

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

12-May-1994 10:57am

Carol H. Rasco

Stanley S. Herr
Domestic Policy Council

: Gallaudet event tomorrow

umber of concerns and queries about tomorrow's Presidential

eds to know who from the Administration is going and needs to be
marks?

anning to go?

Judy Heumann and Deval Patrick are planning to attend

t attends, as he well might, should he be recognized in remarks?

man" [words I've heard the President use about Justin] and a
f the civil rights of persons with disabilities, and now of
rm?

ask the University to give him dias or other special seating?

ne has promised me a draft of the speech. I'll look it over and
u ASAP. *He's still editing and will have 2 hours*

in 10 min. wanted you to have early draft for
ocess of trying to find out who is doing the substantive
event for the President since here are some of the pitfalls that

within the deaf community about appropriate educational,
nd cultural stances to deafness, and the Federal responses to
ies

regs and approaches to telecommunications issues in the FCC
th of administartion support for HR3626 (the Telecommunications
al access and universal design to telecommuniactions (apparently
nt has endorsed it; the President may not ahve addressed it yet.

x66620 and Lorraine Miller, in legislative affairs are supposed
briefing memo. They are all up on the Hill so I've left them a
re status of their memo that will deal with some of this very
ive matters.

g concern is that Gallaudet is an extremely activist campus. As
ack in late 80s its students seized a building to enure that a
me its president. The National Law Center on the Deaf is also

housed there, and its staff may love to pigeonhole the President with tough questions. Ditto student leaders. For example, not beyond the realm of possibility from a deaf culture-oriented student is: "Why are you backing cochlear implants through research at the National Science Foundation? There's nothing wrong with being deaf and we don't want to be physically altered"

7. Sorry for the length and tone of this, but there are some downside risks here and I would like to help to make this disability event as successful as possible. I am willing to go to this event, and do whatever I can before noon, late this afternoon, and all of tomorrow.

p.s. I assume that the White House has an interpreter. If so, who is it so that s/he/they can thoroughly review the speech ahead of time? I assume also understands that the audience reaction may be silent, and far different from any other speeches he's given.

8. Todd Siern in Paraglide shop is looking at where doing the surfing book -- behind, but will go with me.

GALLAUDET FIRST DRAFT

plan to new content
for
We
You have reached this extraordinary moment in your life at a special moment in the life of your country -- and what it stands for.

Nations and people everywhere are moving towards freedom. Much of the world seems to be trying to lay claim to democracy and to our values. Our example continues to be the single most powerful instrument of good on earth.

Yet, each day across the globe fundamental questions arise about whether people can achieve peace across divisions of race and region and religion. Each day mutual respect and the bonds of civility seem to break down a little more. Each day barriers to cooperation and trust seem to rise a little higher.

Some suggest that this has spread to America, and that your generation feels a sense of futurelessness. They say young people will no longer engage in changing what is wrong. That they will no longer take responsibility for the hard work of turning diversity into democracy and individuality into community. And that without faith in our ideals, we will split off, and stay divided. And squander our birthright.

This is a fundamental mis-reading of democracy, of America, of the world, and of you.

For those who think that nothing can change centuries of bloodshed and strife and turn it into hope and yearning for a common destiny, I say don't tell it to Prime Minister Rabin and Chairman Arafat.

For those who proclaim that there is no future in racial harmony and no hope in our common humanity, I say tell it to President Mandela and Deputy Executive President deKlerk of South Africa, and the people of South Africa who never lost their faith in the rights of all people to be free.

And finally, for those who say that your generation has lost its center; that you won't demand the best from yourselves or take responsibility for making your country a better place -- I say tell it to the students of Gallaudet University, who have demolished all kinds of barriers and built themselves and all Americans a better world, and today are taking their proud place in the next great generation of Americans.

Gallaudet is a national treasure. It is fitting that President Lincoln granted your charter. He understood better than any the sacrifices required to preserve a democracy rich in diversity. He ultimately gave his life in the cause of renewing

our national life -- because he understood democracy is about constant renewal.

He signed your first charter -- in the midst of the Civil War. Where others saw farm land and a tiny school, he had the vision to use education to tear down the walls between us and tangibly touch and improve all of our lives.

Private citizens and pioneering educators have built Gallaudet over the years, sustained by generations of students and faculty committed to the richness of the deaf community and the fullness of the American dream. Yours is a glorious history.

That charter was an important law. But let me refer to another President to make an equally important point -- that just as important as laws are the attitudes that animate our approach to the law, and to each other.

The President I am referring to is your President, King Jordan. When the Americans With Disabilities Act passed, he said: "those of us with disabilities and those without now stand at the threshold of a new era." Paraphrasing, he went on to say that in this pursuit as in every pursuit of democracy, our task will be to reach out, to strive to understand each other and to educate each other about our capabilities, and about who we are.

He knows and speaks the truth. Government can make good laws. And we need them sometimes. But it can't make good people. In the end it's our values and attitudes and the work we do at home and in the neighborhood that bring about change and make the biggest difference. Moral leadership is everyone's responsibility, and everyone's opportunity. That's my belief.

I also believe being deaf or having a disability is not tragic. Stereotypes are tragic. Discrimination is tragic. Not getting a job, or having the chance to reach your God-given potential because someone else is "handicapped" by prejudice, is tragic. That is the tragedy and it must not be tolerated.

But you know that. This great university is a testimony to moral courage, individual responsibility, and shared dreams.

Because previous generations refused to be denied a place at the table simply because others thought they were different, the world is now open to you. Most of you came here knowing you could be doctors, actors, software engineers. Because over the years those who came before you spoke up, you have the chance to move up.

From the beginning you have made a difference because you believed in debate, you believed in justice, you believed in broadening the unique world you share with each other by joining

it to the community at large. There is no better example of how America should work.

But I believe the greatest moment in your history occurred in 1988. That March your community came together and said: we will no longer accept the paternalistic judgement of others about our lives and the leadership of this university. This is our responsibility, and we gladly accept the challenge.

In days, the "Deaf President Now" movement changed the way America looks at deaf people. The nation watched as you organized and strategized and built a movement of conscience unlike any other. As King Jordan has said, you removed the barriers of limited expectations, and America saw that deaf people can do anything that hearing people can -- but hear.

That was one of the defining moments in a great people's movement, the American disability rights movement. Two months after King Jordan took office, the American's with Disability Act was introduced. In two years, it became law, and proved once again that the right cause can unite us, where once partisanship divided us.

For more than 40 million Americans who are deaf or disabled, the signing of the ADA was the most important event in history. For almost a billion persons with disabilities around the world, it symbolized simple human rights.

The ADA is your civil rights law. And as your President I pledge to see it is fully implemented and aggressively enforced across America -- in schools, the workplace, in government, and public places. It is time disability policy moved from exclusion to inclusion; from dependence to independence; and from paternalism to empowerment. And together we will see that it does.

Of course, our work goes on. We've begun to build a bridge to freedom. But it is just a beginning. As I said, many of the most important things we must do as Americans I cannot do and government cannot do. They are matters of values and attitudes and faith. But personal acts and public acts should share the same goal: more cooperation, more community, more opportunity for each individual to achieve their dreams.

That's why the Family and Medial Leave Act was important. It empowered parents to be good parents and good workers. The Brady Bill and banning assault weapons were important because they let us pursue our lives in safety. National Service -- and 6 of you will be part of AmeriCorps, the very first class and I am proud of you -- allows young people a great freedom -- the freedom to give something back.

This is all part of our shared, unfinished agenda. Let me briefly mention three additional important matters.

When the health care system denies coverage to millions of people with pre-existing conditions, it is discriminating and it must be changed. Health security is about preserving the freedom to pursue our careers and our dreams, because without it any of us can be wiped out at any time. I believe economic freedom is a right every American should have. That's why after 60 years we will pass guaranteed private insurance for every American.

Also, we are trying very hard to work with the private sector to build the best information highway in the world. Among other things, these technologies will open up vast new opportunities for deaf and hard of hearing people, and other persons with disabilities to study, work, and to live full and fruitful lives. To make sure the information age empowers everyone with the talents to engage it, I am committed to ensuring accessibility and universal service, and we are going to work with you to make sure this becomes a reality.

Finally, today I am delighted to have the opportunity to make an important announcement concerning the enforcement of the ADA. The Justice Department has just reached a settlement on its first ADA case. It involves deaf and hard-of-hearing students who are preparing for their professional exams ~~in law~~ and accounting.

From now on those of you taking these preparatory courses will be provided sign language interpreters or auxiliary services when you need them. It is a good settlement. Like the ADA itself, it provides economic freedom. It will make good citizens and a stronger America.

Graduations are very special occasions, particularly for parents and family members. It is also a chaotic day, and it is quite possible that many of you graduating will remember little of what transpires. If there is one thing I would like you to take away from today, it is this.

You have achieved a great deal -- and we applaud you. But you did not do it alone -- and none of us do. For all families, but especially for families that work hard to reach this day -- there is a special closeness.

The wonderful truth is that someone believed in their country enough to prepare you for this day and for full participation in democracy and all its rewards. Someone believed in you enough to help you reach the point of building a life of your own. Someone took responsibility for you. Someone cared for you. Someone loved you.

This is the foundation of success and happiness. The most important thing in any child's life is the support of an adult who loves them without qualification. You have had that, you must honor that, and I know that you do.

Today the words freedom and opportunity take on real meaning for you.

But in our own nation and around the world democracy is in the balance. There are millions of young people who cannot imagine a future. Walls are going up among people, the debate is growing harsher, too many are defining themselves by looking down on someone else.

I know, as Lincoln taught us, it has always been hard to preserve democracy. It has always been hard to build one from many. Acrimony is easier than harmony, stereotypes are easier than understanding. And I know in many ways it is getting even more difficult.

But I have a message for all of the doubters. We can change, we can change for the better, we can respect our uniqueness, grow closer and become stronger.

How do I know this is true? Because of Arafat and Rabin. Because of Mandela and deKlerk. Because this week is the fortieth anniversary of Brown versus The Board Of Education, a promise we made to our children that no matter what their color they could get an equal education. Because in a few weeks I am going to Europe to commemorate the fiftieth anniversary of D-Day, where my parent's generation risked their freedom to give America fifty more years of freedom.

And I know it because of a place called Gallaudet. Where for 124 years young people have believed in themselves, their country, their family, and their future. Where good people had the courage to dream, and have worked to make that dream come true for millions of their fellow man.



PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Washington, D.C. 20201-0000

MEMORANDUM

DATE: December 12, 1994

TO: PCMR Committee Members
PCMR Associates

FROM: Robert Dinerstein
Professor of Law and Member
President's Committee on Mental Retardation

SUBJECT: Executive Orders #11280, #11776 and #12869

As you may know, the President's Committee on Mental Retardation ("PCMR" or "President's Committee") was created by an Executive Order originally signed by President Lyndon Johnson on May 11, 1966. Since then, each President has re-authorized PCMR for successive two-year periods. PCMR also falls within the jurisdiction of the Federal Advisory Board Act.

The latest Executive Order re-authorizing PCMR was signed by President Bill Clinton on September 30, 1993. The President is expected to renew PCMR in September 1995, when the current Executive Order expires. At our November 18, 1994, meeting the members of the President's Committee requested that the Mission and Public Awareness Subcommittee draft a new proposed substantive Executive Order for consideration by the President.

Since the initial Executive Order of 1966, there has been only one truly substantive Executive Order, No. 11776, signed by President Nixon on March 28, 1974. Executive Order No. 11776 was significant and far-reaching in (1) establishing a national goal of reducing the occurrence of mental retardation by one-half by the year 2000; and (2) calling for the return to the community of one-third of the people then in institutions for people with mental retardation so that they might once again live useful lives within their own communities. The second goal has been met; the first has not yet been achieved. But beyond these goals, the President's Committee believes the Executive Order must be revised to reflect the dynamic changes and paradigm shifts that have occurred within the mental retardation field in the last twenty years.

Page 2

The President's Committee would greatly appreciate your advice and recommendations concerning the goals, direction and membership of the Committee in the years ahead. It is our hope that, through collaboration with and contributions of people such as you, we will be able to present President Clinton with a draft Executive Order that reflects current thinking within the field and responds to the administration's desire and support for greater inclusion, independence, empowerment and productivity for citizens with mental retardation.

We have enclosed the following materials for your review:

1. Executive Order No. 11280, signed by President Johnson (1966)
2. Executive Order No. 11776, signed by President Nixon (1974)
3. Executive Order No. 12869, signed by President Clinton (1993)

Please provide your suggestions for revisions or modifications by January 20, 1995. Comments should be sent to:

Gary H. Blumenthal
Executive Director
President's Committee on Mental Retardation
Wilbur J. Cohen Building - Room 5325
330 Independence Avenue, S.W.
Washington, D.C. 20201

If you prefer, you may communicate by FAX at (202) 205-9519. Your comments and observations will greatly assist the Mission and Public Awareness Subcommittee in Making our recommendations to the full PCMR for submission to the President.

Thank you for your consideration.

Attachments

ESTABLISHING THE PRESIDENT'S COMMITTEE ON
MENTAL RETARDATION

WHEREAS the Maternal and Child Health and Mental Retardation Planning Amendments of 1963 and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (77 Stat. 273; 282) have established a firm statutory basis for combating mental retardation; and

WHEREAS the mental retardation activities of Federal, State and local government agencies and foundations and other private organizations are expanding rapidly and require careful review in order that maximum benefits may be achieved; and

WHEREAS there is a continuing need to mobilize the support of the general public and of specialized professional groups for mental retardation activities; and

WHEREAS re-evaluation of existing programs to determine their adequacy and consideration of proposals for new mental retardation activities is necessary:

NOW, THEREFORE, by virtue of the authority vested in me as President of the United States, it is ordered as follows:

SECTION 1. Committee established. There is hereby established the President's Committee on Mental Retardation (hereinafter referred to as the Committee).

SEC. 2. Composition of Committee. The Committee shall be composed of the following members:

(1) The Secretary of Health, Education, and Welfare, who shall be the Chairman of the Committee.

(2) The Secretary of Labor.

(3) The Director of the Office of Economic Opportunity.

(4) Not more than twenty-one other members who shall be appointed by the President from public or private life and may include specialists in medicine and other healing arts, human development, special education and employment problems, and members of foundations and other private organizations active in the mental retardation field. Except as the President may from time to time otherwise direct, appointees under this paragraph shall have terms as follows:

(A) of the members first appointed hereunder, the terms of seven shall expire on the first anniversary of the date of the Order, the terms of seven shall expire on the second anniversary, and the terms of seven shall expire on the third anniversary. (B) The term of each succeeding appointment shall expire on the third anniversary of the expiration of the predecessor term, except that an appointment made to fill a vacancy occurring before the expiration of a term shall be made for the balance of the unexpired term.

SEC. 3. Functions of the Committee. (a) The Committee shall provide such advice and assistance in the area of mental retardation as the President may from time to time request; including assistance with respect to:

(1) evaluation of the adequacy of the national effort to combat mental retardation;

(2) coordination of activities of Federal agencies in the mental retardation field;

(3) provision of adequate liaison between such Federal activities and related activities of State and local governments, foundations, and other private organizations; and

(4) development of such information, designed for dissemination to the general public, as will tend to reduce the incidence of mental retardation and ameliorate its effects.

(b) The Committee shall mobilize support for mental retardation activities by meeting with, and providing information for, appropriate professional organizations and groups broadly representative of the general public.

(c) The Committee shall make such reports or recommendations to the President concerning mental retardation as he may require or the Committee may deem appropriate. Such reports shall be made at least once annually.

SEC. 4. Cooperation with the Committee. All who may be in a position to do so are requested to furnish the Committee information pertinent to its work and otherwise to facilitate the work of the Committee.

SEC. 5. Administrative arrangements. (a) As may be necessary, each Federal agency which is represented on the Committee shall furnish assistance to the Committee in accordance with the provisions of Section 214 of the Act of May 3, 1945 (59 Stat. 134; 31 U.S.C. 691), or as otherwise permitted by law. The Committee may have an Executive Director who shall be designated and compensated in consonance with the law. The Department of Health, Education, and Welfare is hereby designated as the agency which principally shall provide the Committee with necessary administrative services and facilities.

(b) Each member of the Committee, except any member who then receives other compensation from the United States, shall receive compensation for each day he or she is engaged upon the work of the Committee, as authorized by law (5 U.S.C. 55a), and shall also be entitled to receive travel expenses, including per diem in lieu of subsistence, as authorized by law (5 U.S.C. 73b-2) for persons in the Government service employed intermittently.

SEC. 6. Construction. Nothing in this Order shall be construed as subjecting any Federal agency, or any function vested by law in, or assigned pursuant to law to, any Federal agency, to the authority of the Committee or as abrogating or restricting any such function in any manner.

LYNDON B. JOHNSON

THE WHITE HOUSE,
May 11, 1966.

(F.R. Doc. 66-5456; Filed, May 16, 1966; 11:04 a.m.)

Source: FEDERAL REGISTER, Vol. 31, No. 95 -- Tuesday, May 17, 1966
pages 7167 and 7168

**Continuing the President's Committee on Mental Retardation and
Broadening Its Membership and Responsibilities**

The President's Committee on Mental Retardation, established by Executive Order No. 11280 on May 11, 1966, has mobilized national planning and carried out basic programs in the field of mental retardation. National goals have been established to reduce the occurrence of mental retardation by one-half before the end of the century and to return one-third of the people in mental institutions to useful lives in their communities. The achievement of these goals will require the most effective possible use of public and private resources.

Our country has become increasingly aware in recent years of the need to assure those who are retarded their full status as citizens under the law, and of the continuing need to mobilize the support of the general public and of specialized professional and volunteer groups for mental retardation activities. We also know that we must constantly evaluate existing programs to determine their adequacy and must continually consider a broad range of proposals for new mental retardation activities.

NOW, THEREFORE, by virtue of the authority vested in me as President of the United States, it is hereby ordered as follows:

SECTION 1. *Committee continued and responsibilities expanded.* The President's Committee on Mental Retardation (hereinafter referred to as the Committee), with expanded membership and expanded responsibilities, is hereby continued in operation.

SEC. 2. *Composition of Committee.* The Committee shall be composed of the following members:

(1) The Secretary of Health, Education, and Welfare, who shall be the Chairman of the Committee.

(2) The Attorney General.

(3) The Secretary of Labor.

(4) The Secretary of Housing and Urban Development.

(5) The Director of the Office of Economic Opportunity.

(6) The Director of ACTION.

(7) Not more than twenty-one other members who shall be appointed to the Committee by the President. These persons may be employed in either the public or the private sectors and may include specialists in medicine and other healing arts, human development, special education, law, and employment problems, as well as members of foundations and other private organizations active in the mental retardation field. Except as the President may from time to time otherwise direct, appointees under this paragraph shall have three-year terms, except that an appointment made to fill a vacancy occurring before the expiration of a term shall be made for the balance of the unexpired term.

SEC. 3. *Functions of the Committee.* (a) The Committee shall provide such advice and assistance in the area of mental retardation as the President or Secretary of the Department of Health, Education, and Welfare

may request and particularly shall advise with respect to the following areas:

(1) evaluation of the adequacy of the national effort to combat mental retardation;

(2) identification of the potential of various Federal programs for achieving Presidential goals in mental retardation;

(3) provision of adequate liaison between Federal activities and related activities of State and local governments, foundations, and other private organizations; and

(4) development and dissemination of such information as will tend to reduce the incidence of retardation and ameliorate its effects.

(b) The Committee shall make an annual report to the President concerning mental retardation. Such additional reports or recommendations may be made as the President may require or as the Committee may deem appropriate.

SEC. 4. Cooperation by other agencies. To assist the Committee in providing advice to the President, Federal departments and agencies requested to do so by the Committee shall designate liaison officers with the Committee. Such officers shall, on request by the Committee, and to the extent permitted by law, provide it with information on department and agency programs which do contribute to or which could contribute to achievement of the President's goals in the field of mental retardation.

SEC. 5. Administrative arrangements. (a) The office of the Secretary of the Department of Health, Education, and Welfare shall, to the extent permitted by law, provide the Committee with necessary staff, administrative services, and facilities.

(b) Each member of the Committee, except any member who then receives other compensation from the United States, may receive compensation for each day he or she is engaged upon the work of the Committee, as authorized by law (5 U.S.C. 3109), and may also receive travel expenses, including per diem in lieu of subsistence, as authorized by law (5 U.S.C. 5703) for persons in the Government service employed intermittently.

(c) The Secretary of Health, Education, and Welfare shall perform such other functions with respect to the Committee as may be required by the provisions of the Federal Advisory Committee Act (5 U.S.C. App. I; 86 Stat. 770).

SEC. 6. Construction. Nothing in this order shall be construed as subjecting any Federal agency, or any function vested by law in, or assigned pursuant to law to, any Federal agency, to the authority of the Committee or as abrogating or restricting any such function in any manner.

SEC. 7. Executive Order No. 11280 of May 11, 1966, is hereby superseded.

RICHARD NIXON

THE WHITE HOUSE,
March 28, 1974.

Presidential Documents

Executive Order 12889 of September 30, 1993

Continuance of Certain Federal Advisory Committees

By the authority vested in me as President by the Constitution and the laws of the United States of America, and in accordance with the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C. App.), it is hereby ordered as follows:

Section 1. Each advisory committee listed below is continued until September 30, 1995:

(a) Committee for the Preservation of the White House; Executive Order No. 11145, as amended (Department of the Interior);

(b) Federal Advisory Council on Occupational Safety and Health; Executive Order No. 12196, as amended (Department of Labor);

(c) President's Commission on White House Fellowships; Executive Order No. 11183, as amended (Office of Personnel Management);

(d) President's Committee on the Arts and Humanities; Executive Order No. 12387, as amended (National Endowment for the Arts);

(e) President's Committee on the International Labor Organization; Executive Order No. 12216 (Department of Labor);

(f) President's Committee on Mental Retardation; Executive Order No. 11776, as amended (Department of Health and Human Services);

(g) President's Committee on the National Medal of Science; Executive Order No. 11287, as amended (National Science Foundation);

(h) President's Council on Physical Fitness and Sports; Executive Order No. 12345, as amended (Department of Health and Human Services);

(i) President's Export Council; Executive Order No. 12131, as amended (Department of Commerce); and

(j) President's National Security Telecommunications Advisory Committee; Executive Order No. 12382, as amended (Department of Defense).

Sec. 2. The President's Council of Advisors on Science and Technology; Executive Order No. 12700, as amended (Office of Science and Technology Policy), the authority for which expired on June 30, 1993, is hereby reestablished in accordance with the provisions of Executive Order No. 12700, as amended, and shall continue until September 30, 1995.

Sec. 3. Notwithstanding the provisions of any other Executive order, the functions of the President under the Federal Advisory Committee Act that are applicable to the committees listed in sections 1 and 2 of this order, except that of reporting annually to the Congress, shall be performed by the head of the department or agency designated after each committee, in accordance with the guidelines and procedures established by the Administrator of General Services.

Sec. 4. The following Executive orders or sections thereof, which established committees that have terminated or whose work is completed, are revoked:

(a) Executive Order No. 12792, establishing the National Commission on America's Urban Families;

(b) Executive Order No. 12813, as amended by Executive Order No. 12815, establishing the President's Commission on the Management of the Agency for International Development (AID) Programs;

(c) Executive Order No. 12720, as amended by Executive Order No. 12783, establishing the President's Council on Rural America;

(d) Executive Order No. 12696, as amended by Executive Order No. 12756, establishing the President's Drug Advisory Council;

(e) Executive Order No. 12687, as amended by Executive Orders Nos. 12741 and 12785, establishing the President's Education Policy Advisory Committee; and

(f) Section 5 of Executive Order No. 12675, establishing the Vice President's Space Policy Advisory Board.

Sec. 5. Executive Order No. 12774 is superseded.

Sec. 6. This order shall be effective September 30, 1993.

William Clinton

THE WHITE HOUSE,
September 30, 1993.

FR Doc. 93-24533

Filed 10-1-93; 1:14 pm

Billing code 3195-01-P

Important to
Read

**PHOTOCOPY
PRESERVATION**



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

JUN 21 1994

Dear Colleague,

On behalf of the President's Committee on Mental Retardation (PCMR), I wanted to take this opportunity to share with you the enclosed DRAFT RECOMMENDATIONS of the Health Care Reform, Long Term Care Reform and Welfare Reform Workgroups.

These draft recommendations were generated at the recent PCMR Presidential Forum focusing on how citizens with mental retardation and related developmental disabilities would be impacted by reform initiatives under consideration by the Administration and Congress.

As you may know, PCMR plans to produce two publications as a result of the Presidential Forum: the FORUM TECHNICAL PROCEEDINGS and the 1994 REPORT TO THE PRESIDENT.

The Forum Technical Proceedings Publication will include a transcript of all plenary sessions, publication of all work group papers designated by each respective work group leader, and recommendations endorsed by each respective work group. The Forum Technical Proceedings will be published and released in advance of the 1994 PCMR Report to the President.

The 1994 PCMR Report to the President will be prepared by Glenn Fujiura, for acceptance by the membership of the PCMR. The report will be based upon, but not limited to, the information, recommendations and reports shared and generated at the Presidential Forum.

We are currently completing the preparation for publication of the Proceedings, however I wanted to take this opportunity to share with you an advance draft copy of enclosed recommendations since these topics are under active consideration by Congress and the White House. We believe it is important that the concerns of citizens with mental retardation and related developmental disabilities be clearly on the table as decisions are being made. Thus we are forwarding the enclosed draft recommendations prior to publication to ensure that our common concerns are addressed.

We anticipate that the full Forum Technical Proceedings Publication will be printed and ready for distribution within the next two months.

**PHOTOCOPY
PRESERVATION**

Any reference to the enclosed recommendations should note that the enclosed workgroup reports represent DRAFT PCMR Recommendations, and should be referred to exclusively as DRAFT PCMR Recommendations.

The additional workgroup reports (Education Reform, Housing Reform and Employment & Financing Reform) have been completed and will be printed in the Forum Technical Proceedings Publication shortly. If you desire to have an early copy of those reports, please let me know by contacting John Pride, Deputy Executive Director, or Ashot Mnatzakanian, Forum Project Officer.

If I can provide any additional information, please do not hesitate to contact me at 202-619-0634.

Sincerely,


Gary H. Blumenthal
Executive Director

Enclosures

PHOTOCOPY
PRESERVATION

PARTICIPANTS

THE PRESIDENT'S REFORM AGENDA AND PEOPLE WITH MENTAL RETARDATION 21st CENTURY REALITIES

HEALTH CARE REFORM

Patricia Allison, D.O.
Kathy Beyer
Arnold Birenbaum, Ph.D.
Peter Blanck, J.D.
David Braddock, Ph.D.
Dennis Braden
Edward Brann, M.D.
Herbert J. Cohen, M.D.
Allen Crocker, M.D.
Jeannie Cummins
Elaine M. Eklund
Ethan Ellis
Neal Glaser
Robert Gris
Lucy Hackney
Stanley Handmaker, M.D., Ph.D.
Alfred Healy, M.D.
Joseph Hollowell, Jr., M.D.
Ted Kastner, M.D.
Greg Kattouf
Samuel Kessel, M.D., M.P.H.
Thomas Lottman
Kathleen McGinley, Ph.D.
Merle McPherson, M.D.
Magarita Miranda, Ph.D., MPHE
Peter P. Polloni
Raymond M. Peterson, M.D.
Laverdia T. Roach
Beverly Roberts
Cordelia Robinson, R.N., Ph.D.
E. Halsey Sandford
Linda A. Siegenthaler
Deborah Spitalnik, Ph.D.
Mark Swanson, M.D.
Alexander J. Tymchuk, Ph.D.
Kevin Walsh, Ph.D.
Valerie N. Williams, M.P.A.
Philip R. Ziring, M.D.

WELFARE REFORM

Michelle Adler
Steve Bartholomei-Hill
Laurel Beedon, Ph.D.
Elizabeth M. Boggs, Ph.D.
Edward P. Burke
Tamar Heller, Ph.D.
James W. Hubbard
Matthew P. Janicki, Ph.D.
Bette Keltner, R.N., Ph.D.
Irving Martin
J. Kenneth McGill
Charlotte B. Parkinson, D.S.W.
Cliff Poetz
John L. Pride
Craig T. Ramey, Ph.D.
Sharon Landesman Ramey, Ph.D.
John B. Regan
Aase J. Righter
Leonard S. Rubenstein, Esq.
Mary Lou de Leon Siantz, Ph.D.
Loren Simonds
Rosalyn Simon, Ph.D.
Robyn Stone
Zolinda Stoneman, Ph.D.
Virginia Williams

LONG TERM CARE REFORM

Carol Beaty
Alan Bergman
Valerie J. Bradley
Robert Brown
Dennis M. Byars
Robin Cooper
M. Doreen Croser
Steve Eidelman
Martha Ford, Esq.
Joni Fritz
Glenn Fujiura, Ph.D.
James F. Gardner, Ph.D.
Robert M. Gettings
Gail Jacobs
Tecla M. Jaskulski
Ruth Katz
Cindy Kauffman
Fred Krause

Page 3

Frank Laski
Dick LePore
Michael Kennedy
Joel M. Levy
Paul Marchand
Isabel T. Mills
Debbie Robinson
Lynne Seagle
Michael Smull, Ph.D.
Michael A. Strouse, M.A.
Nancy Thaler
E. Duane Thompson
Brenda Kaye Turner
L. Carl Volpe
Nancy Ward
Robert C. Wardwell
Marci Whiteman
Colleen Wieck, Ph.D.

HOUSING REFORM

Susan Babin
Marian J. Barber
M. Alton (Al) Barnes
Elizabeth W. Bauer
Robert E. Brown
Ken Campbell
Russell Daniels
Susan Daniels, Ph.D.
Robert G. Davies
Gunnar Dybwad, Ph.D.
Becky Donofrio
Joe Donofrio
Judy England-Joseph
Andrew F. Eustin, FAIA
Suellen R. Galbraith
Charlie Galloway
Vicki Grosch
Dennis E. Haggerty, Esq.
David S. Harre
Reggie Jaramillo
Jay Klein
Patricia A. Laird
K. Charlie Lakin, Ph.D.
Margaret Milner
Ashot P. Mnatzakanian
T.J. Monroe

John O'Brien
Patrick Rafter
Wesley Riggins
Bud Seltzer
Bonnie Shoultz
Otto Shulz
Gary A. Smith
William J. Sparling
Cathy Ficker Terrill
David Wetherow
Gail G. Williamson

EDUCATION REFORM

Alan Abeson, Ed.D.
Maureen E. Babula
Donald B. Bailey, Jr., Ph.D.
Louise Bauer
Amy Bennett
Gwen Benson, Ph.D.
Jane Browning
Nitina Chavan
Diane Ferguson
Marvin G. Fifield, Ed.D.
Alison Ford
Ann Forts
Hiawatha Fountain, Ed.D.
William Halloran, Ph.D.
Mike Hardman, Ph.D.
Dawn Hunter
Terry Ingram
David R. Johnson, Ph.D.
William E. Jones, Ph.D.
Cheryl Jorgensen
Naomi Karp
William R. Langner
Mark Malawer
John McClain, Ph.D.
Patricia McGill-Smith
Celane McWhorter
James Meadours
Christina Metzler
Tom Nurney, Ph.D.
Jan Nisbet, Ph.D.
Dolores Norley, Esq.
Liz Obermayer
Jim Piet
Virginia Roach
Donna M. Rosenthal

Page 5

Tom Skirtic
Bena L. Smith
Vicki Smith
Ann P. Turnbull, Ed.D.
Rich Villa, Ed.D.
Marilyn Wessels

EMPLOYMENT

Robert Anderson, Ph.D.
Tom Baffuto
Dr. Richard Balser
Kammie Barfield
Yolande Bestgen
George N. Bouthilet, Ph.D.
Michael Collins
Barbara Coppens
Sharon Davis, Ph.D.
Gordon Dawson
Rick Douglas
David Dunn
Terry Edelstein
Larry Goldberg, Esq.
Judith Gran, Esq.
Chris Grandy
Jim Harper
Paul Hippolitus
Ron Inlow
Fred Isbister
Sharman Davis Jamison
Pat Juhrs
Orv C. Karan, Ph.D.
William E. Kiernan, Ph.D.
David M. Mank, Ph.D.
John McDonnell, Ph.D.
William McLaughlin
Tia Nelis
John Nietupski
Stephanie J. Powers
Ian Pumpian, Ph.D.
Pat Rogan
Daniel B. Rosen, Ph.D.
Frank Rusch, Ph.D.
Joseph K. Scarlett
Mary Jo Snell
Louis Stewart, J.D.
Ronald Torner
Paul Wehman, Ph.D.
Harriet Yaffee

DRAFT

President's Committee on Mental Retardation

**Recommendations of the
Health Care Reform Work Group**

from

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

**April 24-26, 1994
Alexandria, Virginia**

DRAFT

President's Committee on Mental Retardation

**Recommendations of the
Health Care Reform Work Group**

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

April 24-26, 1994

PART ONE: INTRODUCTORY STATEMENT OF PRINCIPLES

Health care is a basic right of all Americans. Disability is a natural part of the human experience. Most people with mental retardation and related disabilities have the same basic health care needs as everyone else; only a small percentage require complex services. Yet the insecurity of insurance coverage, or being underinsured, is most acutely felt by this population and their families.

Rejection of coverage for pre-existing conditions or limited coverage for needed therapies or preventive interventions has jeopardized the capacity of people with mental retardation to lead normal lives. As we enter this critical time when health care policy decisions will shape our lives well into the twenty-first century, the following qualities must be incorporated into the health care reform agenda.

UNIVERSAL COVERAGE

Universal coverage means affordable, quality health care for all Americans that can never be taken away. Key features for people with disabilities are that coverage must not exclude people based on pre-existing conditions or through out-of-pocket expenses. Coverage and benefits must be portable and without lifetime caps. There must be no work disincentives, and comprehensive benefits packages must be guaranteed and specified. There must be access to specialists and other appropriate providers and services not limited by managed care plans or network providers. There needs to be meaningful consumer involvement, accountability, and provision for home and community-based long-term care services.

FIVE KEY PRINCIPLES

We support the principles articulated by the Consortium for Citizens with Disabilities. These principles are:

1. **Non-Discrimination**: People with mental retardation and related disabilities of all ages must be able to fully participate in the nation's health care system, regardless of age, health or disability status, or income.
2. **Comprehensiveness**: People with mental retardation and related disabilities must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal, and support services across all service categories and sites of service delivery.
3. **Appropriateness**: People with mental retardation and related disabilities and their families must be assured that comprehensive health, rehabilitation, personal, and support services are provided on the basis of individual need, preference, and choice.
4. **Equity**: People with mental retardation and related disabilities and their families must be assured equitable participation in the nation's health care system and not be burdened with disproportionate costs. There cannot be financial disincentives for serving people with more complex needs.
5. **Efficiency**: People with mental retardation and related disabilities and their families must have access to a health care system that provides a maximum of appropriate, effective services that includes effective cost controls as well as a minimum of administrative waste.

CONTEXT

The current health care system available to people with mental retardation and related disabilities does not adequately embody these principles. Reform efforts need to consider the context of health care for this group. Some, who are quite healthy, do not need services beyond what is typical for all Americans; others have very complex medical problems with extensive health care needs. This latter group includes people who have disorders associated with certain syndromes, rare or low incidence syndromes, or challenging behavior problems requiring health care professionals with specific education and experience as well as the desire to provide the needed care.

The number of people in this group is increasing due to (1) an increased lifespan associated with medical advances and improved health care during infancy and childhood; (2) an aging population of persons with mental retardation who require treatment for the same diseases that affect all older people, such as cancer, stroke, or coronary disease; and (3) increasing numbers of people living in the

community who formerly resided in and received their health care from institutions.

At present there is a severe shortage of providers with the expertise to properly treat people with mental retardation who have complex health care problems or disabilities in addition to mental retardation. For example, some people with mental retardation also have autism or epilepsy or mental health problems, or they may also be non-verbal. Without appropriate services from physicians and allied health professionals who have training and clinical experience with such significant problems, the problems will worsen, often requiring more costly services, or long term care.

Further, the future of health care delivery in the United States is likely to include some form of managed care. Although managed care may present opportunities such as increased access to primary and preventive care, it may also pose significant problems to people with mental retardation and associated disabilities. Since there are strong forces desiring inclusion of people with disabilities on Medicaid in managed care programs at the state level, and since the majority of adults with mental retardation are on Medicaid, this is of major concern. The implementation of managed care approaches to date suggests certain problems, including:

1. A scarcity of primary care ("gatekeeper") physicians associated with managed care plans who are knowledgeable about mental retardation and related disabilities.
2. Lack of consumer access to providers who have specialized training and experience in treating people with disabilities. This is often related to the unwillingness or inability of gatekeepers to refer to specialists as needed. It is, for example, inappropriate to continue to serve adults with mental retardation in pediatric settings merely because this is where the initial diagnosis was made. We must construct health care services which transition consumers to peer group providers and specialists and to sex appropriate service providers. An appropriately functioning gatekeeper therefore needs to be able to refer and provide access to appropriate health care providers where the appropriateness is determined by need, available resources and fit into the care system with peers. This concept of health care transition is comparable to the concept of inclusion in social, educational, and residential settings.
3. Denial of medically necessary services or the provision of inappropriate services that could increase medical complications, perhaps resulting in increased costs, an

undermining of functional abilities, or a diminished quality of life.

The system components and supports necessary to resolve these problems and address the issues and principles noted above are enumerated in the recommendations in Parts Two and Three of this document.

ROLE OF THE AMERICANS WITH DISABILITIES ACT (ADA)

The ADA provides an important vehicle to ensure access to health care as a civil right. Policies and procedures may not, by design or impact, deny individuals with disabilities, by reason of their disability, the opportunity to participate in or benefit from any aid, benefit, or service that is equal to and as effective and meaningful as that provided to others. Rationing of health care services violates the intent of ADA as does denying coverage based on an undervaluing of outcome based on pre-existing functional impairment. Similarly, medical necessity may not be prioritized in terms of specific conditions and treatments applicable to the average patient. Finally, we must minimize any discriminatory effects that apparently neutral policies may have in practice.

PART TWO: SERVICE DELIVERY AND RESOURCES

Health care resources and the service delivery system for people with mental retardation and related disabilities should reflect the range, intensity, diversity, and specialization needs of this population. Additionally, the system should reflect the diversity of people with disabilities who arise from different cultural, geographic, and socioeconomic backgrounds. In general, health care services for people in this group, as with anyone who has a chronic illness, need to be integrated into the broader, generic American health care system.

Situational factors effect the interface between the person and providers in the health care system. Of fundamental importance in achieving personal health and wellness across the life span are technical and cultural competence in building provider-consumer rapport through the ability to establish trust and create dialogue with individuals and families.

Most individuals with mental retardation and developmental disabilities can be adequately served within the generic health care system given appropriate preparation and training of primary care, specialty care, and allied health care providers. However, for a smaller percentage of such persons, access to specialized health services is essential to their independence, productivity, and health. Therefore, health care reform should prepare generic health care providers to serve persons with mental retardation and related disabilities while at the same time preserving and enhancing specialized services for individuals with complex needs.

Access to appropriate services needs to be assured for consumers with cultural, linguistic or communication traits impeding such access. This will require a broad range of non-medical allied health care providers to convince some consumers and their guardians that they want or need access. For example, the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services has successfully implemented numerous refugee project initiatives in which outreach workers familiar with language and cultural issues facilitate access to appropriate health care services.

I. PREPARATION FOR CARE

1. Adult-oriented specialists, including family physicians, need knowledge, clinical experience and optimal models. Many providers exclude persons with disabilities not because they lack knowledge or skills but because they lack prior experiences permitting them to appreciate that they are fully

capable of providing optimal care. Appropriate knowledge and experience would also expand provider capability to serve low incidence syndromes or complex health problems.

2. Knowledge about appropriate health care methods and programs for people with mental retardation needs to be disseminated to individuals with disabilities and their families, providers, and advocates. This information should be presented in easily understandable formats.
3. Primary consumers of health care services (i.e., people with mental retardation and related disabilities) must be supported in their ability to make knowledgeable and informed choices reflecting their own personal health goals. Health care professionals need more and better training in health promotion and disease prevention for persons with mental retardation.
4. Approximately 500,000 elderly and disabled persons are presently under unnecessarily restrictive guardianships and conservatorships. Non-judicial alternatives to guardianship, such as New York State's Surrogate Decision-Making Committee Program, should be explored as a means to promote health care decision-making for persons with mental retardation and related disabilities.
5. Research regarding best care practices for persons with mental retardation and related disabilities is needed, especially in the following areas: clinical outcome investigations, systems research, and resource utilization studies.

II. DELIVERY OF CARE

6. High quality primary care, including a medical home, must be available for everyone, from infancy through aging, that addresses all aspects of health promotion and wellness including primary and secondary conditions, and prevention efforts. These services are best supplied by the full range of primary care providers.
7. Health care reform must preserve referral to specialists as required for comprehensive health care services, such as mental health practitioners and rehabilitation specialists.
8. Coordination of care is of extraordinary importance and must be viewed as an integral component of health care. It must be based on the needs of the individual not the provider, and it must operate across service systems. For people who require a variety of supports for community living and work, health care services must collaborate and coordinate with these other services.

-
9. It must be recognized that significant elements of health care and health care related services for children may be delivered in schools through education-related and other services. Health care delivery systems must work in partnership with schools and families.
 10. All early childhood programs, such as early intervention programs and Head Start, must include health care components and related services to meet individual child and family needs.
 11. As appropriate, service plans (e.g., Individualized Family Service Plans - IFSP, Individualized Education Plans - IEP, Individualized Habilitation Plans - IHP, Individualized Service Plans - ISP) should include aspects of health care.
 12. A complete range of home health care services must be available.
 13. Carefully planned habilitation and rehabilitation services, including funding of assistive technology and durable medical equipment, must be available as appropriate.
 14. Prevention or amelioration of secondary conditions associated with mental retardation across the life-span must be an integral part of health care.
 15. Health care resource centers, such as University Affiliated Programs, Children's Hospitals, and centers specializing in addressing the health needs of people with mental retardation and related disabilities, must be supported and available.
 16. Persons with special needs and disabilities should receive a comprehensive individual interdisciplinary evaluation at centers independent of managed care providers to assess the individual and family needs, develop service plans and make recommendations as to what specialized care is required.
 17. Health care records which are portable and problem-oriented are an essential element of health care delivery.
 18. Transportation to health care services must be provided as appropriate.

III. EVALUATION AND SUPPORT

19. Broad value-based standards need to be developed that focus on functional outcomes and reflect consumer satisfaction and innovation in practice.
20. The success of the health care system in promoting the values of independence, productivity, health and wellness must be evaluated on a recurring basis. The effectiveness and efficiency of the system in meeting these goals should be judged against standards which are derived from the principles presented in Part One; however reasonable variations in practitioner behavior must be tolerated when the knowledge base is not fully developed or to meet unique needs of specific individual cases.
21. Research on the effectiveness of treatment must be supported.
22. Health outcomes should be monitored and examined to identify patterns of practice not meeting generally accepted professional standards.
23. There must be a requirement for continuing education for all parties in the health care system.
24. To maximize the involvement of people with mental retardation and related disabilities in their own health care, consumer advisory committees to health care providers must exist and reflect the scope and diversity of the population being served.
25. Health care reform initiatives must be coordinated with the development of the National Information Infrastructure (NII) and related to advances in universally accessible telecommunications. The benefits of the NII for people with mental retardation and related disabilities include the enhancement of: (1) access to health care information and expertise and a concomitant reduction in transportation barriers; (2) opportunities for training and education; (3) opportunities for advocacy; (4) collaborative research and care coordination; and (5) cost-effective and efficient means for the provision of health care generally.

PART THREE: FINANCING HEALTH CARE

The high level of public support for health care reform provides an opportunity to enhance the current health care delivery system for all Americans. Historically, people with mental retardation and their families have often been unable to access health care services because of pre-existing conditions and the absence of mechanisms to equitably distribute costs; or they have faced the complete unavailability of health insurance coverage or the insecurity of being underinsured.

The Consortium for Citizens with Disabilities (CCD) has examined reform proposals from the perspective of the principles for health care reform, noted above -- non-discrimination, comprehensiveness, appropriateness, equity, and efficiency. In general, the President's Health Security Act (HR 3600/S 1757) and the Wellstone/McDermott single payor bill, the American Health Security Act (HR 1200/S 491) support the health care goals of people with mental retardation and associated disabilities by ensuring universal coverage, eliminating pre-existing condition exclusions, providing comprehensive benefits, and emphasizing prevention. Other health care proposals such as the Cooper/Breaux Managed Competition Act of 1993 (HR 3222/S 1597) or the Thomas/Chaffee Health Equity and Access Reform Today (HR 3704/S 1770) do not meet these requirements.

Specific recommendations in regard to the financing of proposed health care legislation follow:

26. Health care benefits must be specified in statute to maximize incentives to reduce administrative waste, excess capacity, and excess profits.
27. Reform of the American health care system needs to maximize savings by promoting administrative efficiency and supporting state and local options for the financing of the health care system. It is estimated that approximately 25% of health care costs are currently spent on the administration of services rather than on service provision.
28. Funding for reform of the health care system should be obtained through the use of either broad-based taxes, an employer mandate, and/or cost-sharing through tax-deductible, income-adjusted copayments.
29. Reimbursement of health care providers should reflect the relative value of resources required to meet the health care needs of people with mental retardation and associated disabilities.

05/20/94

Welfare Reform: Summary and Recommendations

Our group worked hard and we struggled in our deliberations about what is most important to bring to the President's Committee for action. Poverty -- especially pervasive and long-term poverty -- has devastating effects on lives and families. We want to emphasize that both poverty and disability disproportionately affect people of color and people from diverse cultural backgrounds. This inequity must be corrected. Welfare, in its present and many different forms, has not succeeded in providing the level and the types of supports needed for individuals and families affected by disabilities:

- to become economically self-sufficient;
- to have the same opportunities as the middle class for education, training, employment, housing, and above all, to have the positive self-esteem that comes with being a contributing, productive citizen.

Intellectual differences and intellectual disabilities are indeed profoundly affected by poverty and the current welfare system, including the rules, regulations, and procedures that influence the federal and state systems that provide cash subsidies and direct supports to families and to individuals.

Our group affirms several basic principles. These include:

(1) the belief that an effective reformed welfare system will be an investment in human capital that will yield large positive returns. These returns will be both economic (that is, cost savings) and human benefits. These returns can reduce the number of people receiving cash subsidies, how long people need cash assistance, and even more importantly, the quality of life for the families and individuals in whom our country invests. An important function affirmed by the Welfare Reform Group is that an effective welfare system should promote independence of people and reduce their long-term total dependence over time;

(2) the recognition that the expression "mental retardation" has become a true stigma, a label that self-advocates and many parents and professionals strongly dislike. We urge the President's Committee to address the reality soon -- and to share

DRAFT

a vision for how to change this situation in its report. This will guarantee that the report resulting from this meeting will be a landmark one, one that will not be ignored or forgotten (Note: We also recognize that in the 1950s and 1960s the, the identification of "mental retardation" as a problem of maternal concern was very positive.)

(3) the reality that intellectual disabilities must always be considered in terms of the entire lifespan and the family. This starts with consideration of family planning and high quality prenatal care. These efforts must include mothers, fathers, extended family members, foster and adoptive parents, and everyone who is part of today's changing family structure and diverse cultures. Support services must be designed for and extend through all ages, with particular awareness positive of the increases in the lifespan of persons with disabilities and the frequent lifelong interdependence among family members; and finally,

(4) the recognition that the expanded knowledge base (i.e., scientific findings) about effective ways to strengthen individuals' and families' lives, including prevention of unnecessary disability and lowering risks to future generations, must be put into action. In some cases, this means being sure that welfare reform builds upon what we know works for whom. In other cases we do not yet know how best to apply important findings in the real world. This means we must invest in a revitalized study of the complex human problems associated with disability, poverty, and cultural diversity -- so that, as a nation, our investments will not continue to be viewed as a collection of only "experiments" and "political compromises," or will not show the same patterns of racial/ethnic discrimination that have long excluded certain families and children from the improved service delivery system. Increasingly, we hope that investments will be based on a sound knowledge base about how people with disabilities can realize their full potential and enjoy a satisfying and contributing quality of life. People are first!

Our recommendations focus on those we think can realistically be acted upon in a timely manner as part of the current national agenda. (We have other recommendations and dreams as well and will share these on a final report.)

DRAFT

(1) REGARDING CHANGES IN SSI, THE SSI MODERNIZATION PROJECT PANEL MADE NUMEROUS RECOMMENDATIONS IN 1992 THAT DESERVE CONSIDERATION BY THIS ADMINISTRATION AND CONGRESS. SOME MUST BE DEFERRED OR PHASED IN GRADUALLY BECAUSE OF POTENTIAL COSTS. HOWEVER, TWO OF THE FOUR HIGHEST PRIORITY ITEMS SHOULD BE PURSUED NOW IN SUPPORT OF THE CLINTON PROPOSALS ON AFDC REFORM AND ON LONG-TERM CARE. THESE ARE:

(a) to increase the assets limits for recipients to encourage thrift and the pursuit of self sufficiency. Contributions to an IRA or other pension plan should be encouraged. Specifically, raise the limit for accessible assets to \$7,500 for an individual and \$10,500 for a couple by \$1,000 or \$1,500 respectively annually over a 6-year period.

(b) to eliminate the rules relative to "in-kind support and maintenance" (for a variety of reasons) set forth in the Experts' Report, not least of which is that the rule penalizes individuals (adults) who are sheltered by family members. (Individuals who live independently are, in principle, eligible for housing, subsidies that limit their housing costs to 1/3 of their (SSI) income. (Currently, that ISM rule imputes a pro rata share of the full value of any housing [home-owned or rented] to the SSI recipient as "in-kind support.")

The public cost of implementing this recommendation completely is a barrier at the present time. We therefore recommend that an otherwise eligible adult who contributes at least 1/2 the FBR to pay for food and shelter in the household of another will not be subjected to any reduction in benefit based on ISM.

This recommendation will support the assumptions of the Medicaid HCBS Waiver that the recipient will receive basic maintenance from a source other than Medicaid and that living with relatives is one of the viable options for adults with severe disabilities.

Two additional recommendations our working committee endorsed are:

(c) to endorse the Clinton plan to extend the EITC to single persons and couples without children living with them;

DRAFT

(d) to have the Secretary reconsider the issue of reduction in benefits when two adults who receive benefits (SSA or SSI) marry. Specifically, we recommend that all eligible spouses each receive the individual disregards of earned income, IRWE, etc. and that for adults who are disabled before marriage and are under 40 at time of marriage, the combined benefit should be 200% of the single FBK (rather than 150%).

(2) TO ESTABLISH A SUPPORT SYSTEM FOR RECIPIENTS OF AFDC WHO THEMSELVES ARE DISABLED WHICH PROMOTES WORK, FAMILY, AND INDEPENDENCE. INCLUDED IN THIS ARE THE FOLLOWING SPECIFIC RECOMMENDATIONS:

(a) to develop and expand comprehensive child care and intervention programs for children under the age of five to enable recipients to participate in activities leading to work, family, preservation, independence, and child development.

A special emphasis must be placed on providing appropriate intensive services for children from birth to three residing in shelters for the homeless, a new underserved disabled population, and to those in foster and other non-parental care;

(b) to establish a tracking system that enables health and social service agencies to determine the status of children in transient living situations so that continuity of services can be ensured (responsibility of AFDC worker);

(c) as appropriate supports are expanded, to assess the direct benefits and cost-savings of early intervention services and find ways to deliver these most efficiently.

(3) TO CHANGE INCENTIVE LEVELS TO WORK AND TO ENCOURAGE INDIVIDUALS TO DISCOVER THEIR ABILITY TO WORK. DEMONSTRATION PROJECTS IN STATES SHOULD BE IMPLEMENTED AND EVALUATED. MANY ARE LIKELY TO BENEFIT FROM MORE LUCRATIVE STANDARDS APPLIED TO THOSE WHO ARE VISUALLY IMPAIRED. AT THE SAME TIME, A "SAFETY NET" FOR INDIVIDUALS WITH DISABILITIES WILL BE NEEDED, BECAUSE OF THE NATURE AND SEVERITY OF SOME INDIVIDUALS' DISABILITIES;

(4) TO DEVELOP AND PROVIDE EFFECTIVE TRAINING FOR WORKERS IN PUBLIC ASSISTANCE PROGRAMS TO BETTER RECOGNIZE, UNDERSTAND, AND RESPOND

TO NEEDS OF PARTICIPANTS OF ALL AGES WITH INTELLECTUAL DISABILITIES, IN ALL LIVING SITUATIONS;

(5) TO TAKE ADVANTAGE OF THE LARGE-SCALE 2-GENERATION INTERVENTION PROGRAMS NOW UNDERWAY (JOBS, NEW CHANCE, CCDP, HEAD START) AND FOCUS ON THE NEEDS OF PARTICIPANTS WITH DISABILITIES, ESPECIALLY THOSE WITH INTELLECTUAL DISABILITIES. THESE PROGRAMS ARE INCLUSIVE, BUT ALL TOO OFTEN THE "INVISIBLE" DISABILITIES OF PARTICIPANTS PREVENT THESE INDIVIDUALS FROM BENEFITTING FULLY FROM THESE COMPREHENSIVE PROGRAMS DESIGNED TO PROMOTE SELF-SUFFICIENCY, SELF-ESTEEM, AND STRONG FAMILIES;

(6) TO FULFILL THE REQUIREMENTS OF ADA, THE REGULATIONS AND WAYS PUBLIC ASSISTANCE ARE ADMINISTERED NEED TO CONSIDER "ACCESSIBILITY" MORE BROADLY, SO THAT THE INFORMATION ABOUT THESE PROGRAMS AND ACCESS TO THEM IS EASY TO UNDERSTAND, CONSISTENT, AND READILY AVAILABLE TO THOSE WITH INTELLECTUAL DISABILITIES.

(7) TO HAVE THE PRESIDENT'S COMMITTEE MOUNT A CAMPAIGN TO HELP THE GENERAL PUBLIC REALIZE THAT "MENTAL RETARDATION" IS NOT AN UNTREATABLE, UNCHANGEABLE, OR ALWAYS PERMANENT CONDITION. WE NEED TO BE SURE THAT OUR SERVICE DELIVERY SYSTEM CHANGES SO THAT DIAGNOSIS OF CONDITIONS IS NOT CONSIDERED TO BE A PREDICTION ABOUT A CHILD'S OR ADULT'S POTENTIAL AND FUTURE ACHIEVEMENT.

NO DIAGNOSIS SHOULD BE GIVEN WITHOUT A PLAN FOR ASSISTANCE. WHAT WE NEED TO FOCUS ON IS A NEW WAY OF TRAINING PROFESSIONALS TO EMPHASIZE UNDERSTANDING HOW IMPORTANT THE ENVIRONMENT IS. DISCUSSIONS ABOUT THE POTENTIAL VALUE OF HAVING PROFESSIONALS WHO ARE TRANSDISCIPLINARY (THAT IS, ABLE TO PROVIDE NEEDED SERVICES IN MORE THAN ONE AREA) -- TO MEET NEEDS IN RURAL AND UNDERSERVED AREAS -- OCCURRED, ALTHOUGH NO SPECIFIC RECOMMENDATION EMERGED.

In conclusion, we underscore the importance in Welfare Reform that the unique needs and appropriate supports of the following types of individuals be recognized:

- (1) an infant born to a mother with mental retardation or other disabilities

- (2) a single mother with a child who has developmental disabilities
- (3) an adult with disabilities having to go to work
- (4) an older adult with disabilities who may want to retire (e.g., from a day program)

We further need to emphasize that the purpose of "determining eligibility" and "making diagnoses" should be how to improve the individual's future, rather than "evaluating" a person or "predicting" that person's future. Let us not forget that our population is multicultural and multilingual. Our support services, treatments, and welfare reform must be culturally appropriate. The positive picture we see today is the result of optimism and a lot of hard work.

Attachments

DRAFT

REPORT OF THE LONG TERM SERVICES AND SUPPORTS WORKING GROUP

In mapping out future long term service and support policies, the group agreed that one of the major challenges facing the field of mental retardation and developmental disabilities is to simultaneously live with the consequences of the past, manage the existing service system, and plan for the future. Unlike many other areas of human services policy, past decisions regarding service modalities and program placements cannot be altered easily, since the customers of the DD service system typically require assistance that spans decades, rather than a few months or years. For example, the decision during the early years of this century to rely on large, multi-purpose residential facilities as the principal modality for meeting the on-going service and support needs of people with lifelong disabilities continues to be a major factor in the policymaking equation, long after most consumers, parents and professionals have embraced the concept of community and family-centered services. The most important policy issue the field faces, therefore, is to find ways of accelerating the transition to a system of services that supports individuals in making meaningful choices about how they live their lives as participating, valued members of the community, while not abandoning society's obligation to people who still are being served in facilities and programs which no longer conform to contemporary views regarding "best practices".

In order to achieve such a transformation, the work group believes that it is essential to begin by articulating a vision of the future. It is the work group's belief that such a vision should include the following elements:

- The provision of services and supports tailored to the needs and aspirations of each individual, rather than a "continuum" of pre-fabricated long term care program options;
- An emphasis on consumer choices, either made directly or, where necessary, through a facilitator;
- The opportunity for people with lifelong disabilities to have dreams and the chance to achieve them;

DRAFT

- Outcome-based accountability systems that operate at all levels of the service delivery system;
- Children with disabilities should live with families;
- Independence and productivity are highly valued service outcomes for all consumers and public policy and funding should be directed toward eliminating barriers to achieving such outcomes;
- Eligibility should be based upon the individual's needs and not labels;
- People closest to those in need of supports should be empowered to help them realize their personal goals, wherever possible;
- Funding should be based on individual needs and wants, not program slots;
- Individuals who work directly with consumers and their families should be given considerable latitude in designing and carrying out support strategies;
- Emphasis should be placed on developing community partnerships in which responsibility is shared by individuals with disabilities, their families and friends as well as the community at large. The role of formal services should be modulated to take into account such informal, indigenous community support networks; and
- Quality assurance mechanisms should be strengthened, with the emphasis on achieving meaningful individual outcomes; people with disabilities should be involved in monitoring the quality of services and supports that are provided.

Though not part of this group's charge, it was agreed that income supports, such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) payments are crucial components of giving people choices and control over their destiny.

DRAFT

Among the principal topics discussed by the work group were the following:

A. Planning, Organizing and Delivering Services

- There is an enormous gap between what we know about organizing and delivering long term supports to people with developmental disabilities and current day-to-day practices in the field. "Best Practices" focusing upon individualized supports and services are happening everywhere, yet the continuation of new, out-moded ICF/MR services is taking place at the same time. As a community, we are falling into a deeper and deeper hole, from which it could take a century to "dig out";
- Our major goal should be to help get people with disabilities connected socially, spiritually and physically within their home communities;
- Mandating the use of person-centered planning may undermine the process of designing and implementing individually tailored services and supports. Person centered planning must be expanded as a moral, leadership issue within the DD community;
- We can learn how everybody wants to live, even individuals who are physically incapable of verbalizing their own needs and aspirations;
- We should focus on how, not where, people want to live;
- An individual with disabilities can begin to form a vision of his or her future once he or she has a life which makes sense. It is hard to have a vision of the future when you live in a controlled environment where you have little, if any, opportunity to make significant life-shaping decisions;
- Severity of disability is not a barrier to giving people control over how they live their lives;
- The human capacity to pervert the "supports paradigm" is virtually unlimited; we cannot eliminate such perversions, but we can and should be aware of such pitfalls and prepare to take corrective action, when necessary;
- We want to create policy environments (i.e., federal, state, local and provider-specific policies and practices) which makes person-centered planning possible;

DRAFT

Start from the ground up in designing services and supports to fit the person; do not make the person conform to existing service arrays and eliminate the "slot" mentality; and

- Specify in federal legislation/regulations a **PROCESS** that requires movement towards the goal of person-centered planning, rather than a rigid set of procedural steps.

- Specify in Federal legislation/regulations a freeze on new ICF/MR development only if it can be combined with "opening up" as a plan amendment CSLA and or 2176 type waivers. One without the other is NOT acceptable.

B. Services Coordination/Case Management

- The service coordination/case management function should be housed in an agency that has no other direct service responsibilities;

- Service coordinators/case managers should advocate on behalf of the individual receiving services/supports;

- Service coordination/case management functions best in formal service systems;

- The service coordinator/case manager needs to be assigned different responsibilities when a supports model of delivering assistance is employed;

- In many states, service coordination/case management services need to be totally reconceptualized to clarify the principal aims to be achieved and operational strategies to be employed -- especially the relationships between the service coordinator/case manager's responsibility for systemic advocacy on behalf of individuals with disabilities versus gatekeeping functions such as helping to ration scarce fiscal resources.

- Agency structure is less important than the environment in which the service coordination/case management functions are performed; and

- The overriding challenge is to modify the role of the service coordinator/case manager so that it is consistent with the "supports paradigm" and the emphasis it assigns to consumer choice and control.

C. Quality Enhancement/Assurance

- Quality should be defined in terms of the people receiving services and supports, rather than simply in terms of the qualifications of the personnel involved in delivering such services or the facilities/programs in which it is furnished;
- Quality should be measured in terms of individual outcomes;
- Each person's service/support priorities are different and service delivery systems must recognize that, while the protection of the health and safety of vulnerable individuals is an absolute priority: (a) individual differences are the antithesis of a "program" model; and (b) these differences have to be taken into account as we attempt to determine whether any given individual is having his needs met.
- The quality assurance professional should be a technician, not a program strategist;
- There is a difference between defining what to measure and knowing how well it is measured;
- The emphasis in quality enhancement/assurance programs needs to shift to assessing outcomes in terms of the changes that have occurred in people's lives;
- Where interdependent relationships exist, it is important to focus on where the locus of control lies;
- Quality must be built in up front, as part of the services and supports for each individual, rather than be considered as an afterthought or something to be "caught";
- Federal policy should demand that appropriate health and safety safeguards are in place and require states to submit a quality assurance/enhancement plan which is developed in partnerships with consumers. The plan should focus on meeting individual needs as defined by the consumers and, where appropriate, his/her family and friends. Training is a crucial component to achieving and maintaining high quality services.

Other Topics

- The "cold bed" methodology of limiting participation in Medicaid home and community-based waiver programs should be abandoned by the Health Care Financing Administration. Consideration also should be given to imposing a national cap on the total number of ICF/MR beds any given state may maintain.
- The provisions of the Americans with Disabilities Act should be applied to the NFPA/ANSI fire safety and accessibility standards.
- Hold housing for people with disabilities to the same basic standard as apply to other similar housing units in the community;
- People of all ability levels can direct their own supports, although the degree and methods by which such direction is furnished will vary from individual to individual;
- Most people with developmental disabilities lack the economic measures to be fully independent and this reality has a profound influence on public policies affecting such individuals.
- Personal assistance, as a concept, is different than long term supports. Personal assistance is something which can take place where one lives or in other community settings.
- PEOPLE WANT THEIR LIVES BACK and building in provisions for consumer choice and control is the only effective way of assuring that individuals have the chance to determine their own destiny.
- The technology exists to support all people with disabilities in the community. The challenge is to obtain (and retain) adequately trained staff, sufficient resources and the programmatic flexibility necessary to provide ongoing supports that are consistent with each person's needs and desires.
- Partnerships between service consumers, their families and local communities are essential to supporting people with severe disabilities in the community.
- Prescriptive government regulations and personally directed services are incompatible.

- Government regulations (federal, state and local) need to be "decoded" so that individuals with disabilities and their families can understand them.
- Consumers should be given the final say in how and where they live and who they live with.
- We know what to do and how to do it. The challenge is to translate "best practices" into the everyday performance of the service system across the country.
- Training is an important agent of change; universities must begin to prepare professionals who are well-grounded in current program ideology and state-of-the-art practices.
- A great deal more work needs to be done with generic service agencies to assure that the specialized needs of people with cognitive disabilities are accommodated.
- In the area of health and medical services in particular, much more attention needs to be given to training all health practitioners to understand and appreciate the special needs of people with mental retardation, so that individuals can be integrated into generic health care systems, rather than relying on segregated services.
- Religion plays a large part in many people's lives. Therefore, we must work with the religious community to be sure that people with disabilities are included in the spiritual and social life of organized religious groups of all faiths and denominations.
- There is reason to be concerned that the more we professionalize services the more we may separate people from their communities. We want to make professionals knowledgeable about persons with cognitive disabilities, but not necessarily experts.
- To improve consumer choice and control, we need to:
 - Give people a direct say in planning their lives (ASK ... LISTEN ... RESPOND)
 - Focus on how and what we communicate to families; and

- Reward people for their success rather than punish them for their mistakes.

With respect to institutional downsizing:

- The goal should be to develop capacity and options in the community, rather than to close institutions.
- Where institutional facilities are closed or downsized, the objective should be to improve services to current facility residents, rather than to save money.
- We must make a commitment to support people as long as they require services and supports, without any reservations or qualifiers.
- Continuous quality improvement is crucial to the success of any facility downsizing initiative.
- Too often, the rationale for maintaining large public institutions is to benefit employees and, in some cases, the economics of local communities, instead of the people they are in business to serve.
- Usually it is necessary to create capacity for "double funding" during the transition periods in order to have a successful downsizing initiative.
- Remember those who wait! Institutional downsizing efforts sometimes divert attention from those living in the community who are on waiting lists for services.
- The goal is not to "deinstitutionalize" but rather to create a full life in the community for all people with disabilities.
- Include people who work in the facility in any downsizing plan and offer them alternative career options.

Don't blame service providers. Generally, they are furnishing the types of services public agencies requested. To the extent that such services are now seen as inappropriate or outmoded, there is an obligation to help such service providers make the transition to "a new way of doing business".

- Give people on the front lines of the service system power and authority to allow people with disabilities to make their own choices.

- Both senior managers and front line personnel need to have access to appropriate, ongoing training opportunities. Any Federal legislation should contain broad funding support, at a minimum % of services similar to other labor-intensive, service industries, which must go the ongoing training and staff development of persons, at all levels, working in the service delivery system.

DEC - 7 1993

President's Committee on Mental Retardation
Family and Community Support Subcommittee

A Presidential Forum:
The President's Reforms and
People with Mental Retardation
21st Century Realities

April 24, 25, 26, 1994

PCMR ADVISORY PLANNING COMMITTEE

1. William E. Jones, Ph.D., * Chairperson
Executive Director
American Association of University
Affiliated Programs
8630 Fenton Street
Suite 410
Silver Spring, Maryland 20910
(301) 588-8252
 2. Ms. Kathy Beyer **
People First of Northern Virginia
100 N. Washington Street - Suite 234
Falls Church, Virginia 22046
(703) 532-3214
 3. David Braddock, Ph.D. ***
Director
University Affiliated Programs
The University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, Illinois 60608
(312) 413-1647
 4. Sharon Davis, Ph.D.
Parent
The ARC - National Headquarters
500 East Border - Suite 300
Arlington, Texas 76010
(817) 261-6003
-
- * Ms. Elaine M. Eklund
Associate Director
American Association of University
Affiliated Programs (staff)
(301) 588-8252
- ** Ms. Jeannie Commins
Youth Leadership Coordinator
The Arc of the Northern Virginia
(Self-Advocacy Advisor)
- *** Group Leader

5. Mr. Steve Eidelman
Executive Director
Joseph P. Kennedy Jr. Foundation
1350 New York Avenue - Suite 500
Washington, D.C. 20005-4709
(202) 393-1250
6. David M. Mank, Ph.D.
Associate Professor
Specialized Training Program
1235 University of Oregon
Eugene, Oregon 97403-1235
(503) 346-2477
FAX (503) 346-5517
7. Matthew P. Janicki, Ph.D.
Director
Aging Services for the New York
State Office of Mental Retardation
and Developmental Disabilities
44 Holland Avenue
Albany, New York 12229-0001
(518) 473-7855
FAX (518) 473-9695
8. K. Charlie Lakin, Ph.D. ***
Director for Research and Dissemination
Minnesota University Affiliated Programs
on Developmental Disabilities
University of Minnesota
6 Pattee Hall
Minneapolis, Minnesota 55455
(612) 624-5005
9. Paul Marchand
Chairperson
Consortium for Citizens with Disabilities
1522 K Street, N.W. - Suite 516
Washington, D.C. 20005
(202) 785-3388
10. Jan Nisbet, Ph.D. ***
Director
Institute on Disability
University of New Hampshire
UNH 312 Morrill Hall
62 College Road
Durham, New Hampshire 03824
(603) 862-4320

11. Frank R. Rusch, Ph.D.
Director and Professor
Secondary Transition Intervention
Effectiveness Institute
College of Education
University of Illinois at Urbana Champaign
110 Education Building
1310 South Sixth Street
Champaign, Illinois 61820
(217) 333-2325
 12. Marsha Mailick Seltzer, Ph.D. ***
Professor
Waisman Center
University of Wisconsin-Madison
1500 Highland Avenue
Madison, Wisconsin 53705-2280
(608) 263-7878
FAX (608) 262-8848
 13. Steven Taylor, Ph.D.
Director
The Center On Human Policy
School of Education
200 Huntington Hall
Syracuse University
Syracuse, New York 13244-2340
(315) 443-3851
 14. Alexander J. Tymchuk, Ph.D.
Associate Professor and Director
of the Parenting Project
UCLA Neuropsychiatric Institute
and Hospital
760 Westwood Plaza
Los Angeles, California 90024-1759
(310) 825-0026
 15. Paul Wehman, Ph.D.
Rehabilitation Research and Training Center
School of Education
Virginia Commonwealth University
Richmond, Virginia 23284-0001
(804) 367-1851
- Ashot P. Mnatzakanian
PCMR Project Officer
(202) 619-3636

PCMR Committee Members and Staff

1. Gary H. Blumenthal
President's Committee on Mental Retardation
Wilbur J. Cohen Building - Room 5325
330 Independence Avenue, S.W.
Washington, D.C. 20201-0001
(202) 619-0634
2. John L. Pride
President's Committee on Mental Retardation
Wilbur J. Cohen Building - Room 5325
330 Independence Avenue, S.W.
Washington, D.C. 20201-0001
3. George N. Bouthilet, Ph.D.
PCMR Coordinator
Full Citizenship and Justice Subcommittee
Wilbur J. Cohen Building - Room 5325
330 Independence Avenue, S.W.
Washington, D.C. 20201-0001
(202) 619-3463
4. Robert E. Brown
PCMR Member and Chairperson
Family and Community Support Subcommittee
P.O. Box 462
Put-In-Bay, Ohio 43456
(419) 285-3500
5. Ashot P. Mnatzakanian
PCMR Coordinator
Family and Community Support Subcommittee
Wilbur J. Cohen Building - Room 5325
330 Independence Avenue, S.W.
Washington, D.C. 20201-0001
6. Laverdia T. Roach
PCMR Coordinator
Prevention Subcommittee
Wilbur J. Cohen Building - Room 5325
330 Independence Avenue, S.W.
Washington, D.C. 20201-0001
(202) 619-3636

Page 2 - PCMR Committee Members and Staff

7. Bena Smith
PCMR Coordinator
Public Awareness Subcommittee
Wilbur J. Cohen Building - Room 5325
330 Independence Avenue, S.W.
Washington, D.C. 20201-0001
(202) 619-3463
8. E. Duane Thompson
PCMR Member and Vice Chairperson
Family and Community Support Subcommittee
205 Oakwood
Geneva, Illinois 60134
(708) 232-1233

Draft

THE WHITE HOUSE

WASHINGTON

April 20, 1994

Greetings to the members of the President's Committee on Mental Retardation. I am pleased that so many of you have gathered to participate in 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 disability is 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 loved ones.

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 compassion. 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 conference.

***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
AT MARK CENTER
5000 SEMINARY ROAD
ALEXANDRIA, VIRGINIA, 22311
(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:

Health Care Reform and People with Mental Retardation and Related Disabilities;

Welfare Reform and People with Mental Retardation and Related Disabilities;

Long-Term Care Reform and People with Mental Retardation and Related Disabilities;

Housing Policy Reform and People with Mental Retardation and Related Disabilities;

Education Reform and People with Mental Retardation and Related Disabilities; and

Employment/Financing and People with Mental Retardation and Related Disabilities.

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***

***Radisson Plaza Hotel
April 24-26, 1994***

Tentative Agenda

Sunday, April 24, 1994

10:00 a.m.

Registration

PLENARY SESSION

12:00 Noon

Greetings and Purpose

Gary H. Blumenthal

Executive Director

President's Committee on Mental Retardation

Vice Chair

President's Committee on Mental Retardation

Valerie Bradley

President

Human Services Research Institute, Cambridge, Massachusetts

Welcome

Vincent C. Gray

Director

Department of Human Services, District of Columbia

12:15 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

12:30 p.m.

Panel I: Setting Visions and Goals

Moderator: David J. Dunn

President

The Arc, Rochester, Minnesota

Self-Advocates' Perspective

T.J. Monroe

Knoxville, Tennessee

Tia Nelis

Wayne, Illinois

Parents' Perspective

Koquese Collins

Detroit, Michigan

Don and Dawn Merriman

Salina, Kansas

Linda Charlton

Bel Air, Maryland

1:30 p.m.

**PANEL II: Implications of the President's Reform Agenda on
Citizens with Mental Retardation and Related Disabilities**

Moderator: Valerie Bradley

President

Human Services Research Institute, Cambridge, Massachusetts

Susan Daniels, Ph.D.

Associate Commissioner

Administration on Developmental Disabilities

Katherine Seelman, Ph.D.

Director

National Institute on Disability and Rehabilitation Research

Paul Miller

Deputy Director

White House Office of Consumer Affairs

The White House

2:30 p.m. -

2:45 p.m.

BREAK

2:45 p.m.

Legislative Concerns of Consortium for Citizens with Disabilities (CCD)
Paul Marchand
Chairperson
Consortium for Citizens with Disabilities (CCD)

Tony Young
Co-Chairman
CCD Long Term Services and Support Task Force

3:15 p.m.

Panel III: 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

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

Andy Imparato
Counsel
Senate Subcommittee on Disability Policy

Christine Ferguson
Legislative Director
Office of Senator John Chafee

3:50 p.m.

Questions and Answers

4:05 p.m.

Work Group Session Assignments

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

4:15 p.m. -

4:30 p.m.

BREAK

4:30 p.m. -

6:00 p.m.

WORK GROUP SESSIONS (convening concurrent)

I. Health Care Reform and People with Mental Retardation

Leaders: David Braddock, Ph.D.
Theodore Kastner, M.D.

II. Welfare Reform and People with Mental Retardation

Leaders: Marsha M. Seltzer, Ph.D.
Sharon L. Ramey, Ph.D.

III. Long-Term Care Reform and People with Mental Retardation

Leaders: Steve Eidelman
Robert Gettings

IV. Housing Reform and People with Mental Retardation

Leaders: K. Charlie Lakin, Ph.D.
Jay Klein

V. Education Reform and People with Mental Retardation

Leaders: Jan Nisbet, Ph.D.
Diane Ferguson, Ph.D.

VI. Employment/Financing and People with Mental Retardation

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

6:00 p.m.

RECESS

6:30 p.m. -

7:30 p.m.

NETWORKING SOCIAL

Monday, April 25, 1994

7:30 a.m.

Registration/Continental Breakfast

8:30 a.m.

PLENARY SESSION

Moderator: John Pride

Acting Deputy Executive Director

President's Committee on Mental Retardation

Goals 2000... School to Work

Judith E. Heumann

Assistant Secretary

Office of Special Education and Rehabilitative Services

U.S. Department of Education

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

Cultural Diversity and Citizens with Mental Retardation and
Related Disabilities

Robert Williams

Commissioner

Administration on Developmental Disabilities

Administration for Children and Families

9:05 a.m. -

9:15 a.m.

Questions and Answers

9:15 a.m.

10:45 a.m.

WORK GROUPS SESSIONS, continued

Health Care Reform

Welfare Reform

Long-Term Care Reform

Housing Reform

Education Reform

Employment/Financing Reform

10:45 a.m. -

11:00 a.m.

BREAK

(At the discretion of the Group Leader)

11:00 a.m. -

12:15 p.m.

WORK GROUPS

Health Reform and Welfare Reform, (*convening jointly*)

Long-Term Care Reform

Housing Reform

Education Reform

Employment/Financing Reform

12:30 p.m. -

2:00 p.m.

FORUM LUNCHEON

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. -
3:45 p.m.

WORK GROUPS

Education Reform and Employment/Financing Reform, (*convening jointly*)
Health Care Reform
Welfare Reform
Long-Term Care Reform
Housing

BREAK

(At the discretion of the Group Leader)

4:00 p.m. -
5:30 p.m.

WORK GROUPS

Long-Term Care Reform and Housing Reform, (*convening jointly*)
Health Care Reform
Welfare Reform
Education Reform
Employment/Financing Reform

5:30 p.m.

RECESS

Tuesday, April 26, 1994

8:00 a.m. -
8:30 a.m.

Registration/Continental Breakfast

8:30 a.m. -
10:00 a.m.

WORK GROUP - Concluding Session

Health Care Reform
Welfare Reform
Long-Term Care Reform
Housing Reform
Education Reform
Employment/Financing Reform

10:00 a.m. -
11:00 a.m.

BREAK

11:00 a.m. -
12:30 p.m.

FORUM SUMMATION

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

Work Group Reports and Recommendations
(Chairperson for each work group)

Summary and Acknowledgement of Recommendations
Glen Fujiira, Ph.D.

Introduction of Closing Speaker
Stanley Herr, Esq.
Kennedy Public Policy Fellow
Office of Domestic Policy
The White House

Speaker: Carol Rasco
Assistant to the President for Domestic Policy
The White House

Summary and Closing Remarks
Valerie Bradley
Human Services Research Institute

12:30 p.m.

ADJOURNMENT

Thank you for your participation!



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

Mr. Stanley Herr
Kennedy Public Policy Fellow
Office of Domestic Policy
The White House
Washington, D.C. 20500

Dear Mr. Herr: *Stan*

Thank you for agreeing to participate in the April 24-26, 1994, Presidential Forum: "The President's Reform Agenda and People with Mental Retardation -- 21st Century Reality." The Forum will be convened at the Radisson Plaza Hotel at Mark Center, 5000 Seminary Road, Arlington, Virginia. A tentative agenda accompanies this letter.

Please note that the Forum is scheduled to begin at 12:30 p.m., Sunday, April 24, 1994, and you are scheduled to speak at 11:00 a.m., Tuesday, April 26. Your expertise will be of great benefit to the participants in developing quality recommendations to the President.

I look forward to seeing you at the Forum.

Sincerely,

Gary
Gary H. Blumenthal
Executive Director

Enclosure

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
bold)

DATE: April 21, 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.. [no questions].

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 may hear from folks about their concerns for appointment delays in PCMR. Here's the status as I understand it as of today: 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].

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.

MORE TO COME AND WITH HARD-COPY ATTACHMENTS TOMORROW.

- 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-advoactes 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 Blumental by COB 4-21

- site add page

Cheers!

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

21-Apr-1994 11:56am

TO: Stanley S. Herr

FROM: Carol H. Rasco
 Economic and Domestic Policy

CC: Rosalyn A. Miller

SUBJECT: Pres. Comm. on Mental Retardation

Be sure to get to Rosalyn the name of the room I will be coming to...Rosalyn, because of notes Stan has sent me on the schedule for the meeting, I would like to be there for the start of a 10:15 a.m. session although I don't actually speak until 11:00. Please arrange the car accordingly.

Thirty minutes is fine for the speech, Stan; there should be a clear understanding with the folks in charge that I will not be taking questions. This is too big a group to do questions.

The speaking points look great. Thanks.

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

21-Apr-1994 12:26pm

TO: Carol H. Rasco

FROM: Stanley S. Herr
Domestic Policy Council

CC: Rosalyn A. Miller

SUBJECT: RE: Pres. Comm. on Mental Retardation

Carol will be presenting in the PLAZA BALLROOM at the Radisson Plaza Hotel.
If partitions are up, its Plaza Ballroom B.
Ballroom is on the ground floor on the right as you come in.

"No questions" is understood and confirmed by the session moderator, Gary Blumenthal.

Clinton Presidential Records Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

Report to the President

Citizens with Mental Retardation and the Criminal Justice System



1991



**U.S. Department of Health and Human Services
Administration for Children and Families
President's Committee on Mental Retardation
Washington, D.C. 20201**