#### DCCUMENT RESUME

ED 049 585 EC 032 165

TITLE The Fresident's Committee on Mental Retardation: The

Decisive Decade.

INSTITUTION President's Committee on Mental Retardation,

Washington, D.C.

PUE DATE 71 NOTE 53p.

EDRS PRICE EDRS Price MF-%0.65 HC+\$3.29

DESCRIPTORS \*Annual Reports, \*Exceptional Child Education,

\*Mentally Handicarred, \*Mental Retardation, Research

Needs, Services

IDENTIFIERS \*Presidents Committee on Mental Retardation

#### ABSTRACT

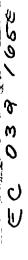
The tourth annual report of the President's Committee on Mental Retardation comments upon areas of significant progress and of critical need in mental retardation. The problem of malnutrition, improvements in residential care, and advancements in diagnosis, treatment, and prevention through research are discussed. Specific recommendations for action in inner city schools and better school services are listed. Also summarized are the Committee's present and future studies and initiatives in the areas of delivery of state services, legal rights and grandianship of the retarded, manpower planning and utilization, and international information exchange. (KW)



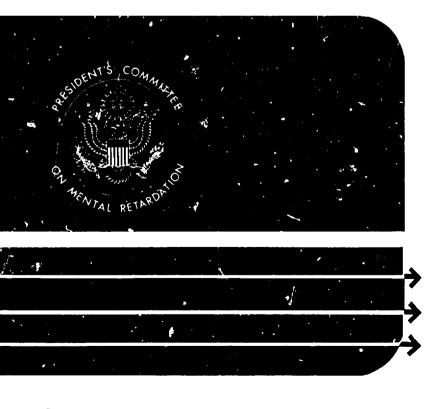
# The President's Committee on Mental

THE DECISIVE DECADE

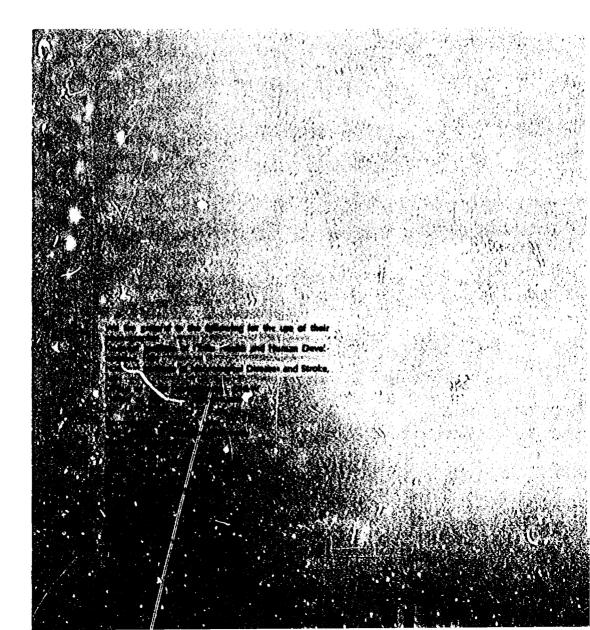




# s Committee on Mental Retardation









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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 area: in which the Committee has focused its attention in 1970. It also previews promises of the coming decade for preventive measures and antelioration 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,

Eviora Richardson

Elliot L. Richardson Chairman



President's Committee on Mental Retardation





### 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 heiping 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.





THE DECISIV





or the approximately 275,000 people who live in the nation's public and private residential facilities for the mentally retarted, and the thousands more who are on waiting lists to enter those facilities, there's bit 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 seif-reliant.

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

A key development has been the formation of a Federally funded Council for the Accreditation of Nental 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 stand-

ards now being formulated will eventhose guidelines and cover previous fined areas such as day care stan of the major national citizen orgworking in the area of care, rehand education of the mentally recooperating in the accreditation development project.

Simultaneously, there has been ma ress in clefining desirable condigoals for services to the retarded

The International League of Society Mentally Handicapped has focused interest on residential services for tarded, with a Special Symposium to the definition of ideal program

The National Association for Children, in a conference on r services, urged that the reasons tarded individual's admission to a r facility be specified and the individual gram be geared to attain those en

The President's Committee on Mardation, culminating four years' spromotion of action in the reservice field, has issued an action proposal; sponsored a national coof facility and agency leaders to diways of spurring meaningful chang dential programs for the retard

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# **Residential Services**

formulated will evolve from and cover previously undehas day care standards. All ational citizen organizations area of care, rehabilitation of the mentally retarded are the accreditation standards roject.

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Association for Retarded conference on residential that the reasons for a real's admission to a residential fied and the individual's produced to attain those ends.

S Committee on Mental Reninating four years' study and action in the residential has issued an action policy prored a national conference agency leaders to discuss the ng meaningful change in resi-

ims for the retarded; and

tional 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 charges, 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.

stimulated press and broadcast media ac-

counts of the proposal nationwide. The Na-

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. . . .

\*NACSPIMR 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.



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

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

Both the National Association for Letarded Children and the American Association on

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Mental Deficiency are promoting implementation 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 Federai Developmental Disabilities Act and take appropriate action to bring the

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

benefits of the logislation to the retarded.

states.

And that is good news indeed.

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# M alnutrition and major causes of mental developm

Animal studies prove the undernutrition of mother tain critical pre-birth and of rapid growth:

- impair both physical at ment;
- O can cause permanent tardation, regardless of nutrition:
- o are most harmful whe lack of specific nutrients sential vitamins, amino

Moreover, neurologic a malities caused by poor rat those early, rapid stag have been found to be when physical signs of poor rational corrected.

Chronic food deprivation than one generation has duce increasingly serious in reduction of learning

And pourly nourished an behavioral and emotion interact with the econeurological and mental pairing learning ability.

## Malnutrition

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

nimal studies prove that malnutrition or adernutrition of mother or offspring at cerin critical pre-birth and post-birth periods rapid growth:

impair both physical and mental developent;

can cause permanent and irreversible rerdation, regardless of the quality of later

are most harmful when they consist of a ck of specific nutrients such as certain esential vitamins, amino acids or proteins.

toreover, reurologic and mental abnorlalities caused by poor nutrition that occur those early, rapid stages of development ave been found to be permanent, even hen physical signs of poor nutrition have sen corrected.

hronic food deprivation spanning more an one generation has been found to prouce increasingly serious effects, particularly reduction of learning ability.

nd poorly nourished animals usually show ehavioral and emotional aberrations that teract with the equally-hard-to-treat eurological and mental deficiencies in imairing 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:

- O A large number of studies conducted with controls for age, sex, race and socio-economic background have shown that malnourished children have severely impaired or retarded neurological and mental functions as well as emotional and behavioral abnormalities.
- O 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.
- O 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





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

O A study in which genetic difference allowed for found that children with cal signs of earlier malnutrition rated sistently and significantly low in test neurological functioning.

O A preliminary report of the Nation trition Survey, in which the U.S. Health Service is collecting nutrition on 70,000 persons, found evidence of nutrition in an unexpectedly large per age of low income group members, which is the children studied shims!nutrition-associated characteristics.

lar to those of undernourished popul in some of the world's poorest nation

The evidence that poor nutrition in n and child causes mental retardation a as other major handicaps is so overwing that it is time to cease quibbling incomplete-as-yet research on the planeary of poor nutrition's effect on beings. It is time ... and past time get on with the essential work of previa cause of mental retardation that is o extensive and so possible to eradic

the United States.



visual and motor dies in Mexico and existing abnormaliencies among chileurished before 6

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ible to eradicate in





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Poor nutrition in the United States is almost completel/ a phenomenon of urban and rural low income areas. Nor is there any mystery about why the condition exists in those are is. 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."

Impaid

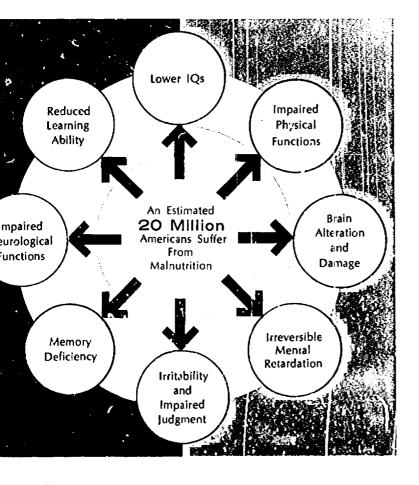
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Functi-

Upwards of 25 million Americans live on incomes of less than \$3,300 a year for a family of jour, 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







clainoring competition of necessities in the lives of the "hard core" poor is an endemic sen i-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 myrad 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 attle.

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 infa sed meals, fast increafood outside the hom habit trends through eat too much of the tionally speaking, or to food. And, finally, the could make fuller util programs to bring this tion of the American

These are all developm must do something abo health and fiber of our and our children's chi-

In 1971, the President's tal Retardation will penting in detail whe through research and crelationships of malnut mental deficiency and sing the report, which stages of preparation, make practical recombat private organization at all levels can take to and most needless of retardation—lack of a our land of plenty.







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## Research

B iomedical 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 magazino.

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 relardation.

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 alone accounts for 10 percent of the living in residential facilities for tally retarded at an average lifetime taxpayers of over \$100,000 per per

A related procedure now makes it to identify individuals who face a than-average risk of producing a ding genetic detects that could lead retardation. This procedure, just available through medical and rescues, studies ar adult's tissues or cellular evidences of genetic irrewhich may, especially when in convith similar irregularities in a specialce a defective fetus.

These products of biomedical resegution with evolution of new attabortion, are making it possible for time in history to predict an inchances of conceiving a normal know whether a fetus is normal or and to give affected persons opportuate their decisions in these mather basis of facts.

Fact. Viral diseases that can lead defects and mental retardation hadealt heavy blows by research teating on new vaccines. The most important of these vaccines just of



10 percent of the people al facilities for the mennaverage lifetime cost to \$100,000 per person.

The now makes it possible luals who face a greater-of producing a child havis that could lead to mental procedure, just becoming medical and research cendult's tissues or blood for

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ses that can lead to birth ntal retardation have been is by research teams workccines. The most critically se vaccines just now is the







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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

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

produced thousands of babies afflicted by

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 sen-

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.

sitizing antibodies that react on the child.

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

many more answers before decisive act ment in the prevention or relief of n retardation can be claimed.

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

Studies of the effects of viruses on h development—both in the short and terms—are in their infancy, despite th nificant achievement of vaccines for ru and other conditions. The rubella imm that can presently be given is incomand may not be permanent. The infit on human growth and development viruses that lie dormant in the bod years may be immense. Especially not are cooperative, interdisciplinary studit both biomedical and behavioral societinto improved early diagnosis and programing for mild and moderate development problems—the great majority and the

This Committee urges, as it has since establishment and as did the Preside Panel on Mental Retardation almost a ade ago, that basic research in all phase the biomedical and behavioral sciences continue with as broad support as possible of the most significant discoverithe diagnosis and prevention of mentardation made during the past decade

known.



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of the most significant discoveries in

liagnosis and prevention of mental retion made during the past decade have come from studies not originally concerned with retardation.

FREQUENCY OF SPECIFIC DEFECTS

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

AMONG 376 CHILDREN FOLLOWING MATERNAL RUBELLA

Only Defect

70 252 68 Heart disease 182 58 Cataract (1) Glaucoma 12 Retinopathy only **Psychometor** retardation 170 84 (cerebral palsy 21)

46 (cerebral palsy 17) 61 Departified of Pediatrics New York University

40 (cerebral palsy 8)



School of Medicine, New York, NY (Dr. Louis

Mild

Moderate

Severe

Purpura

Deaths

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 chaid 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.

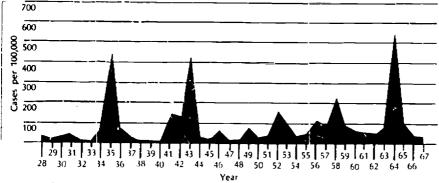
Defect
Neonatal purpura
Heart disease
Cataract or glaucon
Deafness
Neurologic deficit
Total children\*

CLINICAL M

Department of Peo of Medicine, New



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. Wile)

## CLINICAL MANIFESTATIONS OF CONGENITAL RUBELLA CORRELATED WITH TIME OF MATERNAL INFECTION

Month of Pregnancy No Clinical Insufficient Defect First Second Third Fourth Rubella Information >Fourth Neonatal purpura Heart disease Cataract or glaucorna o Deafness Neurologic deficit Total children \* 

Department of Pediatrics, New York University School. \*Includes multiple defects of Medicine New York NY (Dr. Louis Z Cooper)



# Education

n 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 con-

cern 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 IO 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 classifica-

tion. 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

PCMR's interest in this area has grown out of a bload-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.

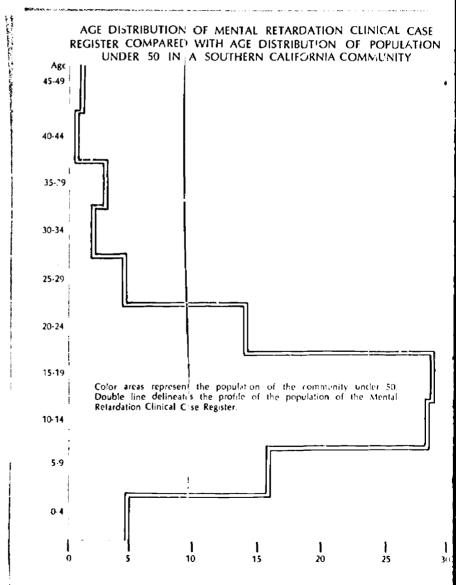
**RECOMMENDATION 2** Conduct a study of histories of successful inner-city families who have learned to cope effectively with their environment.

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



already have been filed.

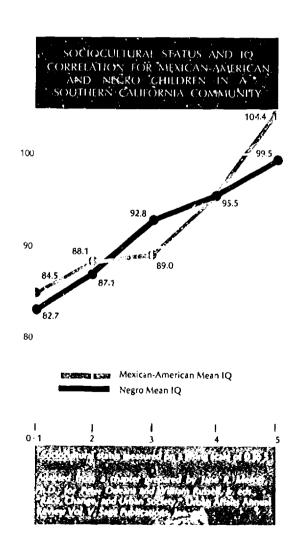






Adapted from forthcoming report, The Eligibles and the Labeled, by Jane R. Mercer, Ph.D. ; ;

INICAL CASE
POPULATION
AMUNITY



ider 50.



**RECOMMENDATION 4** Recitelligence testing and classific.

**RECOMMENDATION 5** Confunding for research and desprovement for disadvantaged

RECOMMENDATION 6 The tutes accountability, allocate the responsibility entailed an for providing quality education

RECOMMENDATION 7 Invicitizen groups, students, and in total educational effort.

As a major follow-up to the ence, PCMR plans a national and evaluation of instruction for the mentally retarded. by the Council for Exception Education for the Handicapp tion will be held in 1971. reexamination of intelligen recommended by the inne Some 100 special educate psychologists, curriculum ar and minority group represer labeling, testing and screein U.S. schools. Both currer and program changes that would require will be exam-

In another phase of its bregams for the mentally retained workshops to evaluate cursuse in classes for the education mittee as a result is urging and publishers to develop be materials for the retarded

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**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 mproved 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.











ny

uring 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 (c. 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. If ey have become people!

Along the way of most retard that potential, wition and work tors in program tarded. Vocation the skills and daretarded individual can guernial can

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# **Employment**

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 criented 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 or 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.

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# State Services

P rogress 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 interven-

tion 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

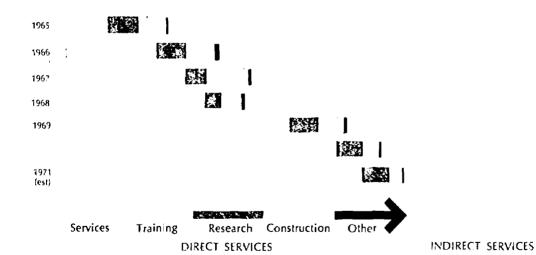
the period between completion or leaving



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Secretary's Committee on Mental Retardation, Department of Health, Education, and Welfare

#### FEDERAL MENTAL RETARDATION BUDGET 1965-1970—1971 (EST) INCLUDED



The Committee is continuing its special project on economics. The study and analysis of economic factors and comparative cost of programs at 1 services will provide us understanding on which we may base future direction and plan services.



school vocational training practual beginning of a job. numbers of the retarded a during this period to the wolachievement of self-reliance. Far too few vocational training the retarded operate to predents for jobs that will actual ence and available when the completed training, and there facilities available for the retarded workers when employed.

The mentally retarded adultuman being in many states welfare recipient or an instance is likely to be eking outlevel existence through wo margins of the economy. Few munities have an adequate shop, activity or recreation the adult retarded living in and fewer still have effect counseling resources.

Five states currently being states made significant prog-



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adult is a forgotten states. If he is not a i institution resident, g out a subsistencen work on the very

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g in the community, effective, on-going ng studied by PCMR

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 in-

adequacies 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.



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## **Additional Action Areas**

uring 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.

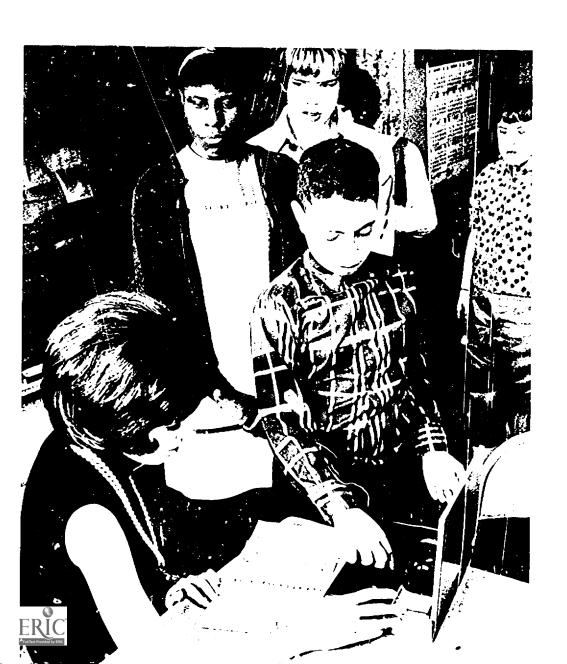
Most states' provisions for guardianship of the retarded are relics of a time when the mentally retarded individual was considered an incompetent who had to be kept away from normal social and work contacts. They largely consider or assume the retarded person to be without rights, deny him due process 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 worl roles if services







to the mentally retarded are to effectiveness. Especially urged work obstacles that prevent the bennent, assignment and career groard other supportive personne retardation programs. The report mends:

- Intensive re-evaluation of spection programs in schools, partic for the educable mentally retained the over-all objectives of putting resources of the school to work tarded child, enlarging the teachitives of special education per giving regular classroom teachers administrators better understandicial education aims and method
- The setting of performance stall levels of basic and supportive with the maintenance of those made the responsibility of a porganization.
- The development of accreditated dures for all facilities serving the the retarded.
- O The setting up of in-service trigrams for all categories of staff with the retarded.
- A broadening of national artional work study exchanges to ir portive staff "so that everyone



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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:

O 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.

O 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.

O The development of accreditation procedures for all facilities serving the needs of the retarded.

O The setting up of in-service training programs for all categories of staff who work with the retarded.

O A broadening of national and internationa 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 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.









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The Committee is grateful to the many individuals in government at all levels, in the voluntary organizations and in private life who have furnished invaluable encouragement and assistance.

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