

**Dear President Clinton:**

**People with disabilities want lives that are as typical and as varied as their fellow citizens. They want what all Americans want - a place to live, a job, reliable transportation, and enjoyment of life. People with disabilities are impoverished in terms of money, choices and opportunities. The long term care system is broken and must be reformed. Too often current funding is used for:**

- exclusion than inclusion; and**
- creates a bias toward institutional services rather than leveling the playing field between institutional and community services.**

**The current system supports programs not people. Your proposals begin the process of developing a system that supports people in the lives that they want. We want services in the community that support people in being members of their communities.**

**We commend you for your long term services advocacy and strongly urge you to protect long term care reform as part of the health care initiative.**

**Signed by the participants of the President's Committee on Mental Retardation's Reform Agenda Conference, April 26, 1994.**

Steve - LTC

"Design services first-fit people in" - the switch is gradually underway

Move to outcomes, not continuation of process measures

Incentives opened doors in wrong places

ex: Limits on waivers vs. open ended nature of ICF-MR's

### Welfare Reform

Basic prin.

- ① Effective reformed w. system invests in human cap.
- ② M.R. is a term strongly disliked
- ③ Intellectual disability must be considered across the lifetime span and full family
- ④ Expanded knowledge base must be put into action

Key

- SSI modernization efforts

① SSI asset limits

② Elim. family support limits

- Expand EITC to single / couples w/ no children

- AFDC: <sup>expand</sup> child care programs

- Demonst. <sup>work</sup> work for p w/ dis.

- Training for workers in assistance prep.

- Intergenerational prep.

- WR must recog. unique needs of mothers who are disabled, who have disabled children as well as older workers w/ disabilities

## David: Health Care

Basic right  
Pre-existing  
Therapies

Univ. coverage

Specialist

Consumer involvement

Community based / in home services

Compt. pkg. stated

Wellness

## Education reform

Segr. classes / ed. - no proof of value

Lifelong learning

Restructuring of offices / functions in DPC

Funding

Research - need change

## David Beth: E, T, & Financing

① Choice

② Building capacity

③ Funding sources must reward integrated emp.

\* → ④ Integ. employ must be included in HS trans. plans

⑤ Reconcile related Fed policies

that speak to integ. employ.

## Housing

For every person w/ disability  
who owns/leases their own  
home, 12 do not.

T.J. "People need to have control of their front door."

## Incentives

Individual homes, not congregate housing  
Inclusion in all neighborhoods

~~PL 103-230 (April 6, 1994).~~  
~~Cheers!~~

Carol -- re PCMR talk

• As promised here is the quote from ~~the recent TECH Amendments Act that I've previously highlighted for you. See Appendix B. It is identical with a~~ similar Congressional finding in the DD Amendments Act. (App B) §101(a)(2)

Extracts from opening remarks of Gary Blumental, PCMR executive director. (App C)

• some extracts from the findings and purpose clauses of the DD Assistance and Bill of rights Act Amendments of 1994, PL 103-230 (April 6, 1994).  
Cheers! (App B)

• extract from parents' speech re graduation aspirations for their 2-year old daughter with Downs syndrome (App D)

Stan

The question was taken; and (two-thirds having voted in favor thereof) his rules were suspended, and the bill, as amended, was passed.  
A motion to reconsider was laid on the table.

**CONFERENCE REPORT ON S. 1284, DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT AMENDMENTS OF 1994**

Mr. WAXMAN submitted the following conference report and statement on the Senate bill (S. 1284) to amend the Developmental Disabilities Assistance and Bill of Rights Act to expand or modify certain provisions relating to programs for individuals with developmental disabilities, Federal assistance for priority area activities for individuals with developmental disabilities, protection and advocacy of individual rights, university affiliated programs, and projects of national significance, and for other purposes:

**CONFERENCE REPORT (H. REPT. 103-442)**

The committee of conference on the disagreeing votes of the two Houses on the amendment of the House to the bill (S. 1284), to amend the Developmental Disabilities Assistance and Bill of Rights Act to expand or modify certain provisions relating to programs for individuals with developmental disabilities, Federal assistance for priority area activities for individuals with developmental disabilities, protection and advocacy of individual rights, university affiliated programs, and projects of national significance, and for other purposes, having met, after full and free conference, have agreed to recommend and do recommend to their respective Houses as follows:  
That the Senate recede from its disagreement to the amendment of the House and agree to the same with an amendment as follows:

In lieu of the matter proposed to be inserted by the House amendment, insert the following:

**SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

(a) **SHORT TITLE.**—This Act may be cited as the "Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994".

(b) **TABLE OF CONTENTS.**—The table of contents is as follows:

- c. 1. Short title; table of contents.
- c. 2. References.

**TITLE I—GENERAL PROVISIONS**

- c. 101. Headings and short title.
- c. 102. Findings and purposes.
- c. 103. Definitions.
- c. 104. Federal share.
- c. 105. Records and audits.
- c. 106. Recovery.
- c. 107. State control of operations.
- c. 108. Reports.
- c. 109. Responsibilities of the Secretary.
- c. 110. Employment of handicapped individuals.
- c. 111. Rights of the developmentally disabled.

**TITLE II—FEDERAL ASSISTANCE FOR PRIORITY AREA ACTIVITIES FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

- c. 201. Part heading.
- c. 202. Purpose.
- c. 203. State plans.
- c. 204. Habilitation plans.
- c. 205. Councils.

- Sec. 206. State allotments.
- Sec. 207. Federal share and non-Federal share.
- Sec. 208. Payments to the States for planning, administration, and services.

Sec. 209. Withholding of payments for planning, administration, and services.

- Sec. 210. Nonduplication.
- Sec. 211. Appeals by States.
- Sec. 212. Authorization of appropriations.
- Sec. 213. Review, analysis, and report.

**TITLE III—PROTECTION AND ADVOCACY OF THE RIGHTS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

- Sec. 301. Part heading.
- Sec. 302. Purpose.
- Sec. 303. System required.
- Sec. 304. Authorization of appropriations.

**TITLE IV—UNIVERSITY AFFILIATED PROGRAMS**

- Sec. 401. Part heading.
- Sec. 402. Purpose.
- Sec. 403. Grant authority.
- Sec. 404. Applications.
- Sec. 405. Grant awards.
- Sec. 406. Authorization of appropriations and definition.

**TITLE V—PROJECTS OF NATIONAL SIGNIFICANCE**

- Sec. 501. Part heading.
- Sec. 502. Purpose.
- Sec. 503. Grant authority.
- Sec. 504. Authorization of appropriations.

**SEC. 2. REFERENCES.**

Except as otherwise specifically provided, whenever in this Act an amendment or repeal is expressed in terms of an amendment to, or a repeal of, a section or other provision, the reference shall be considered to be made to a section or other provision of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.).

**TITLE I—GENERAL PROVISIONS**

**SEC. 101. HEADINGS AND SHORT TITLE.**

(a) **TITLE.**—The heading of title I of the Act is amended to read as follows:

**"TITLE I—PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES"**

(b) **PART.**—The heading of part A of title I of the Act is amended to read as follows:

**"PART A—GENERAL PROVISIONS"**

(c) **SHORT TITLE.**—Section 100 (42 U.S.C. 6000 note) is amended—

- (1) by striking "SEC. 100"; and
- (2) in the section heading, by striking "SHORT TITLE" and inserting the following new section heading:

**"SEC. 100. SHORT TITLE."**

**SEC. 102. FINDINGS AND PURPOSES.**

Section 101 (42 U.S.C. 6000) is amended to read as follows:

**"SEC. 101. FINDINGS, PURPOSES, AND POLICY.**

**"(a) FINDINGS.**—The Congress finds that—  
"(1) in 1993 there are more than 3,000,000 individuals with developmental disabilities in the United States;

"(2) disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society;

"(3) individuals with developmental disabilities continually encounter various forms of discrimination in critical areas;

"(4) there is a lack of public awareness of the capabilities and competencies of individuals with developmental disabilities;

"(5) individuals whose disabilities occur during their developmental period frequently have severe disabilities that are likely to continue indefinitely;

"(6) individuals with developmental disabilities often require lifelong specialized services and assistance, provided in a coordinated and culturally competent manner by many agencies, professionals, advocates, community representatives, and others to eliminate barriers and to meet the needs of such individuals and their families;

"(7) a substantial portion of individuals with developmental disabilities and their families do not have access to appropriate support and services from generic and specialized service systems and remain unserved or underserved;

"(8) family members, friends, and members of the community can play an important role in enhancing the lives of individuals with developmental disabilities, especially when the family and community are provided with the necessary services and supports;

"(9) there is a need to ensure that services, supports, and other assistance are provided in a culturally competent manner, that individuals from racial and ethnic minority backgrounds are fully included in all activities under this Act, and that greater efforts are made to recruit individuals from minority backgrounds into the field of developmental disabilities; and

"(10) the goals of the Nation properly include the goal of providing individuals with developmental disabilities with the opportunities and support to—

"(A) make informed choices and decisions;

"(B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;

"(C) pursue meaningful and productive lives;

"(D) contribute to their family, community, State, and Nation;

"(E) have interdependent friendships and relationships with others; and

"(F) achieve full integration and inclusion in society, in an individualized manner, consistent with unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual.

"(b) **PURPOSE.**—The purpose of this Act is to assure that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, and integration and inclusion into the community, through—

"(1) support to State Developmental Disabilities Councils in each State to promote, through systemic change, capacity building, and advocacy activities that are consistent with the policy under subsection (c)(2), a consumer and family-centered, comprehensive system, and a coordinated array of services, supports, and other assistance for individuals with developmental disabilities and their families;

"(2) support to protection and advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities;

"(3) support to university affiliated programs to provide interdisciplinary preservice preparation of students and fellows, community service activities, and the dissemination of information and research findings; and

"(4) support to national initiatives to collect necessary data, provide technical assistance to State Developmental Disabilities Councils, protection and advocacy systems and university affiliated programs, and support other nationally significant activities.

"(c) **POLICY.**—It is the policy of the United States that all programs, projects, and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles that—

"(1) individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of achieving independence, productivity, and integration and inclusion into the community, and often require the provision of services, supports and other as-

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assistance to achieve independence, productivity, and integration and inclusion;

"(2) individuals with developmental disabilities and their families have competencies, capabilities and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of the such individuals;

"(3) individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families;

"(4) services, supports, and other assistance are provided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences;

"(5) specific efforts must be made to ensure that individuals from racial and ethnic minority backgrounds enjoy effective and meaningful opportunities for full participation in the developmental disabilities service system;

"(6) recruitment efforts within developmental disabilities at the level of preservice training, community training, practice, administration and policymaking must focus on bringing larger numbers of racial and ethnic minorities into the field in order to provide appropriate skills, knowledge, role models, and sufficient manpower to address the growing needs of an increasingly diverse population.

"(7) with education and support, communities can be responsive to the needs of individuals with developmental disabilities and their families and are enriched by the full and active participation and the contributions by individuals with developmental disabilities and their families; and

"(8) individuals with developmental disabilities should have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, community, State, and Nation."

**SEC. 102. DEFINITIONS.**

Section 102 (42 U.S.C. 6001) is amended to read as follows:

**SEC. 102. DEFINITIONS.**

"For purposes of this title:

"(1) **AMERICAN INDIAN CONSORTIUM.**—The term 'American Indian Consortium' means any consideration of two or more recognized American Indian tribes, created through the official action of each participating tribe, that has a combined total resident population of 150,000 enrolled tribal members and a contiguous territory of Indian lands in two or more States.

"(2) **ASSISTIVE TECHNOLOGY DEVICE.**—The term 'assistive technology device' means any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with developmental disabilities.

"(3) **ASSISTIVE TECHNOLOGY SERVICE.**—The term 'assistive technology service' means any service that directly assists an individual with a developmental disability in the selection, acquisition, or use, of an assistive technology device. Such term includes—

"(A) the evaluation of the needs of an individual with a developmental disability, including a functional evaluation of the individual in the individual's customary environment;

"(B) purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by an individual with a developmental disability;

"(C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or placing assistive technology devices;

"(D) coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing education and rehabilitation plans and programs;

"(E) training or technical assistance for an individual with a developmental disability, or, where appropriate, a family member, guardian, advocate, or authorized representative of an individual with a developmental disability; and

"(F) training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of, an individual with developmental disabilities.

"(4) **CHILD DEVELOPMENT ACTIVITIES.**—The term 'child development activities' means such priority area activities as will assist in the prevention, identification, and alleviation of developmental disabilities in children, including early intervention services.

"(5) **COMMUNITY LIVING ACTIVITIES.**—The term 'community living activities' means such priority area activities as will assist individuals with developmental disabilities to obtain and receive the supports needed to live in their family home or a home of their own with individuals of their choice and to develop supports in the community.

"(6) **COMMUNITY SUPPORTS.**—The term 'community supports' means activities, services, supports, and other assistance designed to—

"(A) assist neighborhoods and communities to be more responsive to the needs of individuals with developmental disabilities and their families;

"(B) develop local networks that can provide informal support; and

"(C) make communities accessible and enable communities to offer their resources and opportunities to individuals with developmental disabilities and their families.

Such term includes community education, personal assistance services, vehicular and home modifications, support at work, and transportation.

"(7) **CULTURALLY COMPETENT.**—The term 'culturally competent' means services, supports or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program.

"(8) **DEVELOPMENTAL DISABILITY.**—The term 'developmental disability' means a severe, chronic disability of an individual 5 years of age or older that—

"(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

"(B) is manifested before the individual attains age 22;

"(C) is likely to continue indefinitely;

"(D) results in substantial functional limitations in three or more of the following areas of major life activity—

"(i) self-care;

"(ii) receptive and expressive language;

"(iii) learning;

"(iv) mobility;

"(v) self-direction;

"(vi) capacity for independent living; and

"(vii) economic self-sufficiency; and

"(E) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

"(9) **EARLY INTERVENTION SERVICES.**—The term 'early intervention services' means services provided to infants, toddlers, young children, and their families to—

"(A) enhance the development of infants, toddlers, and young children with disabilities and to minimize their potential for developmental delay; and

"(B) enhance the capacity of families to meet the special needs of their infants, toddlers, and young children.

"(10) **EMPLOYMENT ACTIVITIES.**—The term 'employment activities' means such priority area activities as will increase the independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities in work settings.

"(11) **FAMILY SUPPORT SERVICE.**—The term 'family support service' means services, supports, and other assistance provided to families with members with developmental disabilities that are designed to—

"(A) strengthen the family's role as primary caregiver;

"(B) prevent inappropriate out-of-the-home placement and maintain family unity; and

"(C) reunite families with members who have been placed out of the home, whenever possible. Such term includes respite care, rehabilitation technology, personal assistance services, parent training and counseling, support for elderly parents, vehicular and home modifications, and assistance with extraordinary expenses associated with the needs of individuals with developmental disabilities.

"(12) **FEDERAL PRIORITY AREAS.**—The term 'Federal priority areas' means community living activities, employment activities, child development activities, and system coordination and community education activities.

"(13) **INDEPENDENCE.**—The term 'independence' means the extent to which individuals with developmental disabilities exert control and choice over their own lives.

"(14) **INDIVIDUAL SUPPORTS.**—The term 'individual supports' means services, supports, and other assistance that enable an individual with a developmental disability to be independent, productive, integrated, and included into such individual's community, and that are designed to—

"(A) enable such individual to control such individual's environment, permitting the most independent life possible;

"(B) prevent placement into a more restrictive living arrangement than is necessary; and

"(C) enable such individual to live, learn, work, and enjoy life in the community. Such term includes personal assistance services, rehabilitation technology, vehicular and home modifications, support at work, and transportation.

"(15) **INTEGRATION AND INCLUSION.**—The term 'integration and inclusion', with respect to individuals with developmental disabilities, means—

"(A) the use by individuals with developmental disabilities of the same community resources that are used by and available to other citizens;

"(B) living in homes close to community resources, with regular contact with citizens without disabilities in their communities;

"(C) the full and active participation by individuals with developmental disabilities in the same community activities and types of employment as citizens without disabilities, and utilization of the same community resources as citizens without disabilities, living, learning, working, and enjoying life in regular contact with citizens without disabilities; and

"(D) having friendships and relationships with individuals and families of their own choosing.

"(16) **NONPROFIT.**—The term 'nonprofit' means an agency, institution, or organization that is owned or operated by one or more corporations or associations, no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual.

"(17) OTHER ORGANIZATIONS.—The term 'other organizations' means those organizations that are not State agencies or nonprofit agencies, except such organizations may be consulting firms, independent proprietary businesses and providers, and local community groups not organizationally incorporated, and that are interested in supporting individuals with developmental disabilities.

"(18) PERSONAL ASSISTANCE SERVICES.—The term 'personal assistance services' means a range of services, provided by one or more individuals, designed to assist an individual with a disability to perform daily living activities on or off a job that such individual would typically perform if such individual did not have a disability. Such services shall be designed to increase such individual's control in life and ability to perform everyday activities on or off such job.

"(19) PREVENTION.—The term 'prevention' means activities that address the causes of developmental disabilities and the exacerbation of functional limitations, such as activities that—

"(A) eliminate or reduce the factors that cause or predispose individuals to developmental disabilities or that increase the prevalence of developmental disabilities;

"(B) increase the early identification of existing problems to eliminate circumstances that create or increase functional limitations; and

"(C) mitigate against the effects of developmental disabilities throughout the individual's lifespan.

"(20) PRODUCTIVITY.—The term 'productivity' means—

"(A) engagement in income-producing work that is measured by increased income, improved employment status, or job advancement; or

"(B) engagement in work that contributes to a household or community.

"(21) PROTECTION AND ADVOCACY SYSTEM.—The term 'protection and advocacy system' means a protection and advocacy system established in accordance with section 142.

"(22) REHABILITATION TECHNOLOGY.—The term 'rehabilitation technology' means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, individuals with developmental disabilities in areas that include education, rehabilitation, employment, transportation, independent living, and recreation. Such term includes rehabilitation engineering, assistive technology devices, and assistive technology services.

"(23) SECRETARY.—The term 'Secretary' means the Secretary of Health and Human Services.

"(24) SERVICE COORDINATION ACTIVITIES.—The term 'service coordination activities' (also referred to as 'case management activities') means activities that assist and enable individuals with developmental disabilities and their families to access services, supports and other assistance, and includes—

"(A) the provision of information to individuals with developmental disabilities and their families about the availability of services, supports, and other assistance;

"(B) assistance in obtaining appropriate services, supports, and other assistance, which may include facilitating and organizing such assistance;

"(C) coordination and monitoring of services, supports, and other assistance provided singly or in combination to individuals with developmental disabilities and their families to ensure accessibility, continuity, and accountability of such assistance; and

"(D) follow-along services that ensure, through a continuing relationship, that the changing needs of individuals with developmental disabilities and their families are recognized and appropriately met.

"(25) STATE.—The term 'State', except as provided in section 155, includes, in addition to each of the several States of the United States;

the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, and the Republic of Palau (until the Compact of Free Association with Palau takes effect).

"(26) STATE DEVELOPMENTAL DISABILITIES COUNCIL.—The term 'State Developmental Disabilities Council' means a Council established under section 124.

"(27) STATE PRIORITY AREA.—The term 'State priority area' means priority area activities in an area considered essential by the State Developmental Disabilities Council.

"(28) SUPPORTED EMPLOYMENT.—The term 'supported employment' means competitive work in integrated work settings for individuals with developmental disabilities—

"(A)(i) for whom competitive employment has not traditionally occurred; or

"(ii) who, for whom competitive employment has been interrupted or intermittent as a result of a severe disability; and

"(B) who, because of the nature and severity of their disability, need intensive supported employment services or extended services in order to perform such work.

"(29) SYSTEM COORDINATION AND COMMUNITY EDUCATION ACTIVITIES.—The term 'system coordination and community education activities' means activities that—

"(A) eliminate barriers to access and eligibility for services, supports, and other assistance;

"(B) enhance systems design, redesign, and integration, including the encouragement of the creation of local service coordination and information and referral statewide systems;

"(C) enhance individual, family, and citizen participation and involvement; and

"(D) develop and support coalitions and individuals through training in self-advocacy, educating policymakers, and citizen leadership skills.

"(30) UNIVERSITY AFFILIATED PROGRAM.—The term 'university affiliated program' means a university affiliated program established under section 152.

"(31) UNSERVED AND UNDERSERVED.—The term 'unserved and underserved' includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited-English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals with developmental disabilities attributable to physical impairment, mental impairment, or a combination of physical and mental impairments."

#### SEC. 104. FEDERAL SHARE.

Section 103 (42 U.S.C. 6002) is repealed.

#### SEC. 105. RECORDS AND AUDITS.

(a) SECTION HEADING.—Section 104 (42 U.S.C. 6003) is amended—

(1) by striking "SEC. 104."; and

(2) in the section heading, by striking "RECORDS AND AUDIT" and inserting the following new section heading:

"SEC. 104. RECORDS AND AUDITS."

(b) RECORDS AND AUDITS.—Section 104 (42 U.S.C. 6003) is amended—

(1) in subsection (a)—

(A) by striking "Each" and inserting "RECORDS.—Each";

(B) by striking "including" and inserting "including—";

(C) by realigning the margins of subparagraphs (A), (B), and (C) of paragraph (1) so as to align with the margins of subparagraphs (A) and (B) of paragraph (2) of section 102;

(D) by realigning the margins of paragraphs (1) and (2) so as to align with the margin of paragraph (3) of section 102;

(E) in paragraph (1), by striking "disclose" and inserting "disclose—"; and

(F) by striking the comma each place such appears and inserting a semicolon; and

(2) in subsection (b), by striking "The Secretary" and inserting "ACCESS.—The Secretary".

#### SEC. 106. RECOVERY.

Section 105 (42 U.S.C. 6004) is repealed.

#### SEC. 107. STATE CONTROL OF OPERATIONS.

Section 106 (42 U.S.C. 6005) is amended—

(1) by striking "SEC. 106.";

(2) in the section heading, by striking "STATE CONTROL OF OPERATIONS" and inserting the following new section heading:

"SEC. 106. STATE CONTROL OF OPERATIONS.;"

and

(3) by striking "facility for persons" and inserting "programs, services, and supports for individuals".

#### SEC. 108. REPORTS.

(a) SECTION HEADING.—Section 107 (42 U.S.C. 6006) is amended—

(1) by striking "SEC. 107."; and

(2) in the section heading, by striking "REPORTS" and inserting the following new section heading:

"SEC. 107. REPORTS."

(b) REPORTS.—Section 107 (42 U.S.C. 6006) is amended—

(1) in subsection (a)—

(A) in the matter preceding paragraph (1)—

(i) by striking "By January" and inserting "DEVELOPMENTAL DISABILITIES COUNCIL REPORTS.—By January";

(ii) by striking "the State Planning Council of each State" and inserting "each State Developmental Disabilities Council";

(iii) by striking "a report concerning" and inserting "a report of"; and

(iv) by striking "such report" and inserting "report";

(B) in paragraph (1), by striking "of such activities" and all that follows through "from such activities" and inserting "of activities and accomplishments";

(C) in paragraph (2)—

(i) by striking "such accomplishments" and inserting "accomplishments"; and

(ii) by striking "by the State";

(D) in paragraph (4)—

(i) by striking "Planning" and inserting "Developmental Disabilities";

(ii) by striking "each" each place such term appears;

(iii) by striking "report" and inserting "reports";

(iv) by striking "1902(a)(31)(C)" and inserting "1902(a)(31)";

(v) by striking "plan" and inserting "plans", and

(vi) by striking ";" and inserting a semicolon;

(E) by striking paragraph (5); and

(F) by adding at the end the following new paragraphs:

"(5) a description of—

"(A) the trends and progress made in the State concerning systemic change (including policy reform), capacity building, advocacy, and other actions on behalf of individuals with developmental disabilities, with attention to individuals who are traditionally unserved and underserved, particularly individuals who are members of ethnic and racial minority groups, and individuals from underserved geographic areas;

"(B) systemic change, capacity building, and advocacy activities that affect individuals with disabilities other than developmental disabilities; and

"(C) a summary of actions taken to improve access and services for unserved and underserved groups;

"(6) a description of resources leveraged by activities directly attributable to State Developmental Disabilities Council actions; and

"(7) a description of the method by which the State Developmental Disabilities Council shall



Carol - Extracts of Gary's Appendix C  
Opening remarks

(See p. 3 of  
seq.)

# "GREETINGS AND PURPOSE" --

## Talking Points

### for

**Gary H. Blumenthal  
Executive Director**

**President's Committee on Mental  
Retardation**

**for presentation at**

**A Presidential Forum:**

**The President's Reform Agenda  
and**

**People with Mental Retardation --  
21st Century Realities**

**Opening Plenary**

**Sunday, April 24-26, 1994**

**12:00 Noon**

**Radisson Plaza Hotel**

**at Mark Center**

**5000 Seminary Road**

**Alexandria, Virginia**

**GREETINGS AND PURPOSE**

**Good afternoon. I am pleased to greet you on behalf of the President's Committee on Mental Retardation and other co-sponsors of this Presidential Forum: The President's Reform Agenda and People with Mental Retardation -- 21st Century Realities the President's Committee on Mental Retardation.**

**During the last several years, the PCMR has intensified its efforts to establish and maintain partnership with public and private sector agencies with which the Committee has cross-cutting objectives. We are fortunate to share sponsorship of the Forum with:**

**The Administration on Aging (AoA);**

**The National Institute on Disability and Rehabilitation Research (NIDRR);**

**The Social Security Administration (SSA);**

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**The Administration of Developmental  
Disabilities (ADD); and**

**The National Institute of Child Health  
and Human Development (NICHD)**

**Will individuals representing the co-  
sponsoring agencies please stand?**

**[APPLAUSE]**

**It is a pleasure for me to extend greetings  
to you this afternoon. We are delighted  
by the broad spectrum of individuals,  
agencies, programs, services, and families  
that comprise this audience. We are  
particularly pleased that  
represented among you are  
consumers/self-advocates who will play a  
substantive role in these deliberations --  
right from the start.**

4

**Our forum participants today have come from the East and from the West; from the North and from the South; and also from America's midlands.**

**You have come from organizations based in both urban and suburban communities; and from rural counties and townships. You bring with you, the myriad expertise and the dedication of individuals and organizations not only interested, but also actively involved in programs and services that:**

- 1) prevent mental retardation and related developmental disabilities;**
- 2) ameliorate the effects of these disabilities on the more than six million Americans so diagnosed; and/or**
- 3) advocate for the rights of citizens**

4

**with mental retardation and their families, and for persons at risk of developing this or related disabilities.**

**The PCMR is cognizant of the fact that concerns of the general public regarding the potential impact of proposed national reforms are of equal, if not greater, concern to citizens with mental retardation and their families. The Committee's awareness of this fact, and its sensitivity to the special needs of citizens with mental retardation, motivated the planning and convening of this Forum. Its purpose is twofold:**

**First, to discuss the impact of the President's major reform areas on citizens with mental retardation and related developmental disabilities by experts in the field. The six areas that will be discussed are: Health Care Reform, Welfare**

Appendix D Extract from Linda  
Chagler speech  
(see last page)  
as P  
last P)

Good afternoon everyone. It's my pleasure to be here today to tell you something about someone dear to my heart. <sup>my husband's</sup> ~~My~~ <sup>Our</sup> daughter.

About ten years ago, my husband Lincoln and I were watching a segment on "60 Minutes" and I don't remember so much the exact content as I do the faces of the children... it was a feature on children with Down Syndrome. At the end, my husband turned to me and said, "I think that must be the worst thing in the world."

Just a little over two years ago, on March 31, 1992, our daughter, Kaitlin Aubrey, was born. She has Down Syndrome. I tell the opening story because I think it shows the point from which we needed to move from... and today, my husband I can honestly say that while having a child with Down Syndrome, or perhaps any disability, is not "great" all the time, or that we wish she didn't have it, it isn't the worst thing in the world either.

In many ways we've been lucky with the experiences we've had to date with Katie...

First, we had a tremendous amount of support from the medical and nursing staff at the hospital where Katie was born. It probably also helped that I was an employee there.

Our doctor immediately recognized about five of the signs that led him to suspect that Katie had Down Syndrome. And although he never labeled it as such initially, after her delivery he held her up to us and said he thought there was a problem. <sup>at the time</sup> We noted her almond-shaped eyes, the Simian crease on her left hand, the flat nose, her small ears and very low muscle tone.

*There wasn't much question - even without the chromosome test, everyone seemed to be 99% sure Katie had Down's. The joy we felt at her birth included then a sadness that wasn't anticipated. A pain that I can tell you was so physical. ~~We knew what it was like to feel our hearts break.~~*

I remained in the hospital for 2 1/2 days -- and in that time, my nurse had made calls and gathered information on Down Syndrome, and also gave us the name and number of our nearest parent support group -- the Chesapeake Down Syndrome Parent Support Group.

My doctor visited me alone on two separate occasions, and once with Lincoln. Friends came... we told them and our families that we thought Katie had Down Syndrome. In spite of that news, and the tears, everyone treated Katie's birth as a celebration. That was a help.

Many mothers I've talked to didn't have a clue as to what was happening at the hospital after their child with Down Syndrome was born. Some reported that their physicians avoided them; that the baby was taken and kept in the nursery while the parents were kept in the dark; others talked about how they blamed their doctor for letting this happen. I think it's really necessary for physicians to be upfront with their patients and that a plan be developed at each hospital on how to handle cases like this. My OB told me that this group of doctors wasn't good at giving bad news... it wasn't exactly the norm for them... say, not like surgeons. But I realize I had a better experience simply because of who was on duty the day Katie was born. If medical and nursing staff can be trained in

4)

articles for our local newspaper on the subject of Down Syndrome; and speaking to various groups about our experience... and there will be more activity along the way, I'm sure. I feel that's part of our responsibility. For we've benefitted from those parents who came before us and fought for their children's rights, and fought to make their lives better.

Our goals for Katie include the following: First, we want her to feel loved... to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has the capacity to make many friends, I wonder how other children will accept her. We envision her attending public schools, at least for the most part, and one day we hope to see her graduate from high school. There's even a part of us that hopes she'll continue her education after that... but we'll have to wait and see, and we'll also have to see what it is that Katie wants to do. I wonder if she'll ever get married... if she doesn't, I hope at least she has a companion to enjoy life with. And if we could, we'd like to see her remain as happy as she is today... Our Katie -- who loves people, music, dogs, rain, sunshine, swings, cookies, apricots, baths and the color red.

Thank you for letting me and her dad share her with you.



Here are my preliminary briefing points for you:

- Thanks to all of you for your three days of hard work to come up with quality recommendations for the President.

- Special thanks to Gary Blumenthal, Executive Director of PCMR and his staff, and Bill Jones, Chair of the Advisory Planning Committee for staging this superb event.

- As I reviewed the list of participants I was struck by the depth and breadth of leadership in the mental retardation community assembled here.

- I also want to commend PCMR for making sure that the voices of self-advocates, and of family members are heard in these proceedings. The large delegation of self-advocates invited here is a tribute to the new directions at PCMR. In I know that their contributions, along with the extraordinary range of talents from the diverse professions that work with persons with mental retardation and their families, will lead to an outstanding Report to the President.

- We meet here to mark the revitalization of the President's Committee on Mental Retardation, and to chart the reform agenda that will transform the realities facing persons with mental retardation and related disabilities in the 21st century.

- Carol, here your personal stories about your concerns as a parent and Hamp's experiences as a self-advocate and graduation speaker would fit well.

- I would devote the bulk of your remarks to health care reform, perhaps with the hope that these experts will turn their talents to convincing the Hill of the importance of universal coverage, no preexisting condition, long-term care for persons with mental retardation.

\* YOU CAN ALSO SAY SOMETHING ABOUT THE SELF-ADVOCATES BEING PATIENT WITH US, AS WE BETTER LEARN HOW TO CREATE FORUMS IN WHICH THEIR VALUABLE INPUT IS BEST ORGANIZED -- SOME ARE LITTLE CONFUSED NAD UNCOMFORTABLE WITH THE ROLE THEY PLAYING HERE.

MORE TO COME AND WITH HARD-COPY ATTACHMENTS LATER THIS AFTERNOON.

- In closing. you may wish to call attention to excerpts from the President's greetings to the Forum. See Appendix A. In particular, the formulation about disability as part of the human experience and the recognition of the importance of getting the valuable perspectives of self-advocates and parents may be worthy of mention.

- Alternatively, you may wish to use the quote from the Congressional findings in the recent TECH Amendments Act that I've previously highlighted for you. See Appendix B.

TO Come

- Opening remarks of Gary Blumenthal by COB 4-21

- site add page

- DD Assistance and Bill of rights Act Amendments of 1994,

**MEMORANDUM TO CAROL H. RASCO**

**FROM:** Stanley S. Herr

**SUBJ:** REVISED TALKING POINTS FOR PCMR PRESIDENTIAL FORUM  
TUESDAY, APRIL 26, 1994 (revisions or amendments in  
astericked paragraphs)

**DATE:** April 25, 1994

You are the main closing speaker to this three-day event. Although your letter of invitation states that you are scheduled to speak at 11am on April 26th, there appears to be a change in their agenda that now has the final wrap-up session ("Forum Summation") beginning at 10:15 with work group reports and summary of recommendations, each approximately ten minutes. I then have the pleasure of introducing you, and your talk can be for about 30 minutes.

So if you can arrive by 10:15 you will have the benefit of hearing of the Forum's deliberations. I expect to attend most of the proceedings, so I'll further brief you when we meet on Monday, at 3:30 pm on how the discussion is going and your remarks.

They have also arranged to have brief closing remarks from the putative vice-chair, Val Bradley, at the end of the session. If you have not met her yet, you're in for a treat. She's great and a very experienced consensus builder.

\*[You are likely to hear from folks about their concerns for appointment delays in PCMR. In fact, Sec. Shalala in her luncheon remarks today made the impromptu, but pointed comment that since you were coming tomorrow they could ask you to "bring the names over or give some explanation of when they'll pop out of the White House." Well, with friends like this ....

Here's the status as I understand it as of Friday: the President has signed off on 5 of the 6 current vacancies, and has a question about the 6th person. I know neither the person nor the question, but gather its routine and can be readily answered. With the vetting still underway, I gather there's nothing that can be officially announced for now. As of May, an additional 8 vacancies will be available to be filled. I'm working closely with Presidential Personnel to try to minimize the amount of time they will be open. Will keep you posted of any further developments. Bottom line: we're aware of the concerns and its being addressed].

THE WHITE HOUSE

WASHINGTON

April 21, 1994

Greetings to the President's Committee on Mental Retardation and the distinguished participants in the Presidential Forum. I am pleased that so many of you have gathered for this important discussion of "The President's Reform Agenda and People with Mental Retardation -- 21st Century Realities."

Now is the time to act on our awareness that mental retardation and related disabilities are a natural part of the human experience. Being disabled does not diminish one's right to participate in all aspects of mainstream society. With the valuable perspectives of self-advocates, parents, and professionals, your forum presents an exciting opportunity to build on this understanding, helping to improve the quality of life for millions of Americans with mental retardation and for their family members.

The President's Committee on Mental Retardation serves a vital purpose -- identifying activities, policies, and implementation strategies that can make the American dream a reality for all of our people. Your knowledge and expertise are essential in advancing the rights of and services for persons with mental retardation. On behalf of all Americans, I thank you for your leadership and dedication. Working together, we can craft policies of inclusion, independence, and empowerment that will inspire positive changes in this country and in nations around the world.

Hillary joins me in sending best wishes for a productive forum.

*Bill Clinton*

APR 15 REC'D

Card - The quote  
that Bobbie  
Silverstein used  
that I think you  
wanted is on page

Calendar No. 181 2-34

103D CONGRESS  
1ST SESSION

# H. R. 2339

this how  
enacted law  
It was not in  
the ADA.  
You might  
want to use  
it in your  
PCMR and  
other disability  
speeches, too.  
St

IN THE SENATE OF THE UNITED STATES

AUGUST 4 (legislative day, AUGUST 30), 1993  
Received; read twice and placed on the calendar

## AN ACT

To revise and extend the programs of the Technology-Related Assistance for Individuals With Disabilities Act of 1988, 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; TABLE OF CONTENTS.**

4 (a) **SHORT TITLE.**—This Act may be cited as the  
5 “Technology-Related Assistance for Individuals With Dis-  
6 abilities Amendments of 199<sup>4</sup>”.

7 (b) **TABLE OF CONTENTS.**—The table of contents for  
8 this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Findings and purposes.
- Sec. 3. Definitions.

TITLE I—GRANTS TO STATES

- Sec. 101. Program authorized.
- Sec. 102. Development grants.
- Sec. 103. Extension grants.
- Sec. 104. Second extension grants.
- Sec. 105. Progress reports.
- Sec. 106. Administrative provisions.
- Sec. 107. Information and technical assistance.
- Sec. 108. Funding.

#### TITLE II—PROGRAMS OF NATIONAL SIGNIFICANCE

- Sec. 201. Programs authorized.

#### TITLE III—ALTERNATIVE FINANCING MECHANISMS

- Sec. 301. Alternative financing mechanisms authorized.

#### TITLE IV—AMENDMENTS TO OTHER ACTS

- Sec. 401. Individuals With Disabilities Education Act.
- Sec. 402. Rehabilitation Act of 1973.
- Sec. 403. Technical and conforming amendments.

#### TITLE V—EFFECTIVE DATE

- Sec. 501. Effective date.

### 1 SEC. 2. FINDINGS AND PURPOSES.

2 (a) FINDINGS.—Section 2(a) of the Technology-Re-  
 3 lated Assistance for Individuals With Disabilities Act of  
 4 1988 (29 U.S.C. 2201(a)) is amended to read as follows:

5 “(a) FINDINGS.—The Congress finds as follows:

6 “(1) Disability is a natural part of the human  
 7 experience and in no way diminishes the right of  
 8 individuals—

9 “(A) to live independently;

10 “(B) to enjoy self-determination;

11 “(C) to make choices;

12 “(D) to contribute to society;

13 “(E) to pursue meaningful careers; and

1           “(F) to enjoy full inclusion and integration  
2           in the economic, political, social, cultural, and  
3           educational mainstream of American society.

4           “(2) During the past decade, there have been  
5           major advances in modern technology. Technology is  
6           now a powerful force in the lives of all residents of  
7           the United States. Technology can provide important  
8           tools for making the performance of tasks quicker  
9           and easier. For some individuals with disabilities,  
10          assistive technology is a necessity that enables them  
11          to engage in or perform many tasks.

12          “(3) The provision of assistive technology de-  
13          vices and services enables some individuals with  
14          disabilities—

15                 “(A) to have greater control over their own  
16                 lives;

17                 “(B) to participate in and contribute more  
18                 fully to activities in their home, school, and  
19                 work environments, and in their communities;

20                 “(C) to interact to a greater extent with  
21                 nondisabled individuals; and

22                 “(D) to otherwise benefit from opportuni-  
23                 ties that are taken for granted by individuals  
24                 who do not have disabilities.

REMARKS BY CAROL H. RASCO

CARNEGIE CORPORATION  
Carnegie Conference Center  
Washington, DC  
November 22, 1993

**Thank you.**

**I am very pleased, honored but somewhat overwhelmed to be in front of you today. As I reviewed the roster of participants and topics for this two day conference, I saw the names of individuals that have looked at me from pieces I have read and studied – often at the suggestion of my boss over our 12+ years together – and I saw names of people to whom I have listened, with whom I've discussed the youth of our country, the conditions facing our families and their needs and hopes. And that's where the overwhelmed part comes in...What can I add to what has even and will be said?**

**I come to you to add my strong commitment and that of the administration as well as to reflect with you on the challenge before us. I might add that if you're like me, a luncheon speaker after a morning packed with stimulating, sometimes provocative thoughts, well a luncheon speaker is sometimes a nuisance...you want to TALK about what you've heard, assimilate it before moving on to the afternoon agenda...so I'll try to add to that assimilation, be quick, and allow you to continue your conversation with one another.**

**During my short number of years as a classroom teacher and elementary counseling when I sometimes had children from homes with outhouses or even a dirt floor, during my volunteer days when I worked on foster care, juvenile justice and adult probation issues, throughout my 20 years of parenting and advocating for a child labelled as cerebral**



**palsied and retarded as well as through 15+ years of actively working in government...throughout all of this I have mourned most two things:**

**An increasing poverty of spirit, particularly in children**

**Professionals' piecemeal views of individuals, families and communities**

**And so, I was particularly gratified to read the name given to this two day conference: Strategies to Reduce Urban Poverty:**

**(and then)....INTEGRATING Human Development and Economic Opportunity.**

**This last half of the title is music to my ears!**

**In 1986-87, then Governor Clinton was the chairman of the National Governors' Association. Like his predecessor, Governor Clinton decided to have a theme for the year. He talked long and hard about moving the next step from the education project of the previous year. And he talked about how it must be an integration of Human Development and Economic Opportunity....and it wasn't easy convincing people inside and outside the organization that the two should be integrated. Governor Clinton pushed and the project "Making America Work" was one of two parts: one called JOBS, GROWTH AND COMPETITIVENESS and one called BRINGING DOWN THE BARRIERS, barriers which included welfare, teen pregnancy, adult literacy issues, substance abuse, and school dropouts. It all sounds fairly familiar doesn't it? And yet, the dialogue began --- and with each passing year I see more people making that connection,**

that need for integration more solidly– but it is not happening quickly enough. I believe this is the greatest "reinventing" that must occur at a policy and program implementation level...we must continue to look hard at how we do business differently to make the integration real.

In the spirit of full disclosure I must add that for me to be speaking in front of a group exploring urban poverty could be seen by some as rather odd...I grew up in a town of 1500 people and have lived in Little Rock, Arkansas most of my adult life...not quite an urban life experience over these 45 years. But through working on various issues across the country, through reading works by people like William Julius Wilson to whom I am quite grateful....and by learning from Bill Clinton, I believe a number of my rural roots can span the gap.

**The Clinton administration has been committed from the beginning to a reinvention of government for families....as you look over our key domestic accomplishments, "family" is central:**

**-an economic package and indicators which show a good beginning: inflation is down, interest rates are down, the deficit is down, investment is up. And in the last 10 months, this economy has produced more jobs in the private sector than in the previous four years.**

**-the Family Leave Law which says you can't be fired if you take a little time off when a baby is born or a parent is sick.**

**-a reform of the college loan program and national service - all designed to give more Americans a chance to broaden the**

**availability of further education while in many cases giving those citizens a chance to serve their communities at home, to help repair the frayed bonds of community.**

**-a change in the Earned Income Tax Credit which on April 15th will give between 15 million and 18 million working families on modest incomes a tax cut, not a tax increase.**

**-the introduction of a comprehensive health care reform plan that guarantees health security to all Americans.**

**But we must do more....we MUST do more.**

**As President Clinton said a little over a week ago in Memphis..."I do not believe we can repair the basic fabric of**

**society until people who are willing to work have work. Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children.**

**Further...we cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline and the reward that work gives.**

**And finally he said that, yes, we will deal with the ravages of crime and drugs and violence, BUT "unless we recognize that it's due to the breakdown of the family, the community and the disappearance of jobs...and unless we say some of this cannot be done by government because we have to reach deep inside to the values, the spirit, the soul and the truth of human**

**nature...none of the other things we seek to do will ever take us where we need to go."**

**No, it can't be done by government PROGRAMS in the traditional sense but we in government need help in thinking through how we best stimulate this process of individual, family and community healing and growth, that is where real reinvention must occur.**

**I am reminded inwardly on a constant basis of what an elderly physical therapist who had dedicated her life to young disabled children told me early in my son's life...she said, "Carol, I don't know a lot of philosophy or theory about programs for children like Hamp, but I think the best thing I can tell you as a parent is to remember the words of Joseph Addison, an essayist, poet "Everyone must have**

**Something to do**

**Someone to love**

**Something to hope for."**

**And how right she was and is in the case of not only Hamp,  
but people with whom I've worked with and worked for....and  
so at each age of life in our quest to reinvent how we  
approach the problems of the urban poor we must ask**

**What do they have to do? If a young child, what is the  
preschool program available? Can they play, dance, sing, and  
soar? If a child, is school relevant? Is school safe? I was  
struck this morning as I went to my door to get the paper.  
My daughter, in an attempt to make SURE I didn't forget to**



call her school early this a.m. to let them know she would not be there due to illness had left me a note in front of the door so that I wouldn't miss it....we had quite a round last night because she didn't WANT to stay home from school...and then I opened the door and the Washington Post stares back at me: **ACROSS U.S., SCHOOLS ARE FALLING APART.** Now, this particular article was about the physical condition of the school plants but I bet you know what I thought....and I thought first of an essay I recently read by Benjamin Barber....and as I read it I thought of the key phrase I learned in an otherwise inadequate higher educational experience designed to prepare me to teach elementary school...I was taught there are two educations, one should teach us how to make a living and the other how to live. We do too far little of heeding that maxim.

**Until our communities get as fired up about our schools as we/they do about athletic teams, car manufacturing plant locations, Olympic sites, etc. we won't have a good answer to the question: What have we given the children – young and adolescent to DO?**

**And for adults: What do they have to do?**

**Number 2: Someone to love...and we all know that before you can love another, you must love yourself. Think about children's faces you've seen in urban poor neighborhoods, adults you've passed on those streets....do they have much to love about themselves? Many don't and therefore we can't truthfully expect the love to flow outward.**

**Number 3: Something to hope for....My daughter who didn't want to miss a day of the eighth grade today has many hopes and I both thrive in that gleam of hope in her eyes constantly look for ways to nurture and keep that sparkle present....help me, help our administration look for ways to create that hope for all citizens of this great country. Health security frees up a family for hopes and dreams, safer streets help free children to look at what education can be for them....but untreated ear infections, uncorrected vision problems, lack of immunizations, school buildings in AMERICA where children must wear their coats in order to be warm enough to even begin to pay attention...and we wonder where hope has gone?**

**In the Enterprise Zone legislation we have an opportunity to test our real commitment to reinvention....will we truthfully recognize the need for integration of human development and**

**economic opportunity? Will we work hard to listen to the communities chosen, follow their lead on how much assistance they need and want, and look for ways to intervene very differently from before? ways that seek to assist individuals to reach down inside themselves? Or will we simply designate the zones, the communities and sit here waiting on quarterly reports, make a site visit or two.**

**I was delighted to see that on the program here among others is Otis Johnson from Savannah. Otis is someone I see as an embodiment of the type reinvention that must occur...the Annie E. Casey New Futures Projects are learning a lot about communities and I encourage you to take the opportunity to visit with him. Person to person contact is quite visible in these projects....we need more of it. It is a program that recognized early on the real links between human**

**development and economic opportunity -- and the struggles some of us had in our communities bringing those two "camps" together was and is a great learning experience.**

**To put things bluntly, it isn't often we see in a community whether a block, a zone, in the power centers of a large city, in the boardroom, public or private...it's not often we find social workers, health care outreach personnel, early childhood and K-12 front line educators, government workers and "big business" types sitting down together....each has had their own niche and seldom the twain have met. I submit to you that until each side - human development and economic development are willing to sit at a common table - real reinvention of government for families will not occur. We can make application procedures simpler for families seeking help, we can legislate incentives and tax credits, we can give health**

**security, we can write more meaningful standards for our students... all on the one side known as human development and we can talk about investments, deficits, inflation, job creation, etc. on the economic development side but until we recognize that giving people at every age**

**(1) something to do;**

**(2) someone to love; and**

**(3) something to hope for**

**are all a part of a mandatory whole just as people and families and communities are both parts and "whole" entities" ...**

**we will not have accomplished the task before us.**

**In closing I am reminded of two pieces that haunt me, motivate me in this area of thought. One, in my freshman philosophy course at Hendrix College in Arkansas, Dr. Ellis repeatedly pounded the table in his quest to motivate us to go out into the world and face the adversity necessary to make positive change, admonishing us to remember that saying from THE PRINCE: "There is nothing more difficult to take in hand, more perilous to conduct, or more uncertain in its success than to take the lead in the introduction of a new order of things." We have not a choice, we must take this moment in time to introduce a new order for our families. For as Governor Clinton said back in 1987 as we closed our year's work on MAKING AMERICA WORK: America won't work if Americans can't work, or learn, or believe in the promise of tomorrow.**

**Thank you.**

## EXECUTIVE OFFICE OF THE PRESIDENT

20-Apr-1994 06:14pm

TO: Carol H. Rasco  
FROM: Stanley S. Herr  
Domestic Policy Council

SUBJECT: PCMR meeting talking points -- preliminary draft

## MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr  
SUBJ: PARTIAL TALKING POINTS FOR PCMR PRESIDENTIAL FORUM  
TUESDAY, APRIL 26, 1994  
DATE: April 20, 1994

You are the main closing speaker to this three day event. Although your letter of invitation states that you are scheduled to speak at 11am on April 26th, there appears to be a change in their agenda that now has the final wrap-up session ("Forum Summation") beginning at 10:15 with work group reports and summary of recommendations, each approximately ten minutes. I then have the pleasure of introducing you, and your talk can be for about 30 minutes.

Decision points: Will 30 minutes be sufficient for your purposes, or would you like more time?

Do you want to entertain a few questions? The audience will be about 210 persons, of whom 26 will be self-advocates, and others will be parents, policymakers, and experts from law, medicine, education, habilitation services, etc..

So if you can arrive by 10:15 you will have the benefit of hearing of the Forum's deliberations. I expect to attend most of the proceedings, so I'll further brief you when we meet on Monday, at 3:30 pm on how the discussion is going and your remarks.

They have also arranged to have brief closing remarks from the putative vice-chair, Val Bradley, at the end of the session. If you have not met her yet, you're in for a treat. She's great and



a very experienced consensus builder.

Here are my preliminary briefing points for you:

? Thanks to all of you for your three days of hard work to come up with quality recommendations for the President.

? Special thanks to Gary Blumenthal, Executive Director of PCMR, and Bill Jones, Chair of the Advisory Planning Committee for staging this superb event.

? As I reviewed the list of participants I was struck by the depth and breadth of leadership in the mental retardation community assembled here.

? I also want to commend PCMR for making sure that the voices of self-advocates, and of family members are heard in these proceedings. The large delegation of self-advocates invited here is a tribute to the new directions at PCMR. In I know that their contributions, along with the extraordinary range of talents from the diverse professions that work with persons with mental retardation and their families, will lead to an

outstanding Report to the President.

? We meet here to mark the revitalization of the President's Committee on Mental Retardation, and to chart the reform agenda that will transform the realities facing persons with mental retardation and related disabilities in the 21st century.

? Carol, here your personal stories about your concerns as a parent and Hamp's experiences as a self-advocate and graduation speaker would fit well.

? I would devote the bulk of your remarks to health care reform, perhaps with the hope that these experts will turn their talents to convincing the Hill of the importance of universal coverage, no preexisting condition, long-term care for persons with mental retardation.

MORE TO COME AND WITH HARD-COPY ATTACHMENTS TOMORROW.

Cheers!



**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION  
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Administration for Children and Families  
Washington, D.C. 20201-0000**

**To: Roz Miller  
From: Gary Blumenthal  
Re: Carol Rasco**

Thank you for meeting with me earlier this week to receive Secretary Shalala's letter of invitation to the PCMR Presidential Forum.

I would like to offer an alternative date to accommodate Carol's schedule.

In Secretary Shalala's letter, Carol is asked to speak on Sunday, April 24, 1994 from 2:00 P.M. to 2:30 P.M.

We would offer the alternative time and date of Tuesday, April 26, 1994 from 10:30 A.M. to 11:30 A.M. for a 30 minute block.

I hope this alternative time block will help accommodate Carol's schedule.

Thank you.

cc: Stan Herr

*10:30 -> Stan intro CHR  
10:40 - 11:00 -> CHR Speech  
@*

MEMORANDUM  
OF CALL

Previous editions usable

TO: *Day*

YOU WERE CALLED BY *H. Blumenthal*  YOU WERE VISITED BY

OF (Organization)

PLEASE PHONE  FTS  AUTOVON

*619-0634*

WILL CALL AGAIN  IS WAITING TO SEE YOU

RETURNED YOUR CALL  WISHES AN APPOINTMENT

MESSAGE

RECEIVED BY: *[Signature]* DATE: *3/4* TIME: *10:24*

EXECUTIVE OFFICE OF THE PRESIDENT

28-Feb-1994 04:28pm

TO: Rosalyn A. Miller  
FROM: Carol H. Rasco  
Economic and Domestic Policy  
SUBJECT: Pres. Committee on Mental Retardation

I'm told when you regret this you may be asked if I would consider coming on Monday, April 25...if so tell them we will consider it and get with me as I would definitely consider a Monday. Know it is a day before I am scheduled to leave for Denver but would indeed consider it.

Speaking of Denver...I need to see that trip file with all that stuff they sent regarding my panels to do message to Health Care folks....thanks.

10:30-11:30  
Summation Speaker

After a.m. Meetings

(10:30 or later)

(back by 4:00)

Accept



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

FEB 28 1994

Mrs. Carol H. Rasco  
Assistant to the President  
for Domestic Policy  
The White House  
Washington, D.C. 20500

Dear Mrs. Rasco:

The President's Committee on Mental Retardation (PCMR) is convening a Presidential Forum entitled, "The President's Reform Agenda and People with Mental Retardation - 21st Century Realities," to be held Sunday through Tuesday, April 24-26, 1994, at the Radisson Plaza Hotel at Mark Center, 5000 Seminary Road, Alexandria, Virginia.

As Chair of the President's Committee on Mental Retardation, please accept my cordial invitation to participate in the above Presidential Forum as the keynote speaker, on Sunday, April 24, 1994, 12:30 p.m., at the Plenary Session-A, Plaza C Ballroom. Your audience will be a group of experts in the field of mental retardation and other developmental disabilities representing a cross section of concerned citizens of our nation. The Committee would appreciate your speaking on the topic of, "The President's Reform Agenda and its Potential Impact on Citizens with Mental Retardation," and also, sharing your personal experiences in the area of disabilities.

The purpose of this Forum is to bring together a group of national leaders in the field of mental retardation and other developmental disabilities to assess the adequacy of the national effort to combat mental retardation during the past three decades; and to discuss the impact of the President's six major reform areas on citizens with mental retardation and other developmental disabilities.

The six topics and group leaders are:

- (a) Health Care Reform and People with Mental Retardation  
--David Braddock, Ph.D.
- (b) Welfare Reform and People with Mental Retardation  
--Marsha M. Seltzer, Ph.D.

- (c) Long-Term Care Reform and People with Mental Retardation--Steve Eidelman
- (d) Housing Policy Reform and People with Mental Retardation--K. Charlie Lakin, Ph.D.
- (e) Education Reform and People with Mental Retardation --Jan Nisbet, Ph.D.
- (f) Employment/Financing and People with Mental Retardation--David M. Mank, Ph.D.

A leadership Forum of this magnitude cannot be achieved unless there is a team effort and true partnership among national leaders in the field of mental retardation from both the private and public sectors. This includes self-advocates, advocates, parents, friends, families, providers, volunteers, professional organizations, foundations and agencies concerned with mental retardation and other developmental disabilities at the national, State and local levels.

Thank you for your consideration of this request. I look forward to your favorable response and the opportunity to see you at the Forum. I am also extending to you an invitation to the Awards Luncheon to be held on Monday, April 25, 1994, at 12:30 p.m., Plaza C&D, where self-advocates and parents will be honored. For additional information, please contact Mr. Gary H. Blumenthal, Acting Executive Director of the PCMR at (202) 619-0634.

Once again, the President's Committee on Mental Retardation appreciates your leadership role in the field of mental retardation and looks forward to your contribution at this important Presidential Forum.

Sincerely,



Donna E. Shalala

Enclosures

# FACT SHEET



**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION**  
**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
**Administration for Children and Families**  
**Washington, D.C. 20201-0000**

## **PRESIDENT'S COMMITTEE ON MENTAL RETARDATION (PCMR)**

### **The Role of the PCMR**

More than seven million Americans of all ages experience mental retardation. One out of every 10 individuals in our country has a family member who has mental retardation. Every five minutes another child is born with mental retardation. Mental retardation presents a major social, educational, health, and economic problem for our Nation.

The President's Committee on Mental Retardation (PCMR) was established in 1966 to focus on this critical subject of national concern. The PCMR acts in an advisory capacity to the President and the Secretary of Health and Human Services on matters relating to programs and services for persons with mental retardation. The Committee is charged with the responsibility of evaluating the adequacy of current practices and programs for persons with mental retardation. The PCMR also coordinates Federal agency activities in mental retardation, conducts studies of existing programs, highlights the need for changes, where appropriate, and promotes research.

### **Composition of the PCMR**

The Committee consists of 21 citizen members, appointed by the President, and six public members, including: the Secretaries of Health and Human Services, Housing and Urban Development, Labor, and Education; the Attorney General; and the Director of ACTION. The Secretary of Health and Human Services serves as Chairperson of the Committee. The members undertake their Committee duties in addition to their daily occupations as physicians, educators, attorneys, business people, and other professionals. The Committee is supported by an Executive Director and a staff which provides assistance and continuity of operations.



## PCMR Subcommittees

The PCMR conducts quarterly meetings, which include member involvement in the following subcommittees:

- . Family and Community Support -- which is concerned with activities to enhance the quality of life of individuals with mental retardation;
- . Full Citizenship and Justice -- which seeks to protect the civil and constitutional rights of citizens with mental retardation;
- . Prevention -- which seeks to reduce the occurrence of mental retardation from biomedical, environmental, socio-cultural, and socio-economic cases; and
- . Public Awareness -- which promotes public awareness of mental retardation and the needs of people with mental retardation.

The Committee also conducts forums and publishes numerous publications in the field of mental retardation. Major publications include: The New Morbidity: Recommendations for Action and an Updated Guide to State Planning for the Prevention of Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions (1993); The Report to the President: Citizens with Mental Retardation and the Criminal Justice System (1992); Summit on the National Effort to Prevent Mental Retardation and Related Disabilities (1990); and Forum Proceedings - A Presidential Forum: Citizens with Mental Retardation and Community Integration (1988).

For over 25 years, the PCMR has continued its commitment to improve the lives of persons with mental retardation.

**DRAFT**  
FEB 25 1994

**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION**  
**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
*Administration for Children and Families*  
Washington, D.C. 20201-0001



**A PRESIDENTIAL FORUM:**  
**THE PRESIDENT'S REFORM AGENDA**  
**AND**  
**PEOPLE WITH MENTAL RETARDATION –**  
**21st CENTURY REALITIES**

**TENTATIVE AGENDA**  
*April 24-26, 1994*

**RADISSON PLAZA HOTEL**  
**ALEXANDRIA, VIRGINIA**  
**(703) 845-1010**

**PRESIDENTIAL FORUM:  
THE PRESIDENT'S REFORM AGENDA AND PEOPLE WITH  
MENTAL RETARDATION - 21st CENTURY REALITIES**

**PURPOSE**

*The twofold purpose of this conference is to provide a forum for selected national leaders in the field of mental retardation and related developmental disabilities to: a) discuss the impact of six of the President's major reform areas on citizens with mental retardation and related developmental disabilities; and b) chart the direction for future activities, policies, and implementation strategies. The issues identified and recommendations developed will form the basis for the next President's Committee on Mental Retardation Annual Report to the President.*

*The six selected reform area topics are:*

- I. Health Care Reform and People with Mental Retardation;*
- II. Welfare Reform and People with Mental Retardation;*
- III. Long-Term Care Reform and People with Mental Retardation;*
- IV. Housing Policy Reform and People with Mental Retardation;*
- V. Education Reform and People with Mental Retardation; and*
- VI. Employment/Financing and People with Mental Retardation.*

*The President's Committee on Mental Retardation (PCMR) acknowledges and extends appreciation to the following organizations and agencies for their co-sponsorship of the Presidential Forum: "The President's Reform Agenda and People with Mental Retardation -- 21st Century Realities."*

*The Administration on Aging (AoA)  
U.S. Department of Health and Human Services*

*The National Institute on Disability  
and Rehabilitation Research (NIDRR)  
Office of Special Education and Rehabilitative Services  
U.S. Department of Education*

*The Social Security Administration (SSA)  
U.S. Department of Health and Human Services*

*The Administration on Developmental Disabilities (ADD)  
Administration for Children and Families  
U.S. Department of Health and Human Services*

*The National Institute of Child Health  
and Human Development (NICHD)  
National Institutes of Health  
U.S. Department of Health and Human Services*

**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION (PCMR)**

*A Presidential Forum:  
The President's Reform Agenda  
and  
People with Mental Retardation --  
21st Century Realities*

*April 24-26, 1994*

*Radisson Plaza Hotel  
At Mark Center  
5000 Seminary Road  
Alexandria, Virginia 22311  
(703) 845-1010*

**TENTATIVE AGENDA**

*Sunday, April 24, 1994*

*8:30 a.m.*

*Registration*

**BALLROOM FOYER**

***PLENARY SESSION***

**PLAZA C**

*12:30 p.m.*

*Opening  
Welcome and Purpose*

*Gary H. Blumenthal  
Executive Director  
President's Committee  
on Mental Retardation  
PCMR Vice-Chair*

*12:45 p.m.*

*Administration for Children  
and Families: Vision and  
Goals*

*Mary Jo Bane, Ph.D.  
Assistant Secretary  
for Children and  
Families  
U.S. Department of  
Health and Human  
Services*

1:00 p.m.

**PANEL I: Setting Visions and Goals**

**Moderator: David J. Dunn**  
**President**  
**The Arc**

1:05 p.m.

**Self-Advocates' Perspective**

**T. J. Monroe**  
**Knoxville, Tennessee**

**Tia Nelis**  
**Wayne, Illinois**

1:25 p.m.

**Parents' Perspective**

**Koquese Collins**  
**Detroit, Michigan**

**Don and Dawn Merriman**  
**Salina, Kansas**

**TBA**

2:00 p.m.

**Introduction of Speaker**  
**Stanley Herr, Esq.**  
**Office of Domestic**  
**Policy**  
**The White House**  
**(invited)**

**The Implications of the**  
**President's Reform**  
**Agenda for Citizens with**  
**Mental Retardation**

**Carol Rasco**  
**Assistant to the**  
**President for**  
**Domestic Policy**  
**The White House**  
**(invited)**

2:30 - 2:40 p.m.

**B R E A K**

2:40 - 3:00 p.m.

*Legislative Concerns of  
Consortium for Citizens  
with Disabilities (CCD)*

*Paul Marchand  
Chairperson  
Consortium for Citizens  
with Disabilities (CCD)  
Selected Members  
CCD Task Force on  
Personal Assistance  
Services*

3:00 - 3:15 p.m.

*Questions and Answers*

3:15 p.m.

**PANEL II: Congressional Perspectives:  
The Impact of Reform  
Initiatives on Policies  
Affecting Citizens with  
Mental Retardation and  
Related Disabilities**

*Moderator: Ann Rosewater  
Deputy Assistant Secretary  
for Policy and External  
Affairs  
Administration for Children  
and Families*

3:20 p.m.

*The Impact of Reform Initiatives on  
Policies Affecting Citizens with  
Mental Retardation and Related  
Disabilities*

*Andy Imparato  
Counsel  
Senate Subcommittee on  
Disability Policy*

3:35 p.m.

*Christine Ferguson  
Legislative Director  
Office of Senator  
John Chafee*

3:50 p.m.

*Questions and Answers*

4:00 - 4:15 p.m.

*Work Group Session  
Assignments*

*William E. Jones, Ph.D.  
Executive Director  
American Association of  
University Affiliated  
Programs*

4:15 - 4:30 p.m.

**B R E A K**

4:30 - 6:00 p.m.

**WORK GROUPS - SESSION I**  
(convening concurrently)

**I. Health Care Reform and People  
with Mental Retardation**  
*Leaders: David Braddock, Ph.D.  
Co-leader TBA*

**AMPHITHEATER**

**II. Welfare Reform and People  
with Mental Retardation**  
*Leaders: Marsha M. Seltzer, Ph.D.,  
Sharon L. Ramey, Ph.D.*

**WALNUT**

**III. Long-Term Care Reform and  
People with Mental Retardation**  
*Leaders: Steve Eidelman  
Co-leader TBA*

**PLAZA III**

**IV. Housing Reform and People  
with Mental Retardation**  
*Leaders: K. Charlie Lakin, Ph.D.  
Mr. Jay Klein*

**PLAZA II**

**V. Education Reform and People  
with Mental Retardation**  
*Leaders: Jan Nisbet, Ph.D.  
Co-leader TBA*

**POPLAR**



**VI. *Employment/Financing and  
People with Mental  
Retardation***

***Leaders: David M. Mank, Ph.D.  
William Kiernan, Ph.D.***

**PLAZA I**

**6:00 p.m.**

**RECESS**

**6:30 - 7:30 p.m.**

**RECEPTION**

**PLAZA C**

**Monday, April 25, 1994**

**7:30 a.m.**

***Continental Breakfast***

**8:00 a.m.**

**PLENARY SESSION**

***Moderator: John Pride***

***Acting Deputy Executive  
Director***

***President's Committee  
on Mental Retardation***

**PLAZA C**

**8:05 a.m.**

***Goals 2000 ... School to Work***

***Judith E. Heumann  
Assistant Secretary  
Office of Special  
Education and  
Rehabilitative Services  
U.S. Department of  
Education***

**8:25 a.m.**

***Community Inclusion and Older  
Americans with Mental Retardation  
and Related Developmental  
Disabilities***

***Fernando M. Torres-Gil  
Assistant Secretary  
for Aging  
U.S. Department of  
Health and Human  
Services***

8:45 a.m.

*Cultural Diversity and Citizens with  
with Mental Retardation and  
Related Disabilities*

*Robert Williams  
Commissioner  
Administration on  
Developmental  
Disabilities  
Administration for  
Children and Families*

9:05 a.m.

*Questions and Answers*

9:15 - 10:40 a.m.

**WORK GROUPS - SESSION II**

10:40 - 10:50 a.m.

**B R E A K \***

10:50 a.m. - 12:15 p.m.

**WORK GROUPS - SESSION III**  
*(Health and Welfare convening jointly)*

12:30 - 2:00 p.m.

**FORUM LUNCHEON**

**PLAZA B & C**

*Introduction of Keynote Speaker  
Mary Jo Bane, Ph.D.  
Assistant Secretary for Children  
and Families  
U.S. Department of Health and  
Human Services*

**KEYNOTE:** *"A Time for National  
Reform: Preparation  
for the 21st Century"*

*The Honorable  
Donna E. Shalala  
Secretary  
U.S. Department of  
Health and Human  
Services  
Chair  
President's Committee on  
Mental Retardation*

*\*At the discretion of the Group Leader*

2:15 p.m.

**WORK GROUPS - SESSION IV**  
*(Education and Employment convening jointly)*

**B R E A K \***

**WORK GROUPS SESSION V**  
*(Long Term Care and Housing convening jointly)*

5:30 p.m.

**R E C E S S**

*\*At the discretion of the Group Leader*

Tuesday, April 26, 1994

8:00 - 8:30 a.m.

*Continental Breakfast*

8:30 - 10:00 a.m.

**WORK GROUPS - Concluding Session**

10:00 - 10:30 a.m.

**B R E A K**

10:30 a.m. - 12:30 p.m.

**PLENARY SESSION**

**PLAZA C**

*Moderator:*

*Work Group Reports and  
Recommendations*

*Ratification of Recommendations*

*Forum Summary*

*Closing Remarks*

12:30 p.m.

**ADJOURNMENT**



**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION**  
**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
**Administration for Children and Families**  
**Washington, D.C. 20201-0000**

*Regret*

**To: Roz Miller**

**From: Cary Blumenthal** *Cary*  
**Executive Director**  
**President's Committee on Mental Retardation**

**Re: Sec. Shalala's Invitation to Carol Rasco**

**Date: February 18, 1994**

I checked with Secretary Shalala's office and they have located the letter from Secretary Shalala to Carol and have sent an additional signed copy in the mail to your office.

I will check with you again late next week.

Have a good weekend.

2/17/94

- Spoke w/ Gary to say we'd review in sched mtg w/o 2/21.  
- In the meantime, he was to check w/ Exec. Secy. @ HHS for status of orig. letter (which we've yet to receive).

Roz,

Gary Blumenthal  
Chairman, President's Commission on Mental Retardation  
619-0634

Called you (per advise of Stan H) to talk about an invitation they have sent to CHR to be a keynote speaker at their conference on April 24.

Please call.

Pat

2-10  
11:20am

**MEMORANDUM OF CALL** Previous editions usable

TO: *Roz Salynn*

YOU WERE CALLED BY  YOU WERE VISITED BY  
*Gary Blumenthal*

OF (Organization):

PLEASE PHONE  FTS  AUTOVON  
*619-0634*

WILL CALL AGAIN  IS WAITING TO SEE YOU  
 RETURNED YOUR CALL  WISHES AN APPOINTMENT

MESSAGE:  
*President's Commission on Mental Retardation*

RECEIVED BY: <i>Pat</i>	DATE: <i>2/15</i>	TIME: <i>3:50</i>
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63-110 NSN 7540-00-634-4018 **STANDARD FORM 63** (Rev. 8-81)  
U.S. GOVERNMENT PRINTING OFFICE: 1961 281-791/40014 Prescribed by GSA  
 FPMR (41 CFR) 101-11.6

OFFICE OF DOMESTIC POLICY

THE WHITE HOUSE

CAROL H. RASCO  
ASSISTANT TO THE PRESIDENT  
FOR DOMESTIC POLICY

FEB 16 REC'D

TO: \_\_\_\_\_  
\_\_\_\_\_

DRAFT RESPONSE FOR POTUS AND  
FORWARD TO CHR BY: \_\_\_\_\_

DRAFT RESPONSE FOR CHR BY: \_\_\_\_\_

PLEASE REPLY DIRECTLY TO THE WRITER  
(COPY TO CHR) BY: \_\_\_\_\_

PLEASE ADVISE BY: \_\_\_\_\_

LET'S DISCUSS: \_\_\_\_\_

FOR YOUR INFORMATION: \_\_\_\_\_

REPLY USING FORM CODE: \_\_\_\_\_

FILE: \_\_\_\_\_

SEND COPY TO (ORIGINAL TO CHR): \_\_\_\_\_

SCHEDULE ? :    ACCEPT                    PENDING                    REGRET

DESIGNEE TO ATTEND: \_\_\_\_\_

REMARKS:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



Facsimile Cover Sheet

**President's Committee on Mental Retardation**  
**Wilbur J. Cohen Bldg. Rm. 5325**  
**330 Independence Avenue, S.W.**  
**Washington, D.C. 20201**

**Fax Number: (202) - 205-9519**

Date: 2-16-94

Time: 2:40

**Please Deliver to the Following Person:**

Name Roz Miller

Organization Domestic Policy

Telephone No. 456 2878

**Note:**

**We are transmitting 15 pages including this cover sheet. Please call us as soon as possible if you do not receive all pages.**

Name of Sender Gary Blumenthal

Telephone No. (202) 619-0634





**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION  
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Administration for Children and Families  
Washington, D.C. 20201-0000**

**To: Ros Miller**

**From: Gary Blumenthal  
Executive Director  
President's Committee on Mental Retardation**

**Date: February 16, 1994**

**Re: Speaking Engagement  
for Carol Rasco**

Attached is a copy of Health and Human Services Secretary Donna Shalala's letter of invitation to Carol Rasco to serve as the keynote speaker at the 1994 PCMR Conference. (Stan Herr has spoken to Mrs. Rasco about reserving this date on her schedule.)

I have been attempting to contact your office as a follow up to Sec. Shalala's invitation to Mrs. Rasco.

Sec. Shalala serves as the Chairperson of the President's Committee on Mental Retardation. It is the sincere wish of PCMR board and staff that Mrs. Rasco will be able to speak both as an administration spokesperson, and as a parent to our conference.

Consumer/Self-Advocates and Parents will play a significant role in the convening of our assembly of experts as we prepare to write our annual Report to the President. The participation of Mrs. Rasco is seen as a critical element of our program.

I would sincerely appreciate the opportunity to speak with you at your earliest convenience.



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

Mrs. Carol H. Rasco  
Assistant to the President  
for Domestic Policy  
The White House  
Washington, D.C. 20500

Dear Mrs. Rasco:

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--Marsha M. Seltzer, Ph.D.

Page 2 - Mrs. Carol H. Rasco

- (c) Long-Term Care Reform and People with Mental Retardation--Steve Eidelman
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Once again, the President's Committee on Mental Retardation appreciates your leadership role in the field of mental retardation and looks forward to your contribution at this important Presidential Forum.

Sincerely,

Donna E. Shalala

Enclosures

SECRET

**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION**  
**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
*Administration for Children and Families*  
**Washington, D.C. 20201-0001**



**A PRESIDENTIAL FORUM:**  
**THE PRESIDENT'S REFORM AGENDA**  
**AND**  
**PEOPLE WITH MENTAL RETARDATION --**  
**21st CENTURY REALITIES**

**TENTATIVE AGENDA**  
**April 24-26, 1994**

**RADISSON PLAZA HOTEL**  
**ALEXANDRIA, VIRGINIA**  
**(703) 845-1010**

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**PURPOSE**

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U.S. Department of Health and Human Services*

**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION (PCMR)**

***A Presidential Forum:  
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and  
People with Mental Retardation --  
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***April 24-26, 1994***

***Radisson Plaza Hotel  
At Mark Center  
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(703) 845-1010***

**TENTATIVE AGENDA**

**Sunday, April 24, 1994**

**8:30 a.m.**

***Registration***

**BALLROOM FOYER**

**PLENARY SESSION**

**12:30 p.m.**

***Opening  
Welcome and Purpose***

***Gary H. Blumenthal  
Executive Director  
President's Committee  
on Mental Retardation  
PCMR Vice-Chair***

**12:45 p.m.**

***Administration for Children  
and Families: Vision and  
Goals***

***Mary Jo Bane, Ph.D.  
Assistant Secretary  
for Children and  
Families  
U.S. Department of  
Health and Human  
Services***

1:00 p.m. **PANEL I: Setting Vision and Goals**  
**Moderator: David J. Dunn**  
**President**  
**The Arc**

1:05 p.m. **A Self-Advocate's Perspective** **T. J. Monroe**  
**Knoxville, Tennessee**

**Tia Nells**  
**Wayne, Illinois**

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**Salina, Kansas**

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**Stanley Herr, Esq.**  
**Office of Domestic**  
**Policy**  
**The White House**  
**(invited)**

**The Implications of the**  
**President's Reform**  
**Agenda for Citizens with**  
**Mental Retardation** **Carol Rasco**  
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**President for**  
**Domestic Policy**  
**The White House**  
**(invited)**

2:15 - 2:30 p.m. **B R E A K**

2:30 - 3:00 p.m. **Legislative Concerns of**  
**Consortium for Citizens**  
**with Disabilities (CCD)** **Paul Marchand**  
**Chairperson**  
**Consortium for Citizens**  
**with Disabilities (CCD)**  
**Selected Members**  
**CCD Task Force on**  
**Personal Assistance**  
**Services**

3:00 - 3:15 p.m. **Questions and Answers**





3:15 p.m.

**PANEL II: Congressional Perspectives:  
The Impact of Reform Initiatives  
on Policies Affecting Citizens  
with Mental Retardation and  
Related Disabilities**

**Moderator: Ann Rosewater  
Deputy Assistant Secretary  
for Policy and External Affairs  
Administration for Children  
and Families**

3:20 p.m.

**The Impact of Reform Initiatives on  
Policies Affecting Citizens with  
Mental Retardation and Related  
Disabilities**

**Andy Imperato  
Counsel  
Senate Subcommittee on  
Disability Policy**

3:35 p.m.

**Christine Ferguson  
Legislative Director  
Office of Senator  
John Chafee**

3:50 p.m.

**Questions and Answers**

4:00 - 4:15 p.m.

**Work Group Session  
Assignments**

**William E. Jones, Ph.D.  
Executive Director  
American Association of  
University Affiliated  
Programs**

4:15 - 4:30 p.m.

**B R E A K**

4:30 - 6:00 p.m.

**WORK GROUP SESSIONS (concurrent)**

- I. Health Care Reform and People  
with Mental Retardation**
- II. Welfare Reform and People  
with Mental Retardation**
- III. Long-Term Care Reform and  
People with Mental Retardation**
- IV. Housing Reform and People  
with Mental Retardation**
- V. Education Reform and People  
with Mental Retardation**
- VI. Employment/Financing and People  
with Mental Retardation**

6:00 p.m.

**R E C E S S**

6:30 - 7:30 p.m.

**R E C E P T I O N**

**PLAZA C**

Monday, April 25, 1994

- 7:30 a.m. *Continental Breakfast*
- 8:00 a.m. **PLENARY SESSION** **PLAZA C**  
*Moderator: John Pride*  
*Acting Deputy Executive*  
*Director*  
*President's Committee on*  
*Mental Retardation*
- 8:05 a.m. *Goals 2000 ... School to Work* *Judith E. Heumann*  
*Assistant Secretary*  
*Office of Special*  
*Education and*  
*Rehabilitative Services*  
*U.S. Department of*  
*Education*  
*(invited)*
- 8:25 a.m. *Community Inclusion and Older* *Fernando M. Torres-Gil*  
*Americans with Mental Retardation* *Assistant Secretary*  
*and Related Developmental* *for Aging*  
*Disabilities* *U.S. Department of*  
*Health and Human*  
*Services*  
*(Invited)*
- 8:45 a.m. *Cultural Diversity and Citizens with* *Robert Williams*  
*with Mental Retardation and* *Commissioner*  
*Related Disabilities* *Administration on*  
*Developmental*  
*Disabilities*  
*Administration for*  
*Children and Families*
- 9:05 a.m. *Questions and Answers*
- 9:15 - 10:40 a.m. **WORK GROUP SESSIONS, continued**

10:40 - 10:50 a.m.

**B R E A K \***

10:50 a.m. - 12:15 p.m.

**WORK GROUP SESSIONS, continued**  
*(Health and Welfare convening jointly)*

12:30 - 2:00 p.m.

**FORUM LUNCHEON**

**PLAZA B & C**

*Introduction of Keynote Speaker*  
*Mary Jo Bane, Ph.D.*  
*Assistant Secretary for Children*  
*and Families*  
*U.S. Department of Health and*  
*Human Services*

**KEYNOTE:** *"A Time for National*  
*Reform: Preparation*  
*for the 21st Century"*

*The Honorable*  
*Donna E. Shalala*  
*Secretary*  
*U.S. Department of*  
*Health and Human*  
*Services*  
*Chair*  
*President's Committee on*  
*Mental Retardation*

2:15 p.m.

**WORK GROUP SESSIONS, continued**

**B R E A K \***

**WORK GROUP SESSIONS, continued**

5:30 p.m.

**R E C E S S**

*\*At the discretion of the Group Leader*

Tuesday, April 26, 1994

8:00 - 8:30 a.m.

*Continental Breakfast*

8:30 - 10:00 a.m.

**WORK GROUP SESSIONS, concluding**

10:00 - 10:30 a.m.

**B R E A K**

10:30 a.m. - 12:30 p.m.

**PLENARY SESSION**

**PLAZA C**

*Moderator:*

*Work Group Reports and  
Recommendations*

*Ratification of Recommendations*

*Forum Summary*

*Closing Remarks*

12:30 p.m.

**ADJOURNMENT**