PRESIDENTS COMMITTEE ON MENTAL RETARDATION
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Human Development Services
Washington, D.C. 20201

JUN 19 1986

Dear Colleague:

This is written to formally acknowledge your role in contributing to the success of the 20th Anniversary Celebration for the President's Committee on Mental Retardation (PCMR). Thank you for joining with present and former members, consultants, constituency organization representatives, and staff in the "Future's Planning Task Force work session which addressed the Committee's goal to maximize the quality of life experienced by individuals with mental retardation and other developmental disabilities. Your assistance in identifying and prioritizing barriers to the quality of life, and your input suggesting their probable impact provides valuable data that can be used by the Committee to further develop its national agenda for early realization of this important goal.

I am pleased to share with you the accompanying Task Force Report entitled "Recommendations to Enhance the Quality of Life of Persons with Mental Retardation and Other Developmental Disabilities in the United States.* The report was prepared and submitted to PCMR by the Task Force Consultant and leader, William Schipper, Ph.D., Associate Director of the National Association of State Directors of Special Education. Your comments are invited and will be appreciated.

Sincerely,

Susan Gleeson, R.N.

Susan Gleeson, R.N., M.S.N.
Executive Director

RECOMMENDATIONS TO ENHANCE THE QUALITY OF LIFE OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES IN THE UNITED STATES

A TASK FORCE REPORT

Submitted to:

President's Committee on Mental Retardation
Washington DC

Task Force Consultant
William Schipper
National Association of State
Directors of Special Education

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RECOMMENDATIONS TO ENHANCE THE QUALITY OF LIFE OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES IN THE UNITED STATES

I

EXECUTIVE SUMMARY

This is a report of activities and recommendations developed during a May 13 meeting of an ad hoc task force of more than 40 persons involved or interested in improving the quality of life of persons with mental retardation and other developmental disabilities.

The purposes of the meeting were to (1) identify barriers which impede maximizing the quality of life of persons with mental retardation and other developmental disabilities, and (2) develop suggestions for reducing or resolving those barriers.

The meeting was conducted in Washington, D.C., as a part of the 20th Anniversary Celebration for the President's Committee on Mental Retardation (PCMR).

Dr. William Schipper of the National Association of State Directors of Special Education, In. (NASDSE) facilitated the meeting procedures and provided this report on behalf of the Task Force.

During the May 6 meeting the Task Force:

. Discussed for clarification a list of 51 statements generated by Task Force members and others prior to the meeting which represented their views as major barriers or problems to achieving the PCMR goal of "maximizing the quality of life of persons with mental retardation and other developmental disabilities";

Analyzed and achieved consensus on the prospects of success of resolving each of those barriers by 1992, and the importance of that success relative to achieving the goal statement;

. Concluded that 14 of the 51 barriers discussed have both a high likelihood of resolution and would have a high impact on goal achievement. Therefore, the task force has put forth those statements to PCMR and other national, state, and local agencies as recommended "first priority" problems to attend to;

. Developed lists of action ideas for PCMR and others to consider in beginning to attend to those first priority problems which impede the PCMR goal. Those 14 barriers cluster into four general deficiency areas which for purposes of this report have been titled (1) legal/final/deficiencies; (2) practitioner/ professional deficiencies; (3) program/model deficiencies; and (4) attitude deficiencies

Section II contains an explanation of the procedures followed by the Task Force. Section III profiles the results and recommendations of the Task Force.

- All high impact statements should receive high priority attention by planners. Low impact statements should receive lower priority attention or should be disregarded.

- The likelihood scale can provide information as to the probabilities of success and the amount of resources needed to achieve resolution of each issue.

- The scores, taken in combination, provide a method of sorting out or rank ordering problem areas for further analysis.

Step 3. Develop alternative solution strategies. The Task Force then used a modified "brainstorming" technique to develop lists of alternative ways to resolve many of the barriers agreed to be high priority for immediate attention by PCMR and other national, state and local agencies. The information generated from this process should be useful to planners and may provide a model for replicating the generation of these types of information on other key problem areas identified by the Task Force.

III

RESULTS

This section profiles the results of procedures used by the Task Force in identifying priority problems to address and in developing recommendations for action by PCMR and other national, state, and local agencies to undertake activities to reduce barriers to maximizing the quality of life of persons with mental retardation and other developmental disabilities in America.

Fifty-one barriers were discussed individually. Of these:

- 14 barriers were determined to have a relatively high likelihood of resolution and would have a high impact on achieving the "quality of life" goal. These "high priority" suggestions are presented at length on the following pages, along with lists of alternative ways of attending to solutions to each barrier.

- 3 barriers were determined to have a great impact on goal achievement, if resolved. However, they were judged as having a low or very low likelihood of resolution by 1992. These statements are presented later in this section.

- 22 barriers were determined to be unlikely to be resolved, but if resolved, would have somewhat of a high impact on goal achievement. These barriers are recommended to be re-analyzed in the future—after progress has been made on the "high priority" barriers.

- 7 barriers were determined to be both unlikely to be achieved and unimportant to goal achievement even if achieved.

- 5 barriers were determined to be relatively achievable, but not important to goal achievement if achieved.

Thus, the Task Force recommends that PCMR, and national, state and local agencies and others begin to undertake activities towards resolving or reducing barrier statements which have been clustered into four "types" of deficiency:

A. Legal/Fiscal Compliance Deficiencies

B. Practitioner/Professional Deficiencies

C. Program/Model Deficiencies

D. Attitude Deficiencies

Barrier statements in each of these clusters follows (Statement numbers indicate the order in which the statement appeared on the master roster of 51 perceived barriers)

A. CLUSTER PROFILE OF BARRIERS TO REDUCE OR RESOLVE IN ORDER TO MAXIMIZE THE QUALITY OF LIFE OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES.

1. Legal/Fiscal/Compliance Deficiencies

30. Impact of high costs of insurance, esp. on transportation, must be addressed.

40. Disproportionate financial resources are spent on institutions vs. community-bases services.

#41. Title 19 ICFMR program requirements do not promote normalization for the MR/DD population.

#43. Volunteer efforts are jeopardized by the Fair Labor Standards Act which prohibits staff from volunteering.

46. Many community services though mandated by law, are not in place.

2. Practitioner/Professional Deficiencies

3 . Limited expertise of physicians re mental retardation, and obstetricians re the "dangers" during pregnancy.

11. Delay in transfer of rehabiliation engineering technology to use by individuals who are handicapped.

29. The courts often ignore the mental incompetence of many jailed individual(s) with MR who have been found guilty of breaking the law.

37. Failure of professionals in the field to communicate with individuals with MR and DD re their desires and future concerns, and to involve them in planning.

3. Program/Model Deficiencies

36. Lack of adequate models in planning by families for future security of disabled member.

31. Lack of programs that focus on prevention, inluding education of parents-to-be and counseling of parents and families.

26. Sexual, mental and physical abuse of individuals with MR is not being adequately addressed.

4. Attitude Deficiencies

9. Unwillingness of Government to support the constitutional rights of MR persons and their families.

17. The false assumption that "being employed" guarantees adequate health coverage for workers with MR or other DD inhibits appropriate public policy development.

B. PROFILE OF "HIGH IMPACT" BARRIERS WHICH APPEAR TO HAVE A LOW LIKELIHOOD OF RESOLUTION BY 1992.

4. Lack of commitment and training for independent vendors in ICF-MR group homes and community practitioners and supervisory personnel employed to insure maximum quality of care to encourage and guide individuals with MR and DD.

14. Lack of accurate data for forecasting service needs in the community.

16. Reduction of Federal funding while the population grows means that many disabled individuals will remain unserved or inadequately served.

C. ACTION STRATEGIES

Action strategies suggested by members of the task force in order to begin activities to reduce or resolve some of the high priority barriers are presented on the following pages:

LEGAL/FISCAL/COMPLIANCE DEFICIENCIES

ACTION STRATEGIES

Statement #30 Impact of high costs of insurance esp. on transportation, must be addressed.

LIST OP STRATEGIES, ACTIONS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS WHO MAY PARTICIPATE IN EACH STRATEGY ACTION OR TACTIC?
1. Examine approaches in various states, Georgia - State's screening as insurance carrier.	. National Insurance Association
2. Examine potential performance incentives to encourage lower claims experience.	

LEGAL/FISCAL/COMPLIANCE DEFICIENCIES

ACTION STRATEGIES

Statement #41 Title 19 ICFMR program requirements do not promote normalization for the MR/DD

LIST OF STRATEGIES, ACTIONS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS WHO MAY PARTICIPATE IN EACH STRAGEGY ACTION OR TACTIC?
1. Legislation	, Congress, lobbying groups, PCMR Redefine med. vs. devel. model don't know how.
2. Regulation changes	. Government agencies - Involved groups - institutions, ICFMR's

PRACTITIONER/PROFESSIONAL DEFICIENCIES

ACTION STRATEGIES

Statement #37 Failure of professionals in the field to communicate with individuals with MR and DD re their desires and future concerns and to involve them in planning,

LIST OF STRATEGIES, ACTIONS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS WHO MAY PARTICIPATE IN EACH STRATEGY ACTION OR TACTIC?
1. Medical School & Professional education programs.	. Schools & Colleges
2. Continuing Education	. Programs by various societies/ associations.
3. " Dissemination of literature	. Surgeon Generals office; HHS; Advocacy Groups
4. Programs by specialists in verbal communication	. Informational programs in medical facilities.

PRACTITIONER/PROFESSIONAL DEFICIENCIES

ACTION STRATEGIES

Statement_#29 The courts often ignore the mental incompetence of many jailed" individuals with MR who have been found guilty of breaking the law.

LIST OF STRATEGIES, ACTIONS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS WHO MAY PARTICIPATE IN EACH STRATEGY ACTION OR TACTIC?
1. Develop educational opportunities for judges, defense lawyers, prosecuting attorney's .	. PCMR contact ABA - task force on the disability - work with college schools of law.
2. Working strategy conference involving "key players."	. Work thru Justice Department
3. Identify "best" practices of incarcerating individuals (MR) -and identify alternatives.	. PCMR contact ABA.
4. "Ear mark" model programs, and identify possible funding sources.	. ADD
5. Assessment/analyses of existing state statutes/as they address mental incompetence with persons with MR.	. Labor unions representing correctional
6. Assessment of "training program" for correctional officials.	. Law enforcement official

PRACTITIONER/PROFESSIONAL DEFICIENCIES

ACTION STRATEGIES

Statement #11 Delay in transfer of rehabilitation engineering technology to use by individuals who are handicapped.

LIST OP STRATEGIES, ACTIONS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS WHO MAY PARTICIPATE IN EACH STRATEGY ACTICN OR TACTIC?
1. Support the amendment to the Rehab act that addresses engineering technology.	CCDD (Citizens Concerned with CO) ARCDS UCPA NCR (National Council on the Handicapped)
2. Support education and public awareness in the area of Rehab engineering technology.	. PCMR
3. Identify specific results of engineering technology (communicative tools) to specific groups of individuals (profoundly or severely retarded).	. a) "National Association of State MR Program Diretors (Bob Gettings, Exec. Dir.) b) National Association of Superintendents of Public Residential Facilities for the MR.

PROGRAM/MODEL DEFICIENCIES

ACTION STRATEGIES

Statement #36 Lack of adequate models in planning by families for future security of disabled members.

LIST OF STRATEGIES, ACTIONS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS WHO MAY PARTICIPATE IN EACH STRATEGY ACTION OR TACTIC?
1. Maximize family participation in development of services and establishing assurances of security	, Contact organizations that are governed/administered by parents and families of mentally retarded persons.
2. Governments must recognize and utilize the input of families dealing with mental retardation and acknowledge that families have the capacity to self-represent.	. Congress of Advocates for the Retarded (413/773-5155)

ATTITUDE DEFICIENCIES

SOLUTION STRATEGIES

Statement #17 The false assumption that "being employed" guarantees adequate health coverage for workers with MR or other DD inhibits appropriate public policy development.

LIST OF STRATEGIES, ACTIONS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS WHO MAY PARTICIPATE IN EACH STRATEGY ACTION OR TACTIC?
1. Study done to evaluate the full scope of the problem	. Work with National Institute of Employment of the Handicapped.
2. After determination of the problem find out legal status.	. Legal arm of Department of HHS.
3. Look at medicaid eligibility.	. HCFA (Health Care Finance • Administration).
4. Advocacy Group or HCFA to recommend to legislature.	. Legislature to enact

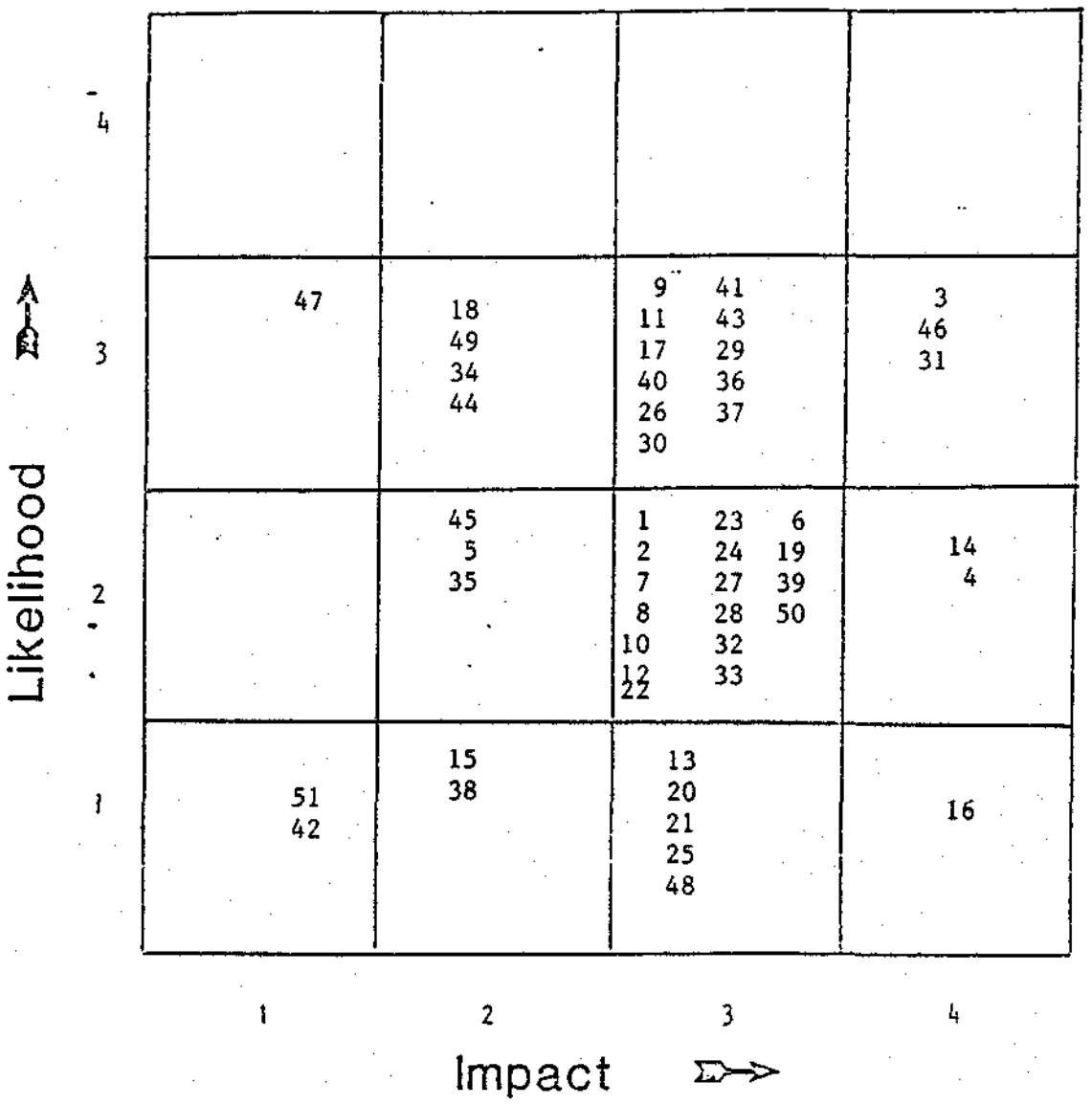
ATTITUDE DEFICIENCIES

ACTION STRATEGIES

Statement #9 Unwillingness of Government to support the constitutional rights of MR persons and their families.

LIST OF STRATEGIES, ACTIOS OR TACTICS TO ASSIST IN RESOLVING BARRIER OR ACHIEVING RECOMMENDATION	POSSIBLE RESOURCES, AGENCIES OR PERSONS MHO MAY PARTICIPATE IN EACH STRATEGY ACTION OR TACTIC?
1. Identify agencies that are not supportive of rights of individuals.	US Dept. of Justice - Civil Rights; PCMR,ADD, ED, NIMH, NICHCY.
2. Identify "class action" type rights of which that Government is not supportive.	. PCMR, as lead coordinating agency, of those cited above
3. Establish Washington based coalition to watch-dog violation of rights or potential problems that need attention.	. PCMR
4. Continue' responding (by resolution) to particular regulations, policies, guidelines, etc. that violate the rights of MR or ED individuals.	. PCMR

IV. LIKELIHOOD-IMPACT MATRIX



- All high impact events should receive high priority attention by planners. Low impact events should receive lower priority attention or should be disregarded.
- The likelihood scale can provide information as to the amount of resources needed to achieve the occurrence of the event.
- The scores, taken in combination, provide an efficient method of sorting out events for further analysis, assuming that limited resources exist to resolve all identified barriers.

V. PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

GOAL: Improve the Quality of Life of Individuals with Mental Retardation and Other Developmental Disabilities

Barriers which impede Goal Achievement	LIKELIHOOD OF ACHIEVEMENT OR RESOLUTION BY 1992				IMPACT ON GOAL IF ACHIEVED			
	LOW		HIGH		LOW		HIGH	
	1	2	3	4	1	2	3	4
1. Networking re community and transitional services is inadequate.								
2. Lack of definition re the role of the schools in "other than academic" preparation of students.								
3. Limited expertise of physicians re mental retardation, and obstetricians re the "dangers" during pregnancy.								
4. Lack of commitment and training for independent vendors in ICF-MR group homes and community practitiioners and supervisory personnel employed to insure maximum quality of care to encourage and guide individuals with MR and DD.								
5. Creative cost control is not clearly understood by many service providers.								
6. Inadequacy or absence of evaluation criteria re quality of service providers.								
7. Negative societal attitudes regarding capabilities and potential of DD workers.								

	LIKELIHOOD				IMPACT			
8. Lack of continuity of community programs intended to prevent recidivism.	1	2	3	4	1	2	3	4
9. Unwillingness of Government to support the constitutional rights of MR persons and their families.	1	2	3	4	1	2	3	4
10. Unwillingness of government to implement coordinated problem solving at the national level.	1	2	3	4	1	2	3	4
11. Delay in transfer of rehabilitation engineering technology to use by individuals who are handicapped.	1	2	3	4	1	2	3	4
12. Lack of methodology in Federal research and its pragmatic application to rehab engineering technology.	1	2	3	4	1	2	3	4
13. Ethical issues prevent utilization of knowledge and methodology re prevention of MR and DD.	1	2	3	4	1	2	3	4
14. Lack of accurate data for forecasting service needs in the community.	1	2	3	4	1	2	3	4
15. Over reliance on private providers of service jeopardizes an entitlement approach to services needed by MR and DD individuals.	1	2	3	4	1	2	3	4
16. Reduction of Federal funding while the population grows means that many disabled individuals will remain unserved or inadequately served.	1	2	3	4	1	2	3	4
17. The false assumption that "being employed" guarantees adequate health coverage for workers with MR or other DD inhibits appropriate public policy development.	1	2	3	4	1	2	3	4

	LIKELIHOOD				IMPACT			
18. Public policy research is poor to non-existent.	1	2	3	4	1	2	3	4
19. The range and complexity of needs represented in diverse MR population is glossed over with glittering generalities (statements that "all--can--.")	1	2	3	4	1	2	3	4
20. There is little or no recognition by many service providers and professionals of individuals with hard-to-serve needs.	1	2	3	4	1	2	3	4
21. Lack of State Zoning Laws allow local communities to create arbitrary barriers to community living.	1	2	3	4	2	2	3	4
22. Earnings during training period (transitional period) are charged against Trial Work Period (TWP) allowance of SSI Program.	1	2	3	4	1	2	3	4
23. Sheltered workshops too often retain (rather than place) best producers--those who are candidates for competitive employment.	1	2	3	4	1	2	3	4
24. Higher wage earnings in competitive employment make worker ineligible for subsidized group home or apartment.	1	2	3	4	1	2	3	4
25. There are many retarded adults having retarded children and living in poverty.	1	2	3	4	1	2	3	4
26. Sexual, mental and physical abuse of individuals with MR is not being adequately addressed.	1	2	3	4	2	2	3	4
27. Many of the homeless are individuals who have been released from institutions for the MR and find themselves in communities lacking appropriate support.	1	2	3	4	1	2	3	4
28. Lack of competent legal assistance for mentally retarded offenders in criminal justice system.	1	2	3	4	1	2	3	4

	LIKELIHOOD				IMPACT			
29. The courts often ignore the mental incompetence of many jailed individual(s) with MR who have been found guilty of breaking the law.	1	2	3	4	1	2	3	4
30. Impact of high costs of insurance, esp. on transportation, must be addressed.	1	2	3	4	1	2	3	4
31. Lack of programs that focus on prevention, including education of parents-to-be and counseling of parents and families.	1	2	3	4	1	2	3	4
32. Mental health programs have abdicated their clinical service responsibilities to mentally retarded individuals who are suffering psychiatric disorders.	1	2	3	4	1	2	3	4
33. Lack of sheltered work opportunities for moderate to severely retarded living in community residential facilities.	1	2	3	4	1	2	3	4
34. Lack of training or supported work opportunities by State Rehab agencies for the mildly retarded.	1	2	3	4	1	2	3	4
35. Curtailing of HUD Sec. 202 and Sec. 8 housing programs for elderly and handicapped.	1	2	3	4	1	2	3	4
36. Lack of adequate models in planning by families for future security of disabled member.	1	2	3	4	1	2	3	4
37. Failure of professionals in the field to communicate with individuals with MR and DD re their desires and future concerns, and to involve them in planning.	1	2	3	4	1	2	3	4
38. Funds are scarce to unavailable for research necessary to identify and explore the positive uses of nutritional pharmacology in the treatment and prevention of mental retardation and developmental disabilities.	1	2	3	4	1	2	3	4

	LIKELIHOOD				IMPACT			
39. Lack of employment opportunities for retarded adults in the community.	1	2	3	4	1	2	3	4
40. Disproportionate financial resources are spent on institutions vs. community-based services.	1	2	3	4	1	2	3	4
41. Title 19 ICFMR program requirements do not promote normalization for the MR/DD population.	1	2	3	4	1	2	3	4
42. Not enough emphasis placed on holistic approach to meeting the needs of persons with MR, and too much emphasis on work, supportive work, and employment.	1	2	3	4	1	2	3	4
43. Volunteer efforts are jeopardized by the Fair Labor Standards Act which prohibits staff from volunteering.	1	2	3	4	1	2	3	4
44. Need for retirement policy for aged or elderly persons with mental retardation.	1	2	3	4	1	2	3	4
45. An "audit trail" for each person with MR or DD from birth to death, is needed.	1	2	3	4	1	2	3	4
46. Many community services though mandated by law, are not in place.	1	2	3	4	1	2	3	4
47. There are no legal assignments of financial responsibility in cases involving unjustifiable prolonging of the life of a mentally retarded or developmentally disabled individual (Baby Doe).	1	2	3	4	1	2	3	4
48. Too many Federal guidelines, requirements and time consuming paperwork that impede coordination.	1	2	3	4	1	2	3	4
49. Not enough quality control over community residences	1	2	3	4	1	2	3	4

	LIKELIHOOD				IMPACT			
50. Provider driven service delivery systems too often take precedence over those based on consumer needs.	1	2	3	4	1	2	3	4
51. Limited expertise on the importance of proper nutrition and the role of nutritional therapist in alleviating detrimental side effects of drug therapy in treating persons with MR/DD.	1	2	3	4	1	2	3	4

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
TWENTIETH ANNIVERSARY CELEBRATION

"Futures Planning Work Session"

Participants

Anderson, Albert, D.D.S.
PCMR Member
San Diego, California

Bopp, James, Jr.
PCMR Member
Terre Haute, Indiana

Bouthilet, George, Ph.D.
PCMR Staff
Washington/ D.C.

Bowen, Irene
PCMR Ex-Officio Representative
U.S. Department of Justice
Washington, D.C.

Christoferson, Lee A., M.D.
PCMR Member
Fargo, North Dakota

Clark, Dorothy
PCMR Member
Provo, Utah

Clark, Geraldine
PCMR Former Member
Bountiful, Utah

Cobb, Henry V.
PCMR Former Member
Chapel Hill, North Carolina

Dickenson, Margaret
Mental Health Officer
Bureau of Community Services
Washington, D.C.

Eargle, Lois
PCMR Member
Conway, South Carolina

Ganges, Arnold
PCMR Former Member
Seattle, Washington

Gleeson, Susan
PCMR Staff
Washington, D.C.

Gray, Vincent
PCMR Member
Washington, D.C.

Guglielrao, Matthew J.
PCMR Member
San Marino, California

Haggerty, Dennis
PCMR Former Consultant
Drexel Hill, Pennsylvania

Harwood, Madeline B.
PCMR Member
Manchester Center, Vermont

Heckt, Melvin
PCMR Former Member
Minneapolis, Minnesota

Helsel, Elsie D., Ph.D.
PCMR Member
Athens, Ohio

Hormuth, Rudolph
Specialist in Services for Mentally Retarded Children
Department of Health and Human Services-Public Health Service
Rockville, Maryland

Hudson, Morley
PCMR Former Member
Shreveport, Louisiana

Johnson, Roger Stanley, M.D.
PCMR Member
Irving, Texas

Jordon, Robert, M.D.
PCMR Former Member
Memphis, Tennessee

Kogan, Richard J.
PCMR Member
Livingston, New Jersey

Konopka, Barbara
Congress of Advocates for the Mentally Retarded, Inc.
Greenfield, Maine

Krause, Fred
PCMR Former Staff
Washington, D.C.

Larson, Jerry P.
PCMR Member
Park Forest, Illinois

Macy, D. Beth
PCMR Member
Lincoln, Nebraska

Mayo, Leonard, S.S.C.D.
President's Panel on Mental Retardation, Member
Chagrin Falls, Ohio

Mnatzakanian, Ashot
PCMR Staff
Washington, D.C.

Moore, Judy
PCMR Staff
Washington, D.C.

Peterson, Raymond, M.D.
PCMR Former Member
San Diego, California

Roach, Laverdia T.
PCMR Staff
Washington, D.C.

Sevick, Cherrie
PCMR Former Member
Lakeside, California

Shine, Marguerite
PCMR Member
Washington, D.C.

Stephens, W. Beth, Ph.D.
PCMR Former Member
Alexandria, Virginia

Touch, David
PCMR Staff
Washington, D..C

Tucker, Thomas A.
PCMR Former Member
Detroit, Michigan

Ulle, Margaret B.
PCMR Former Member
Baltimore, Maryland

Warson, Ruth
PCMR Member
Studio City, California

Whitehead, Claude
Consultant
Administration on Developmental Disabilities
Washington, D.C.

Young, James F.
PCMR Staff
Washington, D.C.