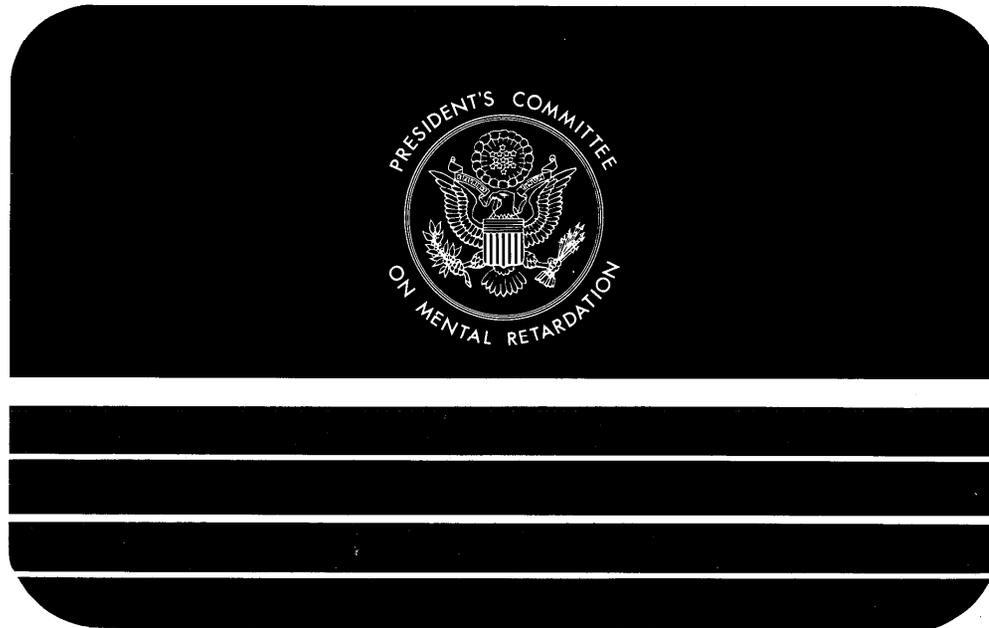


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The President's Committee on Mental Retardation

THE DECISIVE DECADE



MR 70

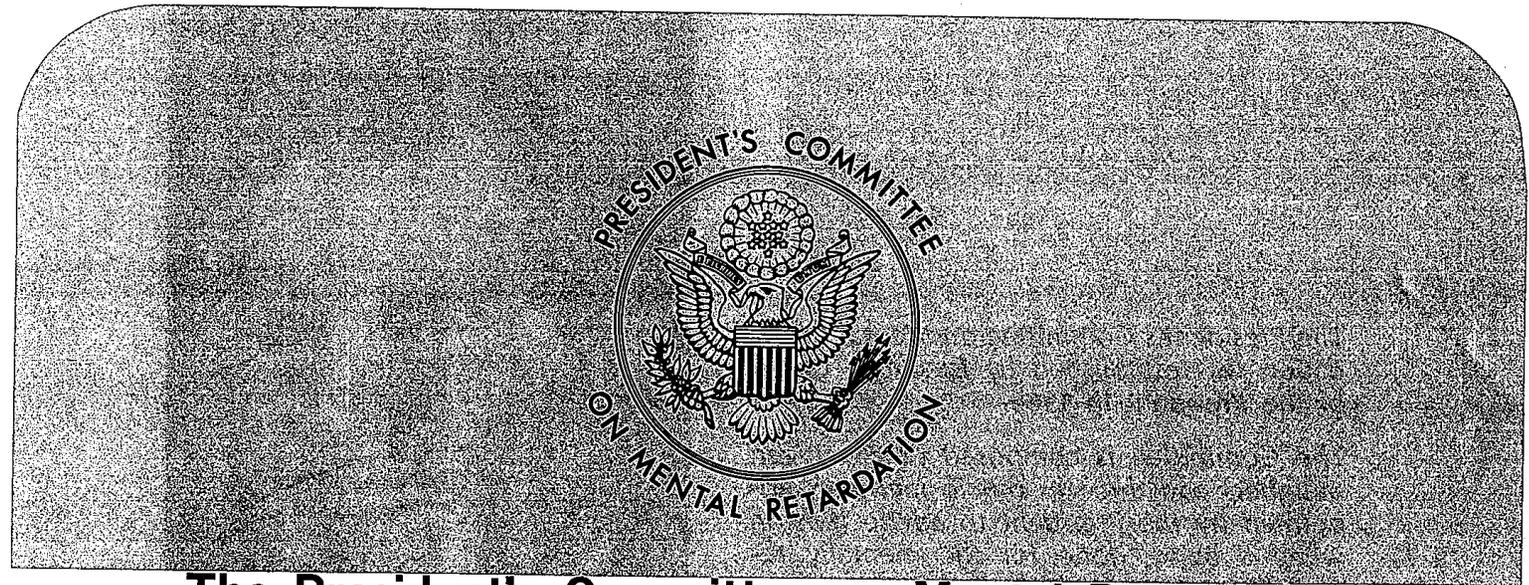
The President's Committee on Mental Retardation

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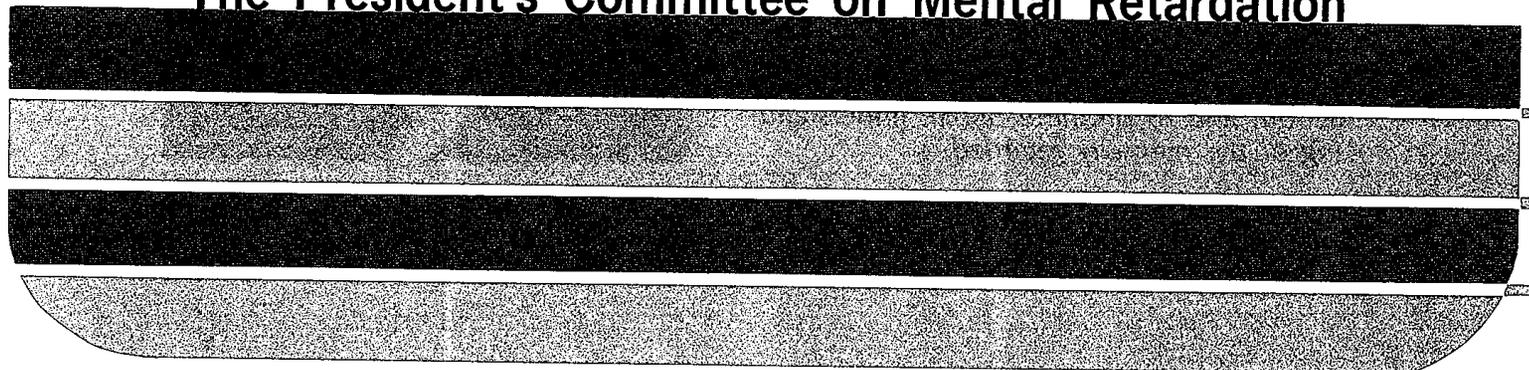
We are grateful to the following for the use of their photographs:
National Institute of Child Health and Human Development, NIH
National Institute of Neurological Diseases and Stroke, NIH
Office of Child Development, DHEW
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Reproductive Genetics Unit
The George Washington University
School of Medicine
Washington, D.C.

Brown Brothers
Paul Conklin
Morton R. Engelberg
James Foote
Jerry Hecht
Ralph Matthews
Roy Perry
Michael D. Sullivan
David Warren
Jim Wells



The President's Committee on Mental Retardation



The President's Committee on Mental Retardation was established by Executive Order of the President in 1966.

The Committee is composed of 21 citizen members and three ex-officio members appointed by the President to advise him on what is being done for the mentally retarded; to recommend Federal action where needed; to promote coordination and cooperation among public and private agencies; to stimulate individual and group action; and to promote public understanding of the mentally retarded.





The President
The White House
Washington, D.C.

My dear Mr. President:

It is my privilege to transmit to you the fourth annual report of the President's Committee on Mental Retardation.

This report concisely reviews the areas in which the Committee has focused its attention in 1970. It also previews promises of the coming decade for preventive measures and amelioration of the national problem of mental retardation. The report highlights improvements in residential care and the breakthrough in research; it also outlines the need for further advancement in programs including education, the delivery of services, and continued behavioral and biomedical research for the mentally retarded.

Among the programs the Committee will focus its attention upon during the coming months will be a work conference on the reexamination of intelligence testing and classification procedures; a study of states' systems for delivery of services to the mentally retarded; and a report on the constitutional rights and guarantees of the mentally retarded.

The Committee is deeply grateful to you for your interest and inspiration and asks your continued guidance.

Faithfully yours,

Elliot L. Richardson
Chairman



Mr. President:

We see the decade of the '70s as one in which decisive progress can be made in overcoming mental retardation and its causes.

□ Exciting work being done in a score of fields and at every level of national life is intensifying toward real achievement in this so-long neglected area. □ Research in the biomedical and behavioral sciences has discovered many causes of this mind-muffling condition. Ways have been found to prevent some of these causes, and we are on the threshold of discovery of other preventive measures. It now seems probable that at least one major cause of retardation could be dramatically diminished by assuring all Americans a basically adequate diet. And the effects of the mental retardation that cannot yet be prevented can be reduced in many cases through education and training programs begun in early childhood. □ These discoveries **can** be translated into practical programs and service delivery systems. Much of the base for making up-to-date, effective programs available to the mentally retarded has been established. Each state has a comprehensive plan for the development and improvement of services for the retarded. A framework for school services for the retarded is established. The Federal Government supports essential research, training and innovative assistance programs. Fundamental reform in the multi-million-dollar-a-year field of residential services for the severely retarded is beginning. Agencies and citizens generally are making the journey from old attitudes of pity and revulsion to a view of the retarded individual as a human being with dignity and potential. Increasingly, programs focus on helping the retarded person participate as fully as he can in the community's life and work.

□ This report, Mr. President, our second to you, will comment on several areas of most significant progress and most critical need in mental retardation. We ask your help in commending this report to key individuals in public and private agencies and organizations whose action can bring about the advances now.

SERVICES



Most days, working with the retina is no bed of roses. It's often so difficult and frustrating you find yourself asking, "Did I volunteer for this?"

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THE DECISIVE DECADE

Residential Services

For the approximately 275,000 people who live in the nation's public and private residential facilities for the mentally retarded, and the thousands more who are on waiting lists to enter those facilities, there's big news: fundamental change and improvement are on the way.

When these changes are made a part of the life of each retarded person who requires care away from home, we will have triumphed over the institutionalized dehumanization and neglect to which we have so long relegated many of our mentally retarded under the guise of care and concern. This will be a major accomplishment in terms of lives made productive and self-reliant.

Several developments during the past year encourage the President's Committee on Mental Retardation to optimism and hope.

A key development has been the formation of a Federally funded Council for the Accreditation of Mental Retardation Facilities, working within the Joint Commission on Accreditation of Hospitals to develop generally accepted standards of performance for mental retardation facilities, programs and staffs. Guidelines, chiefly those developed by the American Association on Mental Deficiency already exist. The standards

now being formulated will evolve from those guidelines and cover previously undefined areas such as day care standards. All of the major national citizen organizations working in the area of care, rehabilitation and education of the mentally retarded are cooperating in the accreditation standards development project.

Simultaneously, there has been major progress in defining desirable conditions and goals for services to the retarded.

The International League of Societies for the Mentally Handicapped has focused major interest on residential services for the retarded, with a Special Symposium devoted to the definition of ideal programs.

The National Association for Retarded Children, in a conference on residential services, urged that the reasons for a retarded individual's admission to a residential facility be specified and the individual's program be geared to attain those ends.

The President's Committee on Mental Retardation, culminating four years' study and promotion of action in the residential service field, has issued an action policy proposal; sponsored a national conference of facility and agency leaders to discuss the ways of spurring meaningful change in residential programs for the retarded;

and stimulated press and broadcast media accounts of the proposal nationwide. The National Association of Coordinators of State Programs for the Mentally Retarded* had an important part in drafting the proposal, which fostered meaningful dialogue among those who clamor for immediate reform, and those—superintendents and program directors for the most part—who, restricted by budget and personnel problems, are unable to make changes, however great their wish to do so may be. The goals of the dialogue are to produce the improvements that can be made now, as well as create a climate of public and legislative awareness from which can come enduring change.

The PCMR's proposal makes the following basic points:

o The primary purpose of residential services is to enable the retarded individual to develop his physical, intellectual and social capabilities to the fullest extent possible . . . develop emotional maturity . . . develop, whenever possible, skills, habits and attitudes essential for return to community living....

* NACSPMR was formed in 1970 on the basis of a PCMR recommendation. It is initially funded by a grant from the Social and Rehabilitation Service, DHEW.

- The mentally retarded shall have the same constitutional rights and guarantees as every other American citizen.
- The residential facility should be used for programming, not punishment.
- Good residential programs provide both long-term and short-term services....
- It is the obligation of the residential facility to develop each individual's economic potential....
- It is essential that a residential facility coordinate its programs with other regional and community mental retardation services for the development of a full range of comprehensive services.
- The model residential environment should provide a warm, stimulating social setting, devoid of dehumanizing conditions.
- Administrative policies should recognize the importance of the interrelationships of parents, volunteers, staff and residents.
- Staff must reflect attitudes and behaviors consistent with the concept that they serve as family surrogates while the retarded are in their care.

Implementation of the action proposal, its introductory statement asserts, "will be a *saving* act—in human resources, in program effectiveness, and in financial cost per individual served through human service programs."

Both the National Association for Retarded Children and the American Association on Mental Deficiency are promoting implemen-

tation of PCMR's Action Policy Proposal on residential care through their regional membership meetings. AAMD plans a series of regional forums to publicize and discuss ways of spurring action follow-up. The proposal's educational implications will be explored during the Council for Exceptional Children's 1971 convention. The recently formed National Association of Superintendents of Public Residential Facilities for the Mentally Retarded is urging the institution field to take every possible action in improving residential services. And PCMR is asking each state to review its mental retardation program planning in light of the new Federal Developmental Disabilities Act and take appropriate action to bring the benefits of the legislation to the retarded.

Thus has come about for the first time a *concerted* national effort to remedy and improve the conditions of residential living for the mentally retarded. This is a major achievement for the countless parents and friends of the retarded throughout the nation, in high places and humble ones, in public and private life, who have worked during the past quarter-century to bring public awareness, concern and action on behalf of the retarded. Although the coming of change where it counts—in the lives and prospects of the individual retarded—may be gallingly slow to those who have worked so hard and waited so long for it, there is now at least certainty that progress is on the way—indeed, is well launched in a few states.

And that is good news indeed.



Malnutrition

Malnutrition and undernutrition are major causes of impaired human mental development.

Animal studies prove that malnutrition or undernutrition of mother or offspring at certain critical pre-birth and post-birth periods of rapid growth:

- impair both physical and mental development;
- can cause permanent and irreversible retardation, regardless of the quality of later nutrition;
- are most harmful when they consist of a lack of specific nutrients such as certain essential vitamins, amino acids or proteins.

Moreover, neurologic and mental abnormalities caused by poor nutrition that occur at those early, rapid stages of development have been found to be permanent, even when physical signs of poor nutrition have been corrected.

Chronic food deprivation spanning more than one generation has been found to produce increasingly serious effects, particularly in reduction of learning ability.

And poorly nourished animals usually show behavioral and emotional aberrations that interact with the equally-hard-to-treat neurological and mental deficiencies in impairing learning ability.

It is difficult to apply the results of experiments on animals to human beings. Similar experimentation on humans is unacceptable. But every observation that researchers have thus far been able to make of human individuals and groups subjected to poor or deprived nutritional conditions argues that the conclusions reached about the effects of inadequate nutrition on animals apply equally to people. Items in the evidence:

- A large number of studies conducted with controls for age, sex, race and socioeconomic background have shown that malnourished children have severely impaired or retarded neurological and mental functions as well as emotional and behavioral abnormalities.
- An examination of the brains of infants who had died of Marasmus (a starvation-related condition marked by progressive emaciation) found their structure and characteristics significantly altered and abnormal in the same ways as the brains of young animals suffering from starvation.
- A group of South African children who had been severely malnourished in infancy was studied for more than 11 years. Although full physical recovery seemed to have taken place, significant IQ differences (over 20 points) between this group and a control group of average children persisted. The heads of the once malnourished children never reached normal size, and these

children had continuing visual and motor abnormalities. Similar studies in Mexico and Guatemala have found persisting abnormalities and memory deficiencies among children who were malnourished before 6 months of age.

○ A study in which genetic differences were allowed for found that children with physical signs of earlier malnutrition rated consistently and significantly low in tests for neurological functioning.

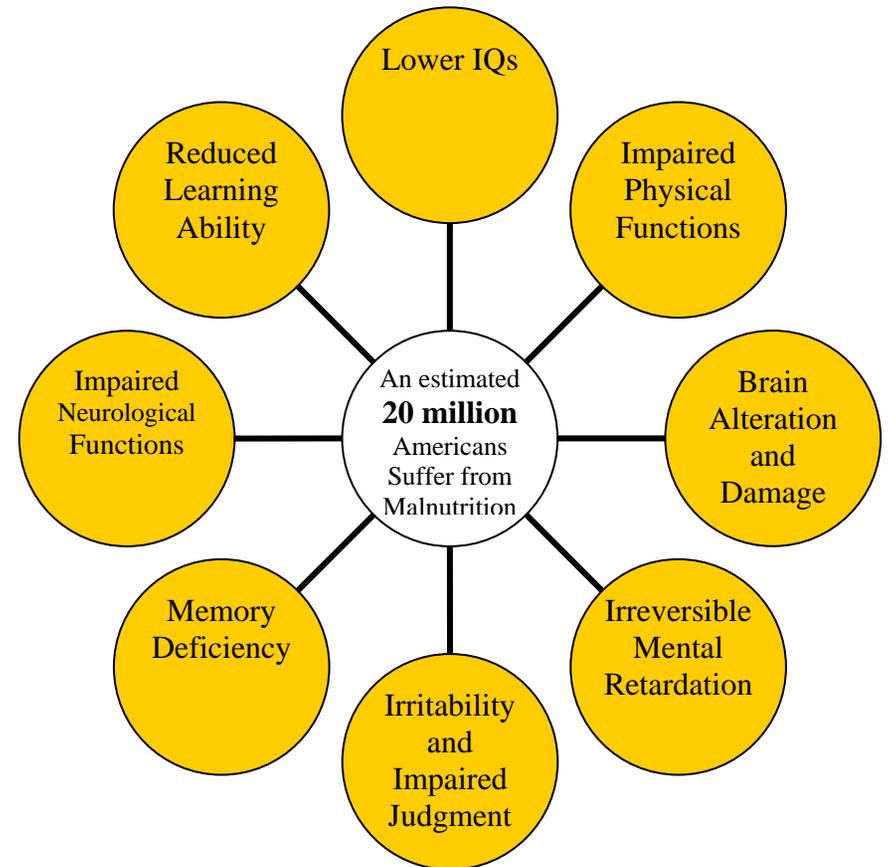
○ A preliminary report of the National Nutrition Survey, in which the U.S. Public Health Service is collecting nutrition data on 70,000 persons, found evidence of malnutrition in an unexpectedly large percentage of low income group members, with up to a third of the children studied showing malnutrition-associated characteristics similar to those of undernourished populations in some of the world's poorest nations.

The evidence that poor nutrition in mother and child causes mental retardation as well as other major handicaps is so overwhelming that it is time to cease quibbling over incomplete-as-yet research on the permanency of poor nutrition's effect on human beings. It is time . . . and past time . . . to get on with the essential work of preventing a cause of mental retardation that is both so extensive and so possible to eradicate in the United States.



Poor nutrition in the United States is almost completely a phenomenon of urban and rural low income areas. Nor is there any mystery about why the condition exists in those areas. It exists there simply because many of the people who live in those areas do not and cannot get enough food and enough of the right kinds of food. The reason is not that poor people cannot recognize or will not buy nutritionally valuable food; a 1965 Department of Agriculture study found, in fact, that low income households get more calories and nutrients per food dollar spent than do higher income households. The reason, President Nixon stated in issuing the call to the 1969 White House Conference on Nutrition: "Millions of Americans are simply too poor to feed their families properly."

Upwards of 25 million Americans live on incomes of less than \$3,300 a year for a family of four, and half of these Americans—including some 5 million children—live in households having an annual income of \$2,200 or less. To maintain an adequate diet, such families would have to spend over half of their income for food. Almost no one realistically can budget so large a part of income for food, and the actual result of the



clamoring competition of necessities in the lives of the "hard core" poor is an endemic semi-starvation. The National Council on Hunger and Malnutrition estimates that perhaps 20 million Americans suffer from malnutrition.

This is not the place, nor this Committee the appropriate group, to wrestle with the myriad economic, social and public policy questions posed by the existence of so large a group of Americans living in poverty. We hope that the various programs and approaches proposed by this administration will open the way to opportunity and a just share of America's prosperity for those who have been living on too little.

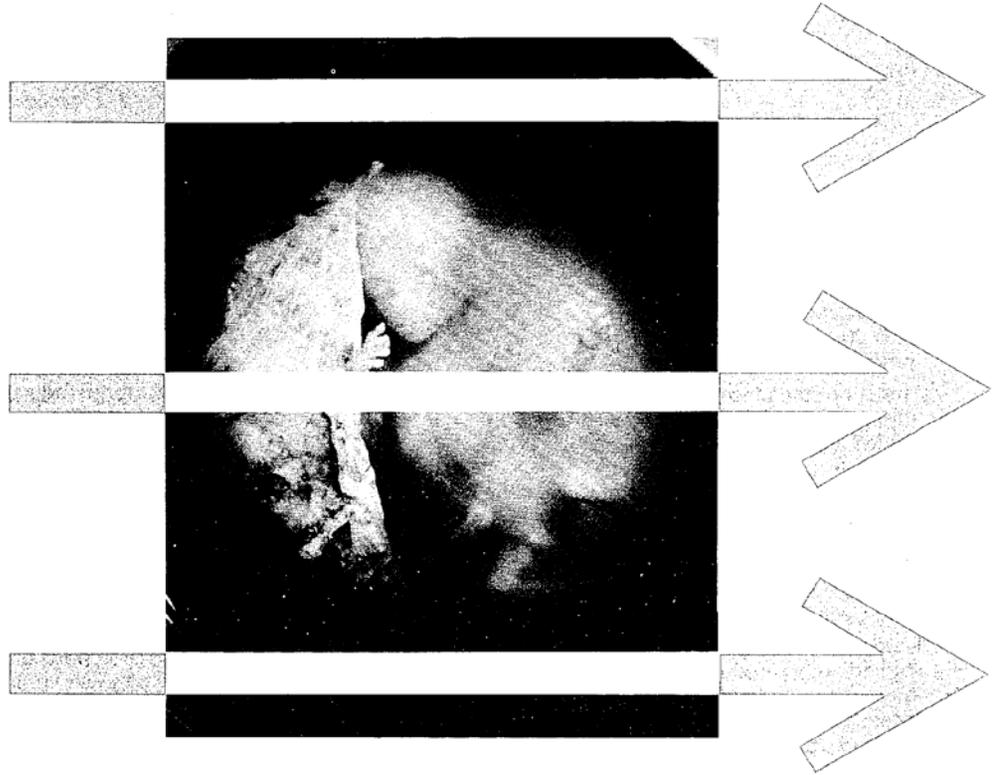
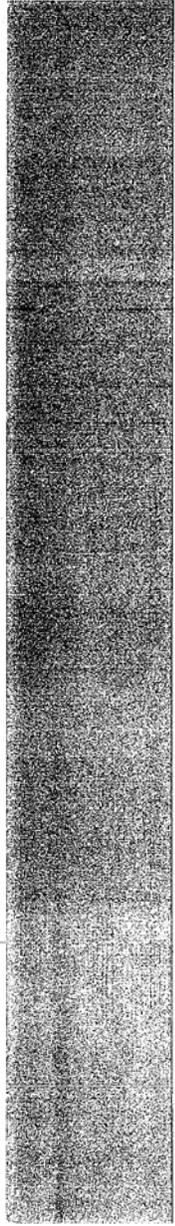
Food has historically been looked on and studied as a production and consumption item in the American economy; until very recently there were few surveys that attempted to link food with people's nutritional status. The small band of nutritionists and dietitians around the country have had to strive against general ignorance and indifference about food as a foundation of health.

That ignorance and indifference, moreover, seems to be growing rather than diminishing. Reduced consumption of milk, less breast feeding for infants, more preprocessed meals, fast

increasing consumption of food outside the home lead the U.S. food habit trends through which many people eat too much of the wrong foods, nutritionally speaking, or too little of any kind of food. And, finally, the U.S. food industry could make fuller utilization of innovative programs to bring this subject to the attention of the American people.

These are all developments that we can and must do something about for the sake of the health and fiber of ourselves, our children, and our children's children.

In 1971, the President's Committee on Mental Retardation will publish a report presenting in detail what is known today through research and observation about the relationships of malnutrition, general health, mental deficiency and allied factors. In issuing the report, which is presently in final stages of preparation, the Committee will make practical recommendations of steps that private organizations and government at all levels can take to reverse this common and most needless of all causes of mental retardation—lack of adequate nutrition in our land of plenty.



Research

Biomedical and behavioral research in mental retardation and allied areas pays off. Little noticed amid the multitude of multi-million-dollar searches for causes of cancer, heart disease and other major cripplers, the comparatively modest efforts of mental retardation, human development, learning handicap and neurological researchers have been making extraordinary progress in early diagnosis, prevention and relief of retardation.

Fact. Some 27 heritable metabolic disorders that can lead to mental retardation (among other effects) can now be identified in the fetus from study of fluid or cells taken from the pregnant mother's amniotic sac. This procedure, called *amniocentesis*, has been developed during the past decade and is now available at most university and other large medical centers. Among the conditions that can be diagnosed through this method are galactosemia, Tay-Sachs disease, Hurler's syndrome, Gaucher's disease and glycogen storage disease, all of which produce severe mental retardation.

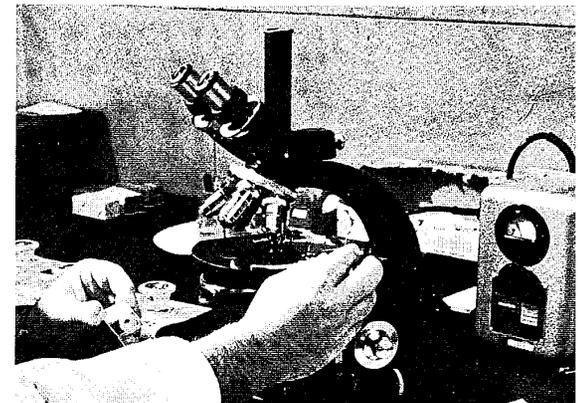
Also identifiable by the same procedure are organic genetic defects in the fetus caused by absences or irregularities in the chromosomes that program an individual's development. One of these chromosomal abnormalities, Down's Syndrome (Mongolism), affects

one baby in every 600 born. This condition alone accounts for 10 percent of the people living in residential facilities for the mentally retarded at an average lifetime cost to taxpayers of over \$100,000 per person.

A related procedure now makes it possible to identify individuals who face a greater-than-average risk of producing a child having genetic defects that could lead to mental retardation. This procedure, just becoming available through medical and research centers, studies an adult's tissues or blood for cellular evidences of genetic irregularities which may, especially when in combination with similar irregularities in a spouse, produce a defective fetus.

These products of biomedical research, together with evolution of new attitudes on abortion, are making it possible for the first time in history to predict an individual's chances of conceiving a normal child, to *know* whether a fetus is normal or defective and to give affected persons opportunity to make their decisions in these matters on the basis of facts.

Fact. Viral diseases that can lead to birth defects and mental retardation have been dealt heavy blows by research teams working on new vaccines. The most critically important of these vaccines just now is the



rubella (German measles) vaccine that has become available during the past 18 months. If enough children can be immunized with this vaccine, there is hope that there can never be a recurrence of the cyclic rubella epidemics, the most recent of which in 1964 produced thousands of babies afflicted by mental retardation and physical birth defects.

Other recently developed vaccines are now greatly reducing the incidence of mumps, measles and other viral diseases whose complications have often led to neurological damage and mental retardation.

Fact. Now intensive research findings have made it possible to prevent nervous system damage in the Rh positive child of an Rh negative mother. This condition can result in mental retardation. Besides the well-known exchange blood transfusion technique (which, dramatically, can now be carried out before birth), there has been developed an immunization that prevents the build-up in the mother's system of sensitizing antibodies that react on the child.

Fact. Sophisticated new techniques of monitoring the fetus before and during birth today make possible the prevention of many physically and mentally crippling "accidents" of pregnancy and birth. These techniques also make possible the instituting of effective measures to help the high-risk baby before, during, and following birth.

These major advances are but beginnings, however, in an endeavor that must find

many more answers before decisive achievement in the prevention or relief of mental retardation can be claimed.

For example, much as we know now about those conditions that result in mental retardation at or soon after birth, there remain great voids in our understanding. The cause of approximately 75 percent of mental retardation is still unknown.

Studies of the effects of viruses on human development—both in the short and long terms—are in their infancy, despite the significant achievement of vaccines for rubella and other conditions. The rubella immunity that can presently be given is incomplete and may not be permanent. The influence on human growth and development of viruses that lie dormant in the body for years may be immense. Especially needed are cooperative, interdisciplinary studies by both biomedical and behavioral scientists into improved early diagnosis and programming for mild and moderate developmental problems—the great majority and the least known.

This Committee urges, as it has since its establishment and as did the President's Panel on Mental Retardation almost a decade ago, that basic research in all phases of the biomedical and behavioral sciences must continue with as broad support as possible. Some of the most significant discoveries in the diagnosis and prevention of mental retardation made during the past decade have come from studies not originally concerned

with retardation.

Fact. Behavioral science has been accumulating evidence over the past two decades on the crucial importance of the early years in the development of personal competence.

FREQUENCY OF SPECIFIC DEFECTS
AMONG 376 CHILDREN FOLLOWING
MATERNAL RUBELLA

		Only Defect
No defect	70	..
Deafness	252	68
Heart disease	182	7
Cataract (2)	58	..
Cataract (1)	50	1
Glaucoma	12	..
Retinopathy only	147	..
	Total 267	
Psychomotor retardation	170	1
Mild	84 (cerebral palsy 21)	..
Moderate	40 (cerebral palsy 8)	..
Severe	46 (cerebral palsy 17)	..
Purpura	85	..
Deaths	61	..

Department of Pediatrics, New York University School of Medicine, New York, N.Y. (Dr. Louis Z. Cooper).

It is becoming increasingly evident that environment plays a major role in shaping both the developmental course and rate of human ability. Earlier concepts saw growth and development occurring according to a fixed genetic pattern and pace in a closed system that did not change. The latest findings point to growth and development as an interacting process between the individual's genetic endowment and his environment in an open system. This new conception will have a profound effect upon child rearing and educational practices in the development of a competent and productive society.

We urge, therefore:

Continued support for biomedical and behavioral research activities and facilities;

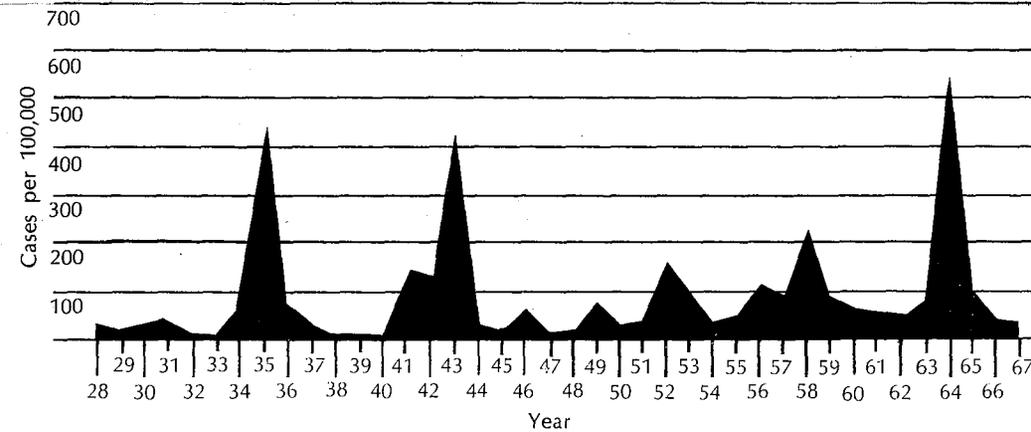
Continued development of programs for training medical students in research careers;

Continued development of needed legislation such as the Developmental Disabilities Act;

Continued dissemination of research results to the agencies and individuals needing them;

Continued widespread involvement of citizens in such activities as measles immunization campaigns, birth defects information efforts and volunteer assistance in the centers, classrooms and agencies where the results of research are being put to work for the people.

Incidence of Rubella from 1928 to 1967, in ten selected areas: Maine, Rhode Island, Connecticut, New York City, Ohio, Illinois, Wisconsin, Maryland, Washington, and Massachusetts.



National Communicable Disease Center, Atlanta (Dr. John J. Witte).

Incidence of Rubella from 1928 to 1967, in ten selected areas: Maine, Rhode Island, Connecticut, New York City, Ohio, Illinois, Wisconsin, Maryland, Washington, and Massachusetts.

National Communicable Disease Center, Atlanta (Dr. John J. Witte).

CLINICAL MANIFESTATIONS OF CONGENITAL RUBELLA CORRELATED WITH TIME OF MATERNAL INFECTION

(-----Month of Pregnancy-----)

Defect	First	Second	Third	Fourth	>Fourth	No Clinical Rubella	Insufficient Information
Neonatal purpura	14	43	7	2	0	12	7
Heart disease	34	62	17	2	1	29	7
Cataract or glaucoma	30	31	6	0	0	28	2
Deafness	50	76	55	21	0	39	11
Neurologic deficit	34	63	20	11	0	33	8
Total children*	60	106	82	43	16	50	19

Department of Pediatrics, New York University School of Medicine, New York, N.Y. (Dr. Louis Z. Cooper).

*Includes multiple defects

Education

In late summer 1969, PCMR sponsored, with the Bureau of Education for the Handicapped of the U.S. Office of Education, a conference on the learning problems of inner city children.

The conference was held at a time of rising national concern about the increasing education problems of the deprived child. Standard techniques for testing and placement seemed to exclude or defeat the child rather than provide the framework for productive, fulfilled living.

For example, when a standard IQ test was given in Spanish to Mexican-American children assigned to classes for the educable mentally retarded, the children's IQ score jumped an average of 14 points—an increase which took some of the children out of the state's mental retardation classification. Already a topic of widespread discussion was a study of classroom performance in relation to teacher expectation which found similar groups of children bearing out widely differing performance expectations on the part of their teachers. Court suits on disproportionate assignment of minority group children to special education classes already have been filed.

PCMR's interest in this area has grown out of a broad-scale effort to find out how many mentally retarded persons of school age there are, how many are in school, whether they receive appropriate school and community services and what might be the best services and curricula for them.

The Committee discovered that making such determinations is no easy thing to do. State laws differ, with one state, for example, calling IQ 78 the level at and below which a child is considered retarded, while another may place the top of the

classification at IQ 70. Some states have vague circumlocutions or obsolete definitions in their statutes concerning the retarded. In few states is the mandatory school attendance law seen as applying to *all* children who can benefit from school services and programs.

The principal facts are: (1) the majority of those Americans declared mentally retarded at any time in their lives are so labeled by the schools, (2) most of the children so named by the schools are from minority and low income groups, and (3) much of the under performance being diagnosed in children as mild mental retardation is preventable and reversible if attacked early, since the cause may be purely environmental.

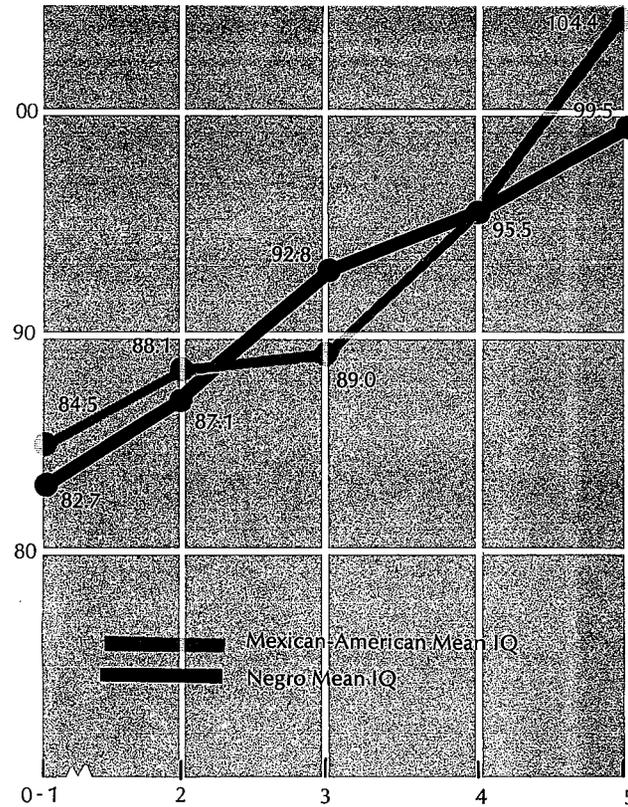
The August 1969 conference delved into these complex questions. It identified a new inhabitant of the troubled school scene—the "six-hour retarded child," the child whose social adjustment is adequate but whose school performance is poor and often grows consistently worse. And the 92 participants—school administrators, teachers, officials, and inner city citizens—made seven recommendations for action in inner city schools and better school services:

RECOMMENDATION 1 Provide early childhood stimulation, education, and evaluation as part of the continuum of public education.

RECOMMENDATION 2 Conduct a study of histories of successful inner-city families who have learned to cope effectively with their environment.

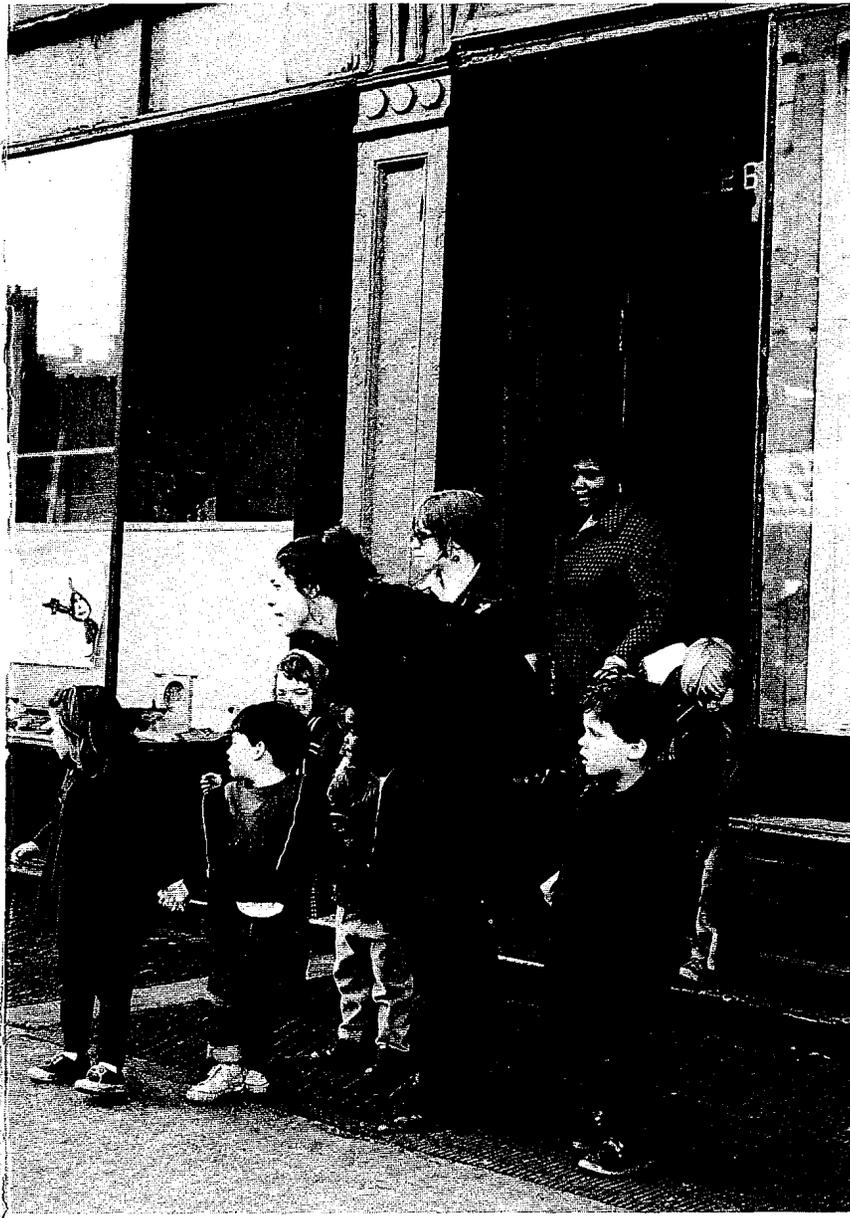
RECOMMENDATION 3 Restructure education of teachers, administrators, counselors. Retrain those now in the field.

**SOCIOCULTURAL STATUS AND IQ
CORRELATION FOR MEXICAN-AMERICAN
AND NEGRO CHILDREN IN A
SOUTHERN CALIFORNIA COMMUNITY**



**Sociocultural status measured on a rising scale
of 0 to 5**

Adapted from a chapter prepared by Lane R. Mercer, Ph.D., for Peter Orleans and William Russell, Jr. eds., "Race, Change, and Urban Society;" Urban Affairs Annual Review Vol. V, Sage Publications, Inc.



RECOMMENDATION 4 Reexamine present system of intelligence testing and classification.

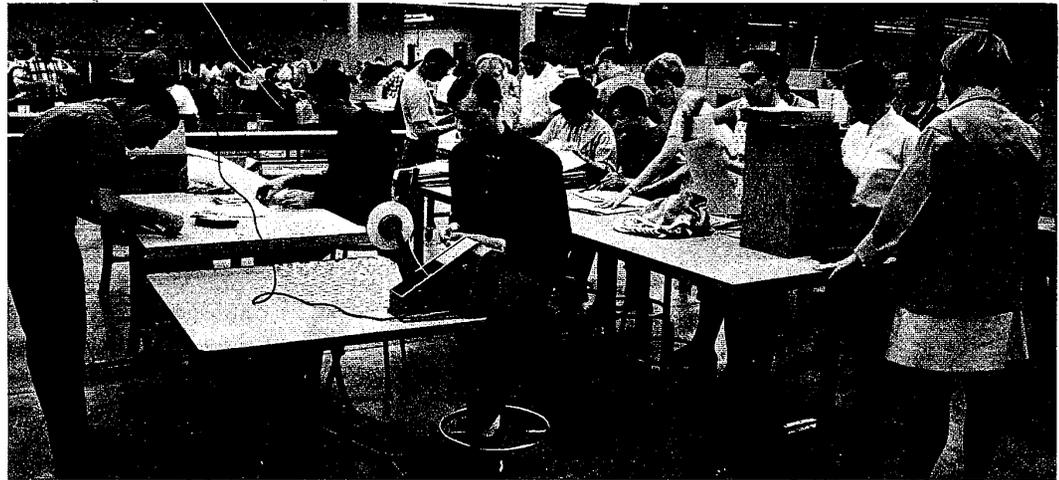
RECOMMENDATION 5 Commit substantial additional funding for research and development in educational improvement for disadvantaged children and youth.

RECOMMENDATION 6 Thoroughly delineate what constitutes accountability, allocate sufficient funds to carry out the responsibility entailed and hold the school accountable for providing quality education for all children.

RECOMMENDATION 7 Involve parents, citizens and citizen groups, students, and general and special educators in total educational effort.

As a major follow-up to the inner city education conference, PCMR plans a national conference on child placement and evaluation of instruction in special education programs for the mentally retarded. This conference, co-sponsored by the Council for Exceptional Children and the Bureau of Education for the Handicapped of the U.S. Office of Education will be held in 1971. Its principal topic will be the reexamination of intelligence testing and classification recommended by the inner city education conference. Some 100 special educators, university representatives, psychologists, curriculum and guidance specialists, parents and minority group representatives will probe the issues of labeling, testing and screening procedures used routinely in U.S. schools. Both current practices and the curriculum and program changes that improved screening procedures would require will be examined.

In another phase of its broad-scale study of school programs for the mentally retarded, PCMR last year held four workshops to evaluate curriculum materials designed for use in classes for the educable mentally retarded. The committee as a result is urging all education materials planners and publishers to develop better, more relevant curriculum materials for the retarded.



Employment

During the past decade the mentally retarded have entered the work world in significant numbers for the first time. It has been an eye-opening experience for all concerned.

Employers whose original motivation in hiring retarded workers came perhaps more from charity than business sense have discovered that there are many jobs that the retarded can do well—often better than other workers—and that intelligence is not the only qualification for successful employment.

Friends and families of the retarded are discovering to their surprise in many cases that the trained retarded can earn and live their own way, that the true dignity of work lies in doing well and productively those things that one *can* do.

And the retarded themselves are finding themselves liberated into "real" life. They go to work, earn pay, have their own places to live and their own possessions. They have become people!

Along the way of discovering the potential of most retarded people and

developing that potential, we have learned that education and work are the most important factors in programs developed to help the retarded. Vocational training, education and the skills and disciplines of work that bring a retarded individual up to producing at his potential can give him new life.

The President's Committee on Employment of the Handicapped and PCMR have together come to the conclusion that the education and training of a mentally retarded person should be vocationally oriented from their beginning. They should be pointed toward the kinds of jobs that will actually exist in the area in coming years. And school programs of education and training for the retarded should be flexible enough to develop good work skills and attitudes in the broad range of ability levels among the retarded who can benefit from school programs. These programs should also continue up to the point at which the retarded individual moves into the job he will hold (no gap between

training and work), with counseling assistance continuing as needed at least until the new worker is demonstrably adjusting well to his working conditions, co-workers, and being on his own.

In a nation that holds as one of the yardsticks of progress and prosperity the number of its people employed, the training and employment of handicapped workers in necessary, productive and economically supporting jobs is a dollars-and-cents investment in the health of the nation's economy. At the same time, the values in the form of dignity and pride accruing to the handicapped workers who receive thereby a piece of the action of real life, are no less real for the difficulty of their measurement. However, the nation must remember, and if necessary be reminded, that training of the mentally retarded which enables them to "get a piece of life's action" is a continuing need, not just a one-shot matter.

State Services

Progress and improvement in the lives and prospects of the nation's millions of mentally retarded individuals depend, ultimately, on how well the services they need are delivered. And how well the services are delivered depends primarily on the planning, efficiency and effectiveness of the state and community agencies that administer and furnish public programs and services for the handicapped.

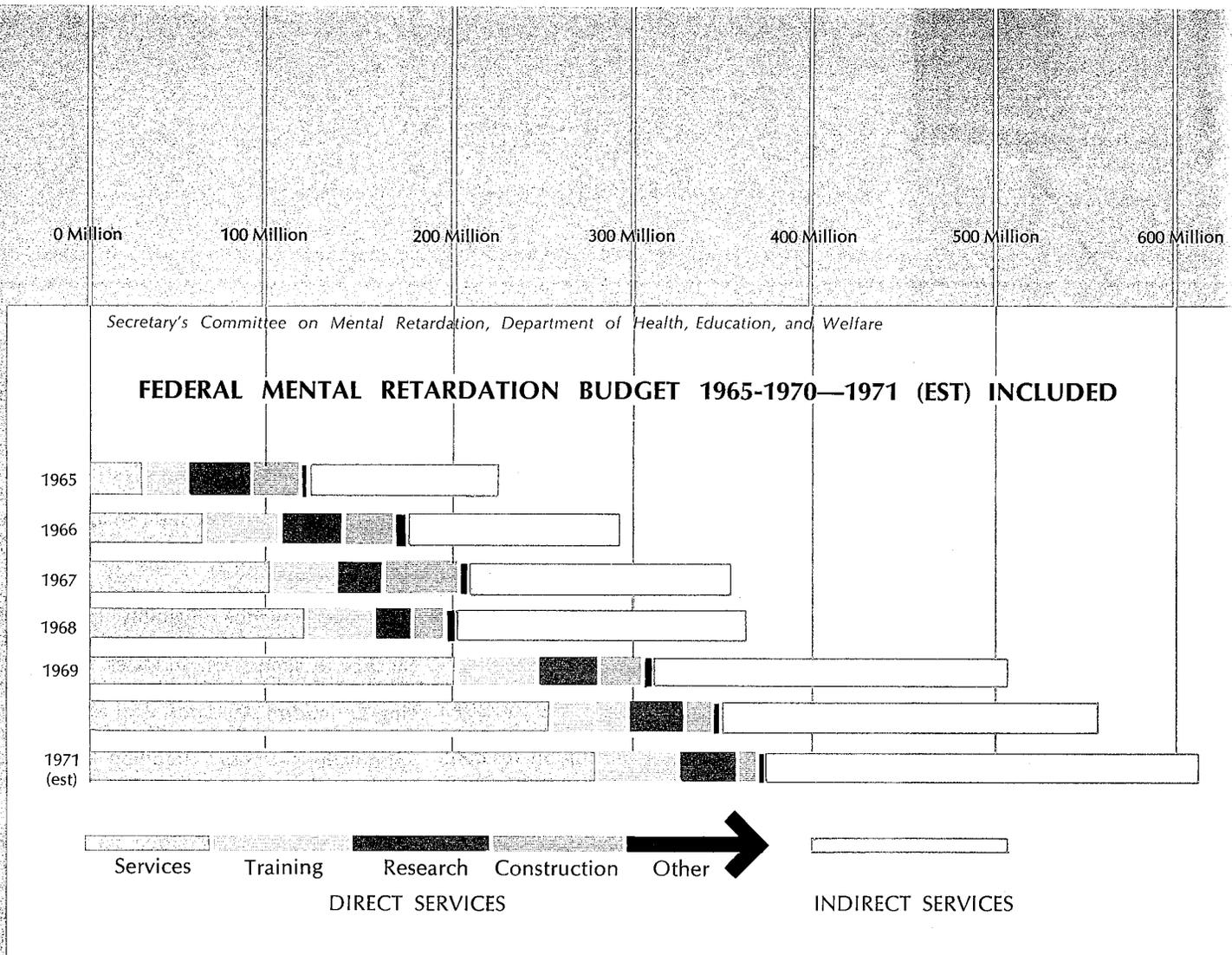
Each of the 50 states and territories has a plan whose purpose is to assure that the retarded receive both the individual and comprehensive services they need through the action of agencies acting singly and cooperatively. However, reports from parents of retarded children as well as specialists working in the field continue to tell of fragmentation in services, insurmountable barriers in bringing individuals the kind or range of services they need, and vast public confusion about what kinds of services, if any, are available.

Early in 1970, the President's Committee on Mental Retardation began a study of the delivery of services to the mentally retarded. Although the advantages of early intervention in developmental problems is

now generally accepted, two of the five states studied refuse admission to a state residential facility to any retarded child under the age of six, regardless of the degree of mental retardation. Retarded children under six in those states are sent to private institutions—for a fee that ranges from \$100 (for welfare recipients) up to \$350 a month, depending on the family's resources.

In most states a constitutional guarantee offers free, public education to all children. But in many states the guarantee is tacitly ignored in regard to those handicapped children whose intelligence range is less than "normal." Special education programs for the mentally retarded are not widespread, and many school districts simply elect not to provide such programs. The programs lag in many school districts, even in the two states in which their attorney general has ruled that the constitutional guarantee of free, public education applies to *all* children.

Still neglected in many states are the post-school period and the adult years. Few states' programs concern themselves about the period between completion or leaving



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school vocational training programs and the actual beginning of a job. Yet, uncounted numbers of the retarded are lost forever during this period to the work force and to achievement of self-reliance for themselves. Far too few vocational training programs for the retarded operate to prepare their students for jobs that will actually be in existence and available when the student has completed training, and there are almost no facilities available for the retraining of retarded workers when employment needs change.

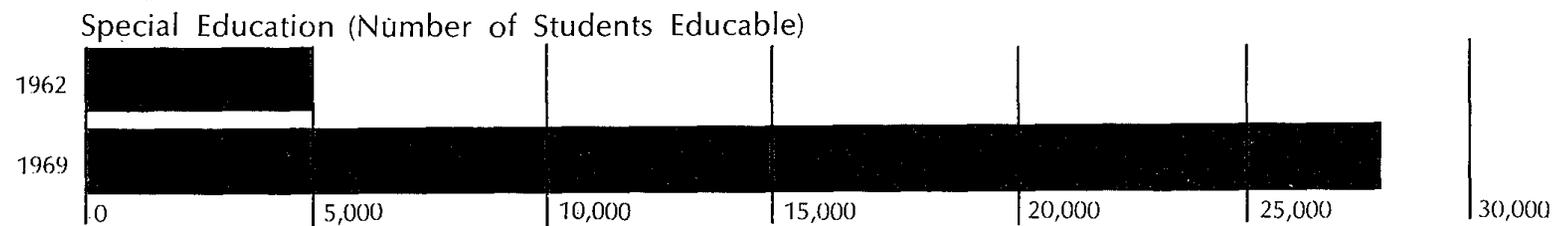
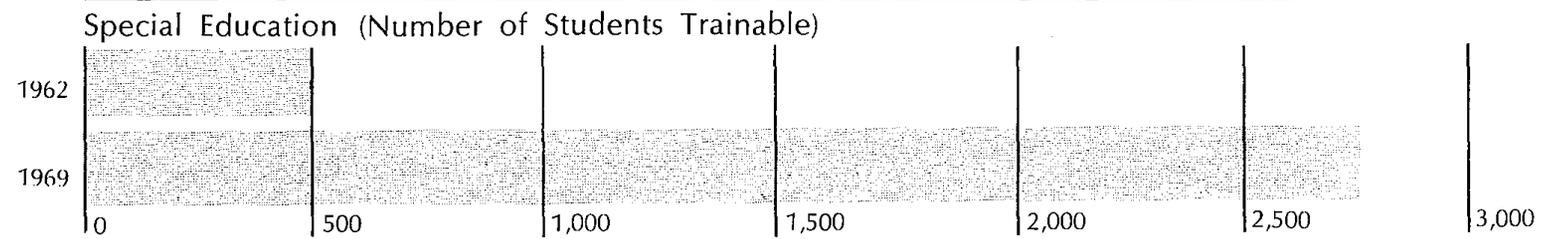
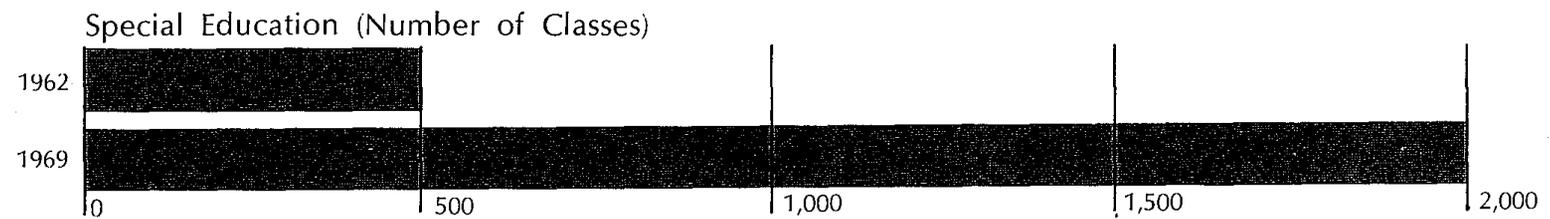
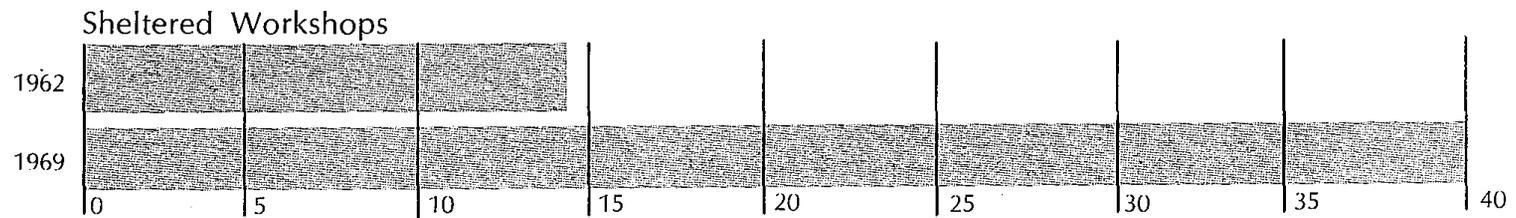
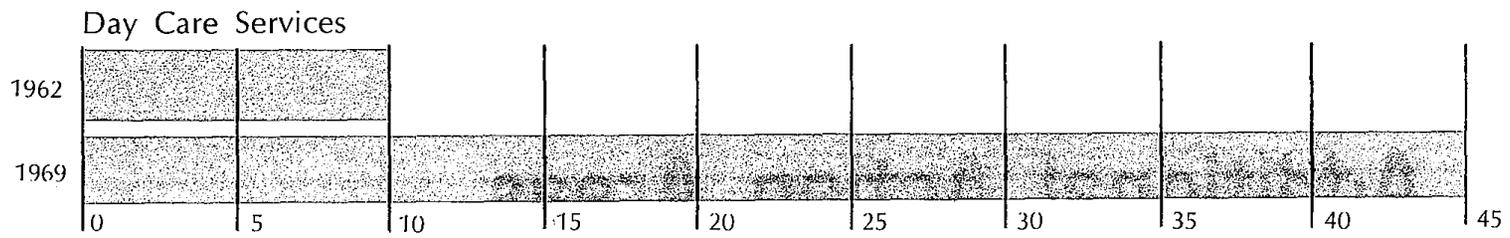
The mentally retarded adult is a forgotten human being in many states. If he is not a welfare recipient or an institution resident, he is likely to be eking out a subsistence-level existence through work on the very margins of the economy. Few states or communities have an adequate range of workshop, activity or recreational programs for the adult retarded living in the community, and fewer still have effective, on-going counseling resources.

Five states currently being studied by PCMR have made significant progress toward the goal of coordinating the activities of state

agencies to provide a flow of service as the mentally retarded child grows and his needs change. But even in these states, services are often limited by agencies' lack of staff and funding—a problem that can create inadequacies in services and can lead to actual neglect of state areas or segments of population, while other areas or population groups are receiving complete services. Moreover, agency eligibility requirements for services vary from state to state and from agency to agency within states. Licensing of facilities for the retarded is not done according to uniform standards. And agencies tend to concentrate their services on particular populations—those traditionally worked with or those with whom the agency most easily makes contact.

The President's Committee on Mental Retardation urges every state to make a close study of its programs and agencies that serve, or are intended to help serve the mentally retarded, and to take every action needed to assure that the needs of the retarded are met through uniform, equitable, high quality and generally available services.

GROWTH OF STATE SERVICES IN NORTH CAROLINA 1962-1969



Additional Action Areas

During the past year, the President's Committee on Mental Retardation has continued its long-term studies and initiatives in the areas of legal rights and guardianship of the retarded, manpower planning and utilization, and international information exchange activities.

Legal Rights and Guardianship

In June, the Committee sponsored a meeting of experts to examine the status of guardianship provisions for the retarded and suggest ways in which those provisions may be made more realistic and effective. Fifteen representatives from state and Federal agencies and from such organizations as the National Association for Retarded Children and the United Cerebral Palsy Associations of America attended.

Most states' provisions for guardianship of the retarded are relics of a time when the mentally retarded individual was considered an incompetent who had to be kept away from normal social and work contacts. They largely consider or assume the retarded person to be without rights, deny him due process or the equal protection of the laws, and often encumber his family's estate for years as the price of the

state's assuming his care. The damage done to retarded individuals who are capable of self-support and self-reliance, to those who have become caught up in the judicial process, and to families who can be in effect held responsible for a retarded individual into a second generation is incalculable.

The President's Committee is working to develop model guardianship provisions that will encourage the retarded individual to exercise all of the citizen rights that he is capable of exercising, give him the benefit of equal protection under the law with all other citizens, and promote the development in states of public advocates for the retarded (and other handicapped) who will serve both as counselors and as surrogates as necessary.

Manpower

Also in June, the President's Committee published the proceedings of a joint United States-Canada conference on manpower planning and use in the mental retardation field. The report calls for new training courses, programs and work roles if services-



enriching his views and approaches to various duties."

International

In September, PCMR sponsored the first international conference on mental retardation needs, resources and approaches in the Caribbean area. Delegates from 25 nations attended.

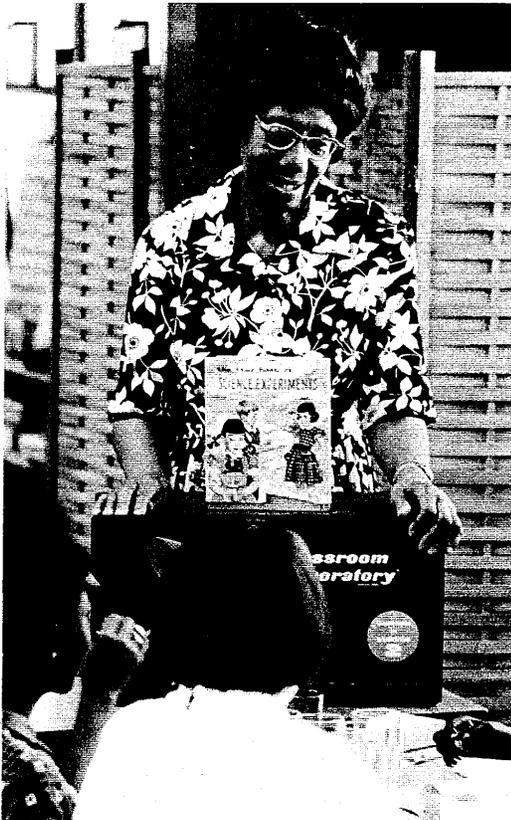
The conference stated the need for the upgrading of existing facilities and the establishment of services in many areas of the Caribbean where none presently exist.

Among other recommendations the conferees urged the establishment of a regional secretariat whose principal function will be to collect and collate all relevant information concerning the needs of the mentally retarded in the Caribbean, and to initiate interdisciplinary studies on relevant subjects.

Although the retarded child of today has a far greater opportunity for a life of active adult citizenship than his predecessors, there are major opportunities to meet and solve problems if the past is to be a prologue to a better future for the retarded individual. The task before us is to apply our current knowledge so that the '70s will, indeed, be The Decisive Decade.

to the mentally retarded are to grow to full effectiveness. Especially urged was removal of obstacles that prevent the best development, assignment and career growth of aides and other supportive personnel in mental retardation programs. The report also recommends:

- Intensive re-evaluation of special education programs in schools, particularly those for the educable mentally retarded, with the over-all objectives of putting the full resources of the school to work for the retarded child, enlarging the teaching perspectives of special education personnel and giving regular classroom teachers and school administrators better understanding of special education aims and methods.
- The setting of performance standards for all levels of basic and supportive personnel, with the maintenance of those standards made the responsibility of a professional organization.
- The development of accreditation procedures for all facilities serving the needs of the retarded.
- The setting up of in-service training programs for all categories of staff who work with the retarded.
- A broadening of national and international work study exchanges to include supportive staff "so that everyone, from the student to the professional, both basic and supportive personnel, has the opportunity of



hope
and
help



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