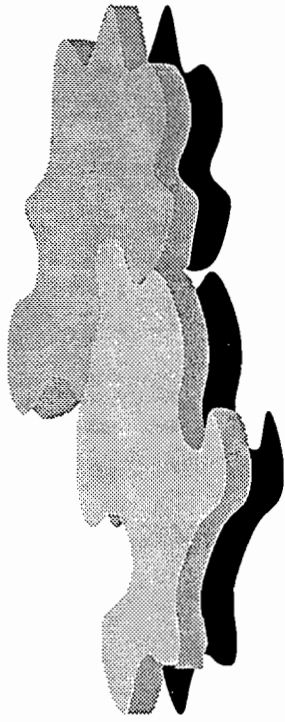
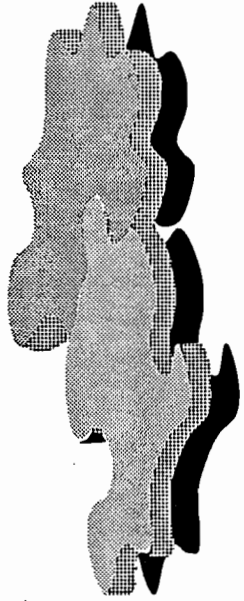
Function and quality of life

Cost vs. benefit

Multi-center trials

Assess technology

Innovative service delivery



Communication and Related Disorders

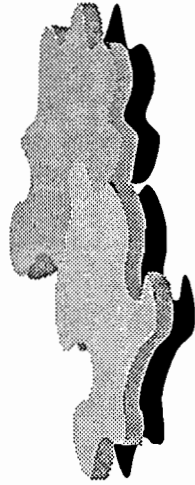
Persisting Questions



Cost of care ?

Effectiveness of the effort ?

How much is a word worth ?



PARALYZED VETERANS
OF AMERICA's
Research & Education Program Presents

4

*NATIONAL
CONFERENCE ON*
ECONOMIC
CONSEQUENCES
OF DISABILITIES

CONFERENCE
GUIDE

September 29, 1993

Mayflower Hotel • Washington, DC

as published in
ROLL CALL
THE NEWSPAPER OF CAPITOL HILL

Can Our Nation Do Without a Veterans' Health-care System?



PVA

**PARALYZED VETERANS
OF AMERICA**
Chartered by the Congress
of the United States

AUG 12 REC'D

August 11, 1993

Dear Colleague:

On July 19, 1993, Washington D.C.'s newspaper, *Roll Call*, published a series of announcements prepared by Paralyzed Veterans of America (PVA) outlining the significant role played by the Department of Veterans Affairs (VA) health-care system in the national health enterprise. We wanted to share a complete version of this series for your review.

The announcements outlined the irreplaceable contribution VA makes in providing a broad range of unique services for millions of disabled veterans. At the same time, the overview shows how VA innovations in health care delivery, cost-effectiveness, medical education and research must be allowed to continue to improve health care for all Americans in a reformed national health care system.

The Administration and the Congress are about to engage in an arduous, but mandatory task: reforming, realigning and improving the nation's cumbersome and inequitable health-care system. In doing so, we hope that all parties concerned in this effort will understand how VA health care performs now, and how it can contribute to help improve and reform health care for all Americans in the future.

If you would like additional information concerning the role of VA health care in the process of health-care reform, contact Mr. Russell Mank, PVA National Legislative Director or Mr. Richard Fuller, PVA Director of Health Policy Program Development at (202) 872-1300.

Sincerely,

Gordon H. Mansfield
Executive Director

②

THE ECONOMIC CONSEQUENCES
OF
TRAUMATIC SPINAL CORD INJURY

*Monroe Berkowitz
Carol Harvey
Carolyn G. Greene
Sven E. Wilson*

Demos

ECONOMIC CONSEQUENCES OF TRAUMATIC SCI: CONCEPT, DEFINITION, AND MEASUREMENT

Traumatic SCI imposes a tremendous burden on both affected individuals and society at large. In addition to pain and personal anguish, SCI persons must also cope with the immediate and long-term impact of this injury on their activities and life plans. Financial resources must be reallocated from other uses to meet the treatment, rehabilitation, and health-maintenance expenses of SCI. At the same time, earnings are reduced, either temporarily or permanently. In short, the SCI individual and close family members experience a decline in well-being.

Our objective is to quantify the costs attributable to traumatic SCI.¹ In this chapter, we begin with an overview of the concept, definition, and measurement of the costs of SCI. We first examine the conceptual framework that underlies the measurement of the costs of any illness or injury. We then provide definitions and descriptions of these costs, and examine measurement methodologies and issues. A brief review and critique of previous attempts to assess the costs of traumatic SCI follows. Finally, we close with a discussion of the data sources that we will utilize to measure the economic consequences of traumatic SCI; this discussion will focus specifically on the informational content of a survey questionnaire administered to a probability sample of SCI persons in the United States.

COSTS: A CONCEPTUAL FRAMEWORK

The incidence of spinal cord injury changes the lives of those who incur it, as well as the lives of their families and friends. These changes can take different forms, including

¹SCI is defined as a traumatic insult to the spinal cord and the associated nerves, whether or not disruption of the spinal cord by the bony vertebrae column is involved. This definition excludes any cases of injury to spinal cord nerves resulting from such diseases as syringomyelia, multiple sclerosis, amyotrophic lateral sclerosis, stroke, and tumors or abscesses of the spinal cord, as well as any traumatic event (e.g., head injury or concussion) where spinal cord injury is a secondary condition.

- changes in present and future consumption patterns as expenditures are reorganized to accommodate medical and rehabilitation costs;
- changes in work patterns, educational plans, or career objectives of the SCI person and of family members; and
- changes in the time available for leisure or the kind of leisure activities that the SCI person and family enjoy.

More technically, the incidence of this kind of injury alters the family's allocation of assets, income, and time. These alterations occur not only during the period in which the injury occurs, but over all future periods, since the effects of SCI are normally permanent.

In formal terms, we assume that rational individuals seek to maximize their welfare, or utility, where their utility function is expressed as follows:

$$U = u(C, L, M)$$

where U is utility or well-being; C indicates quantities of non-medical goods and services consumed; L is the quantity of leisure time consumed; and M is the quantity of medical goods and services consumed.

In other words, individuals will choose that combination of goods and services and leisure time that provides, in each individual's subjective judgment, the best possible outcome in terms of personal well-being. In general, utility or well-being is enhanced if more goods, services, or leisure time is made available for use; conversely, reductions in the amount of goods, services, and/or leisure time will result in a lower level of well-being.

Of course, there are constraints on these consumption opportunities. Specifically, everyone faces an income constraint in making utility-maximizing decisions. In our simple framework, this income constraint is expressed as follows:

$$p_c C + p_m M \leq w(24 - L) + A$$

where p_c and p_m are prices of non-medical and medical goods and services, respectively; w is an hourly wage rate [thus, $w(24 - L)$ indicates earnings from hours allocated to compensated work]; and A is income from financial assets or other non-labor sources.

In other words, expenditures on all goods and services cannot exceed income from all sources.

What does all this mean? In very basic terms, people make choices based on their own personal assessment of what is best for them and others close to them, within constraints imposed by their financial resources and conditioned by their expectations regarding future events. A person makes one set of decisions regarding career, consumption patterns, choice of lifestyle, etc., before the onset of SCI and, very probably, without any expectation that an SCI will occur. However, if SCI becomes a reality in this individual's life, all aspects of well-being are affected. Pre-injury consumption patterns must be shifted to accommodate a greater need for medical goods and services. Time will be reallocated away from preferred activities and towards basic activities of daily living such as personal care and mobility. Consumption of all goods and services may decline if SCI adversely affects the amount of income available.

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The framework presented above is highly simplistic. The model can be extended to present a more realistic view of the utility-maximization process in a variety of ways, including

- expansion to multiple time periods to account for individual maximization of expected lifetime utility;
- expansion or modification of the utility function to allow for additional or different choice variables; and
- explicit specification of risk of SCI.

Other studies, such as that presented by the Bureau of Economic Research (1985), have developed more sophisticated utility-maximization models along these lines. However, these enhancements do not change the basic thrust of our argument. Traumatic SCI affects an individual's well-being in that it forces that individual to make choices that would not have to be made in the absence of this condition. While the impact of SCI on various aspects of individual well-being may be either positive or negative, we would expect, a priori, that the net impact of SCI will be negative, i.e., that SCI persons experience a net decline in well-being after the onset of their injury. It is this change in welfare that constitutes the costs of SCI.

We want to stress that the adverse welfare effects of SCI are not confined to injured persons and their families. For example, SCI necessitates the reallocation of scarce medical goods and services away from competing uses and towards the treatment of SCI. The reduced productivity of SCI individuals means reduced production of goods and services for all to consume. These are but a few of the adverse social welfare implications of SCI.

Our mandate in this study is to estimate the economic consequences of SCI or, to be more specific, the costs incurred by the individual and by society as a whole when SCI occurs. The conceptual model presented above offers a framework for understanding why we can speak of SCI costs. Below, we consider the more concrete aspects of defining and measuring these costs.

DEFINING COSTS OF INJURY

Traditionally, analyses of costs of illness or injury distinguish between monetary and non-monetary impacts. Monetary costs are measurable resource costs and are further disaggregated into direct costs and indirect costs. Non-monetary (or intangible) costs are defined as the psychosocial consequences of illness, such as pain and suffering, changes in family relationships, loss of self-esteem, etc.

DIRECT COSTS

Direct costs are those expenditures that are incurred by the SCI person as a direct result of injury (and that would not have materialized otherwise). In more formal terms, direct costs entail a diversion of *existing* resources from alternative uses to SCI-related uses. Direct costs of SCI include (and are not necessarily limited to) the following:

- additional expenditures on medical care (medical practitioners, hospitalization, drugs, medical tests and procedures, etc.) over and above what a person would incur in the absence of SCI;
- expenditures on mobility aids and devices, hygiene aids, special equipment, etc., necessitated by SCI;
- expenditures on physical therapy, rehabilitation, training, counseling services, etc., resulting directly from the SCI;
- costs of transportation to/from medical facilities, physicians' offices, rehabilitation sessions, etc.;
- costs of environmental modifications to accommodate SCI; and
- costs of personal assistance.

These direct costs are not solely confined to the SCI individual. Other members of society will also bear the direct effects of SCI. An obvious set of external direct costs are those faced by friends and family members of SCI individuals. Friends and family members must often divert their time and other resources from alternate uses to the care of SCI persons. Many of the costs faced by these persons are indirect costs (defined below), but there are direct costs as well. These could include, for instance, the transportation costs entailed in visiting an SCI individual at a distant treatment center.

Another broad category of direct costs are those faced by organizations, such as government, rather than by individuals. These include the construction of hospitals and other treatment facilities, medical and other SCI-related research, insurance administration, and litigation. Any organization that is concerned with the SCI population, whether it provides actual funds for the treatment of SCI individuals or not, incurs direct costs.

One must be careful, however, to avoid double-counting when considering costs imposed on the non-SCI population by SCI. One source of double-counting results from confusing direct costs with indirect costs. For instance, if the value of the services that a spouse provides to the SCI individual is counted as a direct cost, the total value of foregone income for that spouse cannot be included in indirect costs.

Another example of double-counting when estimating external costs is attributing hospital construction costs to SCI. Part of the cost of SCI is found in the construction of hospitals. Hospital construction costs, distributed over the expected life span of the facility, cannot be included separately in SCI direct costs since a portion of this construction expense is passed on to patients in the form of medical charges and is thus already partially accounted for in hospitalization expenses for the SCI individual. This problem is compounded by the difficulty in disaggregating or dividing the costs of the hospital among all different health conditions treated at the hospital. Because of these complicated accounting issues and data limitations, these external costs of SCI are largely ignored in the literature.

INDIRECT COSTS

Indirect costs refer to the value of *potential* output that is lost as a result of any reduction or elimination of work or other activity due to SCI. These costs are measured as the losses in output that occur due to the reductions in productivity that result from morbidity or mortality attributable to SCI. These losses manifest themselves in two

ways. There may be a reduction in actual hours devoted to some productive activity, or there may be a reduction in on-the-job performance, in terms of output per person-hour. These costs, therefore, include the value of output lost as a result of changes in time available for work, reduced efficiency, or both. They also include the loss in the value of other non-market activities, particularly leisure, that the SCI person suffers due to the disability. Additional indirect costs may include time spent visiting a medical care provider, undesired job changes, loss of promotion or educational opportunities, and so on.

For the SCI individual, these losses may be quite sizable, particularly if the onset of SCI completely eliminates any ability to pursue productive activity. On the other hand, there is evidence from existing studies that many SCI persons can and do resume their employment or household responsibilities post-injury; the onset of SCI has meant only a temporary disruption in their employment and earnings patterns. Still, other SCI persons must make some accommodation in their career and employment plans as a result of their injury. These changes may be negative (e.g., a reduction in work hours, or a change to a lower-paid occupation) or positive (e.g., a change in career interests leading to a more highly paid occupation).

Once again, these are costs that are not incurred solely by the SCI person. Family members may be forced to change their current employment status (i.e., either quit work to take care of an SCI person or seek employment in order to pay the bills). Future earnings will be affected if the financial burdens of SCI mean that the education of children or siblings of an SCI person cannot be financed.

PSYCHOSOCIAL COSTS

For the most part, the direct and indirect costs discussed above are, at least conceptually, measurable quantities. The third category of costs, psychosocial costs, are not easily quantified, at least using more traditional cost-of-illness approaches.² These costs are more intangible entities that reflect the impact of traumatic SCI on the emotional, psychological, and social well-being of the SCI person and family.

SCI individuals certainly suffer physical pain as a result of their trauma; however, they are also beset by the emotional and psychological effort of adjusting their attitudes, lifestyles, and activities to accommodate the physical limitations imposed by their injury. Their self-esteem may be adversely affected as they struggle to accept their inability to engage in many of their former pursuits. Limitations on their physical activities and their increased dependence on others for assistance with basic activities of daily living may create resentment, depression, or other emotional problems.

The negative psychosocial costs of SCI may extend beyond the affected individual. Family and friends will also experience emotional and psychological impacts as they too struggle to cope with this condition. Social and familial relationships are redefined as the roles of various family members change in the face of SCI. The spouse who was previously working may now be forced to leave employment in order to care for the SCI person. Funds previously meant for a child's education may now be redirected towards medical and living expenses. While these types of changes have mea-

²The willingness-to-pay (WTP) model does implicitly include these types of costs. We will have more to say about these methodologies below.

asurable impacts as indirect costs, they also exact a toll on the fabric of family relationships. Family members may experience stress and resentment resulting from the changes in their lifestyles forced on them by SCI. Divorce after SCI is not uncommon.

While many of the probable (and documented) psychosocial impacts of traumatic SCI are negative, there remains the potential for some positive impact as a result of this injury. The experience of SCI may strengthen a person's character and will, and may result in the accomplishment of goals that would not have been realized in the absence of SCI. Adversity can also bring people together, as well as drive them apart. For example, a few of our survey respondents reported that SCI in their lives resulted in enhanced relationships with their spouses or others. These positive responses associated with traumatic SCI were, however, few and far between. We will have more to say about some of these non-monetary impacts of SCI in Chapter 10.

MEASURING COSTS OF INJURY

Having defined what constitute the costs of SCI, we now discuss how these impacts should be measured. This discussion provides a framework for reviewing the existing literature on SCI costs presented later in this chapter, and sets the stage for our efforts. We then compare methodologies that have been used to assess the cost of illness or injury, and explain the rationale for the approach that we elect in our analysis.

ISSUES IN THE MEASUREMENT OF COSTS OF SCI

Our discussion will focus on four specific areas:

- the concept of prevalence- versus incidence-based costs;
- the concept of incremental costs;
- the necessity of using a constant (fixed) market price to measure costs; and
- the notion that SCI costs are measured independently of source of payment.

Each point is treated separately below.

Prevalence- Versus Incidence-Based Costs

One major decision faced in estimating the costs of traumatic SCI is the choice between an incidence- and prevalence-based approach. An incidence-based approach measures the costs associated with all new injuries occurring within a given period (usually one year), while a prevalence-based approach measures costs incurred by all SCI individuals alive in a given period.

The primary focus of the incidence approach is on the SCI individual. The goal of the incidence approach is to measure expected lifetime costs for the SCI individual and to pinpoint the stages in that individual's life where different costs occur. The costs incurred by the individual may vary with age, sex, year of injury, functional limitations, and many other factors. The proper incidence approach will take these differences into account and will provide a basis for estimating the lifetime costs of an SCI individual with a particular set of characteristics.

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lar, are the most frequent victims of SCI. These are the persons who engage in the riskier activities where accidents that result in SCI are most likely to occur. No matter which group we examine, veteran or non-veteran, young or old, we find that the leading cause of traumatic SCI is involvement in a motor vehicle accident.

In the aggregate, SCI is costly. Our estimate is that traumatic SCI cost our nation \$5.6 billion in 1988 in lost output and foregone consumption opportunities. If we could have prevented all SCI in 1988 and in all years thereafter, the savings would be well over \$250 billion—quite enough to wipe out the entire 1990 U.S. federal deficit!

By any standard, these estimates are conservative. Our data base represents only those persons who survive their initial trauma; the relatively small direct costs and very large indirect costs associated with SCI fatalities are not reflected in these costs. Furthermore, we could not capture all of the direct and indirect costs incurred by this population, although we included most of the more obvious impacts. Finally, purely monetary measurements of SCI costs cannot hope to convey the full impact of SCI on lives and lifestyles.

All of our costs are incremental costs. We measure not what people spend each year for medical care, but what the SCI person spends on medical care costs because of the SCI. Our indirect costs measure is not one of lost earnings, but the difference between what the SCI person is earning and what that person would have been earning had the SCI not occurred. We do not pretend to be able to measure such incremental costs with absolute precision, but we would argue that our approximations are more accurate than if we had assumed that all costs are SCI costs.

USING THE INFORMATION

The notion of incremental costs is inherently appealing to economists who are fond of examining the changes that take place at the margin. In much the same way, we have to look at what is likely to happen to prevent, treat, or even cure SCI. Nothing is likely to happen overnight to cure all present cases of SCI, or to prevent all future cases from happening. The real issue is not whether we can or cannot save \$200 billion, but whether it is worthwhile to mount a particular research project, install a particular EMS system, or investigate the effects of a particular drug. In this world of limited resources, it is perhaps unfortunate, but true, that different diseases and impairments compete fiercely for both public and private funds. Sometimes the issue is whether research into one particular ailment or injury should be supported over another. In such a world, it is useful to have some information about benefits to be derived from certain activities. Is it cost beneficial to allocate the \$50,000, or the \$250,000, or whatever the sum involved, to fund a particular project? If the claim is made that there is a particular probability that such expenditures can prevent a given number of SCI injuries, or alleviate the effect of these injuries, we have a data base that can provide measures of the costs that might be saved.

The measurement of aggregate impacts ought not be neglected. It can provide a dramatic impact by highlighting overall global costs of SCI, but it is hardly the whole story. The survey data we have accumulated allow us to estimate the costs of small changes. It allows us to look at the costs for particular groups of persons. It also allows us to examine the differences in what we broadly term "outcomes" among dif-

ferent groups in evaluating

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THE WHITE HOUSE

WASHINGTON

September 27, 1993 revised 9-28-93 11a.m.

MEMORANDUM FOR CAROL H. RASCO

From: Stan Herr (x2372)

Subject: Briefing for your presentation to Paralyzed Veterans National Conference on the Economic Consequences of Disabilities

Materials Attached

1. letter of invitation
2. Conference speaker list and agenda
3. Putting People First, pp. 161-163.

- You are making the Keynote Address, September 29th at 10:00 - 10:30 under the not-so-descriptive title "Thanks for Believing."

- You mentioned that you were planning to sit down with someone from the VA in preparation for this speech. If you would like for me to followup or make contact with a particular person there, please advise. I really don't have much information at hand that is on specific point. [GIVEN THE POTENTIAL VALUE OF THIS CONFERENCE, I PUT SOME MORE TIME INTO GATHERING THEMES AND INFORMATION FOR YOUR TALK, WHICH I OFFER AT THE ADDENDUM BELOW).

- PPF on veterans recites pledges to fund programs on mental health problems of veterans, such as post-traumatic stress syndrome. Perhaps a VA or NIMH official could tell us what we have done in that field and how it reduces negative economic consequences.

- PPF also asks veterans and their providers to believe that we will "ensure that the VA receives the funding it needs to provide excellent, timely care to veterans." Here again we need info from the VA on accomplishments, areas for improvement, and the preventive argument --e.g., excellent timely care avoids more costly, custodial care or the harms to the community of untreated impairments, such as Larry Hogue, the so-called wildman of New York's West Side, a veteran with various mental disorders who has been terrorizing the neighborhood around Columbia University and who is now back out of the revolving-door mental health system to the consternation of New Yorkers and the editorialist of the N.Y.

Times.

- The two prior speakers before your keynote are Administration folks -- Paul Miller of Personnel and Peter Edelman of HHS. I can ask Paul and Peter what they intend to cover, to reduce overlap. [PAUL IS STILL WORKING ON HIS REMARKS, BUT IS LIKELY TO HIGHLIGHT JOB BARRIERS, HIS PERSONAL EXPERIENCES, SOME OF THE ADMINISTRATION'S APPOINTEES WITH DISABILITIES, ETC.]

- One of the leading authors in the field of economics and disability is a long-time federal employee. Ron Conley has written The Economics of Mental Retardation and the Economics of Vocational Rehabilitation. I will borrow these books tonight to see if there are any zippy statistics on payoffs per dollar spent on rehabilitation or the like. Please give me some feedback on what themes you intend to stress, or whether I can be of any further help.

- My efforts to gain more information on the size and nature of the audience have so far been for naught, as I've left voice mail messages with three officials at the sponsoring PVA. I'll update you with anything I subsequently learn.

- Do you want to touch on health care reform and some of the preventive measures as reducing disabilities and hence costs (i.e. prenatal checkups to prevent birth defects; public health measures to avoid fetal alcohol syndrome)? If so, the relationship to the VA health care system may come up.

ADDENDUM -- 9-28-93

Additional Documents attached

4. Final program -- "Conference Guide"
5. participant list
6. Excerpts from Ron Conley's book The Economics of Mental Retardation
7. ditto, The Economics of Vocational Rehabilitation.
8. Excerpt from the PVA-commissioned book, Monroe Berkowitz et al, The Economic Consequences of Traumatic Spinal Cord Injury

- Audience of 200 persons expected -- very impressive cross-section of public officials, NGO advocates, academicians with interests in whole spectrum of disabilities (see #5).

- Conference Guide has your detailed bio at page 1, speaker abstracts (see esp Berkowitz, Brigham, Fahey, Parker, Wikler for new data and perspectives, and PVA mission at page 12 ("leading advocate for quality health care for our members [15,000 vets with spinal cord injury or dysfunction] ... civil rights and

opportunities which maximize the independence of our members.")

- PVA can also be commended for its recent publication (Aug. 1993) of the Berkowitz, Harvey, Greene and Wilson book. Its highlights are attached, but the most eye-catching points are the size of this population (177,000 spinal-cord injured persons in the US), average costs of initial hospitalization (+\$95,000) and home modifications (\$8,000), and the huge societal incentives to prevent such injuries (total cost in one year alone = \$5.6 billion; and if we could have prevented all SCI in 1988 and in all years thereafter, a savings of over \$250 billion dollars.). NOW THERE'S A GREAT WAY TO REDUCE THE NATIONAL DEFICIT! See # 8, pp 9-14, p. 192.

- You can draw some dramatic contrasts with the past. In two pioneering studies, Ron Conley drew attention to the prevalence of workplace discrimination against persons with disabilities. In 1960, when DOL surveyed employers on their willingness to hire qualified handicapped persons, 48% openly admitted they would not hire the orthopedically disabled, 65% would not hire those with a back disability, and 70% would not hire persons with epilepsy. Consider the cumulative costs of such discrimination, and the likelihood of even greater prejudice by less candid employers. Under the ADA and Section 504 of the Rehabilitation, the Administration and the disability community now have the tools to combat such discrimination against persons with disabilities. See # 6.

- When Conley wrote in 1965, the total public and private expenditure for all health and medical care was said to be \$29 billion, consuming 5.7% of GNP. He had no means then of even knowing the proportion of that total devoted to chronic disabling conditions. Today the figure is \$900 billion, and the proportion of GNP is 14%. The value of a dollar may have changed in 30 years, but we still have not eliminated the health coverage concerns that persons with disabilities and their families fear. WE KNOW THAT WITHOUT ADOPTING THE PRESIDENT'S AMERICAN HEALTH SECURITY ACT PERSONS WITH DISABILITIES WILL CONTINUE TO EXPERIENCE DISCRIMINATION IN HEALTH INSURANCE AND IN THE JOB MARKET. AND EVEN THOSE WHO MAY LIKE THEIR CURRENT COVERAGE, WILL FEAR TO CHANGE JOBS LEST THEY LOSE THEIR COVERAGE. THOSE ECONOMIC CONSEQUENCES OF DISABILITIES ARE AVOIDABLE, AND WITH YOUR HELP WE WILL ELIMINATE THEM!

- Conley in 1973 -- two decades ago -- wisely focused on the need for prevention noting that with wise medical provisions to expectant parents, the prevention of a single birth of a child with severe retardation would yield a per person savings of a million-dollars, and that's in 1970 dollars. On a cost benefit analysis, he reckoned that every dollar of education costs would yield seven dollars in the present value of future earnings. See # 7.

- Today, the President's Committee on Employment of People

with Disabilities estimates that a dollar of vocational rehabilitation will yield \$18 in future earnings. However, there is no cause for complacency -- with 2/s of the nation's disabled folks unemployed or underemployed, the lost economic costs may reach a staggering \$200 billion. (Source: Rick Douglas, Exec. Dir, PCEPD).

a:speech.PVA



**PARALYZED VETERANS
OF AMERICA**
Chartered by the Congress
of the United States

Item 1

September 18, 1993

Honorable Carol Rasco
Assistant to the President
for Domestic Policy
The White House
Washington, DC 20500

Dear Honorable Ms. Rasco:

This letter provides confirmation of your participation in the National Conference on the Economic Consequences of Disabilities, to be held at the Mayflower Hotel in Washington, DC on September 29, 1993 from 8:30 am to 6:30 pm. You will give the Keynote Address, "Thanks for Believing," from 10:00 to 10:30 a.m.

I would appreciate your presence during the entire conference, but realize that you may have conflicting commitments. Therefore, above I have provided as narrow a time interval for your presentation as I could. Recall that lunch will be provided at 12:30, and that a reception will follow the conference from 6:30 to 8:30 pm. Attached is a copy of our finalized schedule.

Thank you for your support.

Sincerely,

Margaret J. Giannini, M.D., F.A.A.P.
Program Chairperson

2

NATIONAL CONFERENCE ON ECONOMIC CONSEQUENCES OF DISABILITIES

September 29, 1993
8:30 am - 6:30 pm
Mayflower Hotel
Washington, DC

Chairperson - Honorable Margaret J. Giannini, M.D.
First Director of the National Institute on Disability
and Rehabilitation Research

8:30 - 9:00 COFFEE

9:00 - 9:15 WELCOME AND INTRODUCTIONS

Richard F. Johnson, National President
Paralyzed Veterans of America
Washington, DC

John C. Bollinger, Deputy Executive Director
Paralyzed Veterans of America
Washington, DC

9:15 - 10:00 OPENING REMARKS

Honorable Paul S. Miller
Director, Disability Outreach
Office of Presidential Personnel
White House

Peter Edelman, Esq.
Counselor to Secretary Donna Shalala
Department of Health and Human Services
Washington, DC

10:00 - 10:30 KEYNOTE ADDRESS

Honorable Carol H. Rasco, M.S.
Assistant to the President
for Domestic Policy
White House
"Thanks for Believing"

10:30 - 11:00 COFFEE BREAK

11:00 - 12:30 **SESSION ONE**

Moderator

- Margaret J. Giannini, M.D.
Program Chairperson
Paralyzed Veterans of America
Washington, DC

Edward A. Eckenhoff, M.A., M.H.A.

President

National Rehabilitation Hospital

Washington, DC

"Rehabilitation Services in the 21st Century -
Plight, Flight or Fight!"

Dorothy P. Rice, B.A.

Professor

School of Nursing - Institute for

Health and Aging, University of California

San Francisco, California

"The Burden of Disability: Conceptual and Methodological
Issues"

Susan B. Parker, M.S.W.

Former Associate Commissioner for Disability

Social Security Administration

Washington, DC

"Economics and Rehabilitation Outcomes: the U.S. Experience"

Daniel Wikler, Ph.D.

Professor

Program in Medical Ethics

University of Wisconsin

Madison, Wisconsin

"Disability and Health Care Prioritizing"

12:30 - 2:00 **LUNCHEON**

Introduction of Speaker -

Joseph Shapiro

Associate Editor

US News and World Report

Washington, DC

Luncheon Address -

George A. Covington, Esq.

Disability Advocate

Washington, DC

"Myths, Stereotypes and Money"

2:00 - 3:30 **SESSION TWO**

Moderator

- Henry Viscardi, Jr., L.L.B.
Founder and President Emeritus
National Center for
Disabilities
Albertson, NY

David L. Brigham, B.A.

Former Deputy Director of Handicapped

Department of Labor

Washington, DC

"Labor and Disabilities: It Takes All Hands"

Corinne Kirchner, Ph.D.
 Director of Social Research
 American Foundation of Blind
 New York, NY
 "Economic Aspects of Low Vision/Blindness: Rehabilitative Perspectives"

Jonathan C. Javitt, M.D., M.P.H.
 Director, Center for Sight
 Georgetown University Medical Center
 Washington, DC
 "Economic Aspects of Low Vision/Blindness: A Preventive Perspective"

Allen E. Boysen, Ph.D. and Robert Wertz, Ph.D.
 National Director of Speech and Audiology
 Department of Veterans Affairs
 Washington, DC
 "Life Time Cost of Communication and Related Disabilities"

Ernest M. Burgess, M.D.
 President
 Prosthetic Research Institute
 Seattle, Washington
 "Economic Consequences of Rehabilitation Management Systems of Amputees"

3:30 - 4:00 COFFEE BREAK

4:00 - 5:45 SESSION THREE
 Moderator

- Reverend Harold Wilke
 Director
 Community Living
 Claremont, California

Monroe Berkowitz, Ph.D.
 Professor Emeritus of Economics
 Rutgers University
 New Brunswick, New Jersey
 "Economic Consequences of Spinal Cord Injury"

x { Honorable Helen L. Smits, M.D., M.A.C.P.
 Deputy Administrator
 Health Care Financing Administration
 Washington, DC
 "Medicare and Medicaid Financing of Services for the Disabled"

Margaret E. Fahey
 Vice-President and Claims Director
 Commercial Life Insurance Company
 "Insurance Reimbursements and Claims for Disabilities"
 Piscataway, NJ

Kathryn S. McCarty, Esq.
Assistant Staff Director
Commission on Mental and Physical Disabilities Law
American Bar Association
Washington, DC
"Negotiating the Legal Quagmire--Available Resources"

Charles D. Goldman, Esq.
Attorney at Law
Washington, DC
"Coping With Government and Lawyers: A Practical
Primer on ADA"

5:45 - 6:15 **SUMMATION**

Marcus J. Fuhrer, Ph.D.
Director
National Center for Medical Rehabilitation Research
National Institutes of Health
Bethesda, Maryland

6:15 - 6:30 **PRESENTATION OF CAREER ACHIEVEMENT AWARD**

By Laurance S. Johnston, Ph.D.
Director of Research and Education
Paralyzed Veterans of America
Washington, DC

To David B. Gray, Ph.D.
Deputy Director
National Center for Medical Rehabilitation Research
National Institutes of Health
Bethesda, Maryland

6:30 - 8:30 **RECEPTION**

encouraging companies to provide for employee ownership and profit sharing for all employees, not just executives.

- End tax breaks for American companies that shut down their plants here and ship American jobs overseas.

Veterans

FOR DECADES Americans struggled and sacrificed to defend freedom and democracy, and to win the Cold War. Our nation owes a great debt of gratitude to the soldiers, sailors, Marines, airmen, and airwomen whose talent and dedication led to our victory.

We have consistently supported veterans. We deeply appreciate the sacrifices of those who were called to serve our country and fight for the ideals for which it stands. Our veterans deserve only the best.

A Clinton-Gore Administration will work to improve health services at VA hospitals and preserve them strictly for veterans. We must ensure that men and women in the armed services and the defense industries have opportunities to shift their talents to the civilian sector. We offer a detailed plan to utilize their talents and energies to meet our pressing needs at home in the fields of medicine, education, law enforcement, and industrial technology.

Here's what we need to do:

Health Care

- *Appoint a Secretary of Veterans Affairs* who understands the real problems facing veterans and can go di-

Item 3

rectly to the President to cut through bureaucracy and improve services for our veterans.

- *Ensure that the VA receives the funding it needs to provide excellent, timely care to veterans and oppose opening VA hospitals up to nonveterans.*
- *Cut bureaucracy at the VA to decrease waiting periods for outpatient services and to ensure that benefits arrive on time.*
- *Ensure advance notification of any changes in benefits packages and programs for disabled veterans.*
- *Fund programs to deal with the common mental health problems of veterans, such as post-traumatic stress syndrome.*

Employment in a Post-Cold War Economy

- *Gradually scale down our military forces by shifting military personnel from active duty to the National Guard and reserves and gradually limit recruitment and reenlistment efforts.*
- *Provide early retirement incentives, with a prorated pension for military personnel with fifteen to twenty years of service to encourage voluntary military downsizing.*
- *Work with states to provide alternative certification programs for military personnel who retire to take jobs in critical professions like education, health care, or law enforcement, and increase their military credit by one year for each year of such employment.*
- *Train military personnel for critical civilian professions by allowing them to take a one-year educational leave of absence with pay before officially beginning their retirement.*

Taking Care of Our Soldiers

- *Expand veterans centers to help veterans, their spouses, children, and other family members learn to deal with the scars of war.*
- *Assist homeless veterans by converting closed military bases to homeless shelters, with priority for veterans. These centers should provide medical care, job training, and job counseling.*
- *Make resolution of the POW/MIA issue a national priority by insisting on a full accounting of all POWs and MIAs before normalizing relations with Vietnam, working with the Russian government to reveal any information it has on Americans held, and declassifying pertinent government documents.*
- *Reevaluate the discharge process, particularly as it affects Vietnam veterans and the enforcement of the statute of limitations.*

6

The Economics of Mental Retardation

Ronald W. Conley

*The Johns Hopkins University Press
Baltimore and London*

Table 58. Combined costs of educational, clinical, and rehabilitation services to retardates, age 18 in 1970

	Not Compounded	Compounded
Mildly retarded		
All regular education	\$13,500	\$19,000
All special education	21,300	31,300
Combination	17,600	24,500
Moderately retarded	32,500	45,000
	Decrease in benefit-cost ratios of Tables 55 to 57 if combined costs were used in denominator	
Mildly retarded		
All regular education	29%	
All special education	18%	
Combination	22%	
Moderately retarded	16%	

The following observations are made: (1) The lifetime earnings of mildly retarded adults are many times the cost of their education. The present value of the future earnings of continuously employed mildly retarded males who divide their school years between regular academic and special education classes is almost seven times the present value of the cost of their education. Adjusting this figure for the percentage employed reduces the ratio of the present value of future earnings to the present value of costs to a little less than six. This lower figure may represent a more realistic appraisal of the actual ratio of earnings to costs. Adjusting these ratios for this value of unpaid work would, of course, raise them about 25%.

These ratios increase if it is assumed that the retarded attend all regular academic classes and decrease if it is assumed that they attend all special education classes. Although these ratios can be used to represent high and low estimates of the benefits and costs of providing education to the retarded, the intermediate case is the more typical one. Whatever the combination of assumptions used to represent the benefits and costs of educating mildly retarded males, the benefit-cost ratio greatly exceeds the critical value of "1."

2) In the case of continuously employed mildly retarded women, the present value of lifetime earnings was four times the present value of educational costs. If women were assumed to be full-time homemakers, the ratio was over three to one. The lower benefit-cost ratios for mildly retarded women reflect the less favorable earnings position of women in general and probably, also, an under evaluation of home-

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\$1,000 in 1970, and death rates are assumed to be three times normal.

The data in Table 61 are presented in summary form in Table 62. It must be emphasized that these are estimates that are subject to change as better information (or theory) becomes available or as conditions change. In particular, the benefits of preventing moderate retardation may decline if better services enable greater numbers of these individuals to be placed on more productive jobs. On the other hand, an improved quality of maintenance and developmental services may cause an increase in these figures. In addition, these estimates are, as has been emphasized, only partial measures. Although most of the omitted benefits are well known, one that is worth mentioning is that we cannot value the creative and innovative efforts of the scholars and inventors who would be part of the nonretarded groups resulting from the replacement form of prevention.

What conclusions can be drawn? First, the benefits of prevention are large. The prevention of a case of severe retardation (IQ less than 40) among males enables society to make a gross gain (undiscounted) of almost \$900,000 over a person's lifetime in the replacement case. This is the value of the resources, saved and created, that would be available to improve the average standard of living. These estimates are in 1970 dollars—continuing inflation and productivity change will increase the per-person value of preventing severe retardation to the million-dollar level in the near future.

Although the social gain of preventing severe retardation among women appears to be considerably less, it must be emphasized that this is a consequence of the lower average earnings of women and that this difference will decrease and perhaps disappear over time, as the earnings of women approach equality with those of men. On a discounted basis, the benefits remained impressive, being over \$200,000 in the replacement case of preventing severe retardation among males.

In the nonreplacement case the tangible economic benefits are lower but highly significant. In the case of the severely retarded, the nondiscounted value of prevention is about \$250,000 per case and on a discounted basis about \$135,000. The value of preventing severe retardation was slightly greater for women than for men, because earnings were not a factor in the calculations, and severely retarded women were assumed to require more subsidized support than severely retarded men.

The value of prevention declines as less severe levels of retardation are considered, although in no case can the value of prevention be regarded as insignificant.

Total output in the United States was about \$3.4 billion greater in 1970 than it would have been had the prevalence of persons with IQs

SUMMARY

1. Despite the crucial importance of comparisons of benefits and costs for decisionmaking, benefit-cost analyses of expenditures on the mentally retarded have many limitations which must be fully appreciated if these analyses are to be useful. These limitations are both conceptual and empirical. Among the more important of these limitations are the difficulty of identifying all the costs that should be compared with the lifetime earnings of the retarded (or relating a portion of lifetime earnings to a particular cost) and the problem of determining an appropriate discount rate.

2. The lifetime earnings of retarded workers are high. A mildly retarded male who entered the work force at age 18 in 1970 could expect lifetime earnings of over \$600 thousand dollars. This estimate assumed a 2.5% growth rate of productivity and is expressed in terms of 1970 prices. The present value of these earnings when discounted at 7% was \$131,000. Among women and the moderately retarded these values were, of course, considerably lower.

3. Each dollar expended on the vocational rehabilitation of 18-year-old mildly retarded adult males generates an estimated increase in future earnings of \$14 in present-value terms. The ratios declined among older retardates, women, and the more severely retarded, but in all cases were equal to or greater than the critical value of "1," and in most cases, far above this value.

4. The lifetime educational costs of the mildly retarded were far below their estimated lifetime productivity, stated in present-value terms, even if they attended special education classes for the entire time they were in school. These comparisons were much less favorable for the moderately retarded, although it is probable that the data underestimated their earning potential.

5. The custodial costs (those exclusive of normal consumption and developmental expenditures) of lifetime institutionalization of the retarded are almost \$400,000 (1970 dollars). Prevention of institutionalization may be a significant part of the benefits of extending additional community services to the retarded.

6. A substantial share of the benefits of developmental expenditures on the retarded are received by taxpayers, in the form of reduced provision of public maintenance and increased tax payments, probably about one-half of their earnings.

7. The benefits of prevention are large. For each case of severe retardation among males that is averted, the undiscounted total gain to society is almost \$900,000 (1970 dollars). For an 18-year-old adult in 1970, this would have a present value of over \$200,000.

8. Prevention is a percentage of per- white children, th crease by almost \$ about \$800 millio ards.

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or each case of severe retar- undiscounted total gain to or an 18-year-old adult in \$200,000.

8. Prevention is important. If all groups in society had the same percentage of persons with IQs below 50 as upper- and middle-class white children, the prevalence of this level of retardation would decrease by almost 80%. In 1970 this would have meant an increase of about \$800 million in the resources available to improve living standards.

9. Since the causes of retardation are diverse, prevention must be comprised of many programs. The four programs considered in this chapter appeared justified on the basis of economic returns alone.

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THE ECONOMICS OF
VOCATIONAL
REHABILITATION

BY RONALD W. CONLEY
||

THE JOHNS HOPKINS PRESS
BALTIMORE

Community attitudes are more subtle, but are frequently just as effective in denying suitable work to the handicapped. It is unlikely, for example, that many communities would hire an epileptic, especially if he had occasional seizures, as a high school instructor. Some persons would refuse to permit a cerebral palsied sales person to wait on them in a department store. Few employers would place persons suffering from such handicaps in positions of these types; and to cite a final example, few people would knowingly engage the services of a lawyer who had previously suffered from mental illness.

Ultimately, of course, it is the employer who must decide whether or not to hire a disabled person. Two recent studies have collected convincing evidence that most employers, for a variety of reasons, discriminate against one or more types of handicaps when hiring. A 1958 New York City interview survey of the hiring policies of 347 firms employing 200 or more persons found that:

- 14 per cent would not, as a matter of policy, hire the orthopedically handicapped;
- 37 per cent would not hire cardiacs;
- 50 per cent would not hire the cerebral palsied;
- 65 per cent would not hire epileptics; and
- 68 per cent would not hire the visually impaired.¹³

A 1960 questionnaire survey by the Department of Labor elicited replies from 1,221 employers in 6 states, a 41 per cent response, to the question of whether they would be willing to hire qualified handicapped persons. According to the replies:

- 70 per cent would not hire epileptics;
- 65 per cent would not hire individuals with a back disability;
- 61 per cent would not hire individuals with a dust disease or lung ailment;
- 52 per cent would not hire individuals with a heart or circulatory ailment;
- 48 per cent would not hire the orthopedically disabled (other than those with back trouble) or persons suffering from loss of (or loss of use of) limbs; and

¹³ Abram J. Jaffe, Dorly D. Wang, and Preston David, *Survey of Employers' Practices and Policies in the Hiring of Physically Impaired Workers* (New York: Federation Employment and Guidance Service, 1959); percentages estimated from information in tables on pp. 11 and 26.

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45 per cent would not hire individuals with loss of (or loss of use of) hand, foot, arm, or eye.¹⁴

The two surveys clearly show that most employers refuse to hire persons suffering from some types of handicapping conditions. If anything, the surveys understate prejudice against the disabled, since some employers are understandably reluctant to admit the existence of discriminatory hiring practices. According to the surveys, persons with orthopedic handicaps other than back injuries tended to be the least unacceptable to employers, while the epileptic, the blind, and the back-injured were the most often rejected. Other disabling conditions not mentioned in the surveys may be even more unacceptable—e.g., mental retardation.

Although hiring practices prejudicial to the disabled are widespread, hiring policies may not be entirely inflexible. Employers with negative responses in the surveys may have been visualizing the more severe cases of disabling conditions. Handicaps have a wide range of severity, and many of these employers may knowingly have hired well-adjusted handicapped persons, especially those with moderate outward manifestations of their conditions. They might even have been surprised to hear these persons called handicapped.

The bitter remarks of Bonnie Jean Garret, 37, cerebral palsied, add meaning to the statistics:

It was after college, business school, and innumerable stretches as a volunteer worker on community projects that I was often bogged down by the medieval prejudices and superstitions of the business world. Looking for a job was like standing before a firing squad. Employers were shocked that I had the gall to apply for a job. Training and experience were ignored, and ambition was considered an inexcusable form of insanity.¹⁵

Employer resistance to hiring the handicapped springs from numerous personal and economic causes. Apparently the major reason is that many employers feel that the handicap itself, especially if coupled with age or lack of education, constitutes sufficient evidence of the

¹⁴ U.S. Bureau of Labor Standards, *Workmen's Compensation and the Physically Handicapped Worker* (Department of Labor Bulletin 234; Washington: U.S. Government Printing Office, 1961), p. 20 (referred to hereafter as U.S. Department of Labor Bulletin 234).

¹⁵ Bonnie Jean Garret, in Edith Henrich and Leonard Kriegel (eds.), *Experiments in Survival* (New York: Association for the Aid of Crippled Children), pp. 156-157.



**PARALYZED VETERANS
OF AMERICA**

Chartered by the Congress
of the United States

August 10, 1993

Accept
Rick
AUG 11 REC'D

The Honorable Carol Rasco
Assistant to President
for Domestic Policy
White House
Washington, DC 20500

Dear Honorable Rasco:

The Paralyzed Veterans of America (PVA) is sponsoring the National Conference on Economic Consequences of Disabilities on September 29, 1993, 8:30 a.m. - 5:30 p.m. at the Mayflower Hotel, Washington, DC. As chairperson of this very exciting and timely conference, I would be honored if you would address the conference as the keynote speaker. Since you are so universally recognized by professionals, the health care community, and policy decision makers, your leadership would lend such importance to this meeting.

This conference will bring together authorities to present various perspectives on the direct costs (i.e., hospital, physician, prescription and non-prescription drugs, attendant/custodial care, adaptive equipment, home modifications, etc.); indirect costs (i.e., loss of earnings by patient and/or spouse; impact on life style (i.e., educational attainment, marital status, occupational/employment choices) and remaining lifetime costs of various disabilities. An in-depth analysis of this issue will be presented for the first time, in the interest of provoking further research and analysis of how American society views disability.

The conferees who will present and attend this conference will include disability advocates, professionals in the fields of health care, medical-ethics, economics, as well as the insurance industry, Social Security and Department of Labor Administrations and other federal agencies.

I can be reached at (202) 416-7654. Your acceptance will enhance and greatly contribute to the success of the very important event.

Sincerely,

Margaret J. Giannini, M.D., F.A.A.P.
Program Chairman

cc: Paul Miller

TENTATIVE AGENDA

NATIONAL CONFERENCE ON ECONOMIC CONSEQUENCES OF DISABILITIES

September 29, 1993
8:30 am - 5:30 pm

Mayflower Hotel
Washington, DC

Chairperson - Honorable Margaret J. Giannini, M.D.
First Director National Institute on Disability
and Rehabilitation Research

9:00 WELCOME AND INTRODUCTIONS

Richard F. Johnson, National President,
Paralyzed Veterans of America

Gordon H. Mansfield, Executive Director,
Paralyzed Veterans of America

John C. Bollinger, Deputy Executive Director,
Paralyzed Veterans of America

9:30 - 10:30 OPENING REMARKS

Honorable Paul Steven Miller
Director, Disability Outreach
Office of Presidential Personnel
White House

Honorable Bruce C. Vladeck, Ph.D, Administrator
(or representative)
Health-Care Financing Administration

Honorable Bob Dole*
United States Senator

Peter Edleman, Esq.*
Counselor to Secretary Shalala
Department of Health and Human Services

Honorable Judy Heumann, Assistant Secretary*
Office of Special Education and
Rehabilitation, Dept of Education

10:30 - 11:00 COFFEE BREAK

11:00 - 12:00 **KEYNOTE ADDRESS**

12:00 - 2:00 **LUNCH** - Speaker - George Covington, Esq.
Disability Advocate
"Myths, Stereotypes and Money"

2:00 - 3:30 Edward Eckenhoff, President
National Rehabilitation Hospital
Washington, DC

David L. Brigham, Former Deputy Director
of Handicapped, Department of Labor
Washington, DC
"Labor and Disabilities"

Corinne Kirchner, Ph.D.,
Director of Social Research
American Foundation of Blind
New York, NY
"Economic Aspects of Low Vision/Blindness"

Jonathan Javitt, M.D.
Worthen Center for Blindness
Washington, DC
"A Preventive Prospective of Low Vision/Blindness"

Allen Boysen, Ph.D.
National Director of Speech and Audiology
Department of Veterans Affairs
"Life Time Cost of Communication and Related Disabilities"

3:30 - 4:00 **COFFEE BREAK**

Ernest Burgess, M.D., President
Prosthetic Research Institute
Seattle, Washington
*"Economic Consequences of Rehabilitation Management
Systems of Amputees"*

Dorothy P. Rice, Professor
School of Nursing - Institute for
Health and Aging, University of California
San Francisco, California

Susan Parker, Former Associate Commissioner
for Disability in the U.S.
Social Security Administration
"The Economics of Rehabilitation Outcomes"

Daniel Wikler, Ph.D., Professor
Program in Medical Ethics
University of Wisconsin
Madison, Wisconsin
"Disability and Health Care Prioritizing"

Monroe Berkowitz, Ph.D., Professor
Economics and Emeritus
Rutgers University
New Brunswick, New Jersey
"Economic Consequences of Spinal Cord Injury"

5:30 - 6:00 **SUMMATION**

Marcus Fuhrer, Ph.D., Director
National Center Medical Rehabilitation
Research, National Institutes of Health

6:00 - 6:15 **AWARD PRESENTATION**

6:30 - 8:30 **RECEPTION**

* to be confirmed

Put a cc of all
this in my
Sept. 29 Speech
file after mailing
card as well
as the ~~copy~~ back
to me & cc's to Stan

under
log # 11/15

w/ this memo.
(He ~~Stand~~ doesn't
need cc of my
note to Sara)

cc

THE WHITE HOUSE
WASHINGTON

TO: Stan Herr
FROM: Carol H. Rasco
SUBJ: Attached letter/article
DATE: September 14, 1993

See the attached fyi. I will talk to you more next week on the September 29 speech she references.

Thanks.

THE WHITE HOUSE
WASHINGTON

Sara Watson, M.P.P., Ph.D.
Senior Associate
Center for the Study of Social Policy
1250 Eye Street, N.W.
Suite 503
Washington, D.C. 20005-3922

THE WHITE HOUSE
14 September 1993

Dear Sara,

Thank you for your kind letter and the enclosed article. I look forward to reading it this evening and sharing it with the staff here in DPC. I appreciated hearing about the memo you will be sending, and I do look forward to seeing you September 29.

Sincerely,
Carol H. Kasso

Center
for the
Study
of
Social
Policy

September 9, 1993

Ms. Carol Rasco
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue NW
Washington, D.C. 20500

Dear Ms. Rasco:

Dale Brown of the President's Committee on Employment of People with Disabilities told me of her conversation with you in early July and recommended that I send you the enclosed article. It discusses people with disabilities in the mainstream social service system, particularly AFDC. The main point is that people with disabilities are already part of the mainstream system, and if welfare-to-work programs and other reforms are to be effective, they need to remove barriers to effective service delivery to recipients with disabilities. I discuss those barriers and recommend ways to reduce them.

Please accept my heartfelt congratulations on your position -- I am delighted to see such a firm advocate for children and for people with disabilities as the President's Domestic Policy Advisor. I had the pleasure of speaking to you briefly during the campaign -- I was working on health and disability policy issues for Bruce Fried and contacted you about President Clinton's programs in Arkansas. We talked about the Republicans who were newly converted to the Democratic cause.

Dale has also asked if Tom Joe and the Center could write a short memo to you on disability policy's fit with the President's economic agenda. My Kennedy School education has prompted many thoughts along those lines, and we are more than happy to help.

I am greatly looking forward to your remarks at the PVA conference on economic consequences of disabilities on Sept. 29th.

If I can be of any further assistance, please do not hesitate to call. Best wishes.

Tom Joe, Director

1250 Eye Street, NW

Suite 503

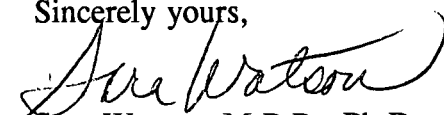
Washington, DC

20005-3922

Fax 202 371-1472

Voice 202 371-1565

Sincerely yours,


Sara Watson, M.P.P., Ph.D.
Senior Associate

**Maximizing the Effectiveness Of Social Services Reform:
People with Disabilities in
AFDC, Children and Family Services, and Child Care**

**By Sara D. Watson, M.P.P., Ph.D.¹
Senior Associate
Center for the Study of Social Policy
1250 Eye St. NW, Suite 503
Washington D.C. 20005
(202) 371-1565**

[Forthcoming in The Journal of Health and Human Resources Administration]

INTRODUCTION

Growing disillusionment with the effectiveness of social welfare programs has produced a prodigious amount of scholarship on this topic. In the past few years, numerous popular and scholarly texts have explored options for reforming Aid to Families with Dependent Children (AFDC) and other programs geared towards assisting disadvantaged individuals, particularly poor families and children (Wilson, 1987; Ellwood, 1988; Schorr, 1988; Golden, 1992; Jencks, 1992). These studies emphasized actions such as instituting limits on eligibility for welfare, developing job training programs for welfare beneficiaries, developing collaborative networks for the delivery of services to children and families, and promoting the availability of child care. Given the convergence of profound and voluminous scholarship, public pressure for reform, and a Presidential administration committed to change, it seems likely that the next few years will see significant changes in how our nation delivers services to families and children. Even if

Congressional gridlock dampens the administration's ability to enact change, some significant service reforms are already happening at the state and local level.

The focus of this paper is on the treatment and inclusion of adults with disabilities in these reforms. Our social policy system tends to separate adults with disabilities from those without disabilities, in perception as well as in reality. People with disabilities usually receive employment services from the vocational rehabilitation system, while those without are served by what I will call "mainstream" (i.e., not disability-specific) job training programs. The popular perception is that poor people with disabilities receive benefits through the SSI (Supplemental Security Income) and SSDI (Social Security Disability Insurance) system, while those without disabilities receive benefits under AFDC. However, in some cases this perception is inaccurate. As a result, reform policies based on it are likely to be less effective because they do not consider how the reforms will affect people with disabilities. While many people with disabilities are served by the disability system, other people with disabilities rely on the mainstream system, either because they are not eligible for disability services, or the disability system does not offer what they need. As the data below indicate, people with disabilities are a substantial portion of the beneficiaries already served by mainstream programs; the argument in this paper is that, in the same way that those systems have recognized the need to be sensitive to cultural and ethnic barriers that exclude people affected by those barriers, so too do they need to consider how to eliminate the barriers to full access by people with disabilities. While some of observations in this paper can be used to facilitate access to public benefits by people with

disabilities, another goal is to ensure that social welfare reforms are equally effective with beneficiaries with disabilities as with those who are non-disabled.

The next section below reports data to show that a significant population of people with disabilities are already part of the mainstream service system. The third section discusses how the mainstream system in several different policy areas needs to change in order to provide equal access for constituents with disabilities. These policy areas are the current AFDC system, potential work incentive reforms of AFDC, collaborative initiatives for families and children, and child care initiatives. The purpose is not to explore any one social policy in depth but rather to provide insights across a variety of areas.

Most of this paper discusses how the mainstream service system could benefit from the insights of the disability community in serving people with disabilities. In addition, the disability service system could in turn benefit from the experiences of mainstream social service programs as they attempt to reform the delivery of services. The final section of the paper, therefore, explores how the research on coordination and integration of services that is being modeled in the human service systems in many localities could be very useful for programs that serve people with disabilities.

Before moving into the body of the paper, three additional comments may be helpful. First, many of the barriers that affect people with disabilities are experienced by other populations or are even inherent in the system and so affect all beneficiaries.² For example,

as mentioned below, transportation problems are not the sole purview of the disability community. However, people with disabilities may be affected more or differently than other populations. I raise the issues simply to raise awareness of these concerns and to encourage officials of the mainstream welfare system to collaborate with disability leaders to explore these issues in their own community.

Second, cash-strapped welfare offices may object that they do not have the funds to meet the needs of people with disabilities. The suggestions herein may indeed raise the number of people applying and qualifying for social welfare benefits and ancillary services such as job training. However, if they do qualify, applicants are entitled to those benefits, and it would be as unjust to deny services based on physical disability as it is to deny them based on a lack of command of English. It is as important to move people with disabilities off AFDC as it is to move those without disabilities. Some of these changes cost little except training time, and they could result in raising the effectiveness of work incentive programs. Furthermore, some accommodations are required by the Americans with Disabilities Act of 1990 (ADA), so agencies have little choice. Finally, many suggestions do not require additional outlays and, often the accommodations needed by people with disabilities are less costly than expected.

Third, just as the social welfare system needs to understand how to work with people with disabilities and the disability system, so too do those consumers and professionals have the responsibility to understand the social welfare system structure, concerns and rhythms as well. While the mainstream system needs to serve people with disabilities when appropriate, the

disability system also needs to make referrals when appropriate, to understand how the other system works and what it truly can and cannot offer, and to consider meeting a broader range of needs (such as those dealing with parenting) when it is appropriate for them to do so.

DATA ON PROGRAM PARTICIPATION

This section presents data to show that people with disabilities are already a substantial portion of the beneficiaries of the main welfare programs. A second point is the substantial number of poor persons with disabilities who are not receiving benefits from any public welfare program.

Mathematica's (a private research firm) recent study (Doyle, Miller and Sears 1990, p. 23) using the Survey of Income and Program Participation provides data to support both the perception that people with disabilities are not served by mainstream programs, and the fact that this perception is in error. They cite a Congressional study from 1984 that showed that only 4% of AFDC families had a parent who was "incapacitated," supporting the perception that people with disabilities are only a minuscule part of that program. Yet Mathematica's analysis showed that 17% of AFDC recipients had a "substantial functional limitation."³ Similarly, the U.S. Department of Agriculture reported that only 2% of individuals receiving food stamps were classified as disabled, yet Mathematica's analysis showed that 22% of these recipients had substantial functional limitations. Additional data comes from Michele Adler of the U.S. Department of Health and Human Services (Adler, 1988), who found that 22% of women on

AFDC under age 45 self-report a disability, compared to only 9% of women under 45 not on AFDC.

There is additional evidence of a substantial portion of poor people with disabilities who are not served by any program. Mathematica (Doyle, Miller and Sears 1990, pp. 35-37) found that SSI and SSDI serve 32% of the population with substantial functional limitations, while the mainstream programs included in their analysis (such as AFDC, food stamps, housing programs, school lunch programs, supplemental food aid for women, infants and children, General Assistance and other cash and in-kind welfare programs) serve 23% of people with disabilities. This means that 45% of people with disabilities, and, most importantly, 24% of the "low-income population with substantial functional limitations," or 1.1 million people, are unserved by disability-specific or mainstream federal assistance programs.

Why are so many poor people with disabilities unserved by either types of programs? On the disability side, there are many people who would be considered disabled who do not qualify under the extremely tight eligibility criteria for SSI or SSDI. Indeed, one of the strongest themes throughout many analyses of the U.S. disability program has been the difficulty of qualifying for these programs and the degradation that applicants must suffer during the long application process (Berkowitz, 1984). On the side of the mainstream program, analysis of the limited written materials and interviews with experts from the disability and mainstream systems reveal the numerous barriers to access for people with disabilities described in the rest of this paper. While AFDC benefits are generally lower than SSI or SSDI benefits, this program could

be an important source of income for those who cannot qualify for SSI or SSDI. AFDC also provides Medicaid coverage for children, and without a waiting period -- significant advantages for parents. In addition, as will be explored below, the employment training programs for people on AFDC could be a source of valuable assistance for people with disabilities.

SOCIAL PROGRAMS FROM A DISABILITY PERSPECTIVE

The Current AFDC Program

The focus of the Clinton administration's efforts regarding AFDC is to encourage people to move off the benefit rolls to gainful employment. This process is essential to the well-being of people with disabilities and is explored in the next section. However, these benefits will still be necessary for some people, including those with disabilities, for an indefinite period of time. Furthermore, gaining access to AFDC also provides people with disabilities with access to the proposed job training programs. Therefore, it is important to consider not only how to move people with disabilities off the AFDC rolls, but also how to ensure that they have access to benefits to which they are entitled.

Unfortunately, potential AFDC recipients who have disabilities often meet substantial barriers to establishing eligibility for, and benefitting from, the AFDC system. (These points may apply to other welfare programs as well, such as food stamps and housing assistance, but the focus here will be on AFDC as the largest example.) In recent decades, welfare offices have increasingly recognized the need to amend their procedures, where possible, to meet the needs

of diverse populations, such as hiring Spanish-speaking staff. Without particular support for, and training on, the needs of people with disabilities, it may be difficult for line staff as well as supervisors and policymakers to know what the needs of people with disabilities are and how to meet them. Yet these needs do exist.

Four major types of barriers will be discussed: administrative barriers, attitudinal barriers, barriers relating to fear of repercussions, and programmatic barriers.

Administrative barriers result from the logistical and informational demands that are made on clients in order to apply and maintain eligibility for benefits. Because of the large caseloads, extensive regulation and tight staffing of many welfare offices, some administrative obstacles may be inevitable. However, officials may be able to eliminate others once their effect is known. Recipients must periodically visit the welfare office, fill out complex forms, provide extensive documentation of their poverty status, and continue to update the caseworker with every change in income or family status.

While these barriers are formidable for people without disabilities, they may be virtually insurmountable for those with disabilities, especially those with mobility or cognitive or sensory disabilities. Megan Kirshbaum (1993), director of Through the Looking Glass, a program to support parents with disabilities, described numerous instances in which AFDC workers sent letters and forms to cognitively impaired people who could not read and had no one to assist them. When the people failed to follow the instructions in the mailings, no one attempted to

follow up with them to investigate the non-response: their benefits were simply denied. (The parallels to non-English-speaking people are evident.) As another example, clients must visit the AFDC office to obtain benefits, yet transportation is often very difficult for people with disabilities. Paratransit services are frequently hours late in picking people up for appointments, and stories are legion of bus lifts breaking down or buses simply refusing to stop for wheelchair-using riders. While regular clients may also face transportation problems, they are unlikely to face delays that are as chronic or severe as those faced by people who need some form of accessible transit. Bonnie O'Day, former director of three centers for independent living (CILs), recounts a story in which the AFDC intake counselor would only see clients in person by appointment. A wheelchair-using applicant was 10 minutes late for an appointment because her paratransit ride was late, and the counselor refused to meet with her. At the other extreme, Patrice Hanks, the administrative director of a Minnesota CIL, comments that another barrier is the refusal to make appointments at all, forcing people to sit in waiting rooms until they can be seen. While this is onerous for anyone, many people with disabilities literally cannot sit for 3 or 4 hours and risk serious health consequences (such as skin sores) by doing so.

Attitudinal barriers exist when agency staff reflect the same negative attitudes toward people with disabilities that are pervasive in society. Without specialized training or personal experiences with people with disabilities, agency staff may feel uncomfortable around people with disabilities and be reluctant to work with them. Beth Langen, a former official in the Illinois Department of Children and Family Services and the Illinois Department of Public Aid, described a palpable sense of discomfort that co-workers felt toward her because she used a

wheelchair (July 8, 1993). She observed, "The cognitive dissonance that I caused other human service professionals was because I was a peer, and in most instances, a superior. Their perceptions of people with disabilities were clearly of non-working, non-independent clients." Richard DiPeppe (June 1993), director of community services for an independent living center in Virginia, has seen clients with disabilities report to their intake workers, only to have the workers suddenly leave to consult their supervisors on how to "handle" these clients because they had a disability. The clients then overheard conversations in which the intake workers expressed their reluctance to work with the clients and asked to be re-assigned. This type of treatment obviously could greatly discourage people from seeking benefits.

A third barrier is the fear of repercussions: trying to access the one system may expose the client to the risk of unwelcome intrusion or changes from other parts of the social welfare system. This category is slightly different than the others in that it does not point to problems with the AFDC system per se, but it does suggest reasons why people may be reluctant to apply for AFDC and other benefits, and why disability and mainstream systems need to work together to meet the needs of clients with disabilities who use mainstream systems. Richard DiPeppe related an example in which a mother with a disability applied for AFDC and then found the intake worker asking a series of questions probing the mother's ability to care for her child. He observed that parents may be reluctant to apply for AFDC for fear that they will be reported to Child Protective Services (CPS) solely because of their disability. Another example is the search for accessible housing, often an accompaniment to an AFDC application. DiPeppe told the story of a mother and her children who were forced to live in a shelter when her husband left them.

Since the mother used a wheelchair, she required accessible housing, which greatly reduced the housing options open to her. A social worker attempted to remove the children from their mother while she remained in the shelter waiting for accessible, affordable housing to become available. Beth Langen related an experience in which women with physical disabilities who required home-based personal assistance services were unable to use shelters because that location did not meet the definition of "home." Once the problem became obvious, the policy was changed, but if the agency had not been willing to respond, women would have been forced to remain in their homes in abusive situations in order to preserve eligibility for a disability service. Obviously, these types of ramifications greatly discourage people with disabilities from seeking the benefits to which they may be entitled.

Finally, there are programmatic barriers: the existing law does not provide the flexibility that people with disabilities may need. For example, Megan Kirshbaum suggested that it would be helpful if women with disabilities could get AFDC benefits early in their pregnancy (this is allowed in some states) to help pay for adaptive equipment and other nursery supplies that will assist them in parenting. (While this is also a problem for non-disabled pregnant mothers, they are more likely to be able to borrow or find inexpensive furniture than a disabled mother who needs specialized equipment.) Another problem that may not be directly under the purview of AFDC is that many women with disabilities find that their physical needs change when they become pregnant, yet there are no funds to provide equipment or other supports that help them adapt to these changes. Sandy Matava (June 1993) also pointed out that many states have supplemental funds for AFDC families to pay for items such as clothing or housing. These

items, and others of daily life, are usually more expensive for people with disabilities than for those without, and it would be helpful if additional allowances were made for specialized items.

There are both short-range and long-range solutions to these problems. Many of these problems may simply reflect (unfortunately) normal societal stereotypes combined with a high-pressure, chronically under-staffed work environment. But there are still steps that can be taken. In the short-range, disability awareness training by local, disability-rights based organizations can be very helpful. They can assist intake workers and supervisors in recognizing the often small acts that can significantly help or hurt a person's ability to work with the system. Just as the supervisor and senior staff in the local and state offices establish relationships with their peers in other departments, so too would it be helpful to have a strong line of communication between the agency and the grass-roots disability community. (Often independent living centers have both experience and a strong reputation in the disability community.)

It would be enormously helpful if agencies could then undertake a variety of changes that would facilitate access to the system: instituting flexible appointment procedures for clients with disabilities (or whose children's disability creates similar barriers); following up with clients if the social worker feels a non-response may be due to a disability; providing home visits if possible; assisting people in navigating through the system, and simply following common courtesies in dealing with people with disabilities. Obviously, some of these steps require additional resources, but others do not.

In the long-range, the disability community can potentially benefit from the systematic reform of the social welfare system that is central to the recommendations of so many mainstream scholars. However, it is essential that reformers establish relationships with the disability community to ensure that reforms do consider people with disabilities as an important and integral constituency. A good example of this is the welfare-to-work reforms.

Welfare to Work

One of the most-discussed aspects of social policy reform is the creation of incentives to move people on welfare to work. David Ellwood, U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation and one of the key welfare reform planners in the Clinton administration, has recommended providing welfare for a limited time while offering job training and guaranteed job assignments for people who have exhausted their benefits (Ellwood, 1988, p. 238). Policymakers need to consider how to ensure that the transition to work program succeeds for people with disabilities as well as for those without disabilities.

There are indications in other literature that discussions on welfare reform have largely overlooked people with disabilities. None of the works in the introduction, in lengthy discussions on welfare reform, mentions the disability of AFDC recipients as one consideration in designing reform. Part of this reason is peculiarities inherent in the definition of "disabled." To many social policy scholars, being "disabled" by definition means unable to work and on the SSI or SSDI rolls. In describing the attitudes towards social benefit programs, Christopher

Jencks characterizes "[t]he deserving poor [as] those whom legislators judged incapable of working, namely the elderly and the disabled" (1992, p. 78) and he does not go on to mention any other types of people with disabilities. However, as explored above, people with disabilities are a heterogeneous population. While many people with disabilities are on SSI and SSDI and do not wish to work, others are eligible for or are receiving AFDC, wish to work and could do so if given assistance.

While vocational rehabilitation programs have been the traditional source of work-related training for people with disabilities, their resources are stretched thin, and a forthcoming General Accounting Office study points out that their performance in terms of helping people get jobs at living wages is questionable at best. Furthermore, the ADA requires that public services are accessible to people with disabilities. While the federal government may be apprehensive about the attractiveness of these programs and the resulting increase in applications, the reality is that people with disabilities are already on AFDC. Giving them access to training programs will ensure that the programs reach and are successful with as many beneficiaries as possible.

The current welfare-to-work program offered to AFDC recipients simply allows women with disabilities to opt out of the work requirements, instead of providing encouragement and accommodations to assist them in using the program to move towards independence (Adler, 1988). Without substantial supports, one would expect case workers to be reluctant to encourage disabled recipients to participate -- they may assume that the recipients will need extra help in order to work, and may feel barely able to keep up with their already large caseloads. This

situation will need to change if AFDC recipients with disabilities are to succeed in making the transition from welfare to work. Case workers will need disability awareness training on working with people with disabilities, and on Americans with Disabilities Act requirements, including accommodation guidelines. Case workers need to know, for example, that a prospective employer cannot refuse to hire an AFDC beneficiary solely on the basis of her disability. If there is a guaranteed work arrangement, the hiring staff will need to be intimately familiar with the ADA and the Rehabilitation Act of 1973. Work arrangements will need to take into account transportation and child care needs that are similar to but probably more complex than those for mothers without disabilities.

In designing the federal welfare-to-work program, HHS officials could involve disability experts from other departments or from the community. These people could review the plans for work incentives and work programs to ensure that they take into account the needs of people with disabilities on AFDC and that they comply with the ADA (for example, ensuring that training classes are held in locations accessible to participants with disabilities). In addition, it may be necessary to provide staff with training on disability issues as well as on the work program itself.

Collaborative Initiatives for Children and Families

One major trend in the delivery of services to families and children has been the creation of collaborative models that bring together different service streams, such as education, welfare,

health care, juvenile justice, child protective services, and other social services. Over and over again, contemporary scholars have emphasized that the key to delivering effective services, with limited resources, that focus on preventing "rotten outcomes" (Schorr, 1988) has been the collaborative model (Golden, 1992; Melaville and Blank, 1993). In this model, service providers from the different agencies collaborate to share resources and knowledge. In this new model, service providers focus on identifying children at risk of failure, providing prevention-oriented services, and creating a coordinated network of assistance. Service providers also recognize that they cannot serve a child well unless they can serve the entire family.

A pervasive goal for this reformed system is to encourage families to stay together, to provide preventive supports before a crisis occurs and to support the ability to parents to care for their children. Golden (1992) describes how a transformed, collaborative system of family support services allowed a child protective services worker to change her perspective on a mother's ability to care for her child. The CPS worker collaborated with a staff person in another agency who provided support services to teen-age mothers. The latter person was more oriented to supporting the mother, while the CPS worker was more oriented to protecting the child. However, when they worked together, the CPS staffperson came to recognize that this mother could indeed parent her child with adequate support. In recommending strategies to preserve families, the Center for the Study of Social Policy (1987, pp. 15-16) recommends

A more effective service system should be based on a policy of promoting parents' ability to care for children -- recognizing that state government and local communities have an interest in helping to avoid the serious problems that now bring families and children into traditional services... Any improved system should be organized to tailor its response to the needs of a child and family, rather than forcing the family's needs to conform to a predetermined array of

services...successful interventions here are likely to include non-traditional methods of linking families to a wide range of community supports.

This trend is ideally suited to meet the needs of people with disabilities, and the point for this paper is to suggest that this collaborative network include the disability community, and in particular that it support parents with disabilities as well as those who have other disadvantages. As several celebrated cases have shown recently, when children are deemed at risk because of a parent's disability, the result is often removal of the children from the home (Shapiro, 1993; Mathews, 1992). As Sandy Matava relates (forthcoming):

Focusing on the protections necessary for child safety, child protection workers are apt to stereotypically discount the abilities of parents with disabilities to raise their children. This situation runs a wide spectrum. It includes parents fully capable of parenting, with no outside assistance, who are nevertheless denied their children on the basis of completely baseless stereotypical assumptions. It includes parents who are mentally fully capable of parenting but who are denied the necessary personal assistance services to perform the physical tasks of child care. [It also includes] parents with mental, emotional or cognitive disabilities who, without assistance to perform the cognitive tasks necessary for safely raising children, could neglect their children.

This situation has created great tensions between the disability community and the mainstream social service system. The disability community would like to see the creative problemsolving techniques that have been used to support parents with many types of problems, such as substance abuse and poverty, applied to parents with disabilities. While it is clear that the right of a child to a safe and nurturing environment is paramount, social service workers need to ensure that they are willing to recognize the strengths of people with disabilities.

(While the focus of this paper is on adults, there are other problems with children with disabilities in the mainstream social service systems. Briefly, Sanda Matava relates that programs for parents of rebellious adolescents often are not physically or programmatically accessible to children with disabilities, leaving the youth to be served by the special education system. Yet their problem may have little to do with disability and the parents may need access to this specialized service. Furthermore, Beth Langen points out that facilities for children in the child welfare system are often inaccessible or refuse to accept children with disabilities -- a practice that may violate the ADA. Additionally, in her experience, older teen-agers with disabilities were not given the same referrals to the independent living programs that are meant to help these young adults learn to live on their own.)

Child Care

Another social policy problem receiving increased attention in this political climate is the need for quality, affordable child care for working parents. While the suggestions above support assisting parents with disabilities to keep their children, equally important is helping these parents obtain the resources they need to raise their children. Campion (1990) comments that for a woman with disability, help with childcare is "what can make the difference between enjoying the experience of bringing up a child or going through hell."

It is difficult to estimate the number of mothers with disabilities who would require child care, but LaPlante (1991) has estimated that there are at least 8.1 million families with children in which one or both parents has a disability or work limitation, comprising about 10.9% of all

American families (families are only defined as families with intact marriages, leaving out the many single mothers and divorced parents with disabilities). Berkeley Planning Associates has analyzed the 1989 Survey of Income and Program Participation and found that 1.25 million married couples with children under six included at least one parent with a work disability and that in over half a million cases the disability was considered severe. An additional half a million single parents with children under six were estimated to have a work disability. In addition, a small study conducted by Berkeley's Center for Independent Living also indicated that accessibility was a problem. Mothers with disabilities indicated that their childcare center/school was not always accessible to them, there was a need for more accessible childcare, the childcare/school needed sensitivity training/education about the subject of disability, and that their disability affected their child's ability to socialize and participate in school and recreational activities (White, no date).

While finding quality, affordable child care is difficult for most women, adding the need to find a site that is accessible to someone who uses a wheelchair or a TDD or who must travel by public transportation narrows the field even further. Compounding the problems of physical accessibility are the problems of programmatic and attitudinal accessibility. Not only the center itself, but also its programs need to be accessible to people with disabilities -- for example, family picnics must be held in accessible locations, and parents with disabilities who are in co-operatives must be welcomed to participate as non-disabled parents are. Furthermore, just as centers (and other social services) are learning about cultural sensitivities for children and families of different cultures, so too do child care staff need to be sensitive to and supportive

of parents with disabilities. While providers need to be aware that every parent (with or without a disability) is different, parents with disabilities should not have to educate each child care provider anew about generic stereotypes and sources of assistance.

Organizations that provide information and technical assistance to child care centers and family child care homes need to include among their offerings information on complying with the ADA and meeting the physical and programmatic accessibility needs of parents with disabilities. If the Congress does pass national child care legislation in the future, it would be very helpful to explore this issue in the legislation as it would give accessibility much-needed visibility.

BENEFITTING FROM THE EXPERIENCES OF MAINSTREAM SOCIAL POLICY REFORM

While the bulk of this paper has focused on examining ways in which the mainstream social service system could learn from the disability community in order to meet the needs of constituents with disabilities, the disability service system could also benefit from the experiences of social policy reform.

The overall problems described as the motivation for reforming the social service sector could just as well be describing many disability service systems, and many of the lessons and solutions gained in the experiments in the mainstream sector could prove useful in improving

disability specific services. For example, a report from the Center for the Study of Social Policy (1991, p. 3) describes how the fragmented nature of services has led to such a widespread agreement on the need for change:

The overriding problem is that we have authorized myriad services at the federal and state level without creating direction for them or the capacity to manage them as a system at the local level. No one is in charge of local community services for children and families. No one governs the totality. No one has overall responsibility for overall outcomes. Instead, many agencies oversee a limited number of services and must restrict their contributions to offering only partial responses to families' and childrens' needs. As a result, multiple disconnected program strategies (which often compete among themselves) exist within the same community to address what often are simply components of the same problem. Differing philosophies and perspectives about families prompt agencies to operate in very different ways -- and often in ways that are contradictory.

This statement could describe the disability specific system as well as the mainstream system. A person with a disability usually needs to go to different sources to find help with health care, eligibility for benefits, accessible housing, training for personal assistance services, vocational training, and assistive devices. While I am not suggesting that the system should be transformed into one overarching "disability agency," just as that is not generally the intent of the mainstream reformers, it would be helpful if the disability system could benefit from the experiences of the mainstream system as it strives to achieve certain goals. This includes collaboration in service delivery, so that all the people dealing with a disability issue communicate with each other.⁴ Another is agreement on assessing the situation so that one service provider is not operating under the assumption that the cause of dissatisfaction is a poor attitude while another sees the "problem" as a conscious reaction to undesirable living conditions. Related to that idea is professionals' complementary, not contradictory, support for the consumer's choice of goals.

CONCLUSION

This paper has tried to show that people with disabilities are an important constituency of many mainstream social welfare programs. While many people with disabilities need no special accommodations to participate in these programs, others do. The point is to consider people with disabilities as a diverse group who warrant attention to ensure complete inclusion. If a programmatic reform is a success for everyone except those with disabilities, it is not a success -- for people with disabilities, or for society at large.

References

Adler, Michele (1988). HEALTH AND DISABILITY STATUS OF AFDC FAMILIES. Paper delivered at the 1988 Proceedings of the American Statistical Association.

Berkowitz, Edward (1984). DISABLED POLICY. Cambridge: Cambridge University Press.

Campion, Mukti Jain (1990). THE BABY CHALLENGE: A HANDBOOK ON PREGNANCY FOR WOMEN WITH PHYSICAL DISABILITY. New York: Tavistock/Routledge.

Center for the Study of Social Policy (December 1987). A FRAMEWORK FOR CHILD WELFARE REFORM. Washington, D.C.: author. Produced under a grant from the Annie E. Casey Foundation.

Center for the Study of Social Policy (September 1991). BUILDING A COMMUNITY AGENDA: DEVELOPING LOCAL GOVERNANCE ENTITIES. Washington, D.C.: author.

DiPeppe, Richard (June, 1993). Personal communication, telephone interview.

Doyle, Pat, Esther Miller and Jim Sears (1990). TASK III: PROGRAM PARTICIPATION PATTERNS AMONG PERSONS WITH DISABILITIES. Prepared by Mathematica Policy Research Inc. for the Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Washington, D.C.

Ellwood, David (1988). POOR SUPPORT: POVERTY IN THE AMERICAN FAMILY. New York: Basic Books.

General Accounting Office (forthcoming). VOCATIONAL REHABILITATION: EVIDENCE FOR PROGRAMS' EFFECTIVENESS IS MIXED. Washington, D.C.: author. (The description in the text is based on an oral presentation by GAO staff.)

Golden, Olivia (1992). POOR CHILDREN AND WELFARE REFORM. Westport, CT: Auburn House.

Jencks, Christopher (1992). RETHINKING SOCIAL POLICY. New York: HarperPerennial.

Jencks, Christopher and Paul E. Peterson (eds.) (1991). THE URBAN UNDERCLASS. Washington, D.C.: Brookings Institution.

Kirshbaum, Megan (1993). Personal communication, telephone interview.

Langen, Beth (July 8, 1993). Personal communication, letter.

LaPlante, Mitchell (1991). **DISABILITY AND THE FAMILY**. San Francisco: University of California, Institute for Health and Aging.

Lonsdale, Susan (1990). **WOMEN AND DISABILITY**. New York: St. Martin's Press.

Matava, Sandy (June 1993). Personal communication, telephone interview.

Matava, Sandy (forthcoming). "The Implications of Parenting Standards in Child Protection: A Paradox in Disability Policy" forthcoming in Watson, Sara and David Pfeiffer, eds. **DISABILITY POLICY AS AN EMERGING FIELD OF MAINSTREAM PUBLIC POLICY RESEARCH AND PEDAGOGY**, symposium edition of the **POLICY STUDIES JOURNAL**.

Mathews, Jay (1992). **A MOTHER'S TOUCH: THE TIFFANY CALLO STORY**. New York: Henry Holt Publishers.

Melaville, Atelia I. and Martin J. Blank with Gelareh Asayesh (April 1993). **TOGETHER WE CAN: A GUIDE FOR CRAFTING A PROFAMILY SYSTEM OF EDUCATION AND HUMAN SERVICES**. Washington, D.C: U.S. Department of Education and U.S. Department of Health and Human Services.

Schorr, Lisbeth with Daniel Schorr (1988). **WITHIN OUR REACH: BREAKING THE CYCLE OF DISADVANTAGE**. New York: Doubleday, Anchor Press.

Shapiro, Joseph (1993). **NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT**. (New York: Times Books).

White, Donna (no date). **NEEDS ASSESSMENT OF SINGLE DISABLED PARENTS AND SINGLE PARENTS OF CHILDREN WITH DISABILITIES**, unpublished monograph. Berkeley, CA: Center for Independent Living.

Wilson, William Julius (1987). **THE INNER CITY, THE UNDERCLASS AND PUBLIC POLICY**. Chicago: University of Chicago Press.

1. I would like to thank the following people for their observations and comments: Beth Langen, Richard DiPeppe, Bonnie O'Day, Patrice Hanks, Megan Kirshbaum, David Pfeiffer, Sandy Matava, Michele Adler and Bill Malleris.

2. I am indebted to Sandy Matava, former Commissioner of the Massachusetts Department of Social Services, for this observation.

3. As Mathematica points out, this discrepancy is probably based in the classification system as the "AFDC program does not classify parents as incapacitated unless they do not qualify as single parents." Since it is extremely difficult to qualify for AFDC unless one is a single parent,

there would be little reason to classify someone as incapacitated. Nevertheless, the publication of the data in this format reinforced the idea that few people on AFDC have disabilities.

4. However, as several reviewers pointed out, the collaborative or case management model can backfire for people with disabilities, if it emphasizes professional control rather than consumer empowerment, or if it fragments the system further.

Office of Domestic Policy

TO: Stan Herr

FROM: Carol H. Rasco

SUBJ: Speech/Meeting/Interview

Nat. Conference on Economic Consequences of Disability
DATE: Sept. 29, 1993

Attached is the background information I have to date on the function listed. I would appreciate briefing materials by noon on Sept. 27.

FAX COVER SHEET

PARALYZED VETERANS OF AMERICA

RESEARCH AND EDUCATION PROGRAM

801 EIGHTEENTH STREET, N.W., WASHINGTON, DC 20006

(202) USA-1300 FAX (202) 416-7641

TO: Honorable Ms. Rasco @ (202) 456-2878

FROM: Margaret J. Giannini, M.D., F.A.A.P.

DATE: September 17, 1993 NUMBER OF PAGES 6



**PARALYZED VETERANS
OF AMERICA**
Chartered by the Congress
of the United States

September 18, 1993

Honorable Carol Rasco
Assistant to the President
for Domestic Policy
The White House
Washington, DC 20500

Dear Honorable Ms. Rasco:

This letter provides confirmation of your participation in the National Conference on the Economic Consequences of Disabilities, to be held at the Mayflower Hotel in Washington, DC on September 29, 1993 from 8:30 am to 6:30 pm. You will give the Keynote Address, "Thanks for Believing," from 10:00 to 10:30 a.m.

I would appreciate your presence during the entire conference, but realize that you may have conflicting commitments. Therefore, above I have provided as narrow a time interval for your presentation as I could. Recall that lunch will be provided at 12:30, and that a reception will follow the conference from 6:30 to 8:30 pm. Attached is a copy of our finalized schedule.

Thank you for your support.

Sincerely,

Margaret J. Giannini, M.D., F.A.A.P.
Program Chairperson

NATIONAL CONFERENCE ON ECONOMIC CONSEQUENCES OF DISABILITIES

September 29, 1993
8:30 am - 6:30 pm
Mayflower Hotel
Washington, DC

Chairperson - Honorable Margaret J. Giannini, M.D.
First Director of the National Institute on Disability
and Rehabilitation Research

8:30 - 9:00 COFFEE

9:00 - 9:15 WELCOME AND INTRODUCTIONS

Richard F. Johnson, National President
Paralyzed Veterans of America
Washington, DC

John C. Bollinger, Deputy Executive Director
Paralyzed Veterans of America
Washington, DC

9:15 - 10:00 OPENING REMARKS

Honorable Paul S. Miller
Director, Disability Outreach
Office of Presidential Personnel
White House

Peter Edelman, Esq.
Counselor to Secretary Donna Shalala
Department of Health and Human Services
Washington, DC

10:00 - 10:30 KEYNOTE ADDRESS

Honorable Carol H. Rasco, M.S.
Assistant to the President
for Domestic Policy
White House
"Thanks for Believing"

10:30 - 11:00 COFFEE BREAK

11:00 - 12:30 **SESSION ONE**

Moderator

- Margaret J. Giannini, M.D.
Program Chairperson
Paralyzed Veterans of America
Washington, DC

Edward A. Eckenhoff, M.A., M.H.A.

President
National Rehabilitation Hospital
Washington, DC
"Rehabilitation Services in the 21st Century -
Plight, Flight or Fight!"

Dorothy P. Rice, B.A.

Professor
School of Nursing - Institute for
Health and Aging, University of California
San Francisco, California
"The Burden of Disability: Conceptual and Methodological
Issues"

Susan B. Parker, M.S.W.

Former Associate Commissioner for Disability
Social Security Administration
Washington, DC
"Economics and Rehabilitation Outcomes: the U.S. Experience"

Daniel Wikler, Ph.D.

Professor
Program in Medical Ethics
University of Wisconsin
Madison, Wisconsin
"Disability and Health Care Prioritizing"

12:30 - 2:00 **LUNCHEON**

Introduction of Speaker -

Joseph Shapiro
Associate Editor
US News and World Report
Washington, DC

Luncheon Address -

George A. Covington, Esq.
Disability Advocate
Washington, DC
"Myths, Stereotypes and Money"

2:00 - 3:30 **SESSION TWO**

Moderator

- Henry Viscardi, Jr., L.L.B.
Founder and President Emeritus
National Center for
Disabilities
Albertson, NY

David L. Brigham, B.A.

Former Deputy Director of Handicapped
Department of Labor
Washington, DC
"Labor and Disabilities: It Takes All Hands"

Corinne Kirchner, Ph.D.
 Director of Social Research
 American Foundation of Blind
 New York, NY
 "Economic Aspects of Low Vision/Blindness: Rehabilitative
 Perspectives"

Jonathan C. Javitt, M.D., M.P.H.
 Director, Center for Sight
 Georgetown University Medical Center
 Washington, DC
 "Economic Aspects of Low Vision/Blindness: A Preventive
 Perspective"

Allen E. Boysen, Ph.D. and Robert Wertz, Ph.D.
 National Director of Speech and Audiology
 Department of Veterans Affairs
 Washington, DC
 "Life Time Cost of Communication and Related Disabilities"

Ernest M. Burgess, M.D.
 President
 Prosthetic Research Institute
 Seattle, Washington
 "Economic Consequences of Rehabilitation Management
 Systems of Amputees"

3:30 - 4:00 COFFEE BREAK

4:00 - 5:45 SESSION THREE

Moderator - Reverend Harold Wilke
 Director
 Community Living
 Claremont, California

Monroe Berkowitz, Ph.D.
 Professor Emeritus of Economics
 Rutgers University
 New Brunswick, New Jersey
 "Economic Consequences of Spinal Cord Injury"

Honorable Helen L. Smits, M.D., M.A.C.P.
 Deputy Administrator
 Health Care Financing Administration
 Washington, DC
 "Medicare and Medicaid Financing of Services for the
 Disabled"

Margaret E. Fahey
 Vice-President and Claims Director
 Commercial Life Insurance Company
 "Insurance Reimbursements and Claims for Disabilities"
 Piscataway, NJ

Kathryn S. McCarty, Esq.
Assistant Staff Director
Commission on Mental and Physical Disabilities Law
American Bar Association
Washington, DC
"Negotiating the Legal Quagmire--Available Resources"

Charles D. Goldman, Esq.
Attorney at Law
Washington, DC
"Coping With Government and Lawyers: A Practical
Primer on ADA"

5:45 - 6:15 **SUMMATION**

Marcus J. Fuhrer, Ph.D.
Director
National Center for Medical Rehabilitation Research
National Institutes of Health
Bethesda, Maryland

6:15 - 6:30 **PRESENTATION OF CAREER ACHIEVEMENT AWARD**

By Laurance S. Johnston, Ph.D.
Director of Research and Education
Paralyzed Veterans of America
Washington, DC

To David B. Gray, Ph.D.
Deputy Director
National Center for Medical Rehabilitation Research
National Institutes of Health
Bethesda, Maryland

6:30 - 8:30 **RECEPTION**




PVA

**PARALYZED VETERANS
OF AMERICA**
Chartered by the Congress
of the United States

August 20, 1993

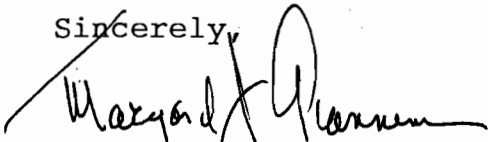
The Honorable Carol Rasco
Assistant to the President
on Domestic Policy
The White House
Washington, DC 20500

Dear Honorable Ms. Rasco:

We are deeply honored that you have accepted our invitation to give the keynote address at the National Conference on the Economic Consequences of Disabilities on September 29, 1993 at the Mayflower Hotel. Shortly, a final program, very similar to the tentative agenda that you have already received, will be sent to you. Rick, in your office has been kind enough to send me your curriculum vitae. I would appreciate it if the title of your presentation could be faxed to me at 202-416-7641 for inclusion on the final printed program. 

Again, we are looking forward to a most exciting and timely meeting. My direct number is 202-416-7654 if there are any further questions.

Sincerely,



Margaret J. Giannini, M.D., F.A.A.P.
Program Chairperson

AUG 25 RECD


9/5/93

Log: Put in speech folder
Fax per #1 the
speech title
"Thanks for
Believing!"

THE WHITE HOUSE
WASHINGTON
September 5, 1993

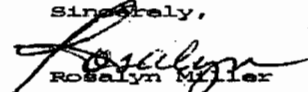
Margaret J. Giannini, M.D. F.A.A.P.
Program Chairperson
Paralyzed Veterans of America
801 Eighteenth Street, NW
Washington, DC 20006

Dear Dr. Giannini:

As requested, Carol H. Rasco will deliver the keynote address at the National Conference on the Economic Consequences of Disabilities on September 29, 1993. Her speech is titled: "Thanks for Believing."

Should you need additional information, please feel free to call (202) 456-2216 and ask for me.

Sincerely,


Rosalyn Miller

TRANSMISSION REPORT

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REMARKS BY CAROL H. RASCO

PARALYZED VETERANS OF AMERICA
Wednesday, September 29, 1993

Thank you. I commend the Paralyzed Veterans of America for your leadership in organizing this conference. I have not before found myself before this type audience, an audience where the focus is primarily on the needs of adult age individuals with disabilities. Preparing for my visit with you today has given me an opportunity to learn more about your organization and to review the summary of your fine publication on The Economic Consequences of Traumatic Spinal Cord Injury.

I also have not often found myself in the position of being somewhat star struck, but there is no other way to describe what I feel as I stand here before all of you today. As I reviewed the roster of participants expected here today, I saw names of individuals that have looked back at me from pieces I have read and studied or names that belong to speakers to whom I have listened over the last twenty-years; I saw names and/or initials of organizations that have consistently provided leadership and services to me and my family as well as friends and acquaintances. For you see, I come to you not as someone who is all knowing in the field of service to and with persons with disabilities...I come to you primarily as the mother of Hamp Rasco, the friend of many families and individuals with disabilities. I come to you with gratitude for your ongoing belief in the worth of every individual and your commitment to empowering each individual to develop to her/his full potential. And therein lies the point at which I also become the person known as the Domestic Policy Advisor within the White House because the underlying theme as we approach domestic issues is that matter of providing the environment/the necessary tools/the opportunity for that empowerment process to unfold.

What do I mean I come to you as a mother of Hampton or Hamp as he is known to his family and friends? Relate birth, institutional choices, status today.

After carefully reviewing your agenda with the expert presentations you will have and recognizing this is a special opportunity to spend a few moments with you, it became clear to me that I should open this morning session of the conference with a call to action. You have before you today an agenda that will crystallize for you in one day the very best in the body of information you will find assembled anywhere on the ECONOMIC CONSEQUENCES OF DISABILITIES. If you then leave here today and don't change anything about the way you are doing business, today will have been for naught....but instead you have the opportunity to say, I AM GOING TO LEAVE HERE TONIGHT and I WILL APPROACH MY WORK DIFFERENTLY TOMORROW and each day thereafter...and it is no fair to say I WILL SIMPLY THINK DIFFERENTLY....WE MUST ACT DIFFERENTLY.

You like me have probably attended many a meeting - whether long or short - where the stunning facts and overwhelming statistics you will hear today have been presented in piecemeal form.....I remember attending the White House Conference on Handicapped Individuals in 1977 in this town...reams of paper were generated, many hopes were raised and good intentions were overflowing....but far too little time was spent throughout that long, grassroots preparatory process in looking at what could be done to harness all those hopes toward significant changes and again, we left DC and what happened? Exactly what I regret I have seen throughout these twenty years I've concentrated on issues related to disabilities occurred....splinter groups were so busy looking at small pieces of issues within that 2000+ set of recommendations that significant movement was not evident. Programs have continued to grow in number, barriers have been erected to an even greater degree between programs, job placements for people with disabilities have not grown as they should, health care is still a problem, housing needs aren't adequately addressed. Let me hasten to add there are significant successes, yes, and I don't want to minimize them but we can do better, we CAN do better and more importantly, we MUST do better.

ACTION STEP: We must each internalize a phrase that was a slogan I came to dream about in the last two years: Putting People First. It just says PEOPLE, not people with economic needs, people with disabilities, people with allergies, people with educational funds lacking, people with teenagers in the family.....simply PEOPLE first. We have done too little of that in our ever growing array of programs to meet the needs of all the categories of people we classify....and now we find that people are lost in the process and instead we are within our service delivery systems putting PIECES of people first....one agency serves this little piece of a person, another serves another little piece and so forth. I am sometimes astonished when I look back at the number of forms I have filled out for my son and always the same questions over and over, the large numbers of caseworkers we've seen, all looking at him at a slightly different angle - and I often FOUND and FIND myself wondering - do any of them really know him as a whole person - and I know for sure few of the professionals with whom we have worked saw us a family UNIT...all were extremely well meaning but seldom was there a person with whom we worked that saw Hamp as a PERSON first. And I've often wondered if it is simply coincidence that the people I remember as BEST -regardless of their professional field/status -serving Hamp were first and foremost self-esteem builders? I believe what this piecemeal approach ultimately does to individuals is compound the disability by which they have been labelled. This is not to say we don't need specialized and/or individualized approaches but it does mean we need to recognize places of similarity/ programs commonly needed by all if we are going to act on the types of things I daresay you will need to act upon when you leave here today.

Besides individual professionals and advocates I have also learned and experienced that organizations have tended to feel they must first and foremost go after a piece they can call their own, their own place in the sun so to speak. I say, we must come together as individuals and organizations to seize special moments when our collective voices can make a real difference for the people we love, the people we serve, for all people. And so, if we're going to put PEOPLE first, what is the real action step other than internalizing the phrase, giving it real meaning?

The Clinton Administration led with an economic package that addressed the health of our economy....we are NOW saying to the American people - join with us in looking at the health of people and together we can make a difference. Yes, you should join in the dialogue and make certain we will serve people appropriately, fully within this plan. But first and foremost, let's seize the moment, join our voices and hard work by looking at those things ALL people need within a health plan and stand together on what people - all people - first require.

Facts About Health Care

- One of every four of us will lose our health coverage sometime in the next two years.
- Insurance companies pick and choose whom they cover. If you change jobs, move, or get sick, they can drop you.
- Insurance companies charge small businesses as much as 35% more than big business.
- Only 3 of every 10 employers with fewer than 500 employees offer any choice of health plan. Millions of Americans have almost no choice today.
- Twenty-five cents out of every dollar on a hospital bill goes to bureaucracy and paperwork -- not patient care.
- Health care fraud costs all of us at least \$80 billion a year. That's a dime of every dollar we spend on health care.
- Our nation's health costs have nearly quadrupled since 1980. If we do nothing, your family's health care costs will double by the year 2000.
- The number of hospital administrators is increasing four times faster than the number of doctors.

Health Security: The Principles

Security. Every American will receive a Health Security Card that guarantees you a comprehensive package of benefits that can never be taken away. If you lose your job, move, or get sick, you're covered. That's not true today.

Savings. To control health care costs we're going to spend smarter and make health plans compete for your business. We're going to cap how fast your health premiums can go up, eliminate wasteful spending, and crack down on fraud.

Quality. We're going to provide free preventive care, give you the information you need to choose, and invest in training more family doctors. We'll make what's best about American health care better.

Choice. We're going to preserve your right to choose your doctor. Many people, in fact, will have increased choices, including a traditional fee-for-service plan that too many of us are denied.

Simplicity. We're going to streamline the paperwork that's choking you and your doctors and nurses. Simplifying forms and cutting back on regulations will give doctors more time to spend caring for you.

Responsibility. Everyone should contribute to health care. Right now, we all pay for those who don't take responsibility. It's time to say: "No one should get a free ride."

These are principles upon which I hope you will join us with insistence. The reform, the transformation of our health system to one of security for ALL people is an action step that could change the whole outlook on the economic consequences of disability within a short period of time if we can come together and work hard for those things upon which we can all agree and not allow ourselves to fracture this debate beyond success with an approach that only focuses on the areas of disagreement.

And so I ask you to join us...I ask you to leave here and resolve to approach tomorrow differently. Hokey as it may sound, take a real action step when you return to your place of work, take some memento of today - your nametag, your program, a business card you exchange --- put it in a tickler file three months ahead, place it there with two questions: (1) Is health care reform further along due to efforts I have made? (2) What am I doing daily that actually empowers further one person with a disability?

Each of us must have the courage to always be changing, to recognize mistakes, to abandon what doesn't work, to challenge ourselves to do better. Concern for people- all people with their own hopes/dreams/potentials- must start at the top - but it can't end there. We must empower clients or customers, parents, friends, advocates, neighborhoods, communities and voluntary organizations across this great nation to do what our people need. The President can and will take the lead but only you can complete the task. We will work with you. We won't always succeed, and we won't always be able to do everything that you - and we - would want.

But I can promise you this....we will never relent in our effort to give every person a chance to develop fully. Because at the end of Bill Clinton's second term, at the dawn of the third millennium, I want to be able to say to Hamp Rasco and Mary-Margaret Rasco and to all the children of America ---with a clear conscience and a full heart....I did my best. And I want all of you at this meeting to join me in being able to look at one another and say: We did our best.

Thank you very much.

REMARKS BY CAROL H. RASCO
NATIONAL EASTER SEAL SOCIETY
CHICAGO, IL
SATURDAY, NOVEMBER 20, 1993

Thank you.

I am very pleased and somewhat overwhelmed to be in front of you today. Little did I know throughout the almost twenty years my family has been a part of the Easter Seals' family that I would have the honor and privilege to come before your national convention. You are special, you represent the services that I have worked for throughout the last twenty years of my life and above ALL, you represent the services that have worked FOR me. You and your peers throughout this country – whether as volunteers, center administrators, front line therapists, teachers, personal assistants, social workers, medical personnel, and so forth – you daily help to enable the determination of families like mine, our capacity to both take on responsibility and teach responsibility...and above all you CARE.

Why is our family a member of the Easter Seals' family? His name is Hamp. Who is this child Hamp and what has he taught me? Howard Hampton Rasco was born twenty years ago this past Wednesday...he was premature, small and very weak. At the end of three weeks in the intensive care nursery I was told to take him home, love him, and start thinking about what residential institution I wanted to utilize. I took him home, loved him and continue to love him – and never once did I think about a residential institution. We learned about Easter Seals at age 18 months when the Ark. Society opened their first parent/infant intervention program, and we've been with them ever since! From that intervention program to intensive individual therapy programs, preschool preparation programs, Easter Seals therapists on contract with the public schools, afternoon after-school care, and now a group living facility, Easter Seals and Hamp and the Rasco family have grown up, cried, laughed, and worked together. Hamp moved into the group living facility a little over a year ago

prior to the start of his senior year in high school, took "college woman" to his high school prom, graduated in a ceremony where the senior class officers asked him to speak because they said they had learned so much from him, and is now preparing for a job....all a long ways from a residential institutional setting.

I come to you today, not as someone who is all knowing in the field of service to and with persons with disabilities....I come to you primarily as the mother of this Hamp Rasco, as the friend and confidant of many families and individuals with disabilities. I come to you with gratitude for your ongoing belief in the worth of every individual and your commitment to empowering each individual to develop to her/his full potential.

Within this empowerment concept for which I commend you is the point at which I also become the person known as the Domestic Policy Advisor within the White House because the underlying

theme as we approach domestic issues is providing the environment/ the necessary tools/ the opportunity for that empowerment process to unfold.

I come to you today not only to thank you for your organization's commitment to the population you serve but in particular for your support of health care reform. It is my serious hope when you meet for your 76th anniversary next year that we will have a bipartisan, nationally accepted health care reform plan in place.

This issue of health care reform is one we know will be discussed throughout this great country in all kinds of meetings like this one, but even more importantly in families living rooms, in coffee shops, in doctor's offices, people are going to be talking about health care reform and I think it is a conversation that is long overdue and very welcome.

Those of you affiliated with Easter Seals have experience in knowing what is needed to make systems respond to human needs, and President Clinton has asked me to personally thank you for the very positive statement that you issued in response to his health care speech. And I want to thank Edward Beck, Robbie Friedner, Randall Rutta and Judith Shaw for their presence at the rally held on the South Lawn the day after the President's speech when we kicked off the reform effort.

You know, often better than many Americans, how easy it is to be victimized by a health care system that discriminates against pre-existing conditions, that does not offer adequate long term care choices such as personal assistance and other supports that people with disabilities and their families need to rely on to fulfill their potential and to be productive citizens.

The Clinton Administration led with an economic package that addressed the health of our economy....we are NOW saying to the American people – join with us in looking at the health of people and together we can make a difference. Yes, you should join in the dialogue and make certain we will serve people with disabilities appropriately and fully within this plan. But first and foremost, let's seize the moment, join our voices and work hard by looking at those things ALL people need within a health plan and stand together on what people – ALL people – first require.

The reform, the transformation of our health system to one of security for ALL people is an action step that could change the whole outlook on the economic consequences of disability within a short period of time if we can come together and work hard for those things upon which we can all agree and not allow ourselves to fracture this debate beyond success with an approach that only focuses on the areas of disagreement.

We are trying in our health care reform approach to deal with several of the problems that are most important to Easter Seals.

We want to expand home and community based services to persons with disabilities.

You know so very well that we must have the capacity, the infrastructure so to speak, to support people while they live in their homes or in alternative living arrangements....you know as I do that it is the right thing to do both in human terms and in terms of the economics. The Health Security Act will finally make it clear that regardless of income or age, individuals with severe disabilities should have the options before them to choose home based care or community based care in addition to the institutions we offer today.

Also, as part of the overall plan we are leaving in place the programs that have provided health and assistance appropriately.

In fact, the theme of health care reform, as far as President Clinton is concerned, is let's preserve what is right about the American system and fix what is wrong. So, one of the features that we will be preserving is ICF/MR facilities and the Medicaid home and community based waiver program.

You know, when the President in his speech held up that health security card, he didn't hold it up and say you will only be able to get this if you are a certain age, or if you have never been sick, or if you do not have a disability. He held it up and said: every American will be entitled to this card and the services that it will represent and we want to make that a right of every American to have.

In your National Easter Seal Society press release supporting health care reform and the President, you restated the six principles you presented to President Clinton in March of this

year: universal access, quality, comprehensiveness, equity, appropriateness, and efficiency. Every one of those fits into the principles that the President outlined. It has to be comprehensive, and that means it has to provide a comprehensive set of benefits.

It cannot discriminate against any American. It must be appropriate in the sense that it should build on what works. It should provide access to adequate quality and affordable health care in appropriate settings, based upon choices that individuals make that are best for them and their families. It must, it absolutely **MUST** have equity, and if it is comprehensive and does not discriminate it should have equity; but, it needs to have safeguards built in so that all of us feel that we are not being taken advantage of or discriminated against. And it must have efficiency. Efficiency in the better delivery of health care services at a more cost effective level. This will be one of the great debates that we will be having as to how much efficiency we are able to

achieve. But you as a Society have seen programs that work. You know of more efficient ways of delivering health care services to people with disabilities. We must build in incentives so that efficiency is rewarded and that those who are inefficient, who don't deliver high quality care at a cost efficient affordable rate, will learn how to do better because there will be incentives in the system for them to become more efficient. We need your voices and your experiences, speaking loudly to people all over America about how we can do the job better.

You like me have probably attended many a meeting like this one....whether long or short, where the stunning facts and overwhelming statistics about people with disabilities, the services needed, etc. have been presented. Often reams of paper are generated, many hopes raised and good intentions are overflowing...but far too little time is spent throughout the meetings in looking at what can be done to harness all those hopes

toward significant changes. Programs continue to grow in number, barriers often erected to an even greater degree between programs, job placements for people with disabilities have not grown as they should, health care is still a problem, housing needs aren't adequately addressed. Let me hasten to add there are significant successes, yes, and I don't want to minimize them but we can do better, we CAN do better and more importantly, we **MUST** do better.

The real action step for us is that we must each internalize a phrase that was a slogan I came to eat, breathe, and dream in the last two years...Putting People First. It just says **PEOPLE**, not people with economic needs, people with disabilities, people with allergies, people with educational funds lacking, people with teenagers in the family....simply **PEOPLE** first. We have done too little of that in our ever growing array of programs to meet the needs of all the people we classify...and now we find that people

are lost in the process and instead we are within our service delivery systems putting PIECES of people first...one agency serves this little piece of a person, another services another little piece and so forth....I am sometimes astonished when I look back at the number of forms I have filled out for Hamp and always the same questions over and over, the large numbers of caseworkers we have seen who were with each identifiable state and federal funding source....and all of these people looking at him at a slightly different angle..and I often FOUND and FIND myself wondering...do any of them really know him as a whole person? This piecemeal approach very frankly often compounds the disability by which a person is labelled.

I commend Easter Seals, for you have through your Arkansas chapter and certainly I know in other places, you have worked hard to look at people as people first and families as the units they are. Government often puts barriers in front of you, indeed all

around and makes it difficult ... through our reinventing government project we want to join with you in bringing those barriers down...help us!

Besides the tendencies of individual professionals, volunteers, and advocates to approach issues in a piecemeal way I have also learned and experienced that organizations have tended to feel they must first and foremost go after a piece they can call their own, their own place in the sun so to speak. I say, we must come together as individuals and organizations to seize special moments when our collective voices can make a real difference for the people we love, the people we serve, for ALL people.

And so I ask you to join us...I ask you to proceed through your meeting here and then as you go back home to approach each tomorrow differently. Take a real action step when you return to your place of work, your home....take some memento of today –

your nametag, your program, a business card you exchange...put it in a tickler file three months ahead, and place it there with these two questions:

(1) Is health care reform further along due to efforts I have made?

(2) What am I doing daily that actually empowers further one person with a disability?

Each of us must have the courage –like the Hamps and all the children's and adult's faces we serve—to always be changing, to recognize mistakes, to abandon what doesn't work, to challenge ourselves to do better. Concern for people – all people with their own hopes/dreams/potentials – must start at the top – but it can't end there. We must empower clients or customers, parents, friends, advocates, neighborhoods, communities and voluntary

organizations across this great nation to do what our people need. The President can and will take the lead but only YOU can complete the task. We will work with you. We won't always succeed, and we won't always be able to do everything that you – and we – would want.

But I can promise you this...we will never relent in our effort to give every person a chance to develop fully. Because at the end of Bill Clinton's second term, at the dawn of the third millennium, I want to be able to say to Hamp Rasco and his sister Mary– Margaret Rasco and to all the children of America out there today...with a clear conscience and a full heart...I did my best. And I want all of you at this meeting to join me in being able to look at one another and say: We did our best. Thank you very much.