

UCPA  
Wednesday, April 28, 1993  
Radisson Plaza Hotel  
Alexandria, Virginia  
1 p.m.

Empowerment

Platform cannot be  
Power cannot be  
taken  
cannot be  
given

no one can  
make you feel  
inferior without  
your consent

Always do  
right - this  
will gratify some  
people &  
disturb  
others. - MIT Man  
Eleanor Roosevelt

It is wonderful to be here before you....as I have told some other selected audiences in recent weeks...what other way is there to start a speech before a group like yours than I am happy to be here...you are special, you represent the services that I have worked for throughout the last twenty years of my life ~~and~~ ~~and~~ and above all you represent the services that have worked FOR me.

*Insert* (explain Hamp if not already done...child diagnosed as cerebral palsied at approximately 10 months of age, I knew it sooner)

You and your peers in the field, be they volunteers (the capacity in which I worked exclusively from my son's until he was 7 and a half), center administrators, center workers, and so forth daily create the success stories in family's lives like my own - you help to enable our determination, our capacity to <sup>take</sup> on responsibility and teach responsibility-and above all you care.

A recent headline in the Ark. Democrat / Gazette which profiled me as one of the Arkansans making the move to DC stated something to the effect that "son's life leads local woman to White House." And indeed it has.

I bring to the Domestic Policy Council what is seen by some as a simple statement of purpose: All children shall be empowered to develop to their fullest potential. You and I know that the only way children can do so is if each of us as human beings are given that ongoing opportunity-and it is in that context I both speak today and carry out the daily tasks entrusted to me by President Clinton.

In order to carry you through specific program priorities let's use the President's five priorities given to us at the cabinet/staff retreat very early in this administration. At the same time it is impossible for me not to relate as much as possible to where I come from in a very personal manner.

① Economic package: this means work, investment in people as well as deficit reduction. The 1992 Rehabilitation Act's presumption of employability is a <sup>valued</sup> tenet here for us in the DPC...personally, my son soon graduates from high school and coming from a community based instruction program in the public schools I am vitally concerned about employability, the job he will obtain and the ongoing lifelong training he will receive, the ~~role~~ of

assistive technology. VP Gore and I have had numerous conversations on this issue...there is a genuine commitment, *on our part* As we move ahead on National Service, school to work transition and these other job training issues we want to be aware always of the words behind me here (inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism)

- ② Health Care Reform: the many pieces being put together, not ready to reveal the details but let's look:

Your statement: non-discrimination

comprehensiveness

appropriateness (one of the few groups to talk about availability)

equity

efficiency

Long term care will be addressed and the need for community based care and the array of services needed to make that real...we can't accomplish it all at once but we hope to present a comprehensive blueprint. Health care is tough...far tougher than living facilities in residential neighborhoods.

NIMBY

- ③ Welfare Reform: *one, again* - *work, education, training, empowerment*

Work in exchange for welfare

Work instead of welfare

- ④ Campaign finance/lobbying reform

- ⑤ National Service: look not only as how you can participate as student participants but also as services within your programs...look to state mechanism.

*where is* ~~finally~~ EDUCATION: (inherent in all but one of the priorities and thus not a separate category)

-reauthorizations

-Goals 2000

mention of disabilities....if we truly mean inclusion, mainstreaming perhaps we have to work on implementation and not set aside words...*as the bank sound* think about it

*Wat Ed* -GOALS: ~~these goals~~ if we mean all children quite naturally my child, my adult now, and quite frankly we as a community of believers should demand that, and stop quibbling over words that don't necessary produce the actions...hard work does. In these goals we find avenues to push for reform, inclusion, early prevention,

intervention programs...we will do it!

ADA, an overlay to all. You help us monitor, you help us determine where we need to give nudges or bulldozing pushes.

*Parent booklet*  
When I look at the last 20 yrs of my life it is an embodiment of I know the meaning of the education goals from early childhood through adult life-long learning... Hamp Rasco was born over 19 years ago and I was told to take him home, love him and make a decision about an institution...we've worked hard with family, medical professionals, therapists, parent educators, teachers, school administrators, you name it... he's been in public schools all his life, he did indeed finally talk at age five, he moved into a small group setting last August, he's taking a college "woman" as he put it to me to his high school prom in less than two weeks and his senior class peers and school administrators approached him to give a speech at graduation...their rationale "We have learned so much from Hamp" - he's unlike anyone we've ever known. And as Hamp says he's going to conclude in that graduation speech: It's been a lot of fun, but now it's time to move on!

His mother is confident he'll move on in a very positive way w/ a ~~good~~ good ~~ground~~ ~~ground~~ ~~in~~ ~~decision~~ ~~making~~, independent thinking, ~~love~~ love of life... ~~love~~ love of people

*f. This Admin-*  
I've talked about what the President ~~has done and what he~~ wants to do. We've begun to shift course. But this is just the beginning. We must have the courage to change--to recognize mistakes, to abandon what doesn't work, to challenge ourselves to do better. ~~In short, we adults have some growing up to do.~~

I know that many of you in this room are <sup>often feel why tired</sup> ~~tired after the~~ *all the battles* ~~last twelve years.~~ Without you, many of the programs that serve children and families would have been gutted. They weren't, and ~~you've earned a rest.~~ *you wage daily for rights, funding, services.*

But we're asking you to go another round. The President can't pass or fund his initiatives alone. He can't break the gridlock alone. He still needs your help, and so do America's children *and adults with disabilities*

~~For the first time in a long time,~~ your efforts will be supported--~~not rebuffed--~~ by the executive branch of this government. ~~The details remain to be worked out.~~ But for sure, there will be an ongoing, high-level focus on children and families, ~~cutting across agency, departmental, and programmatic lines, coordinated by the White House, responsible not to any single constituency but to the national interest and directly to the President of the United States.~~

Concern for our <sup>people with disabilities</sup> children must start at the top--but it can't end there. We must empower parents, neighborhoods, communities and voluntary organizations across this great nation to do what our <sup>own people</sup> children need. The President can take the lead--but only you can complete the task.

<sup>I believe</sup> At last, a new day is dawning for America's <sup>people - all people</sup> children and their families. We will work together with you. We won't always succeed, and we won't always be able to do everything that you--and we--would want.

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

Thank you very much.

# Consortium for Citizens with Disabilities

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## CONSORTIUM FOR CITIZENS WITH DISABILITIES HEALTH TASK FORCE

### "PRINCIPLES FOR HEALTH CARE REFORM FROM A DISABILITY PERSPECTIVE"

December, 1991  
(updated February, 1993)

#### ON BEHALF OF:

AIDS Action Council  
Alliance for Genetic Support Groups  
American Academy of Physical Medicine and Rehabilitation  
American Association for Counseling and Development  
American Association of University Affiliated Programs  
American Association on Mental Retardation  
American Civil Liberties Union  
American Congress of Rehabilitation Medicine  
American Foundation for the Blind  
American Occupational Therapy Association  
American Physical Therapy Association  
American Psychological Association  
American Speech-Language-Hearing Association  
The Arc, Association for Retarded Citizens of the United States  
Epilepsy Foundation of America  
Immune Deficiency Foundation  
International Association of Psychosocial Rehabilitation Services  
Learning Disabilities Association  
National Alliance for the Mentally Ill  
National Association for Music Therapy  
National Association of Developmental Disabilities Councils  
National Association of Medical Equipment Suppliers  
National Association of Private Residential Resources  
National Association of Protection and Advocacy Systems  
National Association of Rehabilitation Facilities  
National Association of State Mental Retardation Program Directors  
National Council for Independent Living  
National Council of Community Mental Health Centers  
National Easter Seal Society  
National Head Injury Foundation  
National Mental Health Association  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
National Parent Network on Disabilities  
National Recreation and Parks Association  
National Rehabilitation Association  
National Transplant Support Network  
Spina Bifida Association of America  
The Association for Persons with Severe Disabilities  
United Cerebral Palsy Associations, Inc.  
World Institute on Disability

### DISABILITY PERSPECTIVE ON HEALTH CARE REFORM

**Non-Discrimination** People with disabilities of all ages and their families must have access to health care which:

- prohibits pre-existing condition exclusions;
- prohibits rating practices that discriminate against higher users of health care;
- ensures that all persons, regardless of income or health status, have access to all needed health-related services; and
- ensures continuity and portability of coverage.

**Comprehensiveness** In addition to acute care hospital and physician services, comprehensive health-related services include:

- preventive services, including services to prevent the worsening of a disability;
- health promotion/education services;
- diagnostic services;
- long and short term home and community-based services;
- prescription drugs, biologicals and medical foods;
- mental health and counseling services;
- rehabilitation services, including audiology, occupational therapy, physical therapy, respiratory therapy, speech-language pathology services, cognitive, vision and behavioral therapies, and therapeutic recreation;
- personal assistance services and independent living services; and
- durable medical equipment and other assistive devices, equipment, and related services.

**Appropriateness** Services must be provided to persons with disabilities on the basis of individual need, preference and choice which:

- ensures consumer choice in relation to services and provider;
- ensures a range of service settings through an integrated delivery system;
- ensures appropriate amount, scope and duration of services; and
- ensures the availability of trained personnel.

**Equity** People with disabilities and their families must be ensured equitable participation in the nation's health care system and not burdened with disproportionate costs. An equitable system:

- limits out-of-pocket expenses and cost sharing requirements for participants;
- provides access to services based on health care need, not income level or employment status; and
- ensures adequate reimbursement for service.

**Efficiency** The health care system should provide maximum appropriate effective quality services with minimum administrative waste. An efficient system:

- reduces administrative complexity and minimizes administrative costs;
- allocates resources in a more balanced way between preventive services, acute care, rehabilitation and chronic care management;
- maintains effective cost controls so that all people can get the health care services which they need.

**17****ADA Technical Assistance Programs**

*with its* The Americans with Disabilities Act (ADA) opens new opportunities for persons with disabilities. It also places <sup>new</sup> responsibilities on employers, transit and communications systems, state and local governments, and public accommodations. To assist covered parties understand and comply with the ADA, NIDRR has funded ten Regional Disability and Business Accommodation Centers. These centers will provide technical assistance, training, and resource referral on all aspects of the ADA. Their work will be complemented by two other NIDRR ADA-related programs: three materials development projects and two national peer-training projects.