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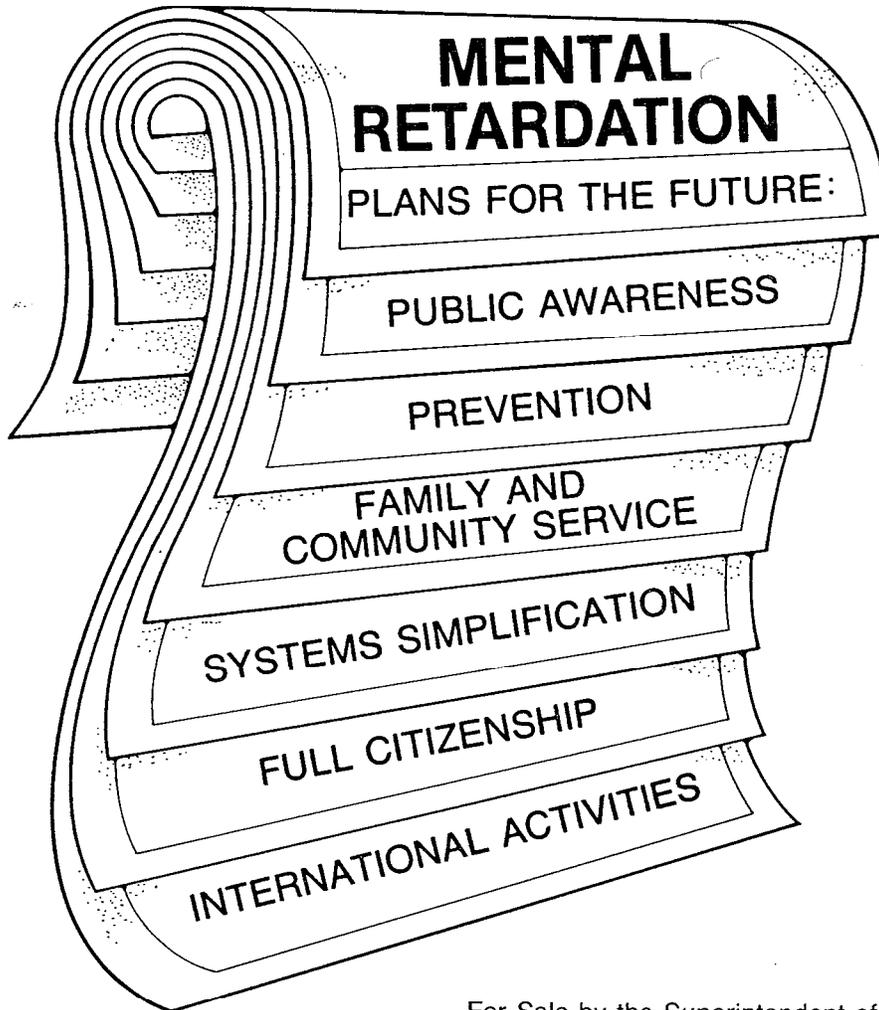
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PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
U.S. DEPARTMENT OF HEALTH AND HUMAN
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Washington, D.C. 20201

Report to the President



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

MAR 7, 1985

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

Dear Mr. President:

We are pleased to transmit to you the 15th annual report of the President's Committee on Mental Retardation entitled, Mental Retardation: Plans for the Future. The committee has worked hard and long on this formidable task, and presents its essential findings in the pages that follow. What emerges from this document is a problem that is massive and multifaceted, but with many of its parts clearly open to solutions. Other parts must yield to further research. Still others appear to have benefited by our success in the past in dealing with the broader problem of the disadvantaged in our society.

The committee has looked at the problem with awareness that, important as it is, mental retardation is not the nation's only social problem, and that it cannot make unlimited demands on limited resources. The committee finds, however, that much can be accomplished through better use of what is now available, and makes the important point that the investments in prevention and human development, wisely planned and administered, can earn significant national dividends.

Sincerely,

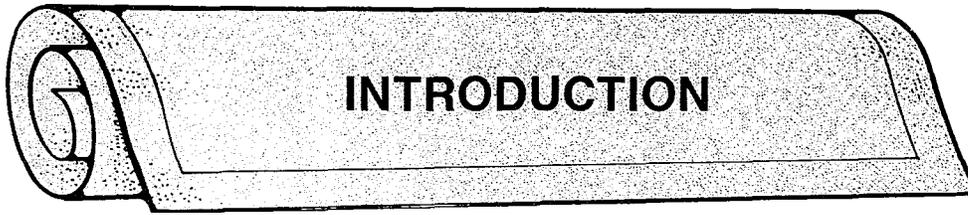
Margaret M. Heckler
Chairperson

Enclosure



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Mr. President:

Since appointment to the President's Committee on Mental Retardation, we have worked diligently toward achieving the goals and objectives designated by the president's Executive Order for this committee, to build for the future of the people who we represent, our citizens with mental retardation.

Our building plans rest upon a firm foundation, a foundation that began with the parents and relatives of family members who were mentally retarded. In the early 1930's, it was parents who first recognized the gaps and deficiencies in services for children who are mentally retarded, and set about to fill the gaps and ameliorate the deficiencies. It was parents, banded together in communities throughout the United States, who first sought to provide services for their children who were denied educational, vocational, social, and recreational opportunities merely because they were mentally retarded. And again, during the same time period, it was parents who launched fundraising campaigns to generate money for improved services in the state institutions in which their children resided. Parent-sponsored grassroots activities first coalesced in 1950 with a national initiative that served as a social catalyst at local, state, and national levels, to galvanize political change, modify public attitudes, and stimulate and support professional attention.

With the establishment of the President's Panel on Mental Retardation in 1961, a new structure was placed on the firm foundation that parent groups had effectively laid to combat mental retardation. This was further strengthened by the establishment of the President's Committee on Mental Retardation in 1966.

Past committee members, acting as singular individuals, or in concert with colleagues, focused on prevention through biological and environmental intervention; developed programs insuring that

people who are mentally retarded would have access to equal opportunities in education, employment, housing, transportation, and health and social services; and fought for the human, civil, and constitutional rights of all citizens who are retarded. To promote these activities, they sought advice and obtained information from various groups within government, from universities, and from concerned consumer and professional organizations.

To meet the challenge of building for the future, present committee members carefully studied the accomplishments of their predecessors. Areas of continued need and problems involved in reaching the goals and objectives were identified.

Recognizing the general lack of public understanding about mental retardation, and responding to the PCMR mandate for "development and dissemination of such information as will tend to reduce the incidence of retardation and ameliorate its effects," the Subcommittee on Public Awareness was formed. It functions as a clearinghouse for the dissemination of informational material generated by other subcommittees. Most importantly, it promotes activities that encourage interest and participation from the general public.

To attack the major goal of reducing the occurrence of mental retardation, the Subcommittee on Prevention was formed to expand programs of previous committees, as well as further efforts in providing new solutions.

The responsibility of ensuring that citizens who are mentally retarded have access to equal opportunities in education, employment, housing, transportation, health, and social services was delegated to the Subcommittee on Family and Community Services. Through commendably hard work, the goal of returning people with mental retardation from institutions to their communities has been achieved in many areas of the country. However, with this accomplishment has come the serious

challenge of providing equal opportunity access to facilities and services. A major activity of this subcommittee has been to develop a plan dealing with these problems.

Laws and programs affecting people with mental retardation emanate from many departments of government, including the Departments of Health and Human Services, Justice, Labor, Housing and Urban Development, and Education. A lack of coordination among these departments often results in confusion, duplication, and poor management. To deal with these problems, the Subcommittee on Systems Simplification was formed. The first plan the subcommittee developed addressed the issue of providing living facilities for the people returning to their communities from institutions.

To protect the human, civil, and constitutional rights of citizens who are retarded, the Subcommittee on Full Citizenship was established. This committee's focus centers on the civil and constitutional rights of all citizens

who are retarded, in the same way as we assure equal rights for all citizens of this country.

But the President's Committee on Mental Retardation recognizes that our country does not exist in isolation from the rest of the world. Mental retardation is not our problem alone. It is a worldwide problem. To underscore our strong convictions on this, we have established the Subcommittee on International Activities to focus on these concerns.

The members of the President's Committee on Mental Retardation serve as advocates, acknowledging the need to identify problems, evaluate programs, and participate in appropriate educational activities that serve the best interests of people who are mentally retarded. This report addresses these needs, and demonstrates this committee's commitment to implementing the objectives of this nation and its President in serving the best interests of people who are mentally retarded.



The goal of the Subcommittee on Public Awareness is to heighten public awareness about the conditions of mental retardation and the needs of our special citizens in the areas of prevention, full citizenship, community and family living, and employment. We believe that only through public awareness, and the acceptance of people who are mentally retarded, will quality assurance and continuity of programs be assured, as well as jobs created, education expanded, and prevention efforts implemented.

A LOOK BACK

Undeniably, parents and relatives have been the primary force in developing public awareness programs on mental retardation. Parents realized that if they

joined forces, they could make a difference on behalf of all people who are mentally retarded. By working together, parents created mutual support systems in a dramatically effective pioneering effort that brought the issue of mental retardation before the people. Parents challenged both the traditional image of mental retardation and the concomitant societal rejection and discrimination. In the initial Executive Order establishing the President's Committee on Mental Retardation, one of the functions of the committee was "the development of such information, designed for dissemination to the general public, as will tend to reduce the incidence of mental retardation and ameliorate its effect." In the revised Executive Order, issued March 28, 1974, this function was expanded to provide for "development and dissemination of such

information." Under this mandate, previous committees have developed and published information booklets and reports that have augmented the informational efforts of State and local governments, professional organizations, foundations, and other private and voluntary organizations. However, we believe that there still remains a large informational gap about mental retardation at the grassroots level of our society.

A LOOK AT THE PRESENT

The initial objectives of the Subcommittee on Public Awareness were:

- to encourage increased involvement with persons who are retarded by churches in the United States;
- to solicit support of civic organizations and youth groups;
- to develop close ties with the media, including, but not limited to, television, radio, newspapers, and magazines, in order to focus on the best methods of informing the public of the continuing needs of our citizens who are mentally retarded;
- to enlist help of public relations firms, in order to form a comprehensive media plan;
- to develop outside private-sector funding sources that would allow us opportunity for implementing a national media campaign; and
- to seek help from nationally known people to provide public service announcements, and develop scripts for media shows which focus on needs of our citizens who are mentally retarded.

The Committee Accomplishments:

The President of Rotary International agreed to let us use their theme: "Mankind Is One". A PCMR member hand-delivered a letter to the President of Rotary International in Toronto, Canada, in 1983, expressing our appreciation, and President Reagan commended Rotary International for their exemplary work in the field of mental retardation.

Churches have been contacted, and a stimulus has been given to start programs within their respective congregations for citizens who are mentally retarded.

Plans have been made for distribution of

educational public service announcements regarding mental retardation.



Our workers who are mentally retarded stay with us and learn their jobs well. It is good business to have them.

Aside from standard mailing to PCMR constituency groups, distribution of the annual report, *The Mentally Retarded Worker: An Economic Discovery*, and an attached press release was sent to each of the Fortune 500 companies employing more than one hundred people. A copy of the report, with a press release, was given wide distribution to newspapers, radio, and television stations.

In the fall of 1983, the first Community Forum on Employment of Handicapped People was sponsored. It was held in Tucson, Arizona, and directed by a member of PCMR. The success of this forum led to the development of a manual to guide others in preparing forums throughout the country.

Members of the President's Committee have been significantly involved in working with other agencies, organizations, and forums in broadcasting findings, promoting visibility, and assembling research concerning the field of mental retardation. Members give speeches; attend meetings, symposiums, and forums; and coordinate with a number of groups.

Committee members have participated in Special Olympics events, including the International Winter Special Olympics games at Park City, Utah, in 1985.

Special news bulletins have been arranged for disbursement throughout the year, to delineate the advances in the field of mental retardation as well as document needs.

An international display has been designed to show at conferences on mental retardation. The display graphically illustrates the current status and future potential of people who are mentally retarded.

A yearly projection of radio and video public service announcements has been pledged, with targeted dates of 1984-85.



We can be winners, too.

In 1984, we began an annual scholarship for advanced graduate study in the field of mental retardation. A private sector donation supported this special accomplishment. The objective of the scholarship program is to recognize those people who work directly with citizens who are mentally retarded, and to encourage bright students to embark on careers in mental retardation. The first annual scholarship was awarded to Karin J. Stromswold, who in spite of a palsy-related disability, graduated magna cum laude and summa cum laude in psychology, and is

currently a first-year medical student at Harvard Medical School. Karin was identified as demonstrating the volunteer spirit encouraged by this Administration. She worked extensively with handicapped students during summers and after school. She has been a strong advocate of the rights of people who are disabled.

Karin Stromswold



The PCMR scholarship program has continued. This year more than 4000 applicants were sent to universities and colleges throughout the nation. Several hundred applications were reviewed in the final selection for the 1985 awards.

Special needs adoption is another vital commitment in this committee. In support of the initiative on the adoption of special needs children within the Department of Health and Human Services, the President's Committee on Mental Retardation is actively represented at weekly and bi-weekly meetings. The President's Committee is represented at the annual HHS National Adoption Week observance, which has a goal to increase public awareness of the 33,000 children who have special needs, require foster care, or who are waiting for a home.

The Subcommittee on Public Awareness has prepared a brief history outlining the memberships and accomplishments of past committees. This will inform the public of the committee's function, its relationship with Federal agency activities, and its contributions towards promoting the goals and objectives of the Presidential Orders.

LOOKING TO THE FUTURE

Acceptance of people who are mentally retarded, the success of prevention efforts, and the provision of facilities and services that are needed are, to a very great degree, dependent upon an informed public. To this end, the Subcommittee on Public Awareness is committed to working in con-

cert with the other subcommittees to provide information to the public focused on each of PCMR's subcommittees. The Subcommittee on Public Awareness is further committed to generating and disseminating information that will narrow the informational gap about mental retardation at all levels of our society.

PLAN FOR PREVENTION

The President's Committee on Mental Retardation remains committed to its primary goal of reducing the occurrence of mental retardation. To develop our building plan in this area, a study of past prevention efforts yielded a wealth of important information regarding the causes of mental retardation that had been identified, and the intervention strategies that had been employed.

More Than 100 Genetically Determined Biochemical Disorders of Metabolism That May Produce Mental Retardation in the Unborn Baby Have Been Identified.

To deal with these problems, services have been developed to provide genetic counseling for parents; screen newborn infants; screen segments of the population to identify individuals and couples at risk in having affected children; provide prenatal genetic diagnosis; and initiate early treatment of affected children.

Neonatal Intensive Care Improves the Outlook for High Risk Infants.

A national network of neonatal intensive care units has been established.

Poor Nutrition for the Baby and Mother Has Been Linked to Impaired Brain Development and Reduced Intellectual Performance.

Nutritional programs for mothers and infants have been established.

Specific Pre- and Perinatal Risk Categories Have Been Identified, Which Include Teenage

Pregnancy, Rapidly Consecutive Pregnancies, Previous Poor Pregnancy Outcome, Food Faddism, Heavy Smoking, Alcohol Abuse, Chronic Systemic Disease, and Serious Over-Or-Under Weight.

Many excellent programs of education in preparation for parenthood have been developed and are being used.

Heavy Metal Poisoning is a Serious and Clearly Preventable Cause of Mental Retardation.

National educational programs to improve the environment have reduced these dangers.

After the First Critical Months of Infancy, Accidents Are the Leading Cause of Brain Damage in Children.

Legislation initiatives were developed by many states to pass laws enforcing automotive safety seats for infants and children.

Infections and Immunological Reaction During Gestation or in the Baby Are Recognized Causes of Brain Damage for Infants.

Immunization programs have prevented several thousand infants from developing brain damage.

Drugs Represent Another Source of Danger.

Information programs have been developed to bring attention to these problems.



Even though you've been exposed to German Measles, being immunized should protect your baby from harm.

The importance of early infant stimulation, mother training, home teaching programs, Head Start, and special education in ameliorating the effects of mental retardation have been emphasized.

UNDER THE PRESENT COMMITTEE, PROGRESS HAS CONTINUED

In June, 1982, during the first meeting of the newly appointed members of the President's Committee on Mental Retardation, the objectives for the committee were defined. Prevention was identified as the highest priority.

In September, 1982, a National Prevention Showcase and Forum was co-sponsored by PCMR and the Atlanta Association for Retarded Citizens, Incorporated. The proceedings of this conference were collated and printed by PCMR.

The committee approved for printing a monograph entitled, "The Role of Institutions of Higher Learning in Preventing or Minimizing Mental Retardation."

The development of a model state plan was initiated. A preliminary document relating to the biomedical aspects of mental retardation for this plan has been developed.

In November, 1983, a conference, "Assessment of the National Efforts to Combat mental Retardation from Biomedical Causes," was

sponsored, and a document reflecting the tone of the conference deliberations has been completed.

In May, 1984, a bilingual national open forum, "The Prevention of Mental Retardation and Focusing on Socio-environmental Causes," was held at Boca Raton, Florida, in conjunction with the Palm Beach County Association for Retarded Citizens, the Florida Atlantic University Exceptional Student Education Department, and Palm Beach County. A document of this conference is also being prepared.

Our committee notes success of educational programs, which have resulted in a large number of states passing legislation that mandates the use of safety seats for infants and children in automobiles.



Thanks to the safety seat, I still have a healthy baby.

A coalition on prevention, involving advocacy organizations, interested public and private groups, medical associations, and PCMR, is currently being formed.

The model state plan is being completed. As part of the nationwide prevention effort, a meeting has been planned to present this information to representatives from all states and regions.

Plans are in progress for a nationwide public awareness campaign on prevention which will focus on future mothers and fathers. Public service announcements and an informational pamphlet are being developed.



If I have a baby, it's good to know what I can do to prevent mental retardation.

A PLAN FOR THE FUTURE

Mr. President, we share your concern that unless active prevention efforts are intensified, three-and-one-half million children who are retarded will be born by the end of the century. This figure will add to the six million citizens who are retarded now in this country. Our report outlines the complexity of this problem, and the progress that has been made identifying and implementing prevention strategies.

We believe that to achieve the goal of reducing the occurrence of retardation, the role of the Federal government should be to implement a plan which would include the following:

- a. Use a nationwide, ongoing informational program directed toward mothers, future mothers, and their

families.

- b. Encourage and support community-based prevention programs.
- c. Encourage adoption of state prevention plans that will:
 - Identify specific needs;
 - expand public interest;
 - encourage collaboration in the use of existing resources;
 - implement strategies for screening and immunization programs; and
 - provide support structure for community-based programs.
- d. Develop an initiative that would direct funding into areas most productive in eliminating biological and social or environmental causes of mental retardation.
- e. Develop and support funding for research strategies in the areas of biological and environment prevention.

The President's Committee on Mental Retardation believes that its efforts, and the work of those who preceded us, provide solid groundwork for this important prevention plan. We are prepared to proceed in working on this monumental task.



The preservation of the family structure and its extensions is one of the most important societal values in our American culture. An equally important value is ensuring that each individual is enabled the maximum opportunity to develop to his or her fullest potential as a valued, contributing member of society.

These values are often taken for granted until barriers are raised which prevent achieving them. People who are mentally retarded have had a long history of facing such barriers. They have been separated from their families because of a lack of adequate family and community support services. The lack of these services has also resulted in our

special citizens being devalued, separated from their communities to spend their lives in segregated facilities, and denied opportunities to be contributing members of society.

Although great strides have been made to correct these senseless injustices by providing family and community support services, much remains to be done. The Subcommittee on Family and Community Services believes that three major national issues need to be addressed:

- quality and continuity of services;
- vocational and employment opportunities and
- dual diagnosis.

Since its inception, PCMR has recognized the importance of family input into the national policymaking process, and has continued to strive toward providing parents with a national forum. PCMR has been responsive to parents and families of people who are mentally retarded, by sponsoring information and planning conferences and publications, which address a wide variety of important topics—such as effective service programs in prevention, employment, and deinstitutionalization. Family issues have been an important component of these conferences and reports. For example, in PCMR's 1978 report to the President, *Mental Retardation: The Leading Edge—Service Programs That Work*, the committee highlighted new directions, "which will richly influence the delivery of services to citizens who are mentally retarded and their families for years to come," including:

- Incentives to Families
- In-Home Service
- Parent Participation Options
- Assistance for Siblings
- Programs for Low Income Families
- Family-Teacher Relationships
- Support the Home First
- Security for Parents
- Parent-to-Parent Peer Relationships
- Consumer Advocacy Systems

When the newly appointed members of PCMR's Subcommittee on Family and Community Services first met in June, 1982, they pledged to work towards the following goal during its tenure:

"To enhance the quality of life for individuals with mental retardation as they progress from family to community, by heightening public

acceptance, and by influencing the provisions of a full continuum of effective services."

In setting out to work on this goal, the committee interviewed parents for their unique perspectives, and their assessment of the quality and continuity of services which family members who are mentally retarded currently receive. The "new direction", which PCMR took in 1978, was re-examined to see if it was becoming a reality.

The subcommittee conducted a series of in-depth, unstructured interviews across the country, to provide parents with a forum to comment about the quality and continuity of services. Thirty-seven parents and caring relatives were interviewed. They represented a wide cross-section of individuals, including: a sampling of age and sex of the parent or caring relative; age and sex of their family member with mental retardation; geographic location (regional as well as urban and rural); ethnic background; and socioeconomic status.

The interviews demonstrated that parents have a unique perspective to offer, and are anxious and willing to be heard. The interviews also revealed a rich potpourri of parental sentiments about the nation's quality and continuity of services. Although each person interviewed spoke from the vantage point of his or her particular family member with mental retardation, certain common themes appeared, centering primarily around the impact and needs of having a family member who is mentally retarded, and the need for service improvements.

QUALITY AND CONTINUITY OF SERVICES: THE PARENT PERSPECTIVE

Diagnosis: When parents first find out that their child is mentally retarded, it is a time of great emotional upheaval. Universally, the parents who were interviewed discussed feeling overwhelmed with such emotions as disbelief, guilt, fear, grief, anger, confusion, panic, and helplessness.

Most parents learn of the diagnosis of mental retardation from members of the medical profession. Several parents recounted that when they needed and wanted a "trusted advisor," their doctor was insensitive and not well informed about mental retardation, service options, advances in programmatic areas, and support services such as

parent associations. While many parents seemed to feel that their doctors responded inappropriately at the time of diagnosis, some parents acknowledged that the emotional upheaval which they were experiencing shrouded perception of their doctors in a negative cast.

Some parents did have doctors who were able to associate with the emotional stresses which parents experience. In so doing, they were able to provide support and information, and facilitate linking parents with appropriate outside resources. These fortunate parents with knowledgeable doctors felt that it made a critical difference in their ability to personally cope with, and be responsive to, the needs of their child with mental retardation.



Having a doctor who understands mental retardation will help us provide the best opportunity for our child.

Transition Points: The experience and feelings shared by the parents who were interviewed revealed that there are other difficult times in families' lives, in addition to the time of the initial diagnosis of mental retardation. The developmental stages in any child's life, and the transition points which these stages represent, can be stressful to both parent and child. When the child is mentally retarded, however, these transition points are much more difficult.

Decisions on the residency of a child with mental retardation, especially decisions centering around whether the child should continue to live at home, were particularly problematic for the interviewed parents. Regardless of the precipitating factors for making a decision about the child's living situation, the parents who were interviewed revealed that it is a traumatic period. It is a time

when there is a great need for reliable and complete information about service options, as well as outside emotional support. The decision is one which impacts on all members of the family.

A common theme expressed by parents was that it is critical to find a residential setting which will not lead to severed family ties.

Family Impact: A child with special needs has a strong impact on the family unit. The most common problems which families seem to encounter are: financial difficulties; emotional stress; physical drain; resentful siblings who feel "left out" or neglected because of the attention given to the family member who is mentally retarded; the problem of balancing the special needs of the child who is mentally retarded with the needs of other family members; and difficulties in doing "normal family things," such as going out to dinner, family outings, and taking family vacations. Two severe reactions were the burn-out, which results from the awesome and overwhelming feeling of responsibility ex-



It's a good thing we can get help to keep our child who is mentally retarded at home.

perienced for the family member who is retarded, and the aspect of it continuing to be a twenty-four hour a day job. Despite these difficulties, a common feeling was that having a child who is mentally retarded greatly enriches the family.

The interviewed parents agreed that good outside support programs make a critical difference in family adjustment, and in how well the relative with mental retardation is integrated into the family.

Parental Roles: A number of external pressures, systems, and authority structures exist which make it easy to relinquish parental responsibilities. Because of this, it is often difficult for parents to maintain a sense of parental control and involvement with their child who is mentally retarded. Although the parents who were interviewed identified these factors as problematic, they believed strongly that they have a critical role to play in the lives of their children, whether they live at home or in an outside residence.



If we unite in our efforts, it will help our children who are retarded.

Interestingly, the advocacy role envisioned by parents is one of an individual, as well as systemic, advocate.

SERVICE NEEDS AND IMPROVEMENTS

Discrete and systemic gaps: The service gaps perceived by interviewed parents varied depending upon the age of their child, geographic region in which they lived, and whether their child lived at home or in an alternative residential setting. The various gaps which were identified included:

- more comprehensive, less expensive, and

better respite and temporary in-home caretaker services;

- summer camps, after-school, and weekend activities;
- recreational activities;
- pre-vocational and vocational training;
- more and improved early intervention services, (including increased use of the Montessori method);
- more speech therapy and general communication skills teaching; and
- better adult and retirement age services.

Quality: Interviewed parents unanimously felt that continuous and sufficient funding of programs and service providers is a key to ensuring the quality of services for their children who are mentally retarded. An equally essential element of high quality services identified by Interviewed parents is the service system's responsiveness to the particular needs of their child.

Continuity: In terms of continuity of services throughout life, a common theme which emerged from those parents who were interviewed was the concern about adequate services once their children were no longer covered by services under the Education for All Handicapped Children Act. In addition to the need for some permanence and continuity in the types of services available from year to year, the interviewed parents stressed the need for day-to-day stability in services.

Finally, in keeping with a perceived need of stability for their children, the parents felt that there is a critical need for service providers to be attentive to and respond to the special transition difficulties which occur when a person who is retarded enters a new program or service setting.

Concerns about the future: While it seemed to be a concern foremost on the minds of the older parents being interviewed, most parents expressed fears about what would happen to their children who are mentally retarded when the parents died, or were no longer capable of taking care of or overseeing services for their children.

Parental concerns about their children's needs, once the parents have died, centered around two major issues: (a) leaving their children with sufficient financial resources; and (b) ensuring that someone trustworthy is directly responsible for providing services for their child.

With the current trends of deinstitutionalization to community-based services, and legal restric-

tions on new institutional placements, parents are concerned that even the option of institutionalization is becoming less and less viable. They want some tangible assurance that their child who is retarded will be provided with a sufficient support system once they are no longer in the picture.



Good care of our child who is mentally retarded should not depend on how long we live.

All of the parent interviews conducted by the PCMR Subcommittee on Family and Community Services are being condensed into a summary videotape that shares the personal sentiments of these parents with a variety of audiences. The tape and companion report will be distributed widely for informational and planning purposes, sent to: State and local government agencies with program planning and administrative responsibilities; professionals; religious and service organizations; and parent and consumer groups.

After reviewing videotapes of the interview, our subcommittee members delineated three additional issues which we feel need to be addressed:

- to identify and respond to the needs of persons who are mentally retarded within institutions, and those who have been deinstitutionalized and have no family support system;
- examine feasible ways in which institutional buildings no longer serving persons with mental retardation can be utilized; and
- develop a fixed, identifiable, comprehensive and coordinated point which is responsible for services to people who are mentally retarded.

VOCATIONAL AND EMPLOYMENT

OPPORTUNITIES

Another activity of the Subcommittee on Family and Community Services has been to follow up on the activities initiated by previous PCMR members, to address the issue of employment opportunities for people who are mentally retarded. During March, 1982, PCMR sponsored the National Conference on Employment and Mentally Retarded People, in conjunction with the President's Committee on Employment of the Handicapped, and the Association for Retarded Citizens of the United States. The information generated at that conference was highlighted in our 1983 report to the President, *The Mentally Retarded Worker: An Economic Discovery*. The report details why the employment of adults and youth who are mentally retarded is an economic boost to the taxpayer and employer, as well as to the worker who is mentally retarded.

Emerging from the National Conference and the PCMR report, is the reminder that comprehensive planning by local communities is a necessary ingredient to maximize employment opportunities for people who are mentally retarded. With this overall theme in mind, the Subcommittee on Family and Community Services, on behalf of PCMR, will be sponsoring community forums on employment of people who are mentally retarded, in concert with the President's Committee on Employment of the Handicapped and the Association for Retarded Citizens of the United States. In this effort to continue both the work and alliance begun by the National Conference, four substantive employment issues will be addressed:

Work Preparation: Identification of the pre-work instructional needs of persons who are mentally retarded. Analysis of the benefits and deficits in available education and skill training programs, including: special education; vocational education and rehabilitation; the Job Training Partnership Act programs; sheltered workshops; community living programs; community college and adult education programs; and private trade or on-the-job training programs.

Work Development: Analysis of the attitudinal barriers which serve to minimize the employment potential for people who are mentally retarded. Examination of subsidized and special programs designed to foster employment.

Work Procurement: Analysis of the opportunities for people who are mentally retarded, preparing to enter the work force through such alternatives as sheltered workshops, work training, and transition centers.

Work Placement: Identification of the issues, concerns, and problems in the areas of counseling, and job development; and recognition of the worker who is mentally retarded. The information exchange with respect to these work issues will serve as a focal point for development of a consensual, comprehensive community plan, to implement concrete improvements that stimulate vocational and employment opportunities for the special needs citizen.

Additionally, the committee has produced a document to assist in conducting community forums on employment of handicapped people, based on a successful forum held in Tucson, Arizona.

Dual Diagnosis

The third major area of activity of the Subcommittee on Family and Community Services during the past year has been the issue of dual diagnosis. We are concerned about the "lost population" of individuals who are both emotionally handicapped and mentally retarded.

A BASIS FOR FUTURE PLANS

Mr. President, based upon the efforts of our subcommittee to regain a sense of parents' perspectives, we offer the following observations:

It is necessary to expand our nation's medical and related health professionals' knowledge of mental retardation, and to increase their sensitivity to the needs of people who are mentally retarded, and to their family members.

Parents are playing critical roles in the lives of their children who are mentally retarded,

and should be encouraged to continue these important contributions.

Although great strides have been made in the development of information and referral, technical assistance, as well as clearinghouse services, parents often lack information and knowledge of these resources.

Parental responsibilities can be eased, and the quality of family life can be enhanced, through support groups and respite services. In addition to parenting roles for their individual child, parents should be systemic advocates and supportive of one another.

The quality of services is dependent upon stable and sufficient funding; low staff turnover, adequate training of service personnel, particularly non-professionals; an environment which is individualized, positive, loving, and staffed with dedicated workers; parental involvement and advocacy; and external monitors and sanctions.

Continuity of services is a function of ensuring the necessary support services are available over the life-span of the person who is mentally retarded; maximizing the day-to-day stability of services; and alleviating the trauma of transitions to new services and different settings.

As we have noted, parental concerns are widespread about the future of their children who are mentally retarded, once the parents have died, or are no longer capable of providing care.

The contributions of the members of the Subcommittee on Family and Community Services, in the areas of quality and continuity of services, vocational and employment opportunities, and dual diagnosis, are a significant beginning to the important work which remains to be done. It is our hope and expectation that the groundwork laid, combined with continued information gathering, will provide the necessary data to enable our subcommittee to recommend major national policy initiatives.



PLAN FOR SYSTEMS SIMPLIFICATION

The work of the President's Committee on Mental Retardation has been and will continue to be supportive of established national goals, which are important to all citizens who are mentally retarded, and to their families. The committee appointed by this President is organized to efficiently meet its mandate to advise the President on issues related to mental retardation, and to provide effective representation for this large and important segment of our population.

In September, 1982, the Subcommittee on Systems Simplification was formed as one part of the organizational efforts of the newly appointed members of the President's Committee on Mental Retardation. The subcommittee seeks to accomplish goals pursuant to the Executive Order, which established PCMR and directs its activities.

Specific objectives which the Executive Order mandates the committee to address are:

- evaluation of the adequacy of the national effort to combat mental retardation, followed by recommendations to the President;
- identification of the potentiality of Federal programs for achieving Presidential goals; and
- provision of adequate liaison between Federal activities and related activities of State and local governments, foundations, and other private organizations.

To accomplish these objectives, PCMR established liaison with Federal agencies serving individuals who are mentally retarded. Committee members dealt with the Departments of Health and Human Services, Housing and Urban Development, Labor, Education, and Justice. Liaison also was established with selected states; with local public, non-profit, and private agencies and organizations and; with individuals. PCMR has identified as an important national concern questions concerning appropriate living arrangements for

persons who are mentally retarded, and the manner in which the government can facilitate such placements.

The Issues

The Federal government has a stated policy of placing persons who are mentally retarded in a "least restrictive environment," and a further policy of community placement or "deinstitutionalization." However, the Federal government has not given parents, providers, State and local agencies, or other interested organizations and individuals, precise guidelines on what "least restrictive environment" or "deinstitutionalization" means, nor has any comprehensive analysis been made of the impact of this policy on the community-based services systems.

Presently, about eighty-five percent of persons who are mentally retarded living out-of-home are housed in public operated and financed institutions; fifteen percent in community-based facilities. Sponsorship of those housed in community facilities should be of interest to the Administration, because it clearly manifests the local, private initiative. Seventy-three percent of local facilities are sponsored by private individuals and organizations. Only ten percent were sponsored by states, one percent by local government, and two percent by the Federal government. More than half of the community-based group homes were started by private individuals with a personal interest in the field.

Reviews of the barriers to implementation of group homes by PCMR, and by the General Accounting Office, have indicated that restrictive zoning or permit requirements at the local level thought to be overly restrictive were not of great significance. Rather, operators reported that *Federal and State regulatory and licensing procedures* create by far the most *critical problems*.

The Extent of the Problem

Data regarding the number of individuals who are mentally retarded in institutional care ready for community placement, in community placement, or receiving or requiring services, are controversial at best. According to a report prepared in May, 1983, by the General Accounting Office, there were about 138,600 persons who are mentally retarded in public institutions in the United States in 1980, of which about 20,000 could or should be accommodated in community-based living facilities. The National Association of Retarded Citizens of the United States, and the National Institute for Mental Health, dispute these figures and indicate a much greater need.

Defining the task of deinstitutionalization, the General Accounting Office has further indicated that "firm data on the numbers of mentally disabled persons in institutions who could be better served in group homes were not available—some groups believe all (138,600) could be better served in group homes."

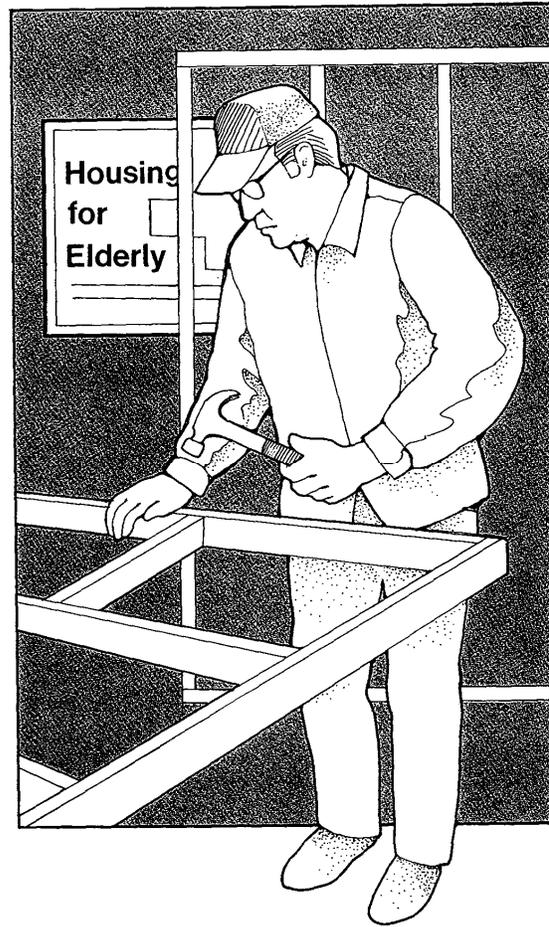
Very conservative assumptions regarding capital and operating costs for the low estimate of relocating 20,000 people indicate this deinstitutionalization effort could require up to one billion dollars for facilities, and two hundred million dollars per year for services. Programs could cost an additional five hundred million dollars per year. To fully deinstitutionalize all residents could cost ten times that much. These costs could, of course, be offset by the savings which would result from terminated institutional programs.

Awareness of the fiscal impact on the country's resources is necessary to understanding the other problems attendant to it. It is clear that dollars alone are not the answer. In fact, extra monies may not be required after the transition is accomplished. The answer lies in imaginative approaches to solving the problems, and in the more efficient and directed use of Federal funds and Federal regulatory powers.

The Role of Group Homes

The 1980 census indicates that, nationally, an estimated 46,000 individuals who are mentally disabled, including those with mental retardation, resided in an estimated 6,500 group homes, slightly over 7 per home average. Although precise data is not available, it is thought that one-half (23,000) of this estimate refers to people

who are mentally retarded.



Persons with mental retardation need a place to live in the community, too.

Of these 6,500 residences, approximately one percent were established before 1960, ten percent between 1960 and 1970, and 68 percent since 1970. There is inadequate information on the other 21 percent. To implement a deinstitutionalization program, simply to house the conservative estimate of 20,000 people who are appropriate for community placement, would require doubling the current total number of community-based facilities.

In terms of funding sources, 57 percent of group homes received start-up funds from the private sector and 14 percent from charities. Only 2.2 percent of start-up funding was provided by the Department of Housing and Urban Development. Other Federal agencies provided about 12.5 percent of start-up funds. The remaining 14.3 percent came from miscellaneous sources.

State Actions

Several states have begun to deal with the issues and the problems of deinstitutionalization in a comprehensive way. Many of the states have introduced, or are in the process of introducing, legislation to oppose, clarify, or implement deinstitutionalization programs. We have heard a special concern about the lack of continuity of care, and lack of comprehensive treatment plans, for individuals as they move to community settings. This also seems to be a consistent concern of parents, providers, and clients, who identify the primary issues as:

- lack of a comprehensive deinstitutionalization strategy and plan which coordinates fiscal resources, programs, personnel, and functions;
- absence of accountability and responsibility;
- fragmentation of funding; and lack of money to develop a continuum of service and care programs necessary before removal of large numbers of people from institutions.

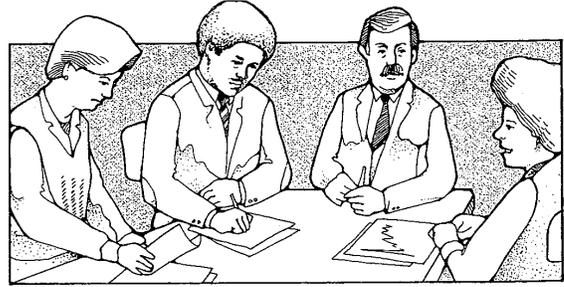
A careful review by PCMR indicates that these concerns apply to the Federal level of effort as well. The General Accounting Office indicates that both startup funding and operational funding are fragmented and poorly coordinated for local facilities. This is evident from the facilities' report of their funding sources to the General Accounting Office, published in May, 1983.

Recommendations

Developing National Policy: In order for the Federal government's effort to complement State efforts, PCMR recommends that the existing policy of deinstitutionalization continue to be pursued, but within specific parameters which address, on a Federal level, the development of a national deinstitutionalization plan. Such a plan should include a comprehensive strategy for:

- funding local facilities where Federal participation in start-up costs is increased, and Federal regulations and guidelines for facilities are simplified;
- continuum of treatment services, and a continuum of facilities, staff, and programs;
- restructuring the Federal role to promote, regulate, and fund community-based facilities, in concert with states, local

government agencies, private providers, and recipients of services and their families.



If persons with mental retardation are going to be deinstitutionalized, we must have ways to care for them in local communities.

Encouraging More Federal Leadership and Coordination: There is no immediate need for additional direct intervention by the Federal government, but there is an evident need for a national strategy and plan to stimulate the construction of at least 500 community-based facilities per year for the next ten years. It is recommended that the Department of Housing and Urban Development be instructed to develop such a strategy and prepare the plan. In order to implement this approach with a minimum of Federal regulation and direct intervention, the following steps are suggested:

- The Departments of Health and Human Services and Housing and Urban Development should be instructed to prepare prototypical master specifications and architectural plans and working drawings for residential care facilities by region of the United States. These proto-typical plans, varying by appropriate construction size and type, should be developed in cooperation with the American Institute of Architects, the National Association of Home Builders, National Association of Building Officials, the Architectural and Transportation Barriers Compliance Board, the County Supervisors Association, the National League of Cities, the National Association of Retarded Citizens of the United States, the National Association of Private Residential Facilities for the Mentally Retarded, and other technically competent, interested parties.

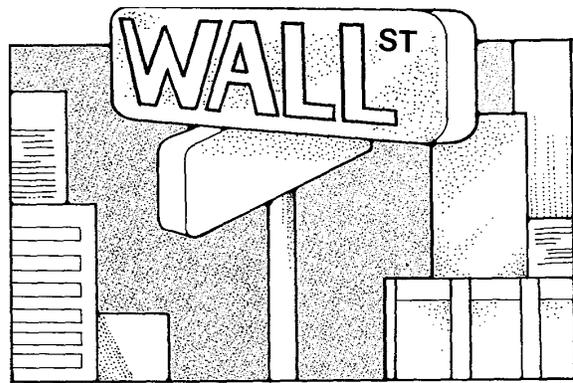
- Upon completion, these plans, working drawings, and specifications should be made available through the Department of Housing and Urban Development regional offices and other local outlets at nominal cost. These proto-typical plans, working drawings, and specifications should incorporate uniform building code requirements and fire safety code requirements, and should be designed to comply fully with Federal, State and local building or permit requirements. Local facility sponsors, if they construct facilities as detailed in these documents, automatically will conform to Federal, State and local licensing regulations. Inspection and certification could be implemented by local building or zoning officials.

Encouraging Private Sector participation:

Banks and other financial institutions could be mandated through appropriate legislation to set aside one hundred million dollars per year in low interest fixed rate thirty-year loans for those facilities. Such loans could be backed by a mortgage guarantee program, underwritten by the State and Federal government, similar to that established for owner occupied housing by the FHA. Since about 500,000 units per year are funded by FHA, GI, VA, or other subsidized ownership policy programs, a prorating of one-tenth of a percent of these funds to housing for citizens who are mentally retarded should not be considered unreasonable.

Conventional practice sets aside approximately one and one-half percent of each monthly debt service payment as a handling fee. A similar handling fee could be instituted and charged to facility operators based upon the following allocation. One percent or two-thirds of this fee could revert to the Federal government as a process fee, and one-half of one percent or one-third of the fee be placed in an operating set aside account to fund the operations of the community facilities operating trust authority described below.

Further, the interest rates for the \$100,000,000 of funding could be provided by institutional lenders at two-thirds the prime rate, and the interest earned by them from this section of their loan portfolio be taxed as a separate, non-integrated item of gross income at prevailing income tax rates. In addition, or in lieu of this write-down, purchase agreements for these loans with FNMA, GNMA, FHLB, or other



Providing incentives to private capital can help build for our needs and save government resources.

secondary lenders at current rates, could also be structured.

The rationale for this institutional financial program, as far as limiting taxable income, is related to the potential cost savings differential between institutional care and community-based care, funded primarily through an entitlement program. Although all estimates of this differential seem to be arguable, there appears to be \$20,000 to \$30,000 savings per capita between the two systems. Whereas the above program may result in approximately \$3,000,000 of taxes foregone, the cost savings per client could be \$20,000 or more per year, or about \$60,000,000 annually, reflecting the Administration's mandate to implement net cost effective system changes.

PCMR suggests that the Administration create a community facilities operating trust authority, composed of a consortium of facility operators, assisted by representatives of Federal, State and local government. This would then provide, through transfer to the authority of either the rights of lien under front money assignment, or the rights of lien under the guarantee programs, powers which would enable it as an oversight trust to intervene in and, if necessary, take over operations of financially insolvent or unstable facilities on behalf of the residents. This trust authority, if it invokes through judicial action (writ of mandamus or other appropriate legal mechanism) a takeover of a facility, will operate it for a limited period until either of two courses of action can be instituted:

- a) orderly relocation of residents to com-

parable facilities in the immediate vicinity; or

- b) a revitalized operating and functioning facility can be turned over to a new or restructured responsible operating entity.

Funding for this trust authority could come from the aforementioned shares in the handling fee, and should be self-sustaining without other appropriation. The goal of this trust authority would be to provide a semi-automatic mechanism, which provides the same continuity of care and program as that allowed for in publicly financed and operated facilities (institutional care). This authority, with its oversight ability, should contain the mechanism for assuring continuity of services and programs in community facilities, which could diffuse one of the legitimate major objections of opponents to deinstitutionalization.

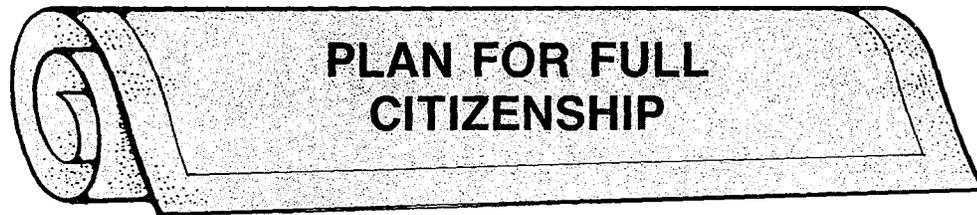
Clarifying Existing Regulations: Several relatively minor changes in existing regulations would permit great strides to be made in improved programming within a continuum of services for persons who are mentally retarded:

- Federal agencies could be directed to prepare an integrated strategy for persons who are mentally retarded for their housing, treatment, employment, and education, in coordination with states and the private sector.
- The Department of Housing and Urban Development could be instructed to designate and define small sized community care facilities as residential, not commercial construction.
- The Departments of Labor and Housing and Urban Development could be instructed to develop a waiver of provisions of the Davis- Bacon Act, where strict enforcement inhibits

both construction and employment goals for handicapped persons.

- The Department of Education could be directed to prepare and publish information on the number of persons who are mentally retarded presently being educated; project annual increases and program needs for teachers and classrooms servicing students who are mentally retarded, as 20,000 institutional residents are transferred into community facilities; and develop a recommended strategy detailing how our citizens with mental retardation are to be educated under current law.
- The Department of Labor could be directed to prepare and publish information on the numbers of persons currently employed who are mentally retarded; forecast employment goals for this population on an annual basis; and prepare a 10-year program, strategy plan, and budget estimate for employment of a targeted population of individuals who are mentally retarded.

As PCMR continues to restructure and strengthen itself to more efficiently implement the Executive Order, the Subcommittee on Systems Simplification, in keeping with this effort, has refined its efforts as well. Its concentration has been on institutionalization, community placement, employment, and education. All areas are of vital concern to the mental retardation community and to this Administration. We consider the above policy recommendations for Federal agencies not only to be consistent with the Administration's policies, but present them as an exciting beginning to solutions for this Administration, and for our nation, as we continue to confront the problems facing our citizens who are mentally retarded.



PLAN FOR FULL CITIZENSHIP

The commitment of the American people to respect and protect the fundamental rights of its citizens is reflected everywhere in our nation. Our country thrives on the diversity of its people. Our dedication to equality under the law inspires us to protect the freedom of all our citizens. When that freedom is denied, or threatened for any one American, it is a cause for concern for all Americans.

Yet it is common knowledge that citizens who are mentally retarded have long suffered extensive discrimination in the exercise of their human, civil, and constitutional rights. PCMR has been in the forefront of the effort to highlight and correct this problem.

Social factors compound the problems created by the systemic denial of these rights. Shunned by society, many people who are mentally retarded have been forced to live dull, unproductive, dependent lives. Too often, ignorance and prejudice on the part of others create a "self-fulfilling prophecy," which dooms persons who are retarded to live far below their potential.

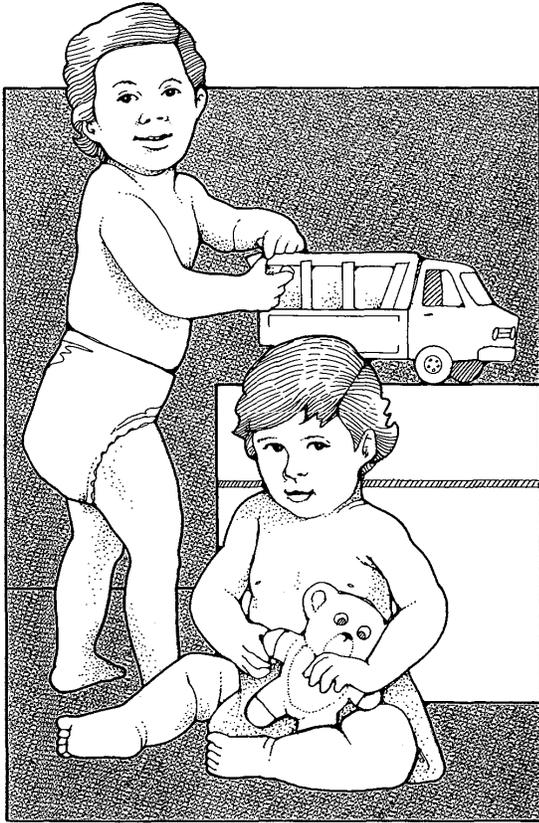
The Injustices

- As has been recently widely publicized, bias on the part of physicians and parents has resulted in withholding essential medical care and sustenance, solely on a diagnosis of mental retardation in some infants, and thus denying full citizenship of those infants.
- Though the right to public education is no longer denied to children who are retarded, constant monitoring is necessary for their education to be effective.
- The freedom of equal access to education, training, employment, social programs, transportation, and housing services has been denied.

- Institutional facilities where persons who are mentally retarded have been placed have failed on too many occasions to provide adequate care and treatment, and have been determined in court cases as harmful to these citizens.
- There are too many examples of a shortage of good community-based residential services for individuals who are retarded.
- Very few persons who are mentally retarded receive any special consideration or treatment in our criminal or juvenile justice systems.
- In old age, few citizens who are retarded can look forward to the availability of services, security, and comfort that the average American enjoys.

Some Rights Have been Assured

- Public Law 94-142, the Education for All Handicapped Children Act of 1975, assured a "free and appropriate public education" for all, setting national standards for special education and providing funds to implement the law.
- Section 504 of the Rehabilitative Act of 1973 guarantees citizens who are disabled equal access to federally supported education, training, and employment, as well as to social, transportation, and housing services.
- Since 1960, with approximately 15 percent of the start-up funds provided by Federal agencies, approximately 6,000 group homes have been developed, housing an estimated 46,000 of our citizens who are mentally disabled.
- As a result of efforts of this Administration and the Congress, the "Child Abuse, Adoption, and Reform Act" (H.R. 1904), containing provisions that insure full citizenship for



Life is equally valuable to the person with mental retardation.

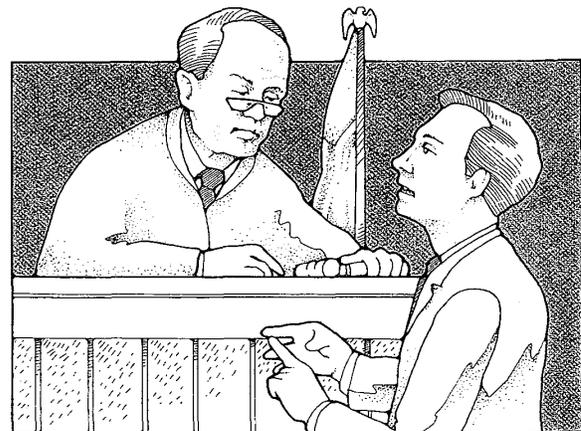
infants with disabling conditions, has been signed into law.

Persisting Obstructions to Full Citizenship

Many school systems still fail to provide appropriate special education services, and although this Administration maintains the original regulations and their safeguards, educational abuses continue. Many children who are retarded are still educated in schools separated from their "normal" peers, and are not provided the opportunity to be in the mainstream of education.

Despite the advances represented by Section 504, problems plague citizens who are retarded in their quest for meaningful employment. As they become too old for public education, many sit at home with nothing to do. Where vocational training is available, it is often conducted in understaffed, poorly supported shelter workshops, or day activity centers. Competitive employment is difficult to obtain, because many employers fail to recognize the potential contribution possible with workers who are retarded, or fail to provide the necessary training and support systems.

Institutional facilities for children and adults who are mentally retarded are still unnecessarily restrictive, and are situated in isolated locations. Residents are sometimes abused. Most community residential facilities have long waiting lists, and thus citizens who are retarded have few choices. In addition, most of the population who are retarded receive inadequate placement assistance and support services. In any emergency, such as the illness or death of a parent, many children and adults who are retarded need short-term respite care, or placement in some form of residential service. Such placement can take months to accomplish.



Being in prison won't help a person with mental retardation to learn the difference between right and wrong.

State prisons currently hold approximately 40,000 inmates who are mentally retarded. Ten to fifteen percent of the populations of juvenile correctional facilities are retarded. Very few receive recognition in any aspect of the criminal or juvenile justice systems. Less than 10 percent of those incarcerated are receiving appropriate treatment. Once released, the majority will return to prison. Given proper attention, this recidivism rate could be reduced drastically.

A mere handful of senior citizens who are retarded can support themselves with pensions, returns on investments, and savings. The few support systems that do exist are frequently unduly restrictive, confining older citizens who are retarded to sometimes expensive, often depressing nursing homes or institutions—not because they are ill, but because no appropriate services exist for them.

Activities of this Committee

The Subcommittee on Full Citizenship has constantly kept a watchful eye on the laws of this country as they relate to mental retardation. We applaud the decisions of this Administration in maintaining the regulations and safeguards in the laws applying to persons who are mentally retarded, and the progress that has been made in expanding their human, civil, and constitutional rights. To fulfill our duty of providing recommendations appropriate to the area of mental retardation, as mandated in the Executive Order that established this committee, the Subcommittee on Full Citizenship developed the following resolutions which were forwarded to you, Mr. President:

THEREFORE, BE IT RESOLVED that the President's Committee on Mental Retardation reaffirms their strong commitment to retaining the existing laws and regulations pertaining to Public Law 94-142 and Section 504 in substantially their present form, and encourages the President to take a positive and public stand to halt all efforts to change these laws through regulatory and legislative reform that would adversely affect citizens who are mentally retarded. Through these laws, the way has been cleared for preparing a large segment of our society to moving from lives of dependency to greater independence by becoming tax-paying citizens. Public Law 94-142 and Section 504, and their implementing regulations, constitute an investment, rather than a burden, to society.

BE IT THEREFORE RESOLVED, that all persons who are mentally retarded including the new-born infants, have the right to be free from the arbitrary denial of lifesaving medical services, and that this right is premised on a recognition that persons who are mentally retarded must be allowed equal access to medical services to preserve their lives, and that such a right rules out any practice which would not allow persons who are retarded their right to life based upon a judgment that the quality of life for a person who is retarded is less than that of other citizens, or any routine policies or guidelines predetermining the withdrawal of life support from impaired newborn babies on

predicted mental potential.

In addition the Subcommittee on Full Citizenship developed policy statements that were subsequently passed unanimously by PCMR. These recommendations, to insure that all agencies and departments within the Executive Branch move in concert with our concept of the President's beliefs, are as follows:

Issue: The Support of Citizens Who are Mentally Retarded Within Their Families, Neighborhoods and Communities.

PCMR Policy Statement: It is the policy of this Administration that, where possible, adults and children who are mentally retarded be provided adequate and meaningful opportunities to remain with their families, or to return to their neighborhoods and communities.

Requested Federal Action: In pursuing this goal, departments and agencies will support persons who are mentally retarded within their families and within other community settings. The efforts of adults who are mentally retarded seeking independent or family residential settings should be encouraged. All Federal departments and agencies will make or propose whatever changes in current law, regulations, or program practices which are necessary to accomplish sustained community integration of persons of all ages who are mentally retarded.

Issue: The Individual Dignity of Every American.

PCMR Policy Statement: It is the policy of this Administration to assure citizens who are mentally retarded full, integral membership in society, with recognition of their contributions to society, and to their families, neighborhoods, and communities.

Requested Federal Action: All Federal departments and agencies will review their program and employment practices, and make whatever changes are necessary to ensure persons who are mentally retarded the same individual dignity afforded other Americans. By assuring citizens who are mentally retarded access and treatment under federally supported or regulated programs and activities, the Federal government will set an example for the nation.

Issue: The Removal of Barriers to the Social

and Economic Growth and Development of Persons Who Are Mentally Retarded.

PCMR Policy Statement: The Administration will promote opportunities for the social and economic growth and development of each individual. This will free citizens who are mentally retarded from stereotyped treatment and forced dependency, thus permitting them to enter the work force.

Requested Federal Action: Current laws and regulations protect the rights of handicapped children to free and appropriate public education. Furthermore, these laws and regulations protect the rights of handicapped children and adults to nondiscrimination under federally assisted programs. Such laws and regulations will be enforced vigorously by the Department of Justice and all other Federal departments and agencies. No substantive changes will be made in the regulations currently in effect under either the Education for All Handicapped Children Act, Section 504 of the Rehabilitation Act of 1973. The Departments of Education, Labor, and Health and Human Services will develop and recommend to the President new initiatives designed to assist states in promoting and fostering the successful transition of handicapped youth from school to competitive employment, or productive life activity.

These actions were based on input from a broad spectrum of concerned citizens from across the country. After careful consideration by the Subcommittee on Full Citizenship, and by the entire membership of the PCMR, this information was sent to the President with the

intention of being of assistance in making executive decisions.

Plans for the Future

A legal conference sponsored by the Department of Education, the Office of Special Education and Rehabilitation Services, The Resident Home for the Mentally Retarded of Hamilton County, Ohio, and by PCMR, was conducted to address the issues of social justice, fairness, and human rights. The conference will generate three major documents: a report to the President on the findings; a broad, general report for public distribution; and a text exploring current legal issues and trends.

In addition, there are plans for revised and updated versions of earlier PCMR publications in the field, namely, *The Mentally Retarded and the Law* and *The Retarded Offender*.

The committee will continue to play a major role in assisting the American Bar Association in drafting their standards on criminal justice and mental health, including mental retardation. The standards are now in draft form, and will be published at a later date. These standards will have wide use in the criminal justice system. Law enforcement officials, prosecuting and defense attorneys, judges, and jailors, as well as probation and parole officers, will refer to these standards in carrying out their responsibilities. Legislators on a national, State, and local level will use them in forming legislation. Parents, advocates, and mental retardation program personnel will use them in their quest for improved support services for persons who are mentally retarded involved in criminal and civil judicial systems.

PLAN FOR INTERNATIONAL ACTIVITIES

Mental retardation knows no national boundaries in its incidence, nor in its impact, on the human condition. Advances in scientific knowledge must, therefore, be international in their application. Early efforts to teach persons who are retarded took place in France, Switzerland, Germany, the Scandinavian countries, Japan, and the United States. Major discoveries in the areas of prevention, the use of sheltered workshops for employment, and assimilation of persons who are retarded into the community, have come from countries throughout the world. These innovations have been, and must continue to be, shared among all nations.

Recognizing that it would be a serious omission to confine our activities in mental retardation solely to efforts within the United States, the Subcommittee on International Activities was formed in late 1983. In its first meeting, the mission of the committee was identified as follows: the attainment of a high and stable level of international relations in cooperative resolution of the problem of mental retardation, with focus on preventing and ameliorating the condition.

Activities on the International Scene

After reviewing the international activities of previous committees, the following initiatives were developed and put into action:

- In their private travels, members visited innovative programs for people who are mentally retarded in several countries of the world. A standard letter of introduction to foreign governments and international organizations was prepared for the use of PCMR members on private travel.
- Members met with UN officials and many mental retardation agency directors and researchers from other nations.

- PCMR publications were exhibited at the XVI Pan-American Congress on the Child.
- PCMR has membership on the U.S. Commission for International Youth Year, and is working to help insure successful implementation of the commission's plan.
- In association with the Subcommittee on Public Awareness, a permanent exhibit has been developed to be used at international meetings. Displays can be modified so that



Sharing our knowledge about mental retardation has helped us all.

the theme of particular meetings will be the focus of the exhibit's information.

- In October, 1984, the President's Committee on Mental Retardation, in association with the President's Committee on Employment of the Handicapped, co-sponsored the International Symposium on Mental Retardation in Washington, D.C.

Initiatives for International Participation

Plans are being made to present highlights of PCMR activities at the International League for the Scientific Study of Mental Deficiency, to be held in New Delhi in 1985. PCMR also hopes to provide a significant contribution toward strengthening economic and social liaison with Caribbean and Latin American countries. Attempts are being made to link our activities with the work of the U.S. State Department, in the preparation and conduct of the Third Pan-American Congress on Mental Retardation. PCMR has agreed to co-sponsor this conference in conjunction with the Inter-American Institute on the Child of the Organization of American States, the International League of Societies for

Persons with Mental Handicaps, and the Argentine government.

PCMR plans to participate in selected initiatives of the U.S. Commission on International Youth Year, as well as the International Decade of the Disabled. We encourage U.S. International service agencies, e.g., the Peace Corps and the Agency for international Development, to include information on mental retardation in their public information resource materials, and in education and training projects. Our liaison relations in the field of mental retardation with UNICEF, the Pan-American Health Organization Institute for the Child, the United Nations Center for Social Development, and Rehabilitation International, will be continued.

PCMR plans to update the International Directory of Mental Retardation Resources. We believe there is no better way of developing social and political ties with other countries throughout the world, and in particular with our Pan-American neighbors, than by sharing knowledge with them. In addition, it can bring us to a broader perspective, and to new ideas, in addressing the problem of mental retardation in this country.

SUMMARY

Building

***For yesterday is but a dream,
and tomorrow is only a vision;
but today well lived,
makes every yesterday a
dream of happiness, and
every tomorrow
a vision of hope.***

Out of yesterday's dreams of parents and relatives came the motivation to unite at the grassroots level to initiate needed programs, and to sponsor activities that would fill gaps in services. The dream that is becoming a reality is the improvement in quality of life experienced by family members who are mentally retarded.

This dream began with a cautiously optimistic vision of a tomorrow when local, State and national leaders would work to effect positive change in legislation, public attitude, and professional exper-

tise, encouraging increased sensitivity toward citizens who are mentally retarded. From this attitude came the inspiration to push for initiatives that would someday guarantee this special population their rightful share in the American dream. The resulting foundation formed from this familial motivation and inspiration proved to be an indispensable ingredient in America's solution to the problem of mental retardation; it led to the Executive Order establishing the President's Panel on Mental Retardation in 1961, and the President's Committee on Mental Retardation (PCMR) in 1966.

The 15th annual report to the President, *Mental Retardation: Plans for the Future*, 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. It highlights today's activities in the life of the committee—activities which serve as building blocks for PCMR's continued achieve-

ment of its objectives in the field of mental retardation.

This report promotes a brighter future for our special citizens, who PCMR will continue to faithfully represent by:

- providing leadership in the national effort to reduce the incidence and prevalence of mental retardation from environmental, sociocultural, biomedical, and multifactorial causes;
- increasing public awareness and involvement in the national effort to combat mental retardation by continually developing and disseminating information which addresses effective strategies for preventing mental retardation in future generations, and ameliorating its effects on individuals already so affected;
- providing guidance and direction to foster the establishment and maintenance of programs and services in the community that encourage and support family continuity;
- establishing liaison relations with other agencies involved in programs and services to citizens who are mentally retarded, providing for them the coordinative arm necessary to simplify the systems through which such programs and services are made available and accessible to individuals who are mentally retarded, and to their families;
- executing exemplary advocacy responsibilities to citizens who are retarded by seeking regular audience with the President, the Secretary of the Department of Health and Human Services, relevant cabinet members, and with the Congress, and with State, and local officials, to "provide advice and assistance" regarding effective initiation and enforcement of legislation, regulations, and public policies needed to guarantee the full citizenship rights of individuals who are mentally retarded; and
- engaging in international dialogue and collaborative activities with other countries to assure that the United States is abreast of and contributing to advancements in the field of mental retardation.

The following specific initiatives have been distilled from "plans for the future" described in this report:

- development and wide dissemination of a comprehensive model state plan to prevent mental retardation;
- continued collection of information to regain a sense of parents' perspectives relative to the quality and continuity of services, vocational and employment opportunities, and dual diagnosis;
- provision of leadership in the early development of national policy wherein Federal government efforts complement State efforts, continuing pursuit of deinstitutionalization policies, and concentrating increased efforts on the vital areas of community placement, employment, and education;
- implementation of a legal summit conference to address the issues of social justice, fairness, and human rights;
- revision and updating of earlier PCMR publications addressing full citizenship (*The Mentally Retarded and the Law and The Retarded Offender*);
- active participation in the International League for the Scientific Study of Mental Deficiency to be held in New Delhi, 1985;
- participation in selected initiatives of the U.S. Commission on International Youth Year, as well as the International Decade of the Disabled;
- updating the International Directory of Mental Retardation Resources; and
- co-sponsorship of the Third Pan American Congress on Mental Retardation.

The President's Committee on Mental Retardation believes this annual report to be a significant vehicle through which the voice of more than six million Americans of all ages who are retarded can be heard. The visible support of your office, Mr. President, is an indispensable ingredient to what the committee believes are viable solutions to the major health, educational, economic, and social problems experienced by those individuals affected by this handicapping condition. Together we can be a catalyst to the nation, to reaffirm our commitment to prevent mental retardation, where possible, and to improve the quality of life experienced by this special population of Americans.

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