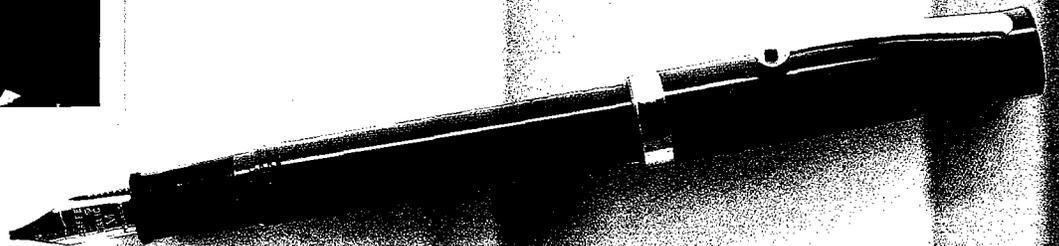




# President's Committee on Mental Retardation



*A Historical Review 1966-1986*





# **President's Committee on Mental Retardation: A Historical Review 1966-1986**

Prepared by:

Fred J. Krause, Former Executive Director, PCMR and PCMR Ad Hoc Committee Members



# A Preface

Over the past three decades, we have witnessed many accomplishments in the field of mental retardation. In the 1950's, in response to the social activism of families and professionals concerned with the condition of mental retardation, the Department of Health, Education, and Welfare established the Secretary's Committee on Mental Retardation. This was the first emerging effort to coordinate Federal activities in mental retardation.

In 1961, President John F. Kennedy established the President's Panel on Mental Retardation, which resulted in the involvement of the executive and legislative branches in setting policies and establishing new programs. Federal initiative was matched by the fifty States as governors and their administrators followed the lead of President Kennedy.

Since 1966, the President's Committee on Mental Retardation has been successful in meeting its objectives through coordination of all three branches of government. In addition, it has encouraged advocacy organizations to keep the rights of people with mental

retardation in the foreground. During the decade of the 1970's to the present, considerable activities have taken place under the leadership of the President's Committee on Mental Retardation. The results of this collaboration between government, voluntary, individual and community efforts, and the private sector are reported, in this publication.

It is hoped that this historical account will be helpful to future members of the President's Committee on Mental Retardation, State Developmental Disabilities Councils, Associations for Retarded Citizens, and to the many voluntary and charitable groups whose contributions are an everyday event.

Today the field of mental retardation is entering a period of change, with greater community involvement and awareness, and the development of closer alliances between organizational interests. Because of this, we feel an historical account is timely—one that will provide both background and direction for future accomplishments.

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## Acknowledgement

In 1986, the President's Committee on Mental Retardation will commemorate its twentieth anniversary. In preparation for this, the committee members requested a report outlining the history of the committee. This account highlights the major accomplishments since the initial President's Panel on Mental Retardation.

The contributions of all committee members have been impressive under the able leadership of Chairpersons Leonard W. Mayo, George Tarjan, M.D., Vice Chairperson, Robert Aldrich, M.D., Congressman Clair Burgener, Lorraine Beebe, Henry Cobb, Ph.D., Herbert Cohen, M.D., Elsie Helsel, Ph.D. and most recently Albert L. Anderson, D.D.S.

The assistance of members, staff, and colleagues

has been invaluable in documenting this history of the President's Committee on Mental Retardation (PCMR). Their expertise and dedication have contributed significantly to establishing the authenticity of this report. Major credit is given to PCMR member Marguerite Shine, whose encouragement to the author helped make this project a reality.

Many of the PCMR staff were important assistants, particularly Nancy Borders and Helen Caldwell, as well as the public affairs staff of PCMR.

The history of PCMR is, in fact, a product of everyone who has served on the President's Committee on Mental Retardation since 1966, including staff and consultants.

Finally, my appreciation to my wife and family, whose understanding and assistance were exceptional.

Fred J. Krause



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

The President  
The White House  
Washington, D.C. 20500

Dear Mr. President:

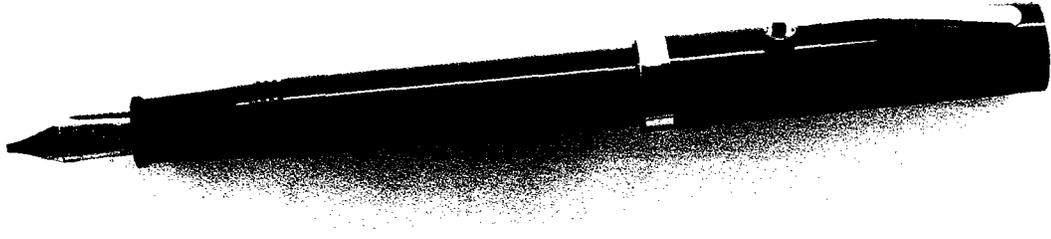
It is an honor to submit an historical account of the President's Committee on Mental Retardation. This report acknowledges the cooperation of Federal and state officials, and literally thousands of people in every state who have responded to the leadership of the President's Committee on Mental Retardation.

The history of the President's Committee on Mental Retardation demonstrates the impact the Committee has had on social, educational, and rehabilitation policies, and the significant contributions made towards the prevention and amelioration of mental retardation. This document provides an encouraging demonstration of public and private sector collaboration, which will continue to influence our society to be more accepting and responsive to our citizens who are mentally retarded.

We appreciate your leadership and the support you have provided, and we look forward to working together for continued progress in the future.

Sincerely,

Otis R. Bowen, M.D.  
Secretary



THE WHITE HOUSE  
WASHINGTON

September 7, 1984

I want to thank all the members of the President's Committee on Mental Retardation for your efforts on behalf of a group of American citizens who have difficulty in representing themselves.

You have served our six million mentally retarded citizens well. Your actions in drawing attention to the special problems that would be created by changes in regulations affecting them, and of our need to support specific legislation, speak well of your concern. These positions correspond with my Administration's policies.

Your continuing support of this Administration on many important issues is greatly appreciated. The report to me calling for the private sector to recognize the wisdom in employing mentally retarded workers was not only a service to them and potential employers; it was a service to all Americans.

Now, once again, you are proving how important your efforts are. The theme of your current meeting, "Mental Retardation Awareness," calls upon all Americans to assist our efforts to combat the causes and effects of mental retardation. The American people are being asked to support appropriate services and to accept mentally retarded people as an integral part of our society. For those goals, you have my complete support.

Nancy and I send you our best wishes for every future success.

Ronald Reagan

# History of President's Committee on Mental Retardation

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## Background



*President John F. Kennedy signing P.L. 88-164. Major legislation for persons with mental retardation.*

**T**he foundation of the President's Committee on Mental Retardation was established in October, 1961, when President John F. Kennedy announced the formation of the Presidential Panel on Mental Retardation. The panel of distinguished Americans, led by its chairman, Leonard Mayo, launched a plan to respond to the President's charge to review the status of programs for persons with mental retardation. Eunice Kennedy Shriver served as a special consultant and liaison between the panel and the White House. With the cooperation of several Federal departments and agencies, the intensive investigation took many of the panel members into every region of the United States,

as well as into various other countries, including Russia, England, Denmark and Sweden.

The President's Panel on Mental Retardation published its report, *A Proposed Program for National Action to Combat Mental Retardation*, in 1962. This report, with three supporting documents by the Task Forces on Education and Rehabilitation, Behavioral and Social Research, and Law, constituted a major milestone in the history of mental retardation in the United States; nothing on this scale had been done before. The panel's plan of action, as laid out in that report, represented a unique effort by twenty-seven committee members of diverse background and wide experience. It included the

findings from a series of public hearings (planned by Leonard Mayo and Eunice Shriver) in several parts of the country, intended to provide broad public input before the report to the President was submitted. In response to the President's charge, the panel completed its work in two days less than the year it had set for itself. (See Appendix A for a list of members.)

The chronology for implementing the proposed program of national action included the following highlights:

October 1961—The President's Panel appointed.

October 1962—Panel report submitted to the President: *A Proposed Program for National Action to Combat Mental Retardation*.

December 1962—Dr. Stafford Warren appointed Special Assistant to the President on Mental Retardation.

February 1963—Presidential Message to Congress on mental health and mental retardation.

February 1963—Four bills introduced in both houses of Congress representing the first phase of implementation of major recommendations.

June 1963—Initial approach to Advertising Council for a national campaign on mental retardation (carried out in 1964-1967 with funding support from the National Association for Retarded Citizens, the Joseph P. Kennedy, Jr., Foundation, and the Department of Health, Education, and Welfare).

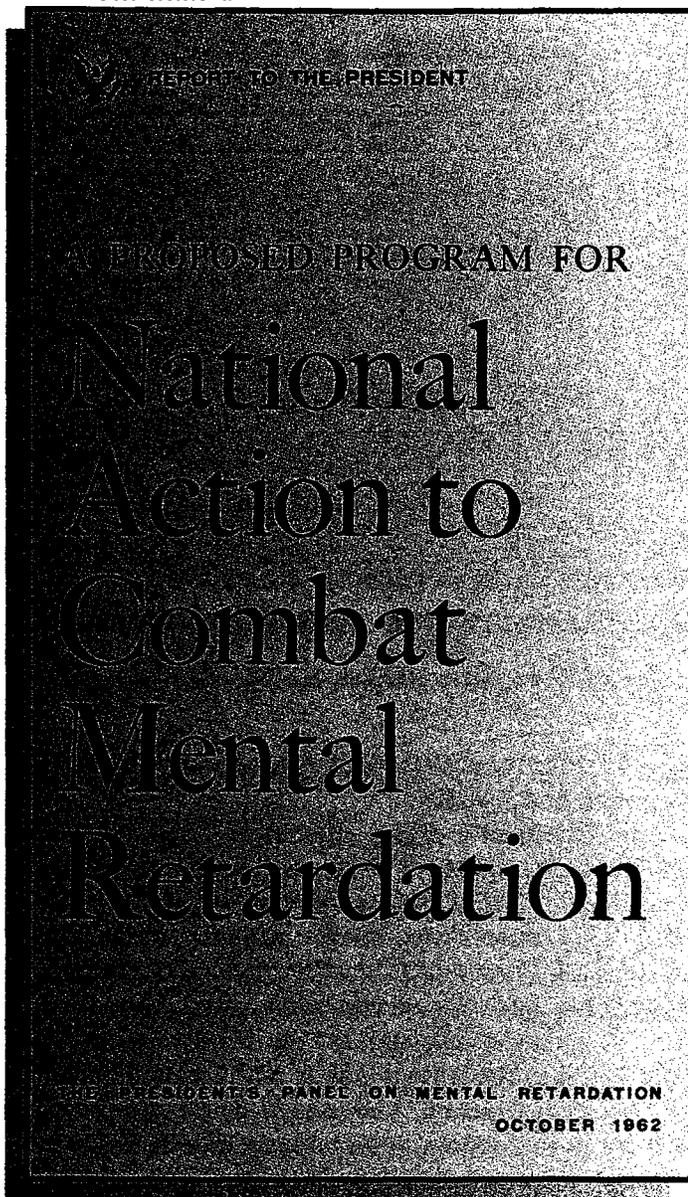
September 1963—White House Conference on Mental Retardation; participants included representation from state governments, as well as leaders in the field.

October 1963—Major legislation for mental retardation planning, program development and construction. Public Law 88-156 and 88-164 signed into law.

The President's Panel saw clearly the need to develop the entire plan of action into a cohesive, flexible, dynamic and effective attack on the total problems concerning programs for the mentally retarded persons in this country. To this end, the panel made several recommendations regarding organization, planning and coordination of programs. The history of subsequent Federal legislation to implement these recommendations during the administrations of Presidents Kennedy, Johnson and Nixon is an interesting and significant story, detailed in the PCMR Report *MR 76• Mental Retardation Past and Present*.

## State Responses

It is noteworthy that state planning and organization of services was a first priority of the Secretary of Health, Education and Welfare. The Secretary was authorized to make grants to states for comprehensive planning in mental retardation. This was the

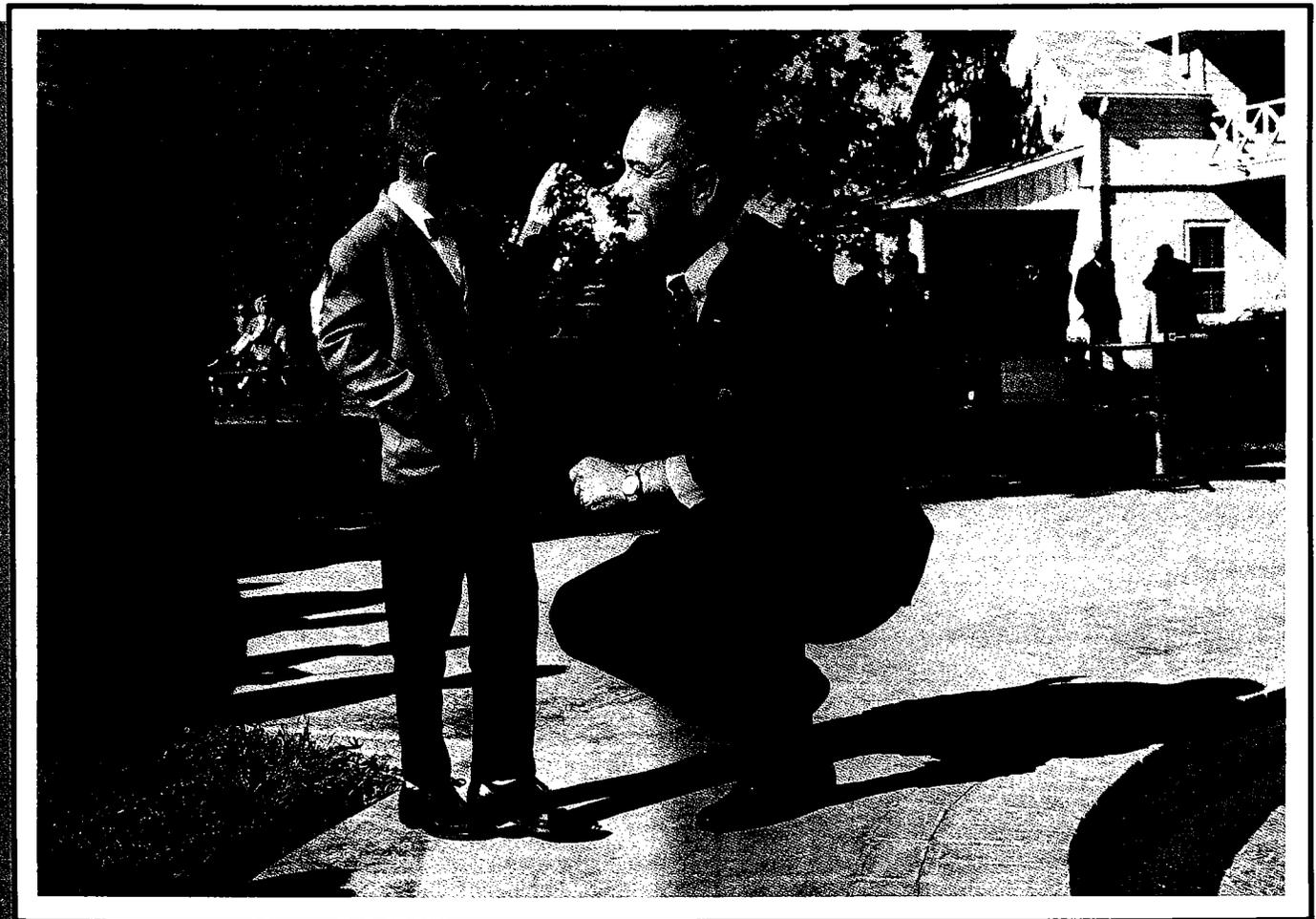


substance of Public Law 88-156 and Planning Amendments of 1964 and 1965, and resulted in comprehensive plans being submitted by fifty-three jurisdictions on an appropriation of \$2.2 million dollars.

The governors of every State were asked to review the array of major services relating to mental retardation outlined in the President's Panel Report. In order to qualify for Federal funds, the States were further required to establish an inter-departmental mechanism for joint planning and coordination. Each State carried out these recommendations in the process of planning and in the subsequent development of a wide variety of organizational models. The State planning processes emerged with a common characteristic of moving toward a coordination of human service programs for individuals with mental retardation in every State of the union.

## President's Committee on Mental Retardation is Formed

As the panel's recommendations began to be implemented, it was becoming obvious that some overview and coordination of the public and private effort in mental retardation on a continuing basis was necessary. This coordination could not come solely from government sources, nor could it come only from the private sector. Clearly a combination of the two would be required for mobilizing and coordinating the wide variety of interests. The original initiatives undertaken by the Office of the Assistant to the President for Mental Retardation had been crucial in the formulation and passage of basic legislation. • Now, however, a new vehicle was needed to mold national forces into a representative alliance of government and private citizens who could provide an ongo-



President Lyndon B. Johnson with National Association for Retarded Citizens Poster Child.



*David Ray*



*John Gardner*



*Robert Aldrich, M.D.*

ing forum to underscore the need for greater well-being of persons with mental retardation. President Lyndon B. Johnson established the President's Committee on Mental Retardation by Executive Order 11280 on May 11, 1966, signed at a White House ceremony. The Secretary of Health, Education and Welfare was named chairperson. The Secretary of Labor and the Directors of the Office of Economic Opportunity and of other Federal agencies were listed as ex-officio members. The main body of the committee was comprised of twenty-one citizen members appointed by the President for staggered three year terms. (The first Executive Order is shown at Appendix B.)

The PCMR Executive Order set forth the following conditions: (1) The Department of Health, Education and Welfare, now the Department of Health and Human Services, was designated as the agency, "which principally shall provide the committee with necessary administrative services and facilities." (2) The post of the Executive Director was established, and David B. Ray, Jr., was appointed as the first Executive Director. Secretary of HEW John W. Gardner, Chairman, swore in the original committee members on June 22, 1966, and named the former Director of the National Institute of Child Health and Human Development, Robert A. Aldrich, M.D., as Vice-Chairman. Chairman Gardner challenged the members to, "look at the whole field and try to see the relative priorities," and to help design the strategies for progress in the mental retardation field.

## ACTIVITIES OF PCMR, 1966-1972

### The Committee Begins Work

The minutes of the first meeting stated that Chairman Gardner enjoined the committee to criticize, to stimulate, to raise questions, to bring information from the grassroots, and to provide the broad perspective that every such large undertaking needs.

The first meeting of the committee members established the broad goals that PCMR has held since that time. These included: (1) environmental and biomedical prevention; factors which cause mental retardation; (2) early recognition and treatment of the condition, with emphasis on special education and habilitation services; (3) identification of human and legal rights, and the attainment of these rights for mentally retarded citizens; and (4) greatly expanded public awareness as the key to realization of the goals.

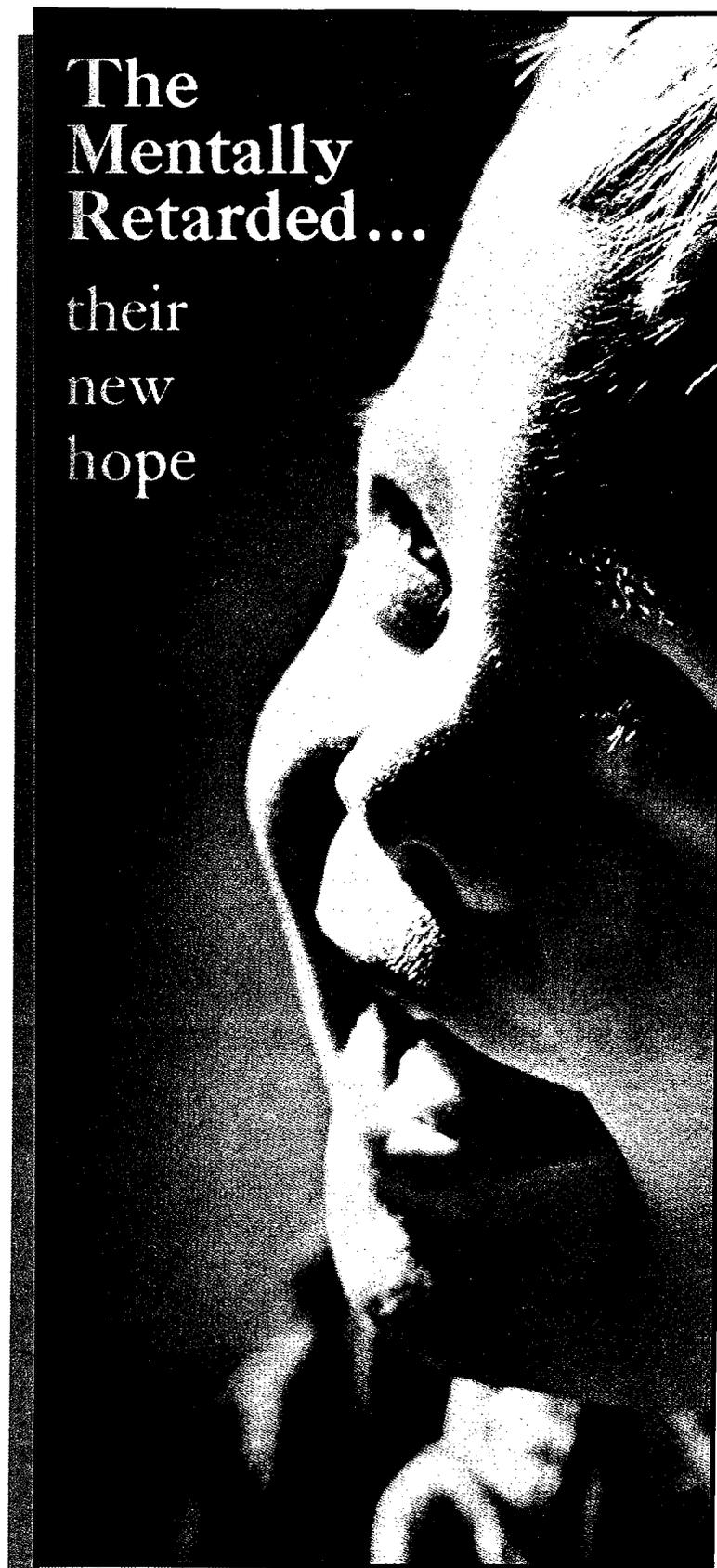
Public awareness has been the fabric on which PCMR has woven its strategies throughout the years. The first PCMR publication was "The Mentally Retarded: Their New Hope." This booklet was distributed through a saturation campaign of radio, television, and print ads conducted by the National Advertising Council, and was sponsored at that time by the Joseph P. Kennedy, Jr., Foundation. Between HEW and the National Association for Retarded Citizens (NARC), approximately two million booklets were distributed in a two-year period.

With the mandate from the Executive Order clearly defining its purposes, the committee began to develop its strategies soon after the initial meeting. The PCMR began to investigate all Federal governmental resources, and to seek support and information from major national health and educational agencies. Public agencies, private volunteer organizations, and many experts in the field of mental retardation provided consultation. --

One of the first activities of the committee was to hold public forums. Through this vehicle, PCMR was briefed by national leaders and provided with valuable information from grassroot sources, especially from families, State and local planners and program managers. A series of meetings, forums, and site visits were conducted in 1967 and 1968 which took PCMR members to various cities across the country.

The committee was also in contact with officials in Cdnada. One result, in cooperation with the Institute for the Study of Mental Retardation and Related Disabilities at the University of Michigan, was a joint United States-Canadian Conference on manpower needs in mental retardation programs held in Banff, Alberta, Canada, in 1969. The President's Committee on Mental Retardation published the proceedings in a booklet, "Manpower and Mental Retardation: An Exploration of the Issues." The First Caribbean Mental Retardation Conference was another joint venture, with a meeting held in Jamaica. A report was published entitled, "Mental Retardation in the Caribbean: Needs, Resources, and Approaches."

Reaching out on a still wider scope, the first Pacific Forum on Mental Retardation was held in Honolulu, Hawaii, in September of 1971, under the sponsorship of the President's Committee on Mental Retardation, with assistance from several co-sponsors. Participants came from Asia and the South Pacific, including New Zealand, Japan, Korea, Hong Kong. A report on the conference was published in 1972.



The first PCMR publication.

gham



*Breaking ground for the National Children's center, Washington D.C., are Commerce Sec. Peter G. Peterson, Assistant Sec. Robert A. Poolesta and two center residents Samantha Coffey and David Dillingham.*

*White House Christmas tour for handicapped individuals with Dr. Cecil Jacobson as Santa.*

**Early Leaders**

From 1970 to 1972, Dr. Joseph Douglass served as the Executive Director. Due to poor health, Dr. Douglass resigned in 1972, and his deputy, Fred J. Krause, formerly the Executive Director of the California Council of Retarded Children, was named as the Executive Director.

One can trace the President's Committee on Mental Retardation's earlier activities through the committee's newsletters. These were published quarterly through October, 1976, at which time Federal funds were no longer authorized for Federal agency and committee newsletters.

The committee's early success was due to the caliber of the members; the active participation of the Secretary of HEW as Chairman; the interest of the ex-officio members from other Federal departments

and agencies; extensive support from the field; and, most importantly, the personal interest and involvement of each of our Presidents. It should be noted that respected public figures, such as Eunice Kennedy Shriver, Muriel Humphrey, Jeannette Rockefeller, Governor Thomas J. Meskill, and Congressman Clair Burgener, served on the President's Committee on Mental Retardation and were always available to lend their help and support.

The support and consultation of many volunteer organizations, such as the American Association on Mental Deficiency and the Council for Exceptional Children, were noted in all the committee's proceedings. It would be difficult to name all the members of the committee who made a measurable

*Secretary Elliot Richardson with PCMR Members, Congressman Clair Burgener and Executive Director Dr. Joseph Douglas.*



contribution, but in the early years, Leonard Mayo, George Tarjan, Robert Cooke, Elizabeth Boggs, and Eunice Kennedy Shriver served both on the President's Panel and the President's Committee on Mental Retardation, providing continuity and balance to the committee's deliberations.

### **Major Publications**

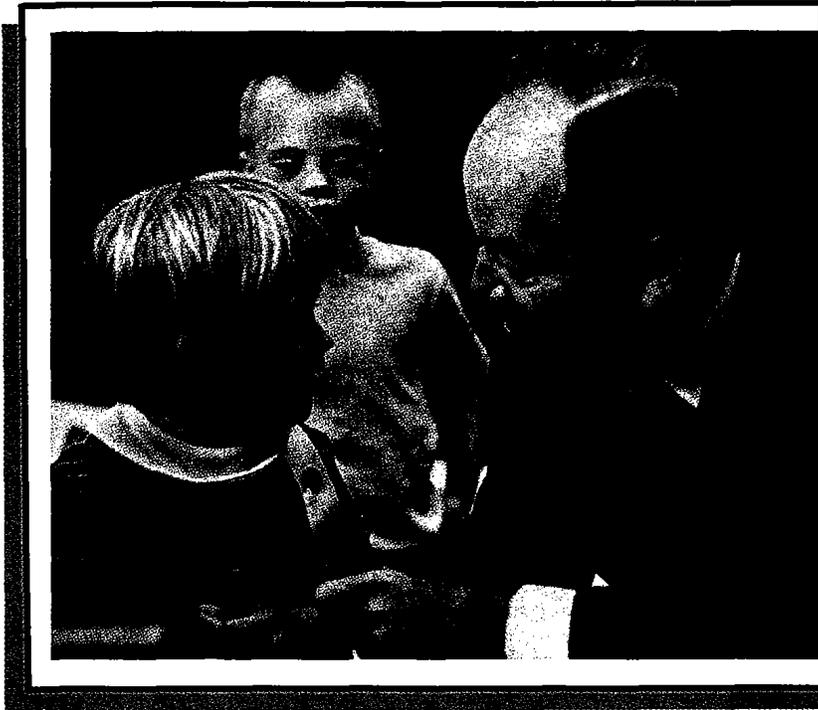
On September 24, 1968, the committee members met with President Lyndon B. Johnson at the White House to present its second report "MR 68—The Edge of Change." Accepting the report, President Johnson drew particular attention to the report's emphasis that "three-fourths of this nation's mentally retarded people live in either urban or rural slums." He continued, "Poverty creates not only misery, but

poverty creates mental handicaps."

A monograph in 1968 titled "Changing Patterns in Residential Services for the Mentally Retarded" was published by PCMR. Some fourteen contributing authors provided the editors, Dr. Robert Kugel and Wolf Wolfensberger, an imaginative planning approach to residential living for mentally retarded people. The principle of normalization made an impact on the American scene. Many other PCMR publications followed on residential and community services.

In 1968, the committee held a national conference on education problems of children in the inner city. The PCMR report, "The Six-Hour Retarded Child," was a product of the conference, and called for change in the special education of children in the public educational system. Robert Finch, HEW

*Vice President Humphrey visits a class of children with Down Syndrome.*



Secretary and Chairman of PCMR, stressed the importance of the recommendations of those attending the conference; participants dealt with early childhood education, the family, teaching, labeling, educational research, school responsibility and community participation. These subjects became the targets of PCMR agenda for the early 1970's.

In April 1970, PCMR met with President Richard Nixon and released the annual report, "The Decisive Decade." PCMR, in concert with the President's Committee on Employment of the Handicapped, published "These, Too, Must Be Equal." The report contained thirty-nine recommendations for habilitation and employment of individuals with mental retardation in the United States. The Chairman of the President's Committee on Employment of the Handicapped, Harold Russell, and Secretary Robert Finch, Chairman of PCMR, jointly announced actions to disseminate the report to all State and local vocational rehabilitation and employment agencies, and to the Governor's Committee on Employment of the Handicapped of each State.

Led by Vice Chairman Clair Burgener, and later, Lorraine Beebe, as vice chairperson, the committee

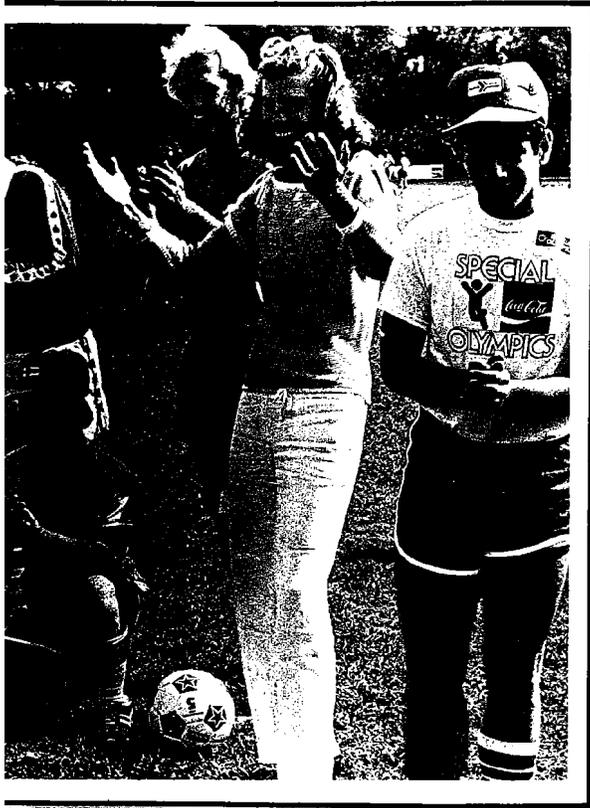
held conferences on early screening of newborn infants and young children. PCMR published reports and recommendations on these important subjects.

### **Concern for Native Americans**

When Lorraine Beebe served as vice chairperson, she asked the committee members to focus attention on the problem of American Indians living on reservations. A subcommittee made site visits and met with various Indian groups. The Departments of Interior and Health, Education and Welfare signed a PCMR joint agreement of cooperation to improve coordination of programs and services, in order to better serve the special education, health and social service needs of families having children with mental retardation who live on Indian reservations.

### **Setting Goals**

On November 16, 1971, President Nixon, after meeting with members of the President's Commission on Mental Retardation, announced from the White House a pledge to continue expansion of Federal and State programs, and called on the nation to pursue two major goals:



*Eunice Shriver working with Coaches and Special Olympics athletes.*



*Mrs. Betty Ford is presented an award from Secretary David Matthews, Mrs. Lorraine Beebe, Mrs. Robert Collier and Fred Krause.*



*President Richard Nixon receives annual report from PCMR members.*

- (1) To reduce by half the occurrence of mental retardation in the United States before the end of this century.
- (2) To enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community.

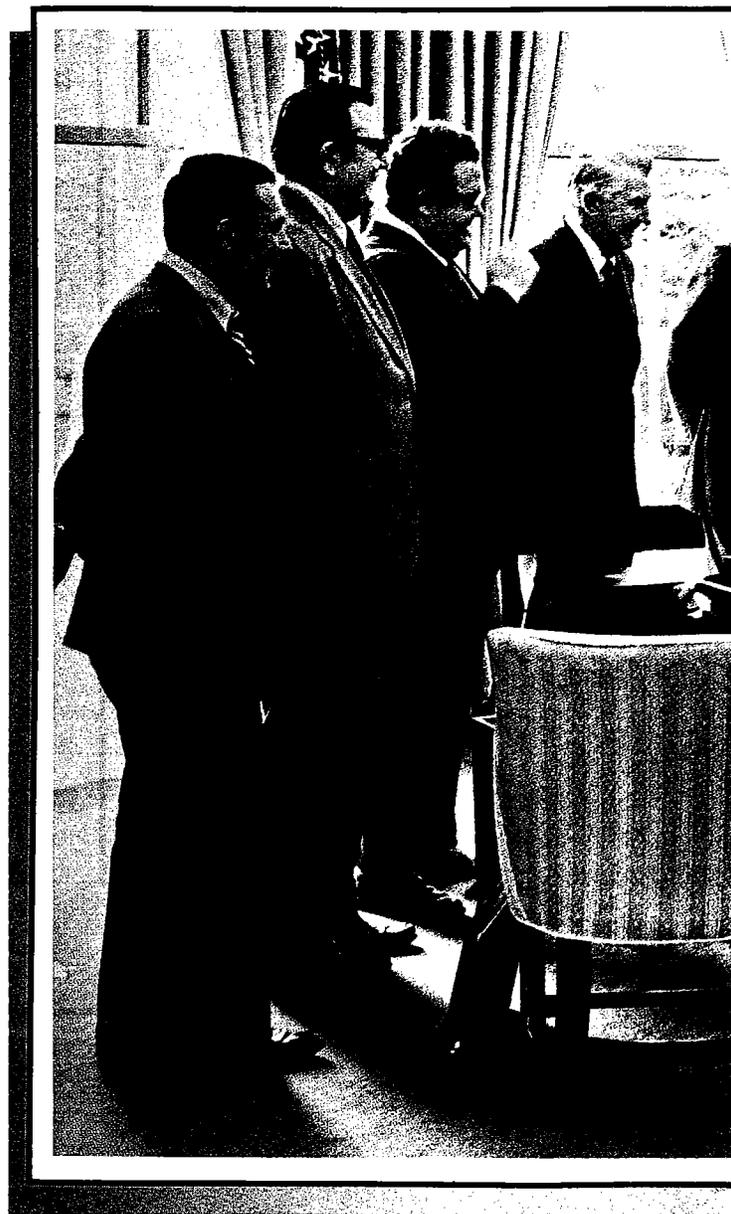
The President stated, "These goals are realistic and achievable; we already have most of the knowledge and many of the techniques they will require, and the rest are within reach of research." President Nixon also directed the Department of Justice to take steps to strengthen the assurance of full legal rights for mentally retarded citizens. In the same statement, he directed other Federal departments and agencies to be energetic in their efforts, and to collaborate with the President's Committee on Mental Retardation toward these national goals.

The Committee and staff built upon this Presidential statement and began to translate the President's goals into specific public awareness activities. The Committee produced films and radio announcements to promote community acceptance and to stress prevention. All executive departments and State agencies were asked by the PCMR chairman to evaluate their programs with a view to provide maximum support to the two goals.

#### Legal Rights Movement of the 1970's

Concurrently with the goals and initiatives growing out of the President's support, legal suits in six states were filed following the Federal court action in Alabama establishing standards for treatment of residents in state institutions. This Alabama legal action on human rights and standards of treatment, along with the Pennsylvania case on the right to education for all handicapped children, resulted in landmark court decisions that were the cornerstone of subsequent legislation establishing legal rights for mentally retarded and other disabled people.

Under the chairmanship of Secretary Elliot Richardson, and later Caspar Weinberger, the President's Committee on Mental Retardation continued through the early 70's with an energetic effort to review the research, training, education and residential services for individuals with mental retardation. Simultaneously, a broad public awareness campaign was undertaken with regional forums in various parts of the country. Emphasis was directed toward implementation among the states of the Presidential goals in 1973. President Nixon sent a message to the first National Conference, "The Mentally Retarded Citizen and the Law," held in Columbus, Ohio.



Lawrence Kane, a Cincinnati attorney and member of the President's Committee on Mental Retardation, was Chairman for this conference sponsored by PCMR. It was supported by HEW funding and had the cooperation of Ohio State University, and resulted in the highly regarded publication, "The Mentally Retarded Citizen and the Law." At that time, a total of forty-four class action suits and legal actions were being pressed on all fronts for the rights of mentally retarded citizens in education, treatment, habilitation, and in zoning for group home living.

In the decade of the 70's, a new self-advocacy movement, People First, began to take form. People First groups organized in the far West and in New England. Later, the organization, United Together,



*President Nixon signing the PCMR Executive Order*

was given support and consultation by PCMR. This self-advocacy movement, for people who were mentally retarded and developmentally disabled, continues to grow as an active and influential group.

PCMR's role in the legal rights of mentally retarded people has been an important one. It can be attributed to many members, with special appreciation to Larry Kane and David Udall, and to consultants Julius Cohen, Dennis Haggerty, Gunnar Dybwad, Michael Kindred, Paul Friedman and Stan Herr, who provided assistance on numerous issues.

The committee was also able to encourage the American Bar Association, Juvenile Justice judges, as well as legal rights groups, to become active on behalf of the rights of people with mental retardation.

Litigation through the Federal courts resulted in measures to protect the right to treatment in institutions, the right of education in public schools, and increased recognition of the right to special services for people with mental retardation within local, State and Federal correction facilities, and in the courts of law.

Stimulated by the 1969 research of Dr. Bertram Brown and Dr. Thomas Courtless, the committee continued to provide leadership in this area of concern through many endeavors, including publishing several documents. The latest, a comprehensive text, "The Retarded Offender," was edited by PCMR staff member, M. B. Santamour. A report by the committee, "Silent Minority," dealt with the quality of life for citizens with mental retardation.

## **PCMR, 1973-1980**

### **"Century of Decision"**

On March 28, 1973, President Richard Nixon invited members of the President's Committee on Mental Retardation to the Oval Office for the signing of a new Executive Order, 11776. The committee announced plans to prepare a comprehensive long-range report examining the history of mental retardation in this century, and setting the future agenda for improvement of services for persons with mental retardation. Dr. Henry Cobb, committee member, coordinated the preparation of this major report, assisted by all the members, divided into key subcommittees. The report, "Mental Retardation: Century of Decision," was presented to President Gerald Ford at a meeting on October 11, 1974. President Ford issued a statement at that time, reaffirming our nation's commitment to the field of mental retardation.

The report, "Century of Decision," consisted of a series of five publications, including, "Report to the President," which projected in detail the nation's needs in mental retardation through the Year 2000, and included recommendations on actions to be taken to meet those needs. The other volumes provided background support for these recommendations. The publication, "Mental Retardation: The Known and the Unknown," presented an account of the knowledge of mental retardation up to that time, pointing up the important gaps in knowledge of the causes and treatments of mental retardation, as well as gaps in data relative to mentally retarded persons in the United States. Another document was a historical publication, "Mental Retardation: Past and Present," prepared by Dr. Henry Cobb. Rounding out the series, "Century of Decision" was a report, "Trends of the States in Provisions of Mentally Retarded Persons," and a book, "Mental Retardation and the Year 2000." As a supplement to the series, PCMR also reviewed Federal programs and described the roles of approximately fifty-two of the programs in the provision of services to persons with mental retardation and other disabilities. PCMR defined action to be taken by organizations or agencies with major resources to enable persons with mental retardation and their families to receive needed services.

### **White House Activities**

President Jimmy Carter came into the White House with national awareness of his past actions in the field of mental retardation while serving as Governor of

Georgia. Mrs. Carter had a special interest in the broad areas of mental illness and mental retardation. In April, 1977, Mrs. Carter met at the Department of Health, Education and Welfare with members of the President's Committee on Mental Retardation. Expressing a high level of interest and sense of priority for programs of mental health and mental retardation, she asked for a detailed report on the practical effects of programs of prevention and treatment.

In November of 1977, the committee, through its Chairman and Secretary of HEW, Joseph A. Califano, Jr., sent Mrs. Carter the report, "A Renewed National Commitment for the Mentally Retarded," containing recommendations directed to numerous Federal agencies. The report emphasized the need to avoid unnecessary institutionalization of individuals with mental retardation and highlighted ways to strengthen mental retardation prevention programs through immunization against childhood diseases. In this report, the committee presented recommendations, as well as estimates of the budgetary impact of the committee's recommendations.

That same year, the White House Conference on the Handicapped was conducted in Washington, D.C. Prior to this meeting, each state held conferences and selected delegates. Mental retardation was emphasized by members of PCMR, as well as by the ARC movement. PCMR was represented through the conference, and its recommendations were highlighted in relation to community services, improvement of health care, strengthening of special education for students with mental retardation, and through vocational education and rehabilitation employment programs, which would increase the economic usefulness of most people with mental retardation. The four-volume report of the White House Conference on the Handicapped was presented to President Carter.

### **Spotlight on Community Programs**

The committee's activities in 1978 included preparation of "Mental Retardation: The Leading Edge, Service Programs That Work," a report in further response to Rosalyn Carter's request of the previous year. PCMR members, consultants, and staff prepared a compilation of service programs found to be working effectively. Illustrations in the report portrayed the warm human qualities of the people involved from all parts of the United States. The report provided the country with examples of public education, community services, and employment programs which demonstrated the improvement

that is possible in the quality of life for people who are mentally retarded.

As a supplement to the report's publication, the committee held nationwide press conferences, providing certificates of achievement to those State and community programs that received attention through the report.

The interest of the committee in community services ranged from pre-school programs, special education, vocational training, and workshops, to job placement. The committee conducted quarterly meetings, and the agenda frequently had deliberations on issues and policies related to community and residential services.

In 1979, PCMR planning began under Herbert Cohen, M.D., Vice Chairman, to examine the delivery of community services. The University of Wisconsin was the site for a national conference, "Mental Retardation-1980—Directions for Community Services." Numerous short and long term strategies were formulated at the conference, attend-

ed by State mental retardation commissioners and Developmental Disability Council members and staff.

### Prevention

In 1979, the committee extended its survey of "programs that work" to the area of prevention, and reconfirmed the high priority of effective prevention strategies. An international conference on prevention was held with the consultative participation of the committee. It was emphasized that mental retardation is America's number one health problem. The conference papers from participating countries indicated that each year, unless there is an intensified international prevention effort, an ever-increasing number of babies who are mentally retarded would be born in all parts of the world. The risks are not only prevalent in impoverished countries, but also in highly industrialized countries.

The PCMR Subcommittee on Prevention em-



*PCMR members at a luncheon meeting at the White House with Mrs. Jimmy Carter*

barked on a study to determine the significant features of strategies known to be successful in preventing mental retardation. With the assistance of State and local ARC groups, PCMR toured America in search of health programs and medical projects implementing prevention strategies. The committee conclusions resulting from this intensive study were presented to President Carter in an annual report, "Prevention Strategies That Work". The report highlighted the benefits of bio-medical prevention through genetic counseling, prenatal and intensive care, and immunizations. It further emphasized the importance of environmental controls in preventing mental retardation, placing heavy emphasis on the

multi-factoral conditions of teenage pregnancy, nutrition, and lead poisoning.

While there are numerous existing prevention resources, the committee undertook efforts to heighten public awareness, and to emphasize the need for higher priorities and financing to carry out these effective prevention initiatives. The committee worked actively with the Department of Justice and with the Department of Health and Human Services, in efforts to strengthen the government's role to enable babies with birth defects to live, to be treated for their conditions, and to be assisted through medical treatment toward a healthier future.



*Mrs. Richard Nixon greets NARC Poster Children, their parents and Marion Smith, President of NARC.*



*President Reagan appoints new members ~ 1982-1984.*

## **PCMR: Into the 1980's**

### **A New Committee**

A new committee was formed in the Spring of 1982, with the appointment of twenty-one new committee members. Richard Schweiker, Secretary of the Department of Health and Human Services, chaired the committee, and Dr. Elsie Helsel was appointed Vice Chairperson. In 1985, Dr. Albert L. Anderson succeeded Dr. Helsel. In 1983, Margaret Heckler succeeded Richard Schweiker as Secretary of the Department, and as Chairperson of the PCMR. In 1985, Dr. Otis Bowen succeeded Margaret Heckler. The nation's commitment to mental retardation was reaffirmed in December 1982, when President Ronald Reagan issued Executive Order 12399, in support of PCMR.

Although the committee membership changed, the core subcommittee structure through which it had operated in the past, (Full Citizenship, Prevention, Family and Community Services, and Public Awareness), was retained for continuity and to facilitate maximum national leadership and impact.

In addition to viewing these topics as important, the committee also believed that both Federal and

State systems to provide services for citizens with mental retardation should be re-examined, in order to determine ways in which these systems could be improved. As a result, at its first meeting the new committee established a Subcommittee on Systems Simplification: a) to review Federal and State laws, regulations, and procedures; b) identify significant gaps, overlaps, or service delivery barriers; and c) make major policy recommendations for revising those factors found to make service delivery more complex or costly than necessary. The committee also sought to establish a more issue oriented focus in certain areas.

In March, 1983, Fred Krause, who had served as Executive Director of PCMR since 1972, became ill and was replaced on an acting basis by Acting Executive Director, Dominic Mastrapasqua. Linda Tarr, Ph.D., was appointed as Executive Director in February, 1984. In December, 1984, Jim F. Young became Acting Executive Director. Susan Gleeson, R.N., M.S.N., was appointed Executive Director in July 1985.

### **Full Citizenship**

This subcommittee became active in maintaining a



*Employment and leisure time activities are objectives of PCMR.*

leadership role in addressing the rights of citizens with mental retardation. With significant input from families, the ARC's, advocates, and other sources, this subcommittee helped develop background materials for a number of PCMR actions. Information collection sessions of each of the initial material provided needed data to the committee:

- development of policy statements for the President on the "Baby Doe" case;
- development of a policy statement on the Education for All Handicapped Children's Act, PL 94-142, and on Section 504 of the Rehabilitation Act, that influenced the White House not to support proposed changes weakening the rights of handicapped persons;
- consultations with the Department of Justice on proposed regulations implementing Section 504 for Federally conducted programs, and influenc-

ing the content of a supplementary notice in the Federal Register modifying the requirements regarding burden of proof;

- implementation of a forum on the Chaffee Bill, SB 2053, "Community and Family Living Amendments of 1983;" and
- formulation of recommendations for statutory and regulatory changes and private initiatives to meet housing needs of mentally retarded people.

In 1983, the committee focused considerable attention on economic issues, with special emphasis on employment. Toward this end, a forum, "Community Forum on Employment and Mentally Retarded Persons," was held in Tucson, Arizona in October 1983. This forum, spearheaded by PCMR member Vicki Click, was to serve as a model for other communities in improving their own employment opportunities for persons with mental retardation. In support of this con-



cept, PCMR plans to publish a "how-to" resource document for community leaders that details steps to be followed in conducting such forums. The guide provides a generic model forum, as well as a case study of the Tucson experience.

To underscore the importance of employment, the 1983 annual report to the President, "The Mentally Retarded Worker: An Economic Discovery," focused on employment of mentally retarded persons.

#### Prevention

Prevention has continued to be a priority agenda item for PCMR, and this committee has continued a series of major conferences on various aspects of prevention. In September 1982, PCMR sponsored a forum, "National Prevention Showcase and Forum," in Atlanta, in cooperation with the Atlanta

Association for Retarded Citizens. This national forum brought together representation from each state, and the Trust Territories, Guam, and Puerto Rico. Models of prevention programs were examined at State and community levels. The U.S. Surgeon General actively participated in this conference, emphasizing the importance of healthy mothers and healthy babies, and acknowledging PCMR's continuous support in alerting the medical community to prevention strategies that are known to be successful in reducing the incidence of mental retardation and ameliorating its effects.

In November 1983, the committee sponsored a conference, "Assessment of the National Efforts to Combat Mental Retardation from Bio-Medical Causes," in Washington, D.C. This biomedical assessment was completed in May of 1984 by the forum, "National Open Forum on the Prevention of Mental Retardation from Environmental and Psychosocial Causes," held in Boca Raton, Florida.

Recognizing the important role for states in the area of prevention, the committee has undertaken a strategy focusing specifically on state issues. Towards this end, PCMR is developing a Model State Prevention Plan addressing causes of mental retardation. This plan will be disseminated to each state and territory as a technical assistance resource, to be used in developing and implementing comprehensive community programming and services to prevent this handicapping condition.

Finally, PCMR has sponsored the development of a series of publications on various aspects of prevention, including:

- "Assessment of the National Effort to Combat Mental Retardation—Technical Proceedings"
- "The Role of Institutions of Higher Learning in Prevention of Mental Retardation" (a monograph)
- "Will You Help Your Baby's Brain Develop?" (a brochure)
- "National Prevention Showcase and Forum—Technical Proceedings"

#### Other Topics of Continued Interest

PCMR remains active in addressing issues of mental retardation as they relate to the criminal justice system. A report, "Mental Retardation and the Law," has been prepared. A PCMR staff member has trained prison officials and staff regarding programs for offenders with mental retardation.

PCMR works with other agencies and programs of systems simplification have been established with the mutual interest. Liaison relationships regarding



*Ronald Reagan, when Governor of California, receiving an award for state efforts in genetic counseling.*

Departments of Housing and Urban Development, Justice, and Education. The interagency committee, Special Needs of Mentally Retarded Offenders in the Criminal Justice System, has been established by PCMR, with the Department of Justice and the Administration on Developmental Disabilities (ADD). PCMR is represented on ADD's Employment Initiative and on the Department of Education's National Institute on Handicapped Research. The Committee is also working with the National Institute of Mental Health on a dual diagnosis conference, i.e., mental retardation and mental illness.

PCMR has continued its major role in international activities. Meetings have been held with United States and United Nations representatives for the International Decade of the Disabled and the International Year on Youth. Liaison has been established with several international organizations, including the Organization of American States, World Bank, United States Information Agency, and the Pan American Health Organization.

In May of 1984, the PCMR inaugurated its first annual scholarship award. This program received national attention, and is well on its way in attracting bright students into careers in the various fields of mental retardation.

#### Conclusion

The President's Committee on Mental Retardation can take pride in the list of its accomplishments and in

its advocacy and advisory role as intermediary between the Federal government, states, localities, and families across the nation, in providing information, identifying needs, and making critical recommendations that provide a powerful influence in the course of improvement of life for retarded people everywhere. In addition, PCMR has successfully achieved, through its quarterly meetings and the work of its subcommittees, a highly significant impact on national policies. It has produced and assured the availability of many highly utilized reports. The influence of the committees has been international as well as national in scope, involving collaboration with the International League of Societies for Mentally Handicapped Persons, and the International Society for Scientific Study of Mental Deficiency, in numerous symposia and international studies, and in consultation with governments of many countries.

The President's Committee on Mental Retardation, with the active leadership of its members and staff, has historically proven itself to be a highly effective voice in the field of mental retardation. And yet PCMR is only on the threshold; its impressive accomplishments can be considered only the prologue to the exciting prospects in the years ahead.

(The best summary of PCMR's accomplishments is one that cites the major goals that PCMR has enunciated, and then reviews the progress made in addressing those goals. This summary is provided in Appendix C.)

# Appendix A

## President's Panel on Mental Retardation

### Members

Leonard W. Mayo, S. ScD., Chairman

George Tarjan, M.D., Vice-Chairman

David L. Bazelon, B.S.L.	Lloyd M. Dunn, Ph.D	Joshua Lederberg, Ph.D	Wendell M. Stanley,
Elmer H. Behrmann, Ph.D. (Msgr.)	Louis M. Hellman, M.D. Herman E. Hilleboe, M.D.	Reginald S. Lourie, M.D. Oliver H. Lowry, Ph.D., M.D.	Ph.D. Harold W. Stevenson, Ph.D.
Elizabeth M. Boggs, Ph.D.	Nicholas Hobbs, Ph.D	Horace W. Magoun, Ph.D.	W. Wallace Tudor
Robert E. Cooke, M.D.	William P. Herder, Ph.D., M.D.	Darrel J. Mase, Ph.D.	Henry Viscardi, Jr., LL.D.
Leonard S. Cottrell, Jr. Ph.D.	Seymour R. Kety, M.D.	F. Ray Power	Ernest P. Willenberg, Ed.D.
Edward Davens, M.D.	Irene A. Wright	Anne M. Ritter, Ph.D.	

Consultant to the Panel: Mrs. Sargent Shriver

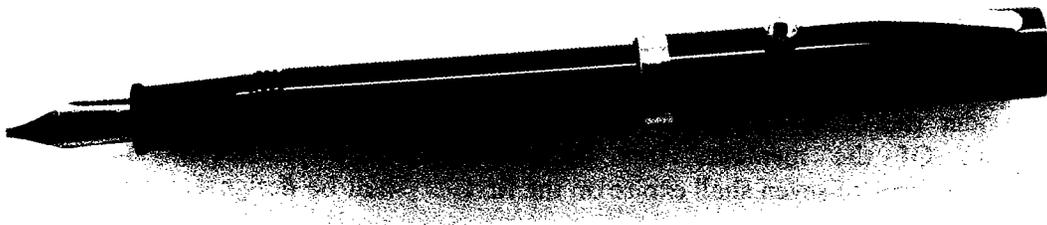
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# Appendix B

## List of Vice Chairpersons and

### Executive Directors

Robert Aldrich, M.D.	1966-1970	Executive Directors:	1966-1970
Clair Burgener	1970-1972	David Ray	
Lorraine Beebe	1972-1976	Joseph Douglass, Ph.D.	1970-1972
Henry Cobb, Ph.D.	1976-1979	Fred J. Krause	1972-1983
Herbert Cohen, M.D.	1979-1981	Dominic Mastrapasqua, Ph.D.	1983-1984
Elsie Helsel, Ph.D.	1982-1984	(Acting Executive Director)	
Albert Anderson, D.D.S.	1985-Present	Linda L. Tarr, Ph.D.	1984-1984
		Jim F. Young	1984-1985
		(Acting Executive Director)	
		Susan Gleeson, R.N., M.S.N.	1985-Present



## Executive Order 11280

### 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 this 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 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



# Appendix C

## **President's Committee on Mental Retardation—Impact Statement on Goals and Accomplishments**

Numerous goals have been established throughout the history of the President's Committee on Mental Retardation. Listed below are the major goals, as well as the relevant accomplishments made by PCMR in seeking to meet these objectives. PCMR has lent its endorsement or support to many other Federal policies that have aided in the progress of service for citizens who are mentally retarded and their families.

**GOAL: To reduce by half the occurrence of mental retardation in the United States before the end of this century**

### **Relevant Accomplishments**

- ❑ Support of a national education effort supporting planned pregnancies.
- ❑ Efforts towards genetic diagnosis and counseling services.
- ❑ Sponsoring of numerous conferences on prevention with medical organizations and State officials.
- ❑ Establishment of a national forum on prevention with representatives from each State.
- ❑ Sponsoring State prevention committees in the field of mental retardation.
- ❑ Reduction in Down's Syndrome and metabolic disorders.
- ❑ Lead poisoning testing mandated in states.
- ❑ Sponsorship of universal measles immunization.
- ❑ Conducted a conference, "Multi-Cultural Aspects of Prevention."

**GOAL: To enable one-third of the more than two hundred thousand persons in public institutions to return to useful lives in the community**

### **Relevant Accomplishments**

- ❑ Coordination with Federal and national organizations supporting deinstitutionalization.
- ❑ A significant contribution toward planning for the reduction of the institutionalized population made by many of PCMR's publications, i.e., "Changing Patterns of Residential Services."
- ❑ Development of alternative services and smaller community residential homes.
- ❑ Reduction in the public institutionalized population.

**GOAL: The attainment of full citizenship status, in law and in fact, for all individuals with mentally retarded individuals in the United States, exercised to the greatest degree possible under the conditions of disability**

### **Relevant Accomplishments**

- ❑ Establishment of a special litigation branch of the Office of Civil Rights, Department of Justice.
- ❑ Encouragement of the rights of education, rehabilitation and treatment for persons with mental retardation.
- ❑ Establishment of a nationwide system of public legal advocacy services specializing in the protection of rights.
- ❑ Sponsorship of important conferences and the publication of major articles and books on the legal rights for citizens with mental retardation.
- ❑ Establishment of the Committee for the Disabled within the American Bar Association, and other legal groups.
- ❑ Establishment of a case law review of the legal status of citizens with mental retardation.
- ❑ The support of numerous State and regional symposia on legal rights of people with mental retardation.

**GOAL: Adequate and humane service systems for all retarded persons**

## Relevant Accomplishments

- ❑ Encouragement of the development of community service systems within states.
- ❑ Emphasizing coordination, simplified and unified procedures of interdepartmental policies at the Federal, State and local levels.
- ❑ Making services more equitable, and encouraging public and private agencies to provide quality services.
- ❑ Increasing the opportunity for mentally retarded persons to live in local community settings of their own choice.
- ❑ Establishment of standards of quality and accountability acceptable to the individuals with mental retardation.
- ❑ Production of data showing increased number of community agencies servicing citizens with mental retardation.

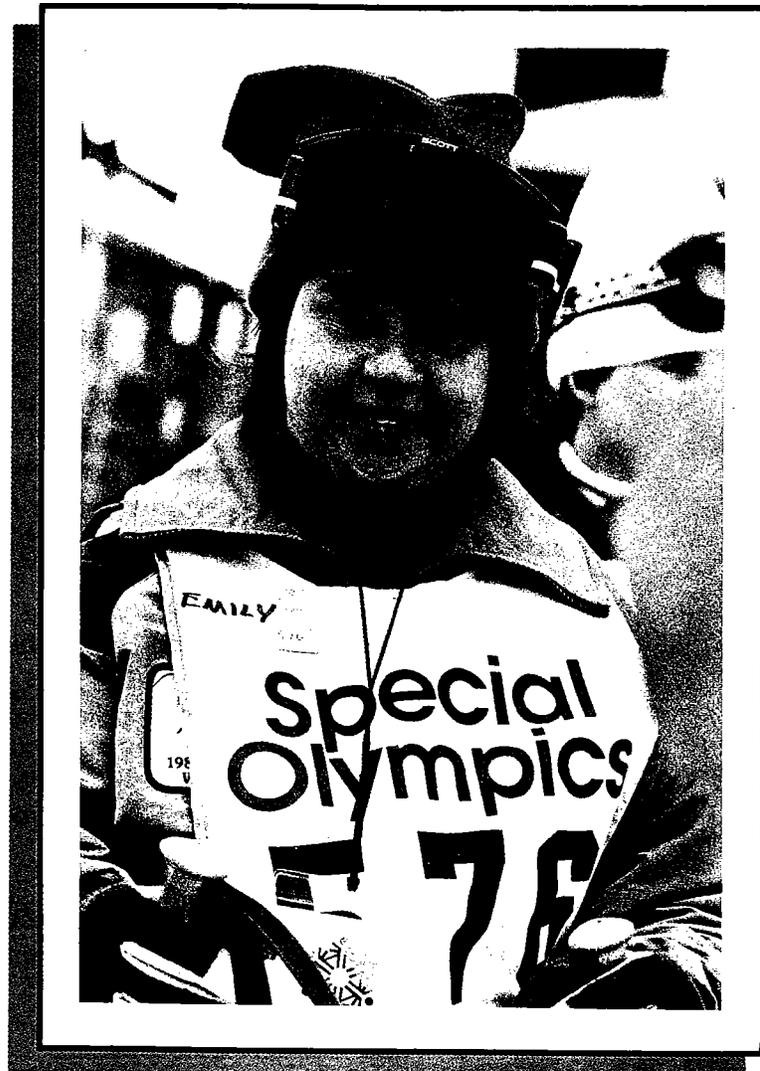
**GOAL: Attainment of a high and stable level of international relations in the cooperative preventing and ameliorating of mental retardation**

## Relevant Accomplishments

- ❑ Maintenance of United States government's participation in international affairs relating to mental retardation.
- ❑ Maintaining a relationship with the U.S. State Department and with the Inter-American Children's Institute of the Organization of American States.
- ❑ Cooperative activity with the International Societies for the Mentally Handicapped and the International Association for the Scientific Study of Mental Deficiency.
- ❑ Conducted conferences in Hawaii with Pacific and Southwest Asian countries, and in Puerto Rico and Panama with Latin American countries.
- ❑ Representatives of PCMR attended many European and Scandinavian conferences.

- ❑ Intensive work with developing countries to study their health and educational systems.
- ❑ Aiding Third World countries in their development of services for persons with mental retardation through Peace Corps operations.

**GOAL: To achieve a firm and deep public acceptance of mentally retarded persons as members in common of the social community and as citizens in their own right**



*Special Olympics now reach the mentally retarded throughout the world.*



*Pan American Congress on mental retardation ~ 1975.*

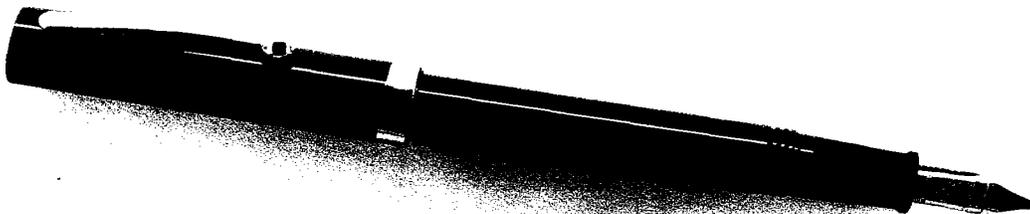
#### **Relevant Accomplishments**

- ❑ Consistent concern by PCMR with public attitudes toward persons with mental retardation, and attempts to advance the value of every person with mental retardation to demonstrate their productivity and accomplishments.
- ❑ The publication of numerous reports which strive toward bringing media attention to implementation of value-oriented approaches of human relationships.
- ❑ Education of children, and greater stress on community living and job placement, via films and meetings.
- ❑ Inclusion of courses on mental retardation and related disabilities in the curricula of students in medicine, law, education, religion, psychology, and numerous other critical professional disciplines.

**GOAL: Equitable, coordinated, efficient and effective use of public resources in all mental retardation programs**

#### **Relevant Accomplishments**

- ❑ Coordinated and comprehensive planning of Federal, State and local efforts in the area of mental retardation.
- ❑ Continuation of an interdepartmental planning system on mental retardation in the Federal governments. Affiliation of PCMR with each department's active participation in inter- and intra-governmental programs.
- ❑ Participation in various planning efforts to create a national information system on mental retardation, and to gather research and data that would assist in policy development.
- ❑ Monitoring the funding processes for people with mental retardation.
- ❑ Establishment of Federal joint agreements for bilateral and multilateral policy and regulations.
- ❑ Reviewing problems in Social Security and Medicaid, and sponsoring meetings or forums to bring a resolution to critical issues.
- ❑ Enactment of administrative procedures as a result of PCMR's consistent and effective relationship with various levels of governmental operations in the field of mental retardation.



## PCMR Members and Years Served

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Robert A. Aldrich, M.D., 1966-1971  
Joseph A. Beirne, 1966-1968  
G. Barry Bingham, 1966-1969  
Horace Busby, 1966-1971  
Robert E. Cooke, M.D., 1966-1969  
John T. Dailey, 1966—one year only  
Patrick J. Doyle, M.D., 1966-1969  
Muriel B. Humphrey, 1966-1969  
George Jones, 1966-1969  
Mathilde Krim, 1966-1969  
Robert B. Kugel, M.D., 1966-1969  
Leonard W. Mayo, 1966-1969  
Lloyd E. Radar, 1966-1976  
Theodore S. Repplier, 1966—one year only  
Bernard Rosenberg, 1966-1970  
Eunice Kennedy Shriver, 1966-1968-1977-1980  
George Tarjan, M.D., 1966-1971  
Thomas A. Tucker, 1966-1971  
Henry Viscardi, Jr., 1966-1968  
Raymond W. Vowell, 1966-1970  
Robert H. O'Brien, 1966—one year only

Leo F. Cain, Ph.D., 1967-1970  
Bess H. Jones, 1967-1970  
Jeannette Rockefeller, 1967-1973

Victor Bussie, 1968-1970  
Victor R. Fuchs, Ph.D., 1968-1971  
Kenneth J. Ryan, M.D., 1968-1971

Marianna Beach, 1969-1975  
William H. Borders, Jr., M.D., 1969-1972  
Susann R. Ora, 1969-1972  
Louise R. Ravenel, 1969-1975  
David K. Udall, 1969-1971

N. Lorraine Beebe, 1970-1979  
Clair W. Burgener, 1970-1973  
David H. Echols, 1970-1973  
Donald Lee Fox, 1970-1972  
Lawrence A. Kane, Jr., 1970-1976  
William B. Robertson, 1970-1976  
Luis D. Rovira, 1970—one year only  
Frank R. DeLuca, 1971-1974  
Cecil B. Johnson, M.D., 1971-1977  
James N. Juliana, 1971-1977

Aris A. Mallas, Jr., 1971-1974  
Kenneth S. Robinson, 1971-1974  
Will Beth Stephens, Ph.D., 1971-1977  
Margaret B. Ulle, 1971-1977  
Robert A. Collier, 1971-1974  
Richard J. Elkus, 1972-1975  
Ralph J. Ferrara, 1972-1975  
Melvin Heckt, 1972-1975  
Miriam G. Wilson, M.D., 1972-1975

Michael R. Gardner, 1973-1978  
Thomas J. Meskill, 1973-1975  
Henry V. Cobb, Ph.D., 1973-1979

Geraldine M. Clark, 1974-1977  
Bill J. Doggett, M. Ed., 1974-1977  
Phillip U. Martinez, M.D., 1974-1977

James D. Clements, M.D., 1975-1978  
Jeanne C. Collier, 1975-1978  
Arnold G. Gangnes, 1975-1978  
John P. Greene, 1975-1978  
Morley A. Hudson, 1975-1978  
Andrew L. Lewis, 1975-1976  
Cherrie Sevick, 1975-1978  
Elizabeth M. Boggs, 1975-1976

David M. Barrett, 1976-1979  
Jean K. Elder, Ph.D., 1976-1979  
Frank J. Menolascino, M.D., 1976-1979  
Dolores T. Norley, 1976-1979  
Margaret V. Tedone, 1976-1979

Robert G. Jordan, M.D., 1977-1981  
Anderson W. Pollard, 1977-1980  
Ludwig Rothbein, 1977-1980  
Florence K. Simons, 1977-1980  
Samuel Whitman, 1977-1980

Andrew I.T. Chang, 1978-1981  
Herbert J. Cohen, M.D., 1978-1981  
Ruth W. Diggs, Ed.D., 1978-1981  
Shirley C. Miller, 1978-1981  
Ana Navarro, M.D., 1978-1981  
Edward J. Quilligan, M.D., 1978-1981  
Aileen A. Weiss, 1978-1981

Harvey A. Abrams, 1979-1981  
Janet Allen-Spilka, 1979-1981  
G. Thomas Bellamy, 1979-1981  
Marlene F. Kopman, 1979-1981  
Guy M. McKhann, M.D., 1979-1981  
Alba A. Ortiz, Ph.D., 1979-1981  
Edward F. Zigler, Ph.D., 1979-1981

A. Omie Brown, 1980-1981  
Joseph A. Buonomo, 1980-1981  
Leonard G. Espinosa, 1980-1981  
Lilia A. Evangelista, M.D., 1980-1981  
Leida Herrell, Ph.D., 1980-1981  
William L. McGowan, 1980-1981  
Valaida Smith Walker, 1980-1981

Kathleen M. Barrett, 1982-1984  
Richard E. Blanton, Ph.D., 1982-1985  
Lee A. Christoferson, M.D., 1982-  
Dorothy Corbin Clark, R.N., 1982  
Vicki M. Click, 1982-1984  
Thomas J. Farrell, 1982-  
Vincent C. Gray, 1982-

Madeline B. Harwood, 1982-  
Elsie D. Helsel, Ph.D., 1982-  
Lawrence A. Kane, Jr., 1982-1985  
Richard J. Kogan, 1982-  
James L. Kuebelbeck, 1982-1985  
D. Beth Macy, 1982-  
Timothy J. O'Brien, 1982-1985  
Raymond M. Peterson, M.D., 1982-1984  
Frederick J. Rose, 1982  
Anne C. Seggerman, 1982-  
Marguerite T. Shine, 1982-  
Lila Thompson, 1982-1985  
Virginia J. Thornburgh, 1982-  
Ruth A. Warson, R.N., 1982-

Albert L. Anderson, D.D.S., 1984-  
Lois Eargle, 1985-  
Matthew Guglielmo, 1985-  
William Hummer, M.D., 1985-  
Roger Stanley Johnson, M.D., 1985-  
James Bopp, Jr., 1984-  
Jerry P. Larson, M.A. R.S.W., 1984-  
U. Yun Ryo, M.D., Ph.D., 1985-



*Susan Gleeson, Executive Director*

## Annual Reports

*MR 67:* The committee's first report. Outlines ten areas in which citizen and agency action can produce progress in combating mental retardation.

*MR 68: The Edge of Change.* The committee's second report. Covers grassroots developments in mental retardation programs. Surveys needs and makes recommendations on residential services, manpower development, and poverty-mental retardation links.

*MR 69: Toward Progress—the Story of A Decade.* Surveys major mental retardation research and service developments of the 1960's. Makes recommendations for programs and approaches to be developed during the 1970's.

*MR 70: The Decisive Decade.* Reports on residential services, malnutrition, research, education, employment, State services, and additional action areas in mental retardation that point up the '70s as decisive years.

*MR 71: Entering the Era of Human Ecology.* Focuses on the environmental and genetic causes of mental retardation, with additional sections on intelligence, genetic damage, the law, Indian health and education, lead poisoning, Pacific Forum on Mental Retardation, economics, and recreation.

*MR 72: Islands of Excellence.* Annual Report of the President's Committee on Mental Retardation. Describes a number of national, State, regional, and local programs that offer promising approaches to prevention and alleviation of mental retardation.

*MR 73: The Goal is Freedom.* PCMR annual Report based on the concept of freeing retarded persons from various handicaps through a system of setting goals to be achieved. The publication also deals with prevention of retardation and corrective measures.

*MR 74: A Friend in WashingtOn.* Eighth annual Report of PCMR, reviewing one year in the life of the committee, as it works to prevent and ameliorate mental retardation.

*MR 76: Mental Retardation Past and Present.* Reviews the historical shifts in our treatment of retarded persons, and assesses where we stand today. (There were three other reports in this series, "Century of Decision, The Known and the Unknown, and Mental Retardation: Trends in State Services.")

*MR 77: A Renewed National Commitment for the Mentally Retarded.* Publication presented to Mrs. Rosalynn Carter, at her request, with focus on proposed national objectives in the total context of treatment, prevention, national objectives and budget criteria for the field of mental retardation.

*MR 78: The Leading Edge-Service Programs That Work.* This PCMR annual report focuses on a number of successful service programs throughout the United States that are currently directly addressing the accomplishments and potential of citizens with mental retardation. The programs address such topics as: the family, public school education, community residences, self assertion, the offender with mental retardation, mental health, and prevention.

*MR 79: Prevention Strategies That Work.* This document, constituting the twelfth annual report of the President's Committee on Mental Retardation, highlights the fact that of the more than two hundred known causes of mental retardation—including injuries at birth, toxic conditions, inherited genetic fac-

tors, measles, x-rays, metabolic disorders, Rh blood disease, etc.—more than 50 percent are preventable. The report cites as even more provocative, committee findings that a significantly larger percentage of mental retardation, resulting from environmental influences including sociocultural disadvantages, are preventable. It presents committee conclusions from an intensive study of the distinguishing features of strategies known to be successful in preventing mental retardation; it describes "representative models" of programs and projects implementing such strategies

*MR 80: The Mentally Retarded Worker: An Economic Discovery.* The goal of this year's report to the President is to increase the awareness of the private sector of the hundreds of thousands of people with mental retardation who are employable, but are unemployed because of misconceptions about their abilities to meet and maintain employment standards. These misconceptions held by some employers, placement officers, trainers, and parents may lead to a life of under-achievement, idleness and public dependency. Yet the overwhelming evidence shows that mentally retarded persons can be productive members of the nation's workforce, and quite often are considered preferred workers.

*Mental Retardation: Plans for the Future:* The fifteenth annual report to the President, describes the number of ways in which PCMR, historically, has engaged in collaborative activities with other Federal agencies, national constituency organizations, private sector groups and individuals, to fulfill its executive mandate.



## List of Publications

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*The Mentally Retarded in Model Cities.* This report provides the long-awaited opening that can change not just the neighborhoods, but also the lives of those in the blighted areas where seventy-five percent of persons with mental retardation live.

*To Your Future With Love.* For young people seeking meaningful volunteer and career opportunities. Many experiences are told by volunteers in their own words.

*Hello World!* Popularly written general information booklet, with individuals who are mentally retarded illustrating levels of retardation, its causes, and means of prevention.

*These, Too, Must Be Equal.* Describes America's need for habilitation and employment of the mentally retarded, and lists proposals for action.

*Residential Services for the Mentally Retarded: An Action Policy Proposal:* A proposed statement on residential services for public and professional review.

*The Mentally Retarded: Their New Hope.* This booklet is part of a national campaign to inform the public about the scope of mental retardation, and what must be done to assure persons with mental retardation their rightful place in our democratic society.

*The Six-Hour Retarded Child.* Report on a conference dealing with educational problems of inner-city children. Includes recommendations for constructive changes in the education system.

*Background Papers.* Presentations from Conference on Problems of Education of Children in the Inner City.

*Manpower and Mental Retardation—An Exploration of the Issues.* Proceedings of a joint United States- Canada Conference, 1970.

*In Service to the Mentally Retarded.* A directory of national voluntary agencies that perform services for persons with mental retardation.

*Mental Retardation in the Caribbean.* Proceedings of a September 1970 conference sponsored by PCMR.

*PCMR Is For People.* Describes the composition, actions, and goals of the President's Committee on Mental Retardation, with suggestions on citizen involvement in the field.

*PCMR Message.* Current news and features related to the committee's activities and other pertinent mental retardation items.

*Delivery of Services to Mentally Retarded Children and Adults in Five States.* A study and analysis of stage systems for delivering services. Presents the problems and interprets the needs of State agencies and departments in providing diversified and integrated services.

*A Very Special Child.* Report from a conference on placement of children in special education programs for persons with mental retardation. Re-examines present system of intelligence testing and classification, from the psychological, social, and legal angles.

*Placement of Children in Special Classes for the Retarded. Background Position Papers.* Papers presented at Conference on Placement of Children in Special Education Programs for the Mentally Retarded.

*Citizen Advocacy.* An exploration of the ways in which citizens can represent the interests of the handicapped.

*The First Pacific Forum on Mental Retardation.* A report on a conference of the Pacific nations on their mental retardation problems and methods on dealing with them.



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*Attitudes Toward the Retarded.* A summary of studies evaluating attitudes toward persons with mental retardation.

*Day Care: Serving Children With Special Needs.* Guidelines to integrated day care programs serving children with special needs.

*Action for the Retarded.* Recommendations to the President on more effective Federal programs for the mentally retarded.

*The Naive Offender.* Findings from a conference on dealing with persons who are retarded who get into difficulties with the law.

*Activity Centers for Retarded Adults.* A study of programs where adults who are mentally retarded participate in organized, personally meaningful activities which help them toward an optimal adjustment to family and community.

*Screening and Assessment of Young Children at Developmental Risk.* A monograph on methods of screening and assessing the needs of children at risk of being developmentally delayed by intellectual, physical, or emotional problems.

*Background Papers.* Presentations from the National Conference on Screening and Assessment of Young Children at Developmental Risk.

*Federal Programs for the Retarded.* A report on a review and evaluation by departments and agencies of Federal programs for persons who are retarded.

*Transportation and the Mentally Retarded.* A report on a study of special transportation needs and problems of citizens who are mentally retarded.

*Changing Patterns in Residential Services for the Mentally Retarded.* A 435 page report by the President's Committee on Mental Retardation on residential facilities for citizens who are mentally retarded.

Originally published in 1969, it includes chapters by fourteen authors discussing models in the United States and abroad, stressing the normalization principle.

*International Symposium on Volunteers.* Report on a symposium co-sponsored by PCMR and NARC at Philadelphia in 1971. Focuses on the role of the volunteer in terms of direct service and community leadership, and the motivation of governments to accept the responsibility to enable the population who are retarded to live within the community.

*Malnutrition, Learning, and Intelligence.* A paper presented by the late Dr. Herbert G. Birch, a leading researcher in the field, to PCMR Leadership Institute. It concludes from a survey of the scientific evidence that malnutrition may contribute to a suboptimal level of intellectual functioning, but that improvements in all facets of life are needed to achieve increased intellectual growth of disadvantaged children.

*Mentally Retarded Citizens and the Law Enforcement Process.* Proceedings of a conference held in St. Louis, Missouri, October 29-November 1, 1972. Subjects covered included correctional administration, recognition by police, and sentencing.

*Experimental Studies of Memory in the Mentally Retarded.* A paper presented at a PCMR Leadership Training Institute, by John M. Belmont, Ph.D. It presents results of research into the strategies of learning used by both subjects who are retarded and normal, focusing on both organization and retrieval of information.

*Mental Retardation and the Law.* A quarterly compilation of legal actions affecting the rights of persons who are retarded. Reports new cases and status of actions previously brought.

*New Neighbors.* Fourteen contributors discuss philosophical and practical aspects of the citizen who is retarded and his need for a home in the community.

*Residential Programming.* Position statement on the contemporary issues affecting residential services for persons who are mentally retarded by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded.

*Silent Minority.* Deals with life, liberty, and the

pursuit of happiness of citizens who are retarded, and what can be done legally to protect their fundamental rights.

*PI-MR.* Directed at persons doing public information work in the field of mental retardation. Reports on media opportunities, activities of PIO's, etc. Issued at irregular intervals.

*Information Office News Clipping Service.* Topical clippings from the mental retardation field nationwide.

*Mental Retardation: Century of Decision.* A report to the President making recommendations for the next twenty-five years on prevention, humane services, and full citizenship for persons who are retarded.

*Mental Retardation: The Known and the Unknown.* This publication compiles for the first time existing statistical and factual information about the extent, the causes, and the treatment program for citizens who are mentally retarded.

*Mental Retardation: Trends in State Services.* Identifies trends in State and local services for persons who are mentally retarded, and the impact of Federal assistance. Based on a telephone survey.

*New Environments for Retarded People.* An album of facility designs from many countries.

*People Live in Houses.* Described representative group homes, foster homes, and other types of residential settings for children and adults.

*What Are We Waiting For?* Report of a conference on Early Intervention with High-Risk Infants and Young Children, focusing on the needs for mother/child/professional interaction.

*International Directory of Mental Retardation Resources.* Resources in the field of mental retardation are briefly listed for the United States and many other countries under governmental, voluntary organizations, research, publications, history of services, and information for visitors.

*P .C. M. R. Newsbreak.* Published quarterly. Provides current information on new innovative programs. Provides source for additional information.

*The Problem of Mental Retardation.* This booklet is designed as a basic introduction to mental retardation, and an overview of the problems related to it. Mental retardation is defined, ways in which the patient can be helped are given, and the causes and the future of the problem are discussed.

*Retardation, Corrections, and Retarded Offenders: A Bibliography of Relevant Research, Programs, and Literature, with Annotations.* A companion piece to a "prescriptive package," *The Retarded Offender and Corrections*, designed to bridge the gap between the field of retardation and correction, and provide directions to individuals who are developing programs for retarded offenders. The five sections of the report include: Introduction to the Field of Retardation, Introduction to the Field of Corrections, Major Research Projects/Treatment Modalities, Conferences and concludes with general literature.

*International Summit on Prevention of Mental Retardation From Biomedical Causes.* A complete 198 page account of the proceedings of an international summit sponsored by the President's Committee on Mental Retardation (PCMR), the American Association on Mental Deficiency (AAMD), the Canadian Association for the Mentally Retarded (CAMR), and the National Association for Retarded Citizens (NARC), in cooperation with the Johnson Foundation. This summit convened at "Wingspread" in Racine, Wisconsin, with the purpose of providing a forum which would facilitate the abilities of participants to think, plan, collaborate, and develop short and long range strategies to prevent mental retardation.

*Proceedings of A National Multicultural Seminar on Mental Retardation Among Minority Disadvantaged Populations.* A complete 116 page record of a national seminar sponsored by the President's Committee on Mental Retardation in cooperation with Norfolk State College/Department of Special Education. The purposes of this "working conference" were 1) to address major issues related to impaired and retarded human development associated with environmental conditions of racial and ethnic discrimination, poverty, deprivation, family disruption, and consequent disadvantage; and 2) to develop recommendations and strategies for affirmative action toward reduction of the prevalence of mental retardation associated with these conditions.

*From Rights to Realities: Advocacy By and For Retarded People in the 1980's.* This 16 page pamphlet traces the legal rights movement for retarded persons through the 1970's and provides the reader with a discussion of resources for legal advocacy in the 1980's. Written in easy style, it discusses legislative successes and legislative landmarks in the quest by citizens with mental retardation for equal treatment. It is an excellent resource for lay people, as well as professionals, in all disciplines associated with the field of mental retardation.

*Retardation and Criminal Justice. A Training Manual for Criminal Justice Personnel.* Published in collaboration with the New Jersey Association for Retarded Citizens. This fifty page booklet is written specifically for criminal justice personnel as an introductory lesson into the nature of mental retardation. It includes detailed curriculum on the development of habilitative correctional programs for offenders who are retarded. Because of its discussion of the problems retarded people encounter in the juvenile and criminal justice systems, retardation professionals will also find this manual of value.

*The Role of Institutions of Higher Learning in Preventing or Minimizing Mental Retardation.* This sixty-nine page monograph is intended to increase professional and community awareness regarding specific prevention—oriented towards functions of colleges and universities. It represents a continuing positive effort to develop and disseminate information that will reduce the incidence and prevalence of mental retardation, especially as it relates to environmental and sociocultural influences.

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## FILMS

*A Little Slow.* Dramatizes through the experience of Billy and Carol the problems persons with retardation face in obtaining their legal rights.

*It's Their World Too.* Documents the experiences of three people who are retarded. The film offers first-hand accounts from a young woman employed by a large corporation and a middle-aged man living in a group home. The parents of a young child who is retarded discuss the child's treatment, and their reaction to professional services.



**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
OFFICE OF HUMAN DEVELOPMENT SERVICES  
**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION**  
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