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ABSTRACT

The 1962 report defines the problem of mental retardation and summarizes both activities of the U.S. Department of Health, Education, and Welfare (DHEW) and objectives of the President's panel to combat mental retardation. Mental retardation is defined to be a condition characterized by faulty intellectual development which impairs learning ability and adaptation to societal demands. Discussed are aspects such as degrees of retardation, etiology, the problem's scope such as the percentage (3%) of retarded children born yearly, national concern expressed in efforts such as diagnostic services, and future trends based on factors such as longevity and changing patterns in U.S. family life. Summarized under the categories of research and studies, professional preparation, services, and facilities and construction are mental retardation programs administered by the following organizational units of DHEW agencies: the National Institute of Mental Health, National Institute of Neurological Diseases and Blindness, Center for Research in Child Health, and Bureau of State Services, and Bureau of Old-Age and Survivors Insurance of the Social Security Administration; the Office of Education; and the Office of Vocational Rehabilitation. Discussed are tasks of the President's Panel such as exploration of ways to prevent and cure mental retardation. Panel members are listed. Also listed are 29 publications on mental retardation available from DHEW.

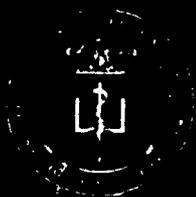
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Mental Retardation

U.S. DEPARTMENT OF HEALTH,
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U. S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

May 1962

Mental Retardation

Activities of the U.S. Department of Health, Education, and Welfare



U. S. DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
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Wilbur J. Cohen, Assistant Secretary (for Legislation)
Departmental Committee on Mental Retardation
Washington 25, D.C. May 1962

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Preface

In the past several decades startling changes have occurred in the society in which we live. Community life has grown more complex, and in the world of work entirely new fields of technology have come to the fore. Competition is more intense and higher levels of educational attainment are today's norm. The individual today faces greater opportunities for the fruitful expenditure of his time, talent, energy, and resources than at any time in our history.

These opportunities offer a challenge to those with normal and superior capabilities. For those who find themselves without the mental capacity to participate fully in today's life, the challenge is to society: to find causes, to seek prevention, and to provide assurance for lives of maximum contribution.

In recent years there has been an acceleration of effort--private and public--in behalf of mentally retarded persons, of whom there are more than 5 million throughout the Nation. The results are encouraging. More is known about the causes of retardation. Special education classes have multiplied. More rehabilitations are recorded. Parents get better counseling. In specific disorders we have witnessed the dawn of prevention.

These forward steps have been accomplished, in part, by the activities administered by the U. S. Department of Health, Education, and Welfare which are described in this publication. We can be proud of these efforts and of the progress that has been made.

Yet, as President Kennedy has said, ". . . we as a Nation have for too long postponed an intensive search for solutions to the problems of the mentally retarded." The needs remain great for more knowledge, more personnel, more facilities, and more services to parents and to retarded persons themselves.

Last year President Kennedy appointed a panel of outstanding experts and laymen to review present programs and needs and to formulate a national plan to combat mental retardation. The Panel's recommendations, to be made before the end of 1962, will provide the inspiration and the guidelines for greater efforts and further progress in the years to come.



Abraham Ribicoff
Secretary of Health, Education,
and Welfare

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SUMMARY

The purpose of this report is to define the problem of mental retardation, to describe the present activities of the U. S. Department of Health, Education, and Welfare in this important field of national concern, and to summarize the objectives of the President in developing a national plan to combat mental retardation. The principal facts and conclusions developed in this report are summarized below:

1. Mental retardation is a condition characterized by the faulty development of intelligence. The degree of retardation varies greatly among individuals. It can be so severe that protective care throughout life is necessary. In others the retardation is so mild that many skills can be learned and a measure of independence in everyday life can be achieved.

2. Although there is no adequate single measure of retardation, experience has shown that virtually all persons with I.Q.'s below about 70 have significant difficulties in adapting adequately to their environment. About 3 percent of the population score below this level. Based on this figure of 3 percent, it is estimated that of the 4.2 million children born each year 126,000 are, or will be, mentally retarded. By applying the same 3 percent to the total population, it is estimated that there are approximately 5.4 million mentally retarded persons in the population. Unless there are major advances in methods of prevention, there will be as many as one million more mentally retarded by 1970.

3. Based on present knowledge, the causes of mental retardation may be divided into two broad categories:

a. Mental retardation caused by incompletely understood factors without any evident damage of the brain. In this group, which comprises 75 to 85 percent of those considered to be retarded, psychological, genetic, and environmental factors are involved, including the specific conditions and diseases listed below. These may operate singly or in combination.

b. Mental retardation caused by a number of specifically identified conditions or diseases known to produce brain damage. Such damage can be demonstrated in 15-25 percent of the diagnosed cases. The conditions so far identified include (1) diseases due to infections in the mother during pregnancy or in the infant after birth; (2) toxic agents ingested by the mother during pregnancy or by the child after birth; (3) diseases due to trauma or physical agent; (4) disorders of metabolism, growth, or nutrition; (5) abnormal growths within the brain; (6) diseases due to unknown prenatal factors; and (7) diseases due to uncertain causes but with evident damage of the brain.

4. Since 1950 interest in the problem of mental retardation has grown very rapidly. Today efforts to meet the problem take eight basic forms: (a) diagnostic and clinical services; (b) care in residential institutions; (c) special education; (d) parent counseling; (e) services through child welfare agencies; (f) vocational rehabilitation; (g) training; and (h) research.

5. Primary responsibility within the Federal government for activities relating to mental retardation is located in the U. S. Department of Health, Education, and Welfare. Within the Department these programs are administered by four operating agencies--the Public Health Service, Social Security Administration, Office of Education, and Office of Vocational Rehabilitation. The programs administered by these agencies may be grouped under four main categories: (a) research and studies, (b) professional preparation, (c) services, and (d) construction of facilities. Departmental coordination is promoted by the Department of Health, Education, and Welfare Committee on Mental Retardation.

6. In the 1963 fiscal year budget the President has requested \$28.3 million for programs of the U. S. Department of Health, Education, and Welfare dealing with the problem of mental retardation. This represents an increase of \$4.3 million over the estimated level of funds available for this purpose for fiscal year 1962 and more than doubles the \$12.4 million spent by the Department 5 years ago.

7. Progress has been made in identifying specific disorders and their treatment, in training professional personnel, in providing additional facilities, and in improving services generally. Nevertheless, the needs remain great for more knowledge, more personnel, more facilities and more services to parents and to the retarded persons themselves.

8. In October 1961 President Kennedy appointed a panel of outstanding experts and laymen to review present programs and needs, to ascertain gaps and any failure in coordination of activities, and to prescribe a program of action. The President has asked the Panel to formulate a national plan to combat mental retardation and to report to him on or before December 31, 1962. The Panel's recommendations will provide the guidelines for future efforts and further progress in the years to come.

I. THE PROBLEM OF MENTAL RETARDATION

Mental Retardation Defined

Mental retardation is a condition, characterized by the faulty development of intelligence, which impairs an individual's ability to learn and to adapt to the demands of society.

The failure of intelligence to develop normally may be due to diseases or conditions--occurring before or at the time of birth, or in infancy or childhood--that damage the brain. It may also be due to factors determined by heredity that affect the development of the brain. It is sometimes accentuated by home or social conditions which fail to provide the child with adequate stimulation or opportunities for learning.

Degrees of Retardation

The degree of retardation varies greatly among individuals. It can be so severe that the afflicted person must have protective care throughout his life. In others the retardation is so mild that many tasks can be learned and a measure of independence in everyday life can be achieved. In a substantial number of cases the affected persons can adjust in a limited way to the demands of society, and in many instances can, with help, become productive members of the labor force.

There is no fully satisfactory way of characterizing the degrees of retardation. They range, according to one classification, from profound to mild, and are related to intelligence quotient (I.Q.) as follows:

Degrees of Mental Retardation

<u>Level</u>	<u>Intelligence Quotient</u>
I. Profound	Below 20
II. Severe	20-35
III. Moderate	36-52
IV. Mild	53-68

The developmental characteristics, potential for education and training, and social and vocational adequacy, according to this classification, are summarized below by age groups.

Degrees of Mental Re- tardation	Pre-School Age 0 - 5 Maturation and Development	School Age 6 - 20 Training and Education	Adult 21 and over Social and Vocational Adequacy
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<u>Profound</u> (I.Q. below 20)	Gross retardation; minimal capacity for functioning in sensorimotor areas; needs nursing care.	Some motor development present; cannot profit from training in self- help; needs total care.	Some motor and speech development; totally incapable of self- maintenance; needs complete care and supervision.
<u>Severe</u> (I.Q. 20-35)	Poor motor develop- ment; speech is mini- mal; generally unable to profit from train- ing in self-help; little or no communi- cation skills.	Can talk or learn to communicate; can be trained in elemental health habits; cannot learn functional ac- ademic skills; profits from systematic habit training.	Can contribute parti- tially to self- support under com- plete supervision; can develop self- protection skills to a minimal useful level in controlled environment.
<u>Moderate</u> (I.Q. 36-52)	Can talk or learn to communicate; poor social awareness; fair motor develop- ment; may profit from self-help; can be managed with moderate supervision.	Can learn functional academic skills to approximately 4th grade level by late teens if given special education.	Capable of self- maintenance in un- skilled or semi- skilled occupations; needs supervision and guidance when under mild social or economic stress.
<u>Mild</u> (I.Q. 53-68)	Can develop social and communication skills; minimal re- tardation in sensori- motor areas; rarely distinguished from normal until later age.	Can learn academic skills to approxi- mately 6th grade level by late teens. Cannot learn general high school subjects. Needs special educa- tion particularly at secondary school age levels.	Capable of social and vocational adequacy with proper education and training. Fre- quently needs super- vision and guidance under serious social or economic stress.

Another classification, used in relation to educational programs, makes use of a three-way division as follows:

<u>Level</u>	<u>Intelligence Quotient</u>
I. Custodial	Below 25
II. Trainable	About 25-50
III. Educable	About 50-75

Other classifications group the retarded in somewhat different ways and make use of other terminology. Nevertheless, all of them recognize gradations of mental retardation, although the exact boundary lines vary. Regardless of the particular classification used, however, it should be understood that seldom, if ever, is I.Q. the only determining factor in mental retardation. Other factors that affect intellectual competency are social adaptability and emotional control.

The Causes of Mental Retardation

Based on present knowledge the causal factors in mental retardation may be divided into two broad categories: (1) mental retardation caused by incompletely understood psychological, environmental, or genetic factors without any evident damage of the brain; and (2) mental retardation caused by a number of specifically identified conditions or diseases. The causal and contributing factors included in each of these categories are as follows:

1. Mental retardation caused by incompletely understood psychological, environmental, or genetic factors without any evident damage of the brain.

This group contains 75 to 85 percent of those diagnosed as retarded. It consists of individuals who show no demonstrable gross abnormality of the brain and who, by and large, are persons with relatively mild degrees of retardation. In general, the prevalence of this type of retardation is greater within the less favored socioeconomic groups within our culture.

A variety of factors may be operating within this large category. It is believed that some members of this group are products of very complex mechanisms of heredity, reflecting the fact that human beings show genetic variability in any characteristic, including measured intelligence. Environmental factors such as the psychological circumstances of life, social interaction patterns, and the richness of the environment with respect to intellectual stimulation play an important definitive or contributory role within this group. Finally, a variety of unfavorable health factors--including maternal health and prenatal care, nutrition, the conditions of birth, and other illnesses or injuries which may produce minimal and undemonstrable brain damage--probably contribute to a lower level of performance in many cases.

The total effect, thus, is a complex one, involving the action or the interaction of genetic factors, psychological experiences, and environmental influences. At the present time, it is impossible to assign clear weights to each of these general causative factors. It is known that all of them, however, operate more strongly in the underprivileged groups than among those more favorably situated in society. The prospects for prevention and amelioration should not be discouraging, however, since many of the environmental and psychological variables are subject to control, opening up the possibility of preventing some of the retardation, especially of milder degree, based upon this class of causation. Some of these conditions are preventable if treatment can be instituted early enough in the child's life. Most of the remainder can be ameliorated through a combination of resources, medicine, social work, education, and rehabilitation.

It should be very clearly stated that these same factors also affect retarded individuals whose difficulty stems from the more specific etiologies enumerated in category 2 below.

2. Mental retardation caused by specifically identified conditions or diseases in which there is demonstrable brain damage.

In approximately 15 to 25 percent of diagnosed cases of mental retardation, a specific disease entity can be held responsible. The impact of such diseases can be most readily demonstrated in those instances where there has been gross brain damage and where the degree of retardation is severe. As mentioned above, it is uncertain to what extent these "organic" factors may operate to produce minor impairment among the less severely retarded groups. Such "organic" factors fall within seven general classes.

a. Diseases due to infections in the mother during pregnancy or in the infant after birth. German measles, occurring during the first three months of pregnancy, is known to result in mental retardation as well as other abnormalities. Other infections occurring during pregnancy have also been implicated. A number of the infectious diseases of infancy and childhood may cause brain injury resulting in retardation.

b. Brain damage resulting from toxic agents which are ingested by the mother during pregnancy or by the child after birth. Jaundice of the newborn due to Rh blood factor incompatibility and carbon monoxide or lead poisoning are examples.

c. Diseases due to trauma or physical agent. Brain injury occurring as a result of difficulty delivery, and asphyxiation due to delay in the onset of breathing at the time of birth are common causes. They occur with particular frequency in premature babies. Brain injury in childhood, especially from automobile accidents, is an added factor.

d. Diseases due to disorders of metabolism, growth or nutrition. A number of disorders of metabolism, some of which are determined by heredity, produce mental retardation. Some of the most important of these disorders are phenylketonuria and galactosemia in which there are abnormalities of amino acid chemistry in the body.

e. Abnormal growths within the brain. A number of rare conditions, some determined by heredity, are characterized by tumor-like and other abnormal growths within the brain and produce mental retardation.

f. Diseases due to unknown prenatal factors. Recent discoveries prove that mongolism results from abnormal grouping of chromosomes probably at the time of formation of the ovum in the mother. Other congenital malformations have a similar basis. For some, however, an undetermined prenatal mechanism must be responsible.

g. Diseases due to uncertain causes but with evident damage of the brain. A sizable group of mentally retarded children have evident damage to the brain which is presumed to be linked to the mental retardation. The causes of the pathology of the brain in this sizable group remains unknown.

Data on patients in institutions show a higher prevalence of pathological conditions among the more severely retarded. Retarded children have other defects more often than the average child. They are often smaller than average, and have poorer muscular coordination. They have a greater than ordinary percentage of defects, such as hearing and vision, and have probably greater difficulty in perceiving what the sense organs bring to their minds. Thus many of them are multihandicapped in some degree.

Scope of the Problem

As stated above, mental retardation is defined as impairment of ability to learn and to adapt to the demands of society. These demands are not the same in every culture. In fact, even within our own community they vary with the age of the individual. We expect little, in terms of intellectual pursuits, from the preschool child. During the school age, the individual is evaluated very critically in terms of social and academic accomplishment. In later life, the intellectual basis of social inadequacy again may be less evident. Numerous surveys directed toward determining the frequency and magnitude of the problem of mental retardation have shown that the number of individuals reported as retarded is highest during the school age. Less than one-fifth as many children in the age group 0-4 were reported by these surveys as mentally retarded as were reported in the age group 10-14. Similarly, only one-fourth as many persons in the age group 20 and over were identified as mentally retarded as compared with the number identified in the age group 10-14.

This varying prevalence by age is to some extent determined by differential survival rates and other demographic factors. However, the very high prevalence at ages 10 to 14 is due primarily to the increased recognition of intellectual handicap of children within the school systems. The very low number of infants from 0 to 1 year old identified as retarded is in part at least due to the fact that their intellectual deficit is not yet apparent. Only gross impairment is evident in early childhood. Of striking significance is the fact that half of the individuals considered retarded during adolescence are no longer so considered in adulthood.

In view of these considerations, only the most crude estimates of the overall magnitude of the problem can be established. One such estimate may be derived through the use of intelligence quotients, and obtained from the samples upon which our intelligence tests have been standardized. The numbers of mentally retarded persons by this criterion can be calculated roughly on the basis of this experience with intelligence testing. On most tests standardized nationally, experience has shown that virtually all persons with I.Q.s below about 70 have significant difficulties in adapting adequately to their environment. About 3 percent of the population score below this level.

Based on this figure of 3 percent, it is estimated that, of the 4.2 million children born each year, 126,000 are, or will be, classed as mentally retarded.

Of the 126,000, some 4,200 (0.1 percent of all births) will be retarded so profoundly or severely that they will be unable to care even for their own creature needs. About 12,600 (0.3 percent of all births) will suffer from "moderate" retardation--they will remain below the 7-year intellectual level. The remaining 110,000 (2.6 percent of births) are those with mild retardation and represent those who can, with special training and assistance, acquire limited job skills and achieve almost complete independence in community living.

Applying these same percentages to the total population it is estimated that there are approximately 5.4 million mentally retarded persons in the population. Of this number:

60,000 to 90,000 are persons, mostly children and adolescents, so profoundly or severely retarded that they cannot survive unless constantly cared for and sheltered.

300,000 to 350,000 are moderately retarded children, adolescents, and adults who can assist in their own care and can even undertake semi-productive endeavors in a protected environment. They can understand the meaning of danger. However, they have limited capacity to learn, and their shortcomings become evident when they are called upon to understand the meaning of symbols as used in the written language. These people can learn many tasks when patiently and properly taught.

• Some 5,000,000 are mildly retarded children, adolescents, and adults who are able to perform more adequately, adjust in a limited way to the demands of society, and play a more positive role as workers.

Economic Costs of Mental Retardation

There are no reliable estimates of the total cost to the Nation, both direct and indirect, of mental retardation. The direct costs to families and to communities include those for institutional and home care and for special services. Indirect costs include the losses that result from the absence of earning capacity and inability to contribute to the production of goods and services.

Only 4 percent of the mentally retarded are confined to institutions. Yet, their care costs relatives and communities some \$300 million annually. Additional amounts are required for the construction of facilities for custodial and educational purposes. The cost of institutional care, facilities construction, and special care in the family home totals more than \$1 billion per year.

The Development of National Concern

Mental retardation thus is a serious problem affecting many aspects of our society. The host of problems presented by these people--to themselves, to their families, and to their communities--include biological, psychological, educational, vocational, and social areas of concern. Mental retardation must be approached through the whole life cycle, from consideration of genetics and conception through pregnancy, delivery, childhood, adolescence, adulthood, and old age.

Since 1950, interest in the problem of mental retardation has grown very rapidly. During the past decade increased activities have been stimulated by a few foundations, by the demands of parents, by interested lay and professional groups, and by members of legislative bodies who have been convinced of the urgent need for programs in this field.

Today, the effort to meet the problem of mental retardation takes eight basic forms:

1. Diagnostic and clinical services. There are over 90 clinics specializing in services to the retarded. Well over half were established within the past five years. These services need still greater expansion. The 20,000 children aided in 1960 represent only a small fraction of those who need the service.

2. Care in residential institutions. Today there are over 200,000 mentally retarded patients in such institutions, approximately 10 percent more than there were five years ago. But the average

waiting list continues to grow, and the quality of the service often suffers from limited budgets and salary levels. Increases in both facilities and manpower are necessary.

3. Special education. The number of mentally retarded enrolled in special educational classes has been doubled over the past decade. In spite of this record, we are not yet meeting our existing requirements, and more such facilities must be provided. Less than 25 percent of our retarded children have access to special education. Moreover, the classes need teachers specially trained to meet the specialized needs of the retarded. To meet minimum standards, at least 75,000 such teachers are required. Today there are less than 20,000, and many of these have not fully met professional standards.

4. Parent counselling. Counselling of parents is now being provided by private physicians, clinic staffs, social workers, nurses, psychologists, and school personnel. Although this service is still in an experimental stage of development, it offers bright prospects for helping parents to meet their social and emotional problems.

5. Social services. Social services provided mentally retarded children and adults include case work, group work, and day care. These services are an integral part of clinical, rehabilitation, and other mental retardation programs. Social workers are also active in community organizations and in working with parents groups.

6. Vocational rehabilitation. In the past five years the number of mentally retarded rehabilitated through State vocational agencies has more than tripled--going from 1,094 in 1957 to 3,562 in 1961. In terms of the number who could benefit from rehabilitation services, this number is very small. However, new knowledge and new techniques are needed, for over 25 percent of those coming out of the special classes still cannot be placed.

7. Preparation of professional personnel. The Federal government is now promoting the training of leadership personnel in education, rehabilitation workers, research personnel, and medical and welfare specialists. In addition, programs are being provided that will increase the competence of the health professions in providing services for retarded persons. Nevertheless, shortages of qualified personnel remain one of the major bottlenecks in providing services to retarded persons and their families.

8. Research. Support for research in the causes and amelioration of mental retardation has been greatly increased, especially during the last five years. Progress has been made in identifying specific conditions and diseases and in establishing basic problems of behavior and learning, but major research breakthroughs must be achieved before there will be adequate understanding of the pathological, genetic, psychological, environmental, and other aspects of mental retardation.

Mental Retardation and the Future

Within the next 10 years, the problem of mental retardation may undergo many changes. Unless there are major advances in methods of prevention, there will be as many as one million more mentally retarded persons by 1970. This increase is predicated on anticipated general population growth, increased life span, and increased infant survival rates. By 1970 the mentally retarded as a group will differ from what it is now. The age composition, the extent of associated handicaps, the assumed potentialities of subgroups, as well as presumed causal factors and resulting treatment approaches, all will undergo changes.

1. Longevity. Disease control, new drugs, and higher standards of living have steadily increased the life span of most Americans. While the mentally retarded as a group fall below the average life expectancy, the number of years the average retarded individual lives has been increasing proportionately with the overall average. Recent studies clearly document a diminishing death rate and an increased life span for the mentally retarded both in and out of institutions in the past decade. This increase in life span adds materially to the number of mentally retarded persons, particularly in the upper age levels. With the increased availability of health services, the life span of mentally retarded persons may continue to increase and move closer to the average life expectancy of the general population.

Improved and more extensive prenatal, obstetrical and pediatric care have brought about marked increases in the infant survival rate in the Nation over the past 20 years. Such efforts, along with increasing the chances of survival of all infants, have also increased the survival rates of infants who are premature or who have congenital handicaps or malformations. Since mental retardation is one of the major conditions associated with such handicaps in infants, improved care has to an extent also increased the number of the retarded for whom special services will be needed.

2. Extent of associated handicaps. The increased survival rates of retarded infants will probably bring with it an increase in the number of retarded persons who have associated physical handicaps. Current reports from clinical programs dealing with retarded children under 6 years of age indicate that even now in this group, 75 percent have associated physical disabilities. Likewise, because the older individuals are now living longer, we can expect many of them to present the physical problems of the aged in our general population.

3. Assumed potentialities. Our present means of assessing potentialities of social development, learning, work training and job placement of retarded persons are crude. Classification in terms of gross achieved scores of intelligence has never served as an adequate gauge of potentiality nor as a good basis for grouping, planning or training. With these many changes in the composition of the group of

mentally retarded individuals there will be an even greater need to develop criteria other than standardized intelligence tests to assess such potentials. More careful assessment of homogeneous subgroups within the category of mental retardation in terms of levels of potentials may considerably change our present concept of which individuals can be helped.

4. Changing patterns in the American way of life. Many problems of mentally retarded persons will become more acute in the future:

a. Families are growing larger and in fewer instances will a retarded child be an only child. Parents will have less time and fewer resources to devote to a retarded child.

b. Changes in family living will continue. Large numbers of families are moving each year, and more people live in metropolitan areas. The large extended family of the past, which included grandparents, maiden aunts, etc., all living in the same household, is disappearing. More and more of the burden of caring for the children is being placed on the mother.

c. More mothers of young children are in the labor force. Many times the factors that induce mothers to work are even more forceful for the mother who has a retarded child. Substitute care for the retarded child, however, is more difficult to obtain. Frequently, too, the retarded child is less able to understand the need for a parent substitute, which makes planning more difficult to carry out.

d. More children are going to school longer. The general level of education is rising in the Nation. As this trend continues, the mentally retarded whose disability shows itself in this area will be more marked. As educational standards and achievements continue to rise, a greater number of individuals who cannot keep up or achieve these levels will be discovered and will demand attention.

e. Machines replace unskilled labor. In the past, the majority of the mentally retarded children completing special classes for the educable in urban areas were able to find jobs on their own. There is some question whether this will continue to be so in the next 10 years without additional special help. Increased industrial specialization, automation and the intensified tempo of industrial production, pose new problems. Elevated educational standards in rural areas also are adding to the problem. Farming, which years ago provided a field of employment for many of the retarded, has become so highly specialized that persons who would have been employed in the past have a difficult time finding employment at all now. Thus, further development of the limited potentialities of mentally retarded persons will require special programs, including the provision of aided and protected conditions of employment.

In the next 10 years, as new programs demonstrate potentials and abilities in various groups of the retarded, extended or additional services will be needed. For example, the increased number of trainable children being offered school programs for the first time will create the problem of what to plan for them after this school experience. Previously most of these children led a sort of vegetative existence at home or in an institution. They are now being trained, stimulated and allowed to develop the limited potentialities that they have. With little likelihood that this group can be absorbed fully into industrial life, new programs will need to be developed.

Thus new demands will arise for information about and services to the mildly retarded who, after a limited amount of schooling, pass into adult society and are no longer identified as retarded. While many live useful, constructive and rewarding lives, others find themselves unemployed, dependent, or otherwise in difficulties. Unfortunately, little is known about the retarded adult and his progress through life. Efforts must be made to identify and study this group as well.

II. ACTIVITIES OF THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE IN MENTAL RETARDATION

A. SUMMARY OF ACTIVITIES AND EXPENDITURES

Four operating agencies of the Department of Health, Education, and Welfare are responsible for activities concerned with the problem of mental retardation. These agencies are the Public Health Service, Social Security Administration, Office of Education, and Office of Vocational Rehabilitation.

The programs administered by these agencies may be grouped under four main categories:

1. Research and studies
2. Professional preparation
3. Services
4. Construction of facilities

More specifically, the programs administered by these agencies are as follows:

Research and Studies

1. Intramural and extramural support programs of the National Institute of Mental Health, the National Institute of Neurological Diseases and Blindness, and the Center for Research in Child Health of the Public Health Service.
2. The Office of Education programs of studies, surveys, and cooperative research.
3. Special project grants under the maternal and child health program of the Children's Bureau, Social Security Administration.
4. Research and demonstration projects of the Office of Vocational Rehabilitation.

Professional Preparation

1. Office of Vocational Rehabilitation grants to educational institutions for training of personnel for all phases of rehabilitation.
2. Teaching and training grants of National Institutes of Mental Health and Neurological Diseases and Blindness.
3. Intramural training programs of the Public Health Service.

4. Office of Education training grants to colleges and universities and State educational agencies for leadership positions in education of the mentally retarded.

Services

1. Consultation by the Office of Education to State and local school systems, educational personnel and voluntary groups.

2. Financial assistance to States under Federal-State programs of public assistance.

3. Benefit payments for the disabled under the Federal program of old-age, survivors, and disability insurance.

4. Consultation and technical services of Children's Bureau staff to State and local communities under the maternal and child health and the child welfare services programs.

5. Consultation and technical services to State rehabilitation agencies under the Office of Vocational Rehabilitation programs.

6. Collection and dissemination by the Office of Education of comprehensive basic statistics and reports concerning the education of exceptional children, including the mentally retarded, and consultation, particularly to State departments of education and to national organizations.

7. Consultation and technical assistance to State and local agencies provided by the National Institute of Mental Health through its Regional Office staffs.

8. Activities relating to the application of knowledge to problems of mental retardation through the neurological and sensory disease service program of the Public Health Service.

Construction

1. Facilities for the mentally retarded under the hospital and medical facilities construction (Hill-Burton) program.

Federal Funds for Mental Retardation Programs, 1959-1963

The following table shows the funds obligated by the Department for its mental retardation activities from FY 1959 through FY 1961, and estimated obligations for the fiscal years 1962 and 1963.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Obligations for Programs on Mental Retardation, F.Y. 1959-1963^{1/}

Agency and Appropriation	Fiscal Year			President's Budget
	1959	1960	1961	
PUBLIC HEALTH SERVICE				
Mental health activities.....	\$ 2,356,000	\$ 2,676,000	\$ 3,644,000	\$ 5,290,000
Neurology and blindness activities.	5,938,000	8,231,089	10,873,850	11,560,000
Subtotal, Public Health Service.	8,294,000	10,907,089	14,517,850	16,850,000
SOCIAL SECURITY ADMINISTRATION 2/				
Bureau of Old-Age and Survivors Insurance				
Estimated benefit payments from trust funds.....	\$(19,300,000)	\$(29,300,000)	\$(39,300,000)	\$(49,700,000)
Trust fund obligations incurred to adjudicate claims of beneficiaries.....	(1,600,000)	(1,900,000)	(1,400,000)	(1,800,000)
Bureau of Family Services				
Salaries and expenses.....	9,500	10,000	15,000	20,000
Children's Bureau				
Grants to States for maternal and child health.....	1,300,000	1,300,000	1,434,300	1,573,700
Salaries and expenses, Children's Bureau.....	76,900	97,800	92,000	96,300
Subtotal, Social Security Administration.....	1,386,400	1,407,800	1,541,300	1,690,000
				1,745,000

1/ Figures in parentheses are for obligations from the old-age and survivors insurance trust fund and the disability insurance trust fund. All others are obligations from appropriated general funds.

2/ Information is not available on the costs due to mentally retarded people who are receiving public assistance, because data secured does not single out this one cause as a factor of disability or dependency. However, it is known that mental retardation is an important cause of disability for those receiving "Aid to the Permanently and Totally Disabled" under the Federal-State Public Assistance program.

Agency and Appropriation	Fiscal Year				1963 President's Budget
	1959	1960	1961	1962 Estimate	
OFFICE OF EDUCATION					
Defense educational activities (new educational media research).....	\$ 9,000	\$ 48,224	\$ 62,875	\$ 80,924	\$ 50,000
Expansion of teaching in education of the mentally retarded.....	---	985,221	993,433	1,000,000	1,000,000
Cooperative research.....	971,722	651,600	346,121	300,000	560,000 ^{3/}
Salaries and expenses (Administra- tion of grant program, "Expansion of teaching," etc.).....	---	43,000	50,000	49,500	61,250
Subtotal, Office of Education..	980,722	1,728,045	1,452,429	1,430,424	1,671,250
OFFICE OF VOCATIONAL REHABILITATION					
Grants to States:					
Basic support program.....	1,000,000	1,633,000	2,055,000	2,771,000	3,486,000
Extension and improvement.....	225,000	165,108	211,287	200,000	200,000
Research and training					
Research and demonstration projects.....	530,245	911,800	993,290	1,012,000	1,200,000
Training and traineeships.....	14,600	32,456	77,886	6,000	135,000
Subtotal, Office of Vocational Rehabilitation....	1,769,845	2,742,364	3,37,463	4,073,000	5,021,000
PRESIDENT'S PANEL ON MENTAL RETARDATION					
	---	---	---	(150,000) ^{4/}	(150,000) ^{4/}
GRAND TOTAL (General funds)...	12,430,967	16,785,298	20,849,042	24,043,424	28,274,250
GRAND TOTAL (Trust funds).....	(20,900,000)	(31,200,000)	(40,700,000)	(51,500,000)	(63,100,000)

^{3/} Includes funds for "full funding," i.e., subsequent year costs of new projects.

^{4/} These amounts are shown as non-add items since they are to be derived by transfer from funds available to the National Institutes of Health for mental retardation activities.

Responsibility for Coordination of Departmental Activities

Within the Office of the Secretary of the Department of Health, Education, and Welfare, responsibility for staff coordination and direction of mental retardation activities is assigned to the Assistant Secretary (for Legislation). The Office of the Assistant Secretary:

1. Serves as the principal adviser to the Secretary for improving the programs and activities of the Department related to mental retardation.
2. Provides staff coordination and direction to the staff offices of the Office of the Secretary and to operating agencies relative to the planning, execution, coordination, reporting, and evaluation of mental retardation activities.
3. Maintains liaison on behalf of the Department with the President's Panel on Mental Retardation, with other interested Federal agencies, and with professional and other groups.
4. Provides leadership to the Department's Committee on Mental Retardation.

Departmental Committee on Mental Retardation

The Committee on Mental Retardation consists of designated representatives of the Office of the Secretary and of a principal and alternates, as required, from certain operating agencies, as follows:

1. Office of the Secretary.
 - a. Assistant to Assistant Secretary (for Legislation) (Chairman).
 - b. Assistant to the Special Assistant to the Secretary (Health and Medical Affairs).
 - c. Program Coordination Officer.
2. Public Health Service.
3. Social Security Administration.
4. Office of Education.
5. Office of Vocational Rehabilitation.

The Departmental Committee on Mental Retardation is responsible for the following activities:

1. Serving the Secretary in an advisory capacity in the consideration of Department-wide policies, programs, procedures, activities, and related matters.

2. Serving in an advisory capacity for the Department as a whole with respect to inter-Departmental programs and activities in the field of mental retardation.

3. Serves as a liaison between the President's Panel on Mental Retardation and related programs and activities in the Department, including discussions on recommendations being formulated by the Panel and the Panel's final report to the President.

The members of the Departmental Committee are as follows:

Mr. Luther W. Stringham
Assistant to Assistant Secretary
(for Legislation) Chairman

Mr. Allen Pond
Office of the Secretary, Office
of Special Assistant for Health
and Medical Affairs

Dr. Grace L. Hewell
Office of the Secretary
Office of Assistant Secretary
(for Legislation)

Dr. James M. Hundley
Public Health Service
Office of the Surgeon General

Dr. Richard L. Masland
Public Health Service
National Institute of Neurolog-
ical Diseases and Blindness

Dr. Joseph M. Bobbitt
Public Health Service
National Institute of Mental Health

Mr. Charles E. Hawkins
Social Security Administration
Office of the Commissioner

Dr. Arthur J. Lesser
Social Security Administration
Children's Bureau

Mr. Rudolf Hormuth
Social Security Administration
Children's Bureau

Dr. Romaine Mackie
Office of Education
Division of State and Local
School Systems

Dr. Morton A. Seidenfeld
Office of Vocational Rehabili-
tation, Research and Training

B. PUBLIC HEALTH SERVICE

The Public Health Service, as the principal health agency of the Federal Government, is responsible for a broad spectrum of programs in research, training, service and facilities construction. Activities of the Public Health Service that are directly related to mental retardation are carried out through several organizational units: (1) within the National Institutes of Health by the National Institute of Mental Health, the National Institute of Neurological Diseases and Blindness, and the Division of General Medical Sciences, which includes the recently established National Center for Child Health; (2) within the Bureau of State Services by the Division of Hospital and Medical Facilities and by the Division of Chronic Diseases.

1. NATIONAL INSTITUTE OF MENTAL HEALTH

Introduction

The National Institute of Mental Health has been deeply interested and concerned with the problem of mental retardation for several years. The effect of the Institute's activities in this field is indicated by the increase in expenditures from \$2,000,000 in 1959 to an estimated \$5,275,000 for 1962. This supports a broadly based program of a varied nature as indicated by the following four general areas:

Program Development--Efforts through special projects, consultation, and support of services;

Research--Contributions to basic knowledge through direct research on the Bethesda campus as well as grant support to investigators throughout the country;

Service--Improvement and expansion of service programs through demonstration projects, technical assistance and consultation, and grants-in-aid to States;

Personnel--Increase in the numbers and competency of professionals in the field through support of training both directly to universities and through special projects concentrating on inservice and staff development.

Describing the Problem

In addition to these four areas, which are described in greater detail below, the Institute has taken a leading responsibility for accurately defining and describing certain aspects of the problem of mental retardation. Its biometrics program serves continuously as the central point for the collection of data on patients resident in institutions for the mentally retarded. More recently the Institute has succeeded in organizing collection of nationwide data on patients seen in

psychiatric clinics. This revealed 26,163 patients with mental retardation who were seen in 1959 in psychiatric outpatient settings. Active planning continues for further development of this vital descriptive analytic work. A substantial part of the Twelfth Annual Conference of Mental Hospital Statisticians, to be held in Madison, Wisconsin, in 1962 under the sponsorship of the Institute, will be devoted to the discussion of mental retardation. Plans will be formulated for the development of uniform definition among States and the design of meaningful tabulations describing the movement and characteristics of patients in institutions for the mentally retarded comparable to developments which have taken place concerning data on hospitals for the mentally ill.

Program Development

The National Institute of Mental Health has given general support to the field both by special projects as well as consultation and technical assistance from its own staff.

A crucial grant of the Institute has played an important role in the general development of the field of mental retardation. In 1955 funds were made available to the professional association in the field, the American Association on Mental Deficiency, for a project entitled, "Technical Planning in Mental Retardation." The basic purpose of this project was seen as the delineation of current needs, the stimulation of creative thinking, integration and organization of work which had already been done, the improvement of liaison between interested groups and individuals--professional, Government, lay, and parents. For functional and organizational structure the broad general problems were thought to fall into three categories: research, training of personnel, and programming.

The results of this concentrated effort have been significant. They include publication of selected abstracts in the American Journal of Mental Deficiency; a bi-monthly newspaper, Project News, disseminated widely throughout the Western World; a ten year index of the American Journal of Mental Deficiency--a mechanism to increase the exchange of information in the field; a manual on terminology and classification in mental retardation to aid in the difficult fields of standards and criteria; a survey study and report of cooperative relationships established between residential facilities for the mentally retarded and colleges and universities; a review of the status of research in mental retardation due for publication in June 1962; a manual on program development; a study of minimal standards for residential institutions; staff consultant services to various professionals in many areas such as school superintendents, State department officials, sheltered workshop directors, and others; and an analysis of existing State laws governing the retarded.

An important activity of the project has been the calling of key conferences in selected areas crucial to the development of the field. These have included a conference to study how mental retardation as a

subject can be introduced into medical schools, how professionals working in the field of rehabilitation can more adequately prepare and place the retarded into suitable employment, how more and better trained psychologists can be recruited into the field; how social workers can be better trained on graduate levels; how inservice training for attendants in residential institutions can be improved; and what moral, ethical, legal, and human problems are involved in the use of human subjects in research. A symposium on research design and methodology in mental retardation was sponsored jointly by the Woods School and the Project. A resulting publication, "Approaches to Research in Mental Retardation" (American Journal of Mental Deficiency, September, 1959), has been useful throughout the field.

As in any project of this nature, many indirect benefits have accrued which are not measurable. Among these are dissemination of new information for large groups and the resulting stimulation to action; the cross-fertilization of ideas among the disciplines; the encouragement of demonstration programs and new research projects; perhaps most important, the rekindling of feelings of security and enthusiasm as well as recognition in individuals and groups who have long been working in isolated units. This project, through Institute support, has presented the most comprehensive attack on the multiple problems in the field of mental retardation today. The full scope of the project's work was made available to the President's Panel through the research associate of the technical project becoming the Research Director of the President's Panel.

Research

1. Intramural

The Institute supports a broad gauge program aimed at obtaining new knowledge in many aspects of the field of mental retardation. Research activity takes place at the Bethesda campus through direct research activities. There is activity in the laboratories relevant to crucial biochemical problems such as those involved in phenylketonuria.

The new Biosocial Growth Center is conducting a series of studies of parents and children. Stress is placed on psychological factors and on patterns of neuromuscular behavior in the infant and young child. The Institute is also conducting a basic study of family relationships as they differ in various socioeconomic classes.

2. Extramural

Extramural research activities are supported by the Institute in the biological, educational, psychological, and sociocultural fields. Quantitatively the extent of this support is indicated by the approximately 80 research projects in or immediately related to mental retardation now being supported by the Institute. This constitutes an expenditure of 2.8 million dollars in fiscal year 1961, an estimated

4.1 million dollars in fiscal year 1962, and over 5 million dollars in fiscal year 1963. Some examples of the kinds of research characteristic of each of these areas are indicated below.

Biological. Research projects range across the full biochemical spectrum. Studies in the metabolism of fats, proteins, carbohydrates, and other substances including their directly relevant clinical entities such as phenylketonuria, maple syrup urine disease, galactosemia, and others are being intensively pursued. An important and fruitful breakthrough in gaining mastery over disease process is the ability to create its parallel in animals. This has recently been achieved by creating mentally retarded monkeys with phenylketonuria. Attempts are being made to get experimental animals with other diseases of errors of inborn metabolism such as galactosemia. Basic biological developments are being studied in such areas as the "Prenatal Development of the Human Cerebral Cortex." Surprising findings which open unexpected roads to new knowledge have already been found. Studies of eight month and seven month old fetal brains have revealed that the number of cells is two to five times higher than in the new born. The biological studies extend into the usual clinical entities such as mongolism and cretinism. The most publicized recent breakthrough in basic biological knowledge relative to mental retardation is the discovery of the chromosome abnormality in mongolism. These abnormalities of the chromosomes, the basic stuff of life, are being pursued in several different areas including their relationships to human behavior. Thus basic knowledge is being pursued from genetics, through studies on the clinical disease process itself, with feedback of knowledge from basic science to the clinical laboratory and ultimately to prevention and treatment of the multiple types of mental retardation.

Psychological. The complex psychological and psychiatric aspects of mental retardation are being studied in several ways. One such study is of "Psychological Development in Cerebral Palsy." Here the focus is on the role of initiative and the increment in psychological development of cerebral palsied children that may take place through an environment that promotes initiative as compared with a more routine environment. Other studies are in language development and speech development. Here the focus may be directly on mental retardation or more basically on the actual processes of development themselves. The many handicaps suffered by mentally retarded children serve as research material for vital questions such as the development of speech in deaf children and the development of motor skills in the cerebral palsied.

Educational. A significant amount of activity is being supported in the area of learning and education. These involve basic studies in animals as well as in mental retardates. These studies in the basic learning process merge into studies of the effectiveness of various teaching techniques. These include several projects on experimental use of machine teaching of reading, arithmetic, and other basic subjects in retarded children. The study of reading ability is pursued in several ways including influence of drugs upon this vital skill.

Sociocultural. The retardate is a member of the family and the community. Several studies have centered on this aspect. A question frequently asked is, "What is the effect of a mentally retarded child on his brothers, sisters, and parents?" An important investigation, looking directly at this problem, is the study of the "Siblings and Parents of a Mentally Retarded Child." This investigation seeks to determine effects of the presence of a severely mentally retarded child upon the relationship between his parents and his normal siblings. It focuses upon aspects of the relationship which appeared to have consequences for the mental health of the intellectually normal sibling of a retarded child. The broad range and scope of the research effort being supported by the Institute is indicated by studies in such general areas so useful for filling out the basis for understanding the problem of the field as the "History of the Problem of Mental Deficiency." Another study is supporting translation and review of the Russian psychiatric literature relative to mental retardation and its rehabilitation techniques.

Service

1. Development of Demonstration, Experimental, and Pilot Projects

Under the program of mental health project grants, the Institute is able to support demonstration, experimental, and pilot studies related to the care, treatment and rehabilitation of the mentally retarded. Among projects currently being supported, a wide range of patients, both in terms of age and severity of retardation, are being treated in a variety of settings utilizing several professional groups and techniques. More specifically, programs now being supported include "Day Hospital Service in a Child Guidance Setting," which serves as a pilot project that will hopefully serve as a guide for further development of day patient services, a language development program for mentally retarded children, a program for preschool retardates and parents, interdisciplinary investigation of learning disorders, an occupation day center for mentally retarded young adults, use of public health nurses in a retarded children's program, and studies in parent counseling. A promising project is that which will explore in depth the "Collaborative Management of the Mentally Retarded." This project is unique because it includes and coordinates the cooperative facilities of a university medical center, the major community resources for education and welfare, and the State facilities within the framework of a teaching hospital.

A recent demonstration program is the counseling and referral service for the mentally retarded in New England. This demonstration of a State-wide service is jointly sponsored by the State Council on Community Services and the State Association for the Mentally Retarded. The purpose of the demonstration is to show what an information, referral and counseling service can do to identify problems of mental retardation, find out why agency services are not available to help families and mentally retarded persons to assess the needs of the community, and to help staff members of

health and welfare agencies and other professional groups become more familiar with the problems of mental retardation and more able to give service.

2. Control Programs in Phenylketonuria

Intense activity had laid the groundwork for large scale demonstration programs for the control of phenylketonuria. This has included a review of the literature (now ready for publication and distribution throughout the Country), study of current State programs, and field visits. As a result of consultation and negotiation with the Institute, several States have submitted programs of various types. Approaches include: a comprehensive screening treatment and follow-up on a statewide basis; intensive clinical and laboratory studies of the population of a State institution; screening of all children in special classes for the mentally retarded throughout a State.

3. State Programs

Organization changes in several States have given increased recognition to the importance of mental retardation programs. Several States, such as New York and New Jersey, have set up central offices of mental retardation to help coordinate the multiple approaches necessary to meet the problem, including health, education, and welfare. The program of nursery centers for preschool mentally retarded children, operated by the Massachusetts Department of Mental Health, continues to expand. Thirty centers are now in operation over the State. The purpose of the program is to aid in better diagnosis and evaluation of retarded children and to provide therapeutic services and training for future placement of the children in special classes of the public schools. Counseling for parents of the children is also part of the program. Other States have now developed similar nursery services such as those in Delaware.

Federal grant-in-aid funds contribute to a variety of programs which include, for example, support of Minnesota's Social Development Center for the Mentally Retarded. The purpose of this Center is to provide an intensive activity program for a group of young adult retardates in the trainable age but too old to participate in special classes. Thus, flexible use of funds can permit gaps to be filled in such areas as the transition from the special education to full community adjustment. While there is an increasing amount of State grants-in-aid funds devoted to mental retardation, initiative on allocation of these funds rests with the States and the total amount spent in this area has not increased as rapidly as would be desirable.

4. Technical Assistance Projects

In 1961 seven technical assistance projects, directly on the subject of mental retardation, were begun in five States. This is more than all the previous technical assistance projects of the past three

years on this subject. Pennsylvania covered several areas, including "Research Opportunities," "Volunteer Services," and "Sheltered Workshops." Reviews of total State's needs, resources, and community problems and subsequent cooperative planning highlighted efforts in North Carolina, Mississippi, Tennessee, and Maine. These meetings, drawing on the best available consultants from NIMH and throughout the Nation have proven especially fruitful in that they bring together a working group of 40 or 50 individuals in a State and community and have shown to be successful in giving impetus, direction, and creativity to efforts to which they address themselves.

5. Consultation Through Regional Offices

The Institute maintains a consultant staff in eight of the Department of Health, Education, and Welfare Regional offices throughout the Country. The consultants provide professional and technical assistance to a wide variety of programs in all of the States. The consultant staffs have become more active and have received more requests for consultation and assistance related to programs for the mentally retarded both in the community and the institutions. The recent increase in technical assistance projects in this field is but one example of this. The offices provide not only direct consultation on the basis of their own wide experience but draw upon expert resources from the Institute and from other consultants who can be retained by the Institute.

Personnel

1. Training Grants

For many years the Institute has been supporting professional training of persons in the basic mental health disciplines. The Institute has been involved in support of the training of over 10,000 professionals, psychiatrists, psychologists, social workers, nurses, social scientists, and others. Many of these devote part of their time to work in mental retardation and those involved in research have made significant contributions to the field.

Current support for psychiatry training has, as its locus, State institutions, such as Letchworth Village, New York, and Walter E. Fernald School, Massachusetts, as well as the University of California, where residents spend some time training in mental retardation.

Other support is for training grants in social work and psychology. Of note is the program at the George Peabody College for Teachers for the training of psychologists at the doctoral level with special competence in mental retardation. This program has developed over a dozen graduates since its inception in 1954, many of whom are in key positions in the field such as the current Research Director of the President's Panel on Mental Retardation.

2. Project Support for Training and Staff Development

Other mechanisms for the development of professional competence of personnel in the field is done through the Mental Health Projects Grant. The Western Interstate Commission for Higher Education in Colorado has begun an "Interstate Cooperation for Hospital Staff Development" program. This is a three year demonstration program of staff development in mental hospitals and schools for the retarded through interstate cooperation. The elements of the demonstration program are (a) regional conferences, (b) travel for career employees to observe and participate in selected new institution programs in other States, (c) continuation education programs to bring faculty--singly or in groups--to institutions which are isolated from university centers. Working through the Western Mental Health Council, State mental administrators, and the regional offices of the United States Public Health Service, the program is demonstrating that the cooperative use of facilities on a regional basis can result in increased professional interaction between public facilities and training centers, and more efficient and effective use of personnel in public mental institutions.

The Southern Regional Education Board has begun a three-year program entitled "A Regional Project to Improve Inservice Training of Attendant Personnel in Institutions for the Mentally Retarded." The purpose of this project is to improve the care of mentally retarded by developing and vigorously applying knowledge about living arrangements conducive to the growth, development, and welfare of the residents of State institutions. Strengthening and expanding the program of inservice training for attendant personnel are viewed as the most direct way to attack this problem. Key officials of 23 institutions have joined with the Southern Regional Education Board to conduct a five year study action program to collect and develop information about such child care and to devise, adopt and test ways of applying this to the operation of the facility.

The central mechanism is a series of seminars attended by representatives of the participating institutions, staff of the project, and consultant personnel. A three-day seminar, held in December 1961, brought together most of the superintendents of the State schools throughout the South and was considered highly successful in clarifying basic issues which will facilitate the full development of this most important program.

2. NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND BLINDNESS

The National Institute of Neurological Diseases and Blindness conducts research in mental retardation and related neurological and sensory disorders of infancy and childhood at its Bethesda, Maryland, laboratories, and supports such research at medical centers across the country through its research grants program. At present the Institute is spending more than \$11 million--about one-quarter of its fiscal year 1962 research appropriation--to support 151 projects aimed at increasing our knowledge of the causes, prevention, and treatment of mental retardation and related disorders.

To meet a critical shortage of scientists trained to conduct clinical research on the nervous system in mental retardation, the National Institute of Neurological Diseases and Blindness has established 15 special training programs in pediatric neurology with an annual budget of \$360,000 in 1962.

The Collaborative Project

The Institute's major research endeavor in this area is the Collaborative Perinatal Research Project. Launched as a broad approach to a national problem, the project has been in operation five and a half years, including two and a half years of extensive preparation. Its primary goal is to discover clues to the causes of mental retardation, cerebral palsy, and kindred disorders of infancy and childhood. To this end, teams of medical and allied scientists at 15 medical centers throughout the country are studying expectant mothers from early pregnancy through labor and delivery, and are examining their babies periodically from birth through school age. As analysis of the information collected reveals suspicious factors, they will be tested and their role evaluated.

A long-term venture in medical research, the Collaborative Project will eventually involve some 50,000 expectant mothers and their children. This is the minimum number that must be studied if the project is to produce valid results that can serve as a basis for further research aimed at an effective program of prevention.

In 1961 data were collected on slightly more than 9,000 pregnancies, and about 8,600 babies were born to mothers enrolled in the project. This increased the total number of participants in the study to about 23,000 mothers and 17,000 children. At the present rate of enrollment of new patients, it is expected that the goal of 50,000 cases will be reached early in 1965.

Early Findings. Useful findings are beginning to emerge from the Collaborative Project. These findings, however, are preliminary and should therefore be viewed with caution.

Prematurity is one of the most important factors in brain damage and deaths among infants. Prematurity is usually defined in terms of birthweight. In a recent review of data collected on about 7,500 project mothers, the relationship between their cigarette smoking history and the birthweight of their infants was investigated. It was found that birthweights were generally lower among smokers than among non-smokers. More specifically, the incidence of prematurity (defined as a birthweight of less than 2,500 grams) was significantly greater among expectant mothers who smoked than among those who did not smoke. In addition, the decrease in birthweight was proportional to the reported amount of smoking. These findings, derived from observations on a broad population base, confirm the results of previous studies which have shown a relationship between smoking and prematurity.

Another analysis carried out in 1961 focused on the association between lack of oxygen at birth and abnormal development at 8 months of age. This analysis revealed that 33 percent of infants with an abnormal or suspect performance on the project 8-month psychological examination had shown evidence of lack of oxygen at or soon after birth. In suspect infants, the incidence of oxygen lack was 22 percent and in definitely abnormal infants the incidence was 44 percent. In a control group of infants whose performance at 8 months was normal, the incidence of oxygen lack at birth was only 7 percent.

These differences are significant and implicate oxygen lack at birth as a factor in abnormal development which can be identified at 8 months of age by means of a psychological examination. Similar findings have been reported by other investigators, but on the basis of birth data collected after the children had been diagnosed as abnormal. The project findings, on the other hand, are based on data collected at birth and are therefore more meaningful.

As part of an investigation of stillbirths and infant deaths in the project, a study was made of the postmortem findings on a group of children born to mothers with diabetes. This study confirmed the generally known fact that infants of diabetic mothers weigh slightly more than infants of nondiabetic mothers. It was found, however, that the brains of infants of diabetic mothers do not show a corresponding increase in weight or volume but, on the contrary, tend to be smaller than the brains of infants of nondiabetic mothers. This discrepancy, moreover, is even greater when dehydrated brains are compared. These findings have considerable practical as well as theoretical importance. Many more cases will have to be studied, however, before they can be considered statistically valid.

Data on the pattern of development of the human brain, and on the rate of growth of its various parts, are almost nonexistent. To help fill this serious gap, the brains of all stillbirths and of all full-term babies dying in the project are being measured. Much valuable information has already been obtained on the development of the brain from the fifth fetal month on.

Related Studies. In 1961 about 50 scientific articles were published presenting findings derived from related studies being carried out at the 15 cooperating hospitals with Collaborative Project support. These findings relate to such subjects as the role of maternal infections in abnormal pregnancy outcome, the identification of "high risk" mothers, and the early detection of neurological abnormalities of infancy and childhood. The findings described below represent only a small sample of the total reported.

Prematurity has been linked in some cases to an infection of the urinary tract of pregnant women. The infection produces no symptoms and cannot be detected by routine urine analysis. Detection is possible, however, by means of a special urine test. Researchers at two other cooperating hospitals are carrying out similar investigations, and still another related study has been launched to pinpoint the mechanism by which this infection affects the unborn child.

An increased incidence of prematurity and perinatal infant deaths has also been found to be associated with inflammation of the placenta, fetal membranes, and umbilical cord. The study which produced this finding also revealed that an infection of the vagina, or the cervix, or both was present in 50 percent of the patients with inflammation of the membranes and cord, compared with only 20 percent of a control group. This finding points to the possibility that better treatment of infections of the vagina and cervix during pregnancy may reduce the incidence of prematurity and infant deaths.

Studies of young animals indicate that brain damage due to prolonged lack of oxygen is followed by an increase in the permeability of the blood-brain barrier to certain enzymes. The resulting rise in the concentration of these enzymes in the cerebrospinal fluid can be measured and could provide a basis for the early diagnosis of brain damage in children. This aspect is now being explored.

Abnormal eye movements or total absence of eye movements in newborn infants subjected to mechanical rotation has been found to be a sign of abnormality of the nervous system. The test developed for this study should become a valuable part of the clinical neurological examination of newborn infants.

Using improved methods, research workers have found that electroencephalograms (EEG's) of newborn infants aid in earlier detection of brain damage. In addition, visual stimulation used in conjunction with EEG's has confirmed a previous finding that premature babies respond more slowly than normal, and postmature babies respond more quickly than normal. This highly significant difference in response time provides an additional scale for measuring brain maturation at birth.

Program Developments. In addition to research accomplishments, the Collaborative Project had two important program developments in 1961. One concerns the blood-testing phase of the project, the other, the development of an examination for testing speech, language, and hearing functions in 3-year-old children.

The blood-testing phase of the project makes use of antigens--substances which stimulate a chemical defense mechanism in the blood--to test the mother's blood serum for evidence of exposure to certain viruses during pregnancy. If a mother has been infected, this fact will be indicated by a greater number of antibodies in her blood.

At each of the collaborating medical centers, blood samples are taken from the expectant mothers during pregnancy and are sent to the National Institutes of Health Laboratories in Bethesda, Maryland, for testing. The blood serum is stored at minus 10 degrees Fahrenheit in two huge, walk-in freezers at the Institute's Serum Center. Specific information on the mother's pregnancy is kept together with data on the sample of her blood serum. This information will be readily available for checking and rechecking for many years.

To test the blood serum, more than 100 viral antigens have been produced. These include 28 ECHO viruses, 30 Coxsackie viruses, 28 adenoviruses, 9 myxoviruses, and 3 polio viruses. These range in severity from common cold viruses to those that cause paralysis and death. As new virus infections are identified in the cities where the project is being carried out, new antigens must be produced.

Development of the antigens has required extensive work in bringing together specific viral materials, performing complicated tests, developing new tests, and in many instances developing suitable conditions to grow the virus for antigen production. In addition, a microserological technique has been devised which reduces the volume of viral antigen required for testing to about one-eighth of that required with previous techniques. Since the viral antigens being used in this investigation are rather costly, the new microtechnique will save money.

Large-scale testing has been started using blood serum samples from mothers of abnormal children and from a matched control group. Testing to date has suggested several possible associations between virus infections during pregnancy and certain abnormalities. The data are very limited, however, and no specific associations or presumptive hypotheses can be made at present.

For many years various kinds of examinations have been used to assess speech, language, and hearing functions in children. When these examinations were found to be unsuitable for use in the Collaborative Project, a group of specialists from the cooperating hospitals was given the task of developing an adequate examination. Their efforts have resulted in an examination for testing speech, language, and hearing functions in 3-year-old children participating in the project.

The examination, which is now being pretested at several of the collaborating medical centers, has three purposes. It will be used primarily as a screening test to spot subtle neurological defects which might have been missed at earlier examinations. It will also provide data for use in confirming or rejecting the results of previous examinations. And it will furnish valuable information for use in describing disorders of the central nervous system as they are manifested in the speech, language, and hearing area. In this connection, it should be noted that the prognostic importance of deviations from the normal pattern of speech, language, and hearing development identified in 3-year-olds requires a reexamination of these children at age 6 to 7.

Future Prospects. Major efforts in the future will be concentrated on processing and analysis of data collected at the 15 collaborating institutions. In fact, the prospects for these activities are such that many additional findings are expected to become available during 1962.

Present plans call for focusing attention on such problems as prematurity (as defined by birthweight), toxemia as a major obstetrical complication, the effects of hyperbilirubinemia on the development of prematures, and the relation of specific virus infections during pregnancy to abnormal pregnancy outcome, including mental retardation.

Other Research Studies

In addition to the long-term collaborative project, Institute scientists at Bethesda and Institute grantees at medical centers throughout the country are conducting a wide range of basic and clinical research projects aimed at saving children from mental retardation. These include studies in the following areas: Biochemistry of the brain and inborn errors of metabolism; pathology and histology of the brain; methodology for early detection of neurological defects, including mental retardation. Also, studies on etiology, including prenatal conditions, neonatal asphyxia, and jaundice; developmental neurology, embryology, and cytogenetics; and evaluation and psychological studies.

During the last few years, these studies have increased our knowledge of many factors in mental retardation. Much more has been learned, for example, about the biochemical aspects of chromosomal disturbances. Numerous abnormalities--which represent deviations in both number and structure of chromosomes--have been observed. Recently an abnormality associated with mental retardation and with a striking feature of failure of speech development has been correlated with chromosome abnormality. Other chromosome abnormalities have been related to cerebral palsy and to the simultaneous occurrence of leukemia and mongolism. Although the causes of these abnormalities are not yet understood, this is believed to be a most promising area of research.

Asphyxia, or oxygen lack, has long been recognized as a factor in brain damage. Much more must be learned, therefore, about when, how, and

why asphyxia occurs. Various current research studies are shedding light on the environment of the baby before birth and during the birth process. Hopefully, such knowledge will lead to a greater understanding of the factors in prenatal and natal asphyxia.

Some scientists have reported that when oxygen lack occurs after normal breathing has been established, the brain damage is especially severe. In an effort to predict respiratory distress in the newborn, a miniature recording instrument called a plethysmograph is now being used to study the sequence of events during the first hours and days of life.

Much progress has been made in the detection of inborn errors of metabolism. The early detection of phenylketonuria, for example, has opened the door to the effective treatment of this disorder by diet. A new, inexpensive test has been developed by an Institute grantee which makes it possible to detect this disorder within a few days after birth. This test, based on a bacterial inhibition principle, uses only a drop of blood blotted on a filter paper to detect phenylketonuria.

Animal Studies

Until the establishment of the Institute's Laboratory of Perinatal Physiology in Puerto Rico, few animal studies had been conducted on neurological disorders which stem from adverse perinatal factors. Few laboratory animals possess a pregnancy physiology sufficiently comparable to that of man to be useful for research. However, the monkey Macaca mulatta, being studied in Puerto Rico, is an ideal subject because of its physiological similarity to man.

Advances in our knowledge resulting from studies at the Puerto Rico Laboratory include the establishment of consistent clinical patterns of mental retardation and physical handicaps resulting from asphyxia during birth. It now seems possible to mitigate the severity of the deficits induced under conditions of asphyxia by the administration of sodium bicarbonate and glucose during birth.

The possibility that abnormally strong uterine contractions during labor may predispose to cerebral hemorrhage will soon be explored in collaboration with others. The possibility that the cerebral hemorrhage signals a condition in which blood is forced from the contracting arteries into a weakened capillary network is being entertained.

The role of hyperbilirubinemia in kernicterus can now be studied more thoroughly, since for the first time a condition comparable to that in human kernicterus has been produced in an experimental animal.

The unique research opportunities this facility affords have drawn the interest of a great many scientists from other countries, especially from Central and South America, who have joined in the research attack.

Thus the laboratory is rapidly becoming a particularly important research center in the Western Hemisphere.

Joint BSS-NINDB Service Program

Recognizing that further advances in the attack on mental retardation and other neurological disorders will depend, in part, on increased application of research findings, the Surgeon General recently established the Neurological and Sensory Disease Service Program.

The new unit will be administered by the Bureau of State Services, Division of Chronic Diseases, in collaboration with the National Institute of Neurological Diseases and Blindness. The Program will be supported by professional and technical assistance funds from NINDB.

The Program will provide consultation, technical, demonstration, training, and educational services to communities directly and through Public Health Service grants. It will also cooperate with State health agencies, medical schools, professional organizations, and other private and public nonprofit groups.

Activities of the Program will include the stimulation, development, and support of activities aimed at prevention, diagnosis, treatment, and rehabilitation in a wide variety of diseases and disorders. To this end, the Program will offer aid to medical schools and other medical facilities for setting up projects, staffed with specialists, to concentrate and coordinate community diagnostic, study, and treatment activities for persons with neurological and sensory disorders, including mental retardation. These projects will give physicians, nurses, and other health personnel an opportunity to learn more about new techniques.

Other activities of the Program will include surveys and studies of the prevalence and location of cases and the number and types of personnel and facilities needed to promote the application of present knowledge. Community services, such as screening programs, will be emphasized.

3. CENTER FOR RESEARCH IN CHILD HEALTH

The Center for Research in Child Health in the Division of General Medical Sciences, National Institutes of Health, is developing a program to encourage research in the basic biological, behavioral and clinical sciences in order to better understand normal and abnormal developmental processes in children, both before and after birth. Greater knowledge of normal developmental processes and the ways immature humans respond to a host of stresses at various stages of development is important to improve our understanding of the etiology, early diagnosis, prevention and treatment of mental retardation. The Center has been assigned responsibility to strengthen the role of the National Institutes of Health in multidisciplinary fields, both intramurally and extramurally, through consultation and advice to the several categorical institutes on problems such as mental retardation.

In addition, the Division of General Medical Sciences promotes and supports an extramural program of research and research training in the basic scientific disciplines, including the behavioral sciences, pertinent to normal and abnormal development of the child. As of June 15, 1961, this Division was supporting 196 research grants in the amount of approximately \$4,000,000 annually, classified broadly in the areas of Genetics, and Reproduction and Development, which might be expected to make varying contributions to our understanding of the underlying processes in mental retardation.

4. BUREAU OF STATE SERVICES

The Division of Hospital and Medical Facilities of the Bureau of State Services administers the Hospital and Medical Facilities Construction Program (popularly known as the Hill-Burton program). This program authorizes aid to assist in constructing and equipping hospitals of all types, public health centers, diagnostic and treatment centers, rehabilitation facilities and nursing homes. The various types of facilities are defined further in Public Health Service Regulations, Part 53 (Title VI of the Public Health Service Act, as amended).

Prior to 1958, the definition of a mental hospital, as established by Regulation, specifically excluded "hospitals for the feeble-minded and epileptic." This restriction was eliminated in 1958 in order that Hill-Burton funds could be approved to assist in constructing facilities which provide an active medical diagnostic and treatment program for the mentally retarded. At the present time, the eligibility of facilities for the mentally retarded is determined on the basis of the purpose and function of the facility. If the facility includes an active medical program and meets the definition of a hospital, diagnostic or treatment center, rehabilitation facility, or nursing home, and other eligibility requirements, it may qualify for aid.

Dormitories and facilities for education and training purposes comprise a relatively large segment of institutions for the mentally retarded. Consequently, the Hill-Burton program under which aid can only be provided to construct medical treatment and care facilities as stated above has had only a minor impact on the total need in this area.

A list of projects constructed, under construction, and approved under this program, is attached.

The Neurological and Sensory Disease Service Program, Division of Chronic Diseases, Bureau of State Services, is engaged in the following activities related to the application of knowledge to problems of mental retardation:

1. Obtaining and disseminating epidemiologic information to professional personnel, public and private agencies, and the general public.
2. Developing and evaluating procedures for early identification and treatment of disorders resulting in mental retardation.
3. Identification and application of preventive and control measures through community service programs.

Facilities for the Mentally Retarded
Approved Under the Hill-Burton Program
As of December 31, 1961

Location	Name of Facility	Type of Facility	Total Cost	Federal Share	Status of Project
<u>Arkansas</u> Conway	Arkansas Children's Colony (3 projects)	D-T Center Rehabilitation Nursing Home	\$ 236,337 281,044 264,479	\$ 23,681 187,363 176,319	Under Construction Under Construction Under Construction
<u>Delaware</u> Stockley	Hospital for the Mentally Retarded	Rehabilitation	200,000	100,000	Under Construction
<u>Georgia</u> Gracewood	Gracewood Evaluation Center	Rehabilitation	580,000	290,000	Under Construction
<u>Idaho</u> Nampa	Nampa State School	Mental Hospital	1,328,297	478,297	Initially Approved
<u>Illinois</u> Chicago	Misericordia Home	Nursing Home	750,000	123,627	In Operation
<u>Kansas</u> Parsons	Parsons State Hospital and Training Center	Rehabilitation	819,500	232,435	Under Construction
<u>Louisiana</u> Albany Pineville	Retarded Children's Home State Colony and Training School	Mental Hospital Nursing Home	2,140,000 760,603	150,000 380,301	Initially Approved Under Construction
<u>Mississippi</u> Ellisville	Ellisville State School	Rehabilitation	1,050,000	700,000	Under Construction
<u>New Jersey</u> Maddenville	Bancroft School	Rehabilitation	500,782	170,100	Under Construction

Location	Name of Facility	Type of Facility	Total Cost	Federal Share	Status of Project
<u>New Mexico</u>					
<u>Los Lunas</u>	Los Lunas Hospital and Training School	Nursing Home D-T Center Rehabilitation	\$ 264,000 266,600 280,000	\$ 132,000 128,000 140,000	Under Construction Under Construction
<u>Ohio</u>					
<u>Columbus Tiffin</u>	Columbus State School Betty Jane Memorial	Rehabilitation Outpatient	637,500 497,927	212,500 165,975	Under Construction Under Construction
<u>Oklahoma</u>					
<u>Sand Springs</u>	Hisson Memorial Center	Mental Hospital	1,427,000	600,000	Initially Approved
<u>Rhode Island</u>					
<u>Exeter</u>	Ladd School (2 projects)	Rehabilitation Nursing Home	700,055 1,363,177	105,922 300,000	Under Construction Under Construction
<u>South Carolina</u>					
<u>Clinton</u>	Whitten Village	Mental Hospital	1,000,000	500,000	Under Construction
<u>Texas</u>					
<u>Abilene Denton</u>	State School State School (3 projects)	Rehabilitation Rehabilitation Nursing Home Nursing Home Rehabilitation	142,000 242,500 971,000 1,250,000 127,000	71,000 121,250 460,500 625,000 63,500	In Operation In Operation In Operation Under Construction In Operation
<u>San Antonio</u>	Incarinate Word College Rehabilitation Center	Rehabilitation	234,146	128,205	In Operation
<u>Virginia</u>					
<u>Arlington</u>	George Mason Center	Rehabilitation	2,672,575	312,800	Under Construction
<u>Wisconsin</u>					
<u>Madison</u>	Central Wisconsin Colony	Rehabilitation			

C. SOCIAL SECURITY ADMINISTRATION

Three Bureaus of the Social Security Administration are making contributions to the fight against mental retardation: The Children's Bureau, the Bureau of Family Services (formerly the Bureau of Public Assistance) and the Bureau of Old-Age and Survivors Insurance.

1. CHILDREN'S BUREAU

The Children's Bureau concern for mentally retarded children stems initially from its responsibility under the Basic Act of 1912 to "investigate and report on all matters pertaining to the welfare of children and child life." In the first 6 years of its existence, three of the major studies produced by the Bureau dealt with mental retardation.

The passage of the Social Security Act in 1935 and the assignment to the Bureau of the added responsibility of administering Federal grants for maternal and child health, crippled children, and child welfare services, emphasized the principle that all of the people, through the Federal Government, share with the State and local governments responsibility for helping to provide community services that children need to have for a good start in life. The Social Security Act also afforded the Bureau an opportunity to help the States develop demonstrations and special programs in areas where there were gaps in services.

A Children's Bureau Technical Committee on Clinical Programs was established in 1958. The Committee consists of physicians and other specialists representing various regions of the country and fields, such as pediatrics, psychiatry, maternal and child health, psychology, medical social work, public health nursing and nutrition. It provides guidance and advice to the Children's Bureau, and the reports of the meetings are helpful to other professional groups as well. Technical assistance and staff help are supplied by the Children's Bureau, Division of Health Services.

Development of Maternal and Child Health Activities in Behalf of Mentally Retarded Children and Their Families

As recently as 1954, maternal and child health activities in behalf of mentally retarded children and their families were extremely limited. Many local public health nurses were reporting suspected mentally retarded children in their caseloads, but for the most part they had few or no resources for establishing a diagnosis. Consultation and guidance as to how to deal with these children and their families generally were not available. Some children who were functioning below the normal expected level of development were being followed in well-child conferences, but adequate developmental and diagnostic appraisal was not

generally available, nor was continuing guidance to parents once such a diagnosis had been made.

Testimony before the House Appropriations Committee in 1956 indicated that the principal needs for mentally retarded children were to find them early, to provide a complete evaluation, to interpret the findings to parents, and to use the findings as a basis for ongoing help and care. By age groups, the greatest gap in available services was in relation to infants and preschool children. It appeared that the services that were lacking could best be provided through program emphasis within the framework of the maternal and child health program. The basic interests of this program, that is, preventive health services, child health supervision, growth and development and the fostering of good parent-child relationships are also the basic interests of a program for mentally retarded children.

It was on this basis and to achieve these goals that the Congress for fiscal year 1957, increased the annual maternal and child health appropriations and earmarked \$1 million specifically for special projects serving this group of children. The Appropriations Committee also expressed the hope that a second million dollars of the increase which was to be distributed to the States on a regular formula basis would be used to implement services for the mentally retarded.

The Special Demonstration Projects

The State health departments have been making use of these grants to establish demonstration projects centering about child health supervision and the problems in growth and development of children who are retarded or suspected of being retarded.

These demonstration projects have one or more purposes:

1. Patient Care--Projects designed to provide early detection, evaluation and care needed by mentally retarded children, or to demonstrate new ways of providing this care.
2. Training of Professional Personnel--Projects designed to train professional persons in better ways of dealing with retarded children and in more effective use of professional skills in their behalf.
3. Demonstration Studies--Projects designed to reveal what is needed for an effective program, how such a program can best be set up and administered, what it will cost, how it can be evaluated, etc.

All of these demonstrations depend on developing a specialized clinical team. The majority of these projects are set up within a maternal and child health program. Their primary focus is early finding of children suspected of being retarded. Project services are geared

chiefly to infants and preschool children. A pediatrician usually heads the treatment team, which includes a social worker, a clinical psychologist and a public health nursing consultant. Additional team members may be added from other specialists, or from different professional backgrounds.

These demonstration projects have not only provided a needed service to retarded children and their parents, but have also allowed the States to demonstrate to local communities how a program might be set up, how cases can be located early, what makes up an evaluation, what kinds of help can be provided to these children and their families. The accumulation of case data and experience by the group of specialists has also made it possible for these groups to pinpoint other gaps and unmet needs in the State.

Services provided through these projects can best be described by the amount and kind of patient care, professional training and demonstration studies that have flowed from them:

1. Patient care

By 1961, 46 States were providing as a part of their demonstration some special direct clinical services to retarded children and their families. Based on reports from 40 States close to 12,000 mentally retarded children and their families were served by these programs during 1960. Three out of four of the children admitted to services each year were under 10 years of age. Over 50 percent had associated handicaps.

While these services would not have been available without this program and while the cost to the Federal Government was comparatively low, the total number of children served represents only a comparatively small proportion of the age group needing this help.

The emphasis in these programs has been on providing a demonstration of high quality service for a limited number. The actual numbers served, therefore, are not the main index of the success of these programs. They must be judged by how well they were able to show what makes up an evaluation of a retarded child, by what kind of help can be given to parents, and by how successful were they in finding abilities in these children which could be used as the basis for training and adjustment.

The real criteria on which these services will have to be judged will be the improved adjustment of the children and the families they serve and the extent to which they can stimulate good service in general to preschool retarded children.

2. Training of Professional Personnel

Almost all of the projects use their services for training of professional workers. Much of this training is on an informal, individual basis. It is accomplished by providing a setting where interested professionals can observe and confer with a specialized team.

It is also achieved through contact with the variety of professionals in the community who have known the individual child being evaluated or treated. Physicians, social workers, public health nurses, teachers, etc., who have known the child are invited to participate in the staff conference and in the development of a program plan for the patient. In the course of this they are exposed to other viewpoints and approaches. Since in the average case at least 3 professionals outside of the clinical team are involved or concerned, it is estimated that more than 25,000 professionals have had such exposure by these projects.

In order to obtain the kinds of services project personnel feel these children need, it usually is necessary to stimulate some inservice training programs for professionals and agencies with whom they need to work closely, and on whose services they are dependent in carrying out plans for the child. Public health nurses are an example of such a group. Through the stimulus of the projects, 9 out of every 10 public health nurses have received some inservice orientation and education in mental retardation during the past 3 years.

More formalized training is also being provided, especially through the 14 projects which have been set up at or in conjunction with medical schools. In these programs, the patient care is used for teaching medical students, interns, residents, and other personnel associated with medical schools. Formal course material is also prepared and presented in the regular curriculum. Last year, approximately 2,520 hours of staff time in these projects were used for training. Fifteen hundred second year residents and medical students, 200 nurses, and 300 teachers were trained. These projects also provide field work placement and supervision for approximately 30 social work students, and a few medical fellowships.

The Tulsa, Oklahoma, project provides special two-week training courses for clinical teams specializing in mental retardation and offers short, similar courses to public health nurses, social workers, nutritionists, physicians, psychologists, teachers, etc. Also, this program has offered special two and three day institutes for the clergy, nursing educators, nutrition consultants and others. An institute on management of mentally retarded persons is planned for police officers.

3. Demonstration Studies

Seven programs have been set up to study a particular phase of mental retardation or special ways of providing care. Some of the areas included in these projects were:

- a. Study of the growth and development patterns of young retarded children (California).
- b. Study of the services a metropolitan area needs for the mentally retarded and an assessment of how these services can be provided (Colorado).
- c. Evaluation and study of the use of a traveling clinic to provide services to the mentally retarded over a large section (Idaho).
- d. Study of record keeping and evaluation of patients in an ongoing program (Maryland).
- e. Assessment of how to provide services in a rural area (Minnesota).

As the projects have developed, however, almost all have set up studies as a part of carrying out their major functions. Facets studied include dental problems of noninstitutionalized retarded children, problems of mental retardation in a population of Indian children living on reservations, waiting lists of children for admission to State institutions, the effect of the religious background of the family on their ability to accept the retarded child, the use of group approaches in family counseling, and attitudes of medical students towards the retarded.

Children Served Under State Health Department Mental Retardation Programs

Mental retardation services provided by State Health Departments are summarized in the accompanying tables.

Application of Public Health Methods to Prevention

A major emphasis within the past year has been the development of large scale screening, diagnosis and treatment of infants and families with phenylketonuria. This inborn error of metabolism has in the past been responsible for 1 percent of the population in our State institutions for the mentally retarded. By detecting families with the condition and by placing young infants with the condition on a special diet, mental retardation apparently can be prevented. The Children's Bureau has been working with State health departments in developing various screening and detection programs as well as developing the necessary laboratory facilities and programs for providing the diet and following

**MENTAL RETARDATION SERVICES PROVIDED BY
STATE MATERNAL AND CHILD HEALTH PROGRAMS**

**Applications for Services, by Source and Disposition:
Reporting States, 1958-1960**

Item	Average annual 1958-1960	1958 1/	1959 2/	1960 3/	Percent change 1960 over 1958 4/
<u>Applications, total</u>					
Number	7,860	7,099	7,873	8,609	+21.3
Percent	100.0	100.0	100.0	100.0	...
<u>Source:</u>					
<u>Carried over from last year</u>					
Number	1,532	1,123	1,788	1,685	+50.0
Percent	19.5	15.8	22.7	19.6	(+3.8)
<u>New applications</u>					
Number	6,328	5,976	6,085	6,924	+15.9
Percent	80.5	84.2	77.3	80.4	(-3.8)
<u>Disposition:</u>					
<u>Applicants admitted to service</u>					
Number	5,506	4,936	5,401	6,180	+25.2
Percent	70.1	69.5	68.6	71.8	(+2.3)
<u>Applications withdrawn</u>					
Number	659	632	644	700	+10.8
Percent	8.4	8.9	8.2	8.1	(-0.8)
<u>Applications carried over to next year</u>					
Number	1,696	1,531	1,828	1,729	+12.9
Percent	21.6	21.6	23.2	20.1	(-1.5)
<hr/>					
Applications carried over per 1,000 admissions	308.0	310.2	338.5	279.8	-9.8

Items may not add to total due to independent rounding.

1/ Based on reports from 37 States, out of 46 States which were providing services. 2/ Based on reports from 38 States, out of 46 States which were providing services. 3/ Based on reports from 40 States, out of 46 States which were providing services. 4/ Items in parentheses are percent of total cases under care in 1960 minus percent of total in 1958.

MENTAL RETARDATION SERVICES PROVIDED BY
STATE MATERNAL AND CHILD HEALTH PROGRAMS

Percent distribution by age of new cases admitted to service
Reporting States, 1958-1960

Age group	Percent distribution							
	1958-1960		1958 ^{1/}		1959 ^{2/}		1960 ^{3/}	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<u>Age reported</u>								
Under 1 year	378	2.5	119	2.8	116	2.3	143	2.4
1-4 years	4,491	29.5	1,211	27.9	1,440	28.9	1,840	31.2
5-9 years	6,713	44.1	1,909	44.0	2,211	44.4	2,593	43.9
10-14 years	2,938	19.3	916	21.1	1,007	20.2	1,015	17.2
15-17 years	511	3.4	146	3.4	158	3.2	207	3.5
18-20 years	188	1.2	35	0.8	48	1.0	105	1.8
Total	15,219	100.0	4,336	100.0	4,980	100.0	5,903	100.0
<u>Age not reported</u>	1,298	...	600	...	421	...	277	...
TOTAL	16,517	...	4,936	...	5,401	...	6,180	...

^{1/} Based on reports from 37 States, out of 46 States which were providing services. ^{2/} Based on reports from 38 States, out of 46 States which were providing services. ^{3/} Based on reports from 40 States, out of 46 States which were providing services.

its results. More than half of the States have set up complete screening and treatment programs for this condition. A start has been made in exploring which of the preventive techniques and programs developed for phenylketonuria can be applied to other inborn errors of metabolism which also result in mental retardation.

As a part of this effort to combat phenylketonuria, the following two projects have been undertaken by the Children's Bureau within the past year:

1. Collaborative Study of Prevention of Mental Retardation in Babies with Phenylketonuria

On recommendation of its Technical Committee on Mental Retardation, the Children's Bureau has begun a collaborative study of children with Phenylketonuria under the care of mental retardation clinics which are supported with maternal and child health funds, but including other clinics that wish to participate. This will be a study of the dietary treatment of this condition and the growth and development of these children. By such a joint study, data on a sufficient number of patients will be forthcoming for the first time to enable us to draw conclusions regarding the conditions controlling the prevention of mental retardation from Phenylketonuria through specific dietary treatment.

An inventory of children with Phenylketonuria known to the special clinical programs and to Maternal and Child Health Programs, was carried out as an initial phase of this study. This inventory revealed that nearly 500 children diagnosed as having PKU were known at some time during the last 5 years to programs responding to the inventory. Approximately 80% were admitted to the special clinical programs, and approximately 54% of these children are currently under the dietary supervision of the clinical program staffs.

2. Application on Wide Scale of New Blood Screening Test in New-born Infants to Locate Babies with Phenylketonuria

The major problem in case finding by the urine tests is that they cannot be carried out in the newborn period when babies are still in the hospital. A simple test using a few drops of blood has been developed by Dr. Robert Guthrie of the Children's Hospital, Buffalo, which is done on newborn infants just before they leave the hospital. Since over 90 percent of births now take place in hospitals, this may simplify case finding if it can be made a routine test.

The Children's Bureau, in collaboration with hospitals and State health departments, is beginning a large-scale study to determine the accuracy of the test and feasibility of its widespread use.

Summary of Achievements, Health Services Program (1957 to date)

The achievements of this program from 1957 to date can be summarized as follows:

49 States and 3 Territories have initiated special program activities on behalf of the mentally retarded as a part of their maternal and child health programs.

46 States are annually providing special clinical services to close to 12,000 mentally retarded children and their families living at home.

Of the Nation's 97 special clinics for retarded children, 64 have been developed through this program.

Over 300 specialists from various disciplines have been recruited and trained to provide service and leadership in these programs for the mentally retarded.

Over 25,000 public health nurses have received some training or orientation in mental retardation and in assisting families in the home care of mentally retarded children.

14 medical schools are using the special clinical services to retarded children as the basis for training of medical students, residents, and interns.

Some 4,500 medical students, residents and interns have received training or orientation in the newer concepts and approaches to the problem of mental retardation.

Over 1,200 nursing students have received some preparation in working with the mentally retarded.

More than 25,000 retarded children have been given complete evaluation and follow-up care. Currently about 12,000 children a year are being served.

Public health methods of screening, detection and prevention of mental retardation in the condition of phenylketonuria, an in-born error of metabolism, have been evolved.

26 States have set up programs for the detection and treatment of phenylketonuria utilizing these methods.

26 infants under one year of age with phenylketonuria were located, diagnosed and placed on a diet which will prevent mental retardation during 1961.

Three films have been developed as a part of this program.

1. "The Public Health Nurse and the Retarded Child"
produced by the Oklahoma State Department of Health

2. "Beyond the Shadows" produced by Western Cine
Production

3. "Pioneering Dental Health for Retarded Children"
produced by Bay State Film Productions for the Joseph Samuels Dental
Clinic of the Rhode Island Hospital.

"The Public Health Nurse and the Retarded Child" has been used
in 40 States. At the 1959 Annual Meeting of the University Film Pro-
ducers Association at Purdue University, it was selected as third best
out of 1,000 films.

"Beyond the Shadows" was selected for the finals in the Inter-
national Film Festival.

A fourth film on which production has been completed and which
will soon be released by the Oklahoma Health Department is entitled
"The Role of The Physician in Mental Retardation" and will deal with
the role of the private physician in mental retardation.

The needs of retarded children are becoming increasingly acute
as the pattern of life in our society becomes more complex. Retarded
children today are confronted with greater difficulty in social adjust-
ment, family stability is often threatened, and communities must cope
with expanded educational and behavioral problems.

Of the more than 2 million retarded children in this country,
96 percent live in the community, most of them with their own families,
others in foster family or group care. These children--frequently
clients of public child-welfare agencies--present a wide range of emo-
tional and practical problems to their families. Though they come
from every walk of life, many, particularly the mildly retarded, are
members of ethnic minorities, live under substandard conditions, lack
proper educational and cultural opportunities, and are deprived of
other essentials basic to healthy development. Not infrequently,
neglect, dependency, or delinquency bring them to the public child-
welfare agency.

As of March 1960, these agencies were providing services to
approximately 375,000 children. An estimated 10 percent of this group
are mentally retarded. An indication of the severe shortage of child
welfare services for retarded children is apparent when it is recog-
nized that 51 per 10,000 of the total child population receive service
and 120 per 10,000 of the child population are mentally retarded.

To meet this tremendous need, the Children's Bureau has directed its efforts in relation to child welfare services for retarded children and their families toward

1. Investigating and reporting upon the effect of mental retardation on family life and the impact of environmental conditions on mental and social growth.
2. Identifying and interpreting the role of social agencies in services to the retarded and stimulating these agencies to assume their responsibilities.
3. Extending and strengthening basic child welfare services and establishing specialized resources and facilities as appropriate.
4. Increasing the knowledge and skill of child welfare and other social work personnel through inservice training and professional education opportunities.

The Bureau has attempted to fulfill its responsibilities through the activities of its staff specialist on social services for mentally retarded children and through other regional and central office staff. Activities have included study and evaluation of needs, resources, and practices; dissemination of information; technical assistance and consultation; development of guide materials; planning and conduct of training and educational experiences. Consultation has been provided to other Federal agencies, national voluntary organizations and groups, State welfare departments, interdepartmental committees, community planning councils, schools of social work, institutions, and other agencies.

The impact of these activities on child welfare and other social agency programs is somewhat intangible and difficult to measure and document. Nevertheless, it is believed that Bureau leadership has contributed in part to some of the following developments:

1. Public and voluntary welfare agencies at National, State, and local levels devote increasing attention to the provision of learning experience in this subject area.
2. In approximately half of the States, preliminary steps to the development of statewide comprehensive programs for retarded children have been undertaken. Public child welfare agencies have participated in these steps including surveys and inventories, legislation, policy formulation, program planning, and methods for coordinating the programs of State departments and in local communities.
3. Child welfare workers in some communities provide services to families and children following diagnostic evaluation and in perhaps one-third of the States, assume responsibility for preadmission and

aftercare services for children in institutions. These services have facilitated the return of some retarded children to the community and enabled more parents to keep their children at home.

4. Basic child welfare services, still in short supply, are nevertheless being increasingly extended to this group. Day care, counseling and guidance, and specialized foster family homes are helping to relieve the burdens of families and contributing to the healthier growth of the children. The removal of some retarded children from damaging homes has greatly enhanced their mental development.

5. Schools of social work are becoming increasingly active in promoting greater knowledge of the needs of the mentally retarded through incorporation of content into the curriculum, sponsorship of training institutes, and development of teaching materials. The number of schools offering field instruction placements in facilities serving the retarded has increased in the past 4 years from approximately 7 to more than 20.

6. Child welfare agencies are recognizing a need for research and demonstration projects regarding the mentally retarded, and schools of social work have conducted some outstanding studies in this area.

7. Growing concern and interest is being reflected in some States in programming for the retarded juvenile offender who frequently becomes a client of public child welfare agencies through the pathways of neglect or delinquency.

8. Public responsibility is growing for the development and financial support of day care centers to provide for care, protection and social development for retarded children of preschool age or for the older child ineligible for public school attendance. This responsibility is also being reflected in the development of pilot demonstration projects and in the stepped-up efforts of States to strengthen the standards and licensing requirements of privately sponsored residential and day care facilities caring for retarded children.

9. Church sponsored organizations are assuming a more active role in identifying their contribution to services for the retarded child and in implementing plans for national action by their membership agencies.

To eliminate gaps in the provision of social services to retarded children, the Bureau plans to extend its help to States in 1962. Serious deficiencies exist in the standards of care provided in some institutions, and social services in these facilities need to be expanded and better coordinated with community resources. In addition, intensified efforts must be devoted to inservice training and professional

education of social work personnel, to the broad aspects of community planning and organization and to the development of comprehensive State and local programs for retarded children.

Plans for the Future

An indication of progress to date is the successful establishment of clinical services for retarded children in most State maternal and child health programs. However, only a few States have opened more than one clinic, and these already have long waiting lists. An increase in the number of these clinics in each State is therefore essential. The number of retarded children will probably increase as a result of the increase in the child population and the increase in life expectancy.

During the next few years it is anticipated that the following developments will take place:

Expansion of community programs for mentally retarded children to provide more diagnostic, evaluative and preventive health services and social services.

Continued emphasis on prevention of retardation through improved prenatal care, the care of premature infants and improved methods for the location, diagnosis and treatment of infants with metabolic disorders which result in retardation.

Greater use of the well-baby clinic for early case finding and supervision.

Development of standards and licensing for the growing number of nursery school and day care programs for young retarded children.

Increasing the availability of home assistance programs for parents in the home care of retarded children.

Development of standards and programs for diagnosis, medical care and health supervision for children in residential institutions.

Development of specialized services for retarded adolescents.

Continued emphasis in the detection of young children functioning on a retarded level by virtue of social and cultural deprivation and the provision of child welfare services aimed at prevention, planning and treatment.

Stimulation of research and demonstration projects that will contribute new knowledge and techniques in promoting the maximum development of retarded children through child welfare services.

2. BUREAU OF FAMILY SERVICES

In the program of aid to the permanently and totally disabled, the Bureau of Family Services makes grants to the States for payments, medical care and social services. A substantial number of the recipients under this program, particularly of the younger ones, are mentally retarded. Similarly, in the case of the grant program of aid to dependent children, a number of mentally retarded children are among the recipients.

Information is not available on how many mentally retarded people are receiving public assistance because periodic reporting does not single out this one cause as a factor in disability or in dependency. However, a study made of the "Characteristics of Recipients of Aid to the Permanently and Totally Disabled" in 1951 (a new study is now in development) showed that mental deficiency was the major cause of disability for 20.3 percent of all recipients under 35 years of age. For those aged 35-54, mental deficiency was the major cause of disability for 8.3 percent; and for those aged 55 and over, for 2.8 percent. There is no completed study of Aid to Dependent Children which shows statistics on this factor in the ADC program, though it is known that some recipients (children and parents) are in this group. A study now in process will give some indication of the incidence of mental retardation among ADC children.

The Bureau of Family Services assists the States through issuance of materials and consultation in developing special services designed to help families handle the needs of the mentally retarded member of the family. Assistance is also given the States in developing effective methods of cooperation and use of community resources serving mentally retarded persons. The Bureau has a project currently underway in cooperation with the Children's Bureau, designed to help State agencies identify ADC children who are living in hazardous situations. This includes aspects of mental retardation--i.e., is there a risk to a child's well-being because of mental retardation which may not be recognized by the parent, or because the parent himself (or caretaker) may be mentally retarded. The cost of staff time utilized for these purposes has been roughly estimated at \$15,000 in FY 1961 and is expected to amount to about \$20,000 in FY 1962 and also in FY 1963.

Some services offered in the States, depending on specific provisions of the State plan, include: financial assistance, which may include payment for medical care; medical and psychological examinations to determine nature and extent of disability and to help plan for treatment, employment, vocational rehabilitation, appropriate living arrangements (e.g., home for the aged, foster care, institutional care for mentally retarded, etc.); other social services--counseling and other help with personal, family and social problems and difficulties; homemaker service, social rehabilitation service; referral to other sources of help such as vocational guidance, sheltered work shops, and employment service (where these facilities are available in the community).

3. BUREAU OF OLD-AGE AND SURVIVORS INSURANCE

The Social Security program administered by the Bureau of Old-Age and Survivors Insurance contributes to the maintenance of the mentally retarded through the payment of monthly benefits to those eligible for such benefits.

The disability insurance program has grown rapidly as the result of a series of legislative changes since it began in 1954. Today payment of cash benefits is made to disabled workers under age 65 and to their dependents when the worker has the required number of quarters of coverage under the Social Security Act. Only a small percentage of the adult population receiving disability benefits is disabled as a result of mental retardation, because severely retarded persons have difficulty acquiring the necessary credits for covered work to be insured under the old-age, survivors and disability insurance program.

A much larger number of retarded people over 18 are able to qualify under another provision of the OASDI law. That provision authorizes payment of childhood disability benefits to seriously disabled persons aged 18 and older who have a disability that began before the age of 18 and has continued without interruption since that time; severely mentally retarded persons are eligible for such benefits when the parent upon whom they were dependent died insured under the program, or when such a parent is living and receiving disability or old-age insurance.

Data on benefit payments to the mentally retarded and obligations incurred to adjudicate their claims are not tabulated separately. The amounts involved for the years 1959 through 1963 have been estimated as follows:

<u>Fiscal year</u>	<u>In millions of dollars by fiscal years</u>	
	<u>Estimated benefit payments from trust funds</u>	<u>Trust fund of ligations incurred to adjudicate claims of beneficiaries</u>
1959	19.3	1.6
1960	29.3	1.9
1961	39.3	1.4
1962 Estimate	49.7	1.8
1963 President's Budget	61.3	1.8

These estimates are based on the proportion of mentally retarded cases in the disabled adult population. Some benefits are paid to retarded children below the age of 18; however, estimates are unavailable as no valid data have been collected. Estimated mentally retarded adult

beneficiaries for the 5 year period FY 1959-1963 are as follows:

<u>Fiscal Year</u>	<u>Number of Beneficiaries End of Year</u>
1959	45,200
1960	63,000
1961	77,000
1962	94,200
1963	108,800

D. OFFICE OF EDUCATION

The Office of Education is the primary education agency of the Federal Government. It offers leadership in contributing to the process of shaping educational goals and policies to insure the optimum development of all our people. It identifies needs, evaluates resources, and provides professional and financial assistance to strengthen areas of education where there is a national interest.

The interest of the Congress and the Executive Branch in developing--at the Federal level--a balanced approach to the problems of mental retardation has brought into sharp focus the importance of special education in an adequate overall program for the mentally retarded and the need for extending and improving special education programs in the schools of the Nation.

Expansion and Improvement of School Programs for the Retarded

In the education of the retarded, one of the major emphases of the Office of Education has been to assist in the expansion and improvement of school programs for the mentally retarded in the Nation.

The activities of the Office of Education in expansion and improvement of educational programs have taken many forms. In recent years, it has been possible to call more conferences, to produce more publications, and to increase the amount of fact-finding in this field. Examples of conferences are: one on "Classroom Procedures for Teaching the Severely Retarded" and a conference on the "Preparation of Mentally Retarded Youth for Gainful Employment," both of which eventuated in publications. Other conferences which emphasized the educational needs of the mentally retarded are the annual conference of State Directors of Special Education and periodic conferences of national organizations concerned with exceptional children. Even though only an estimated one-fourth of the number of mentally retarded children and youth needing special educational provisions are receiving them, progress in improving this situation is being made. Surveys of the extent of special education have been conducted for many years; the most recent survey compared with the survey of 1948 is shown in the following table:

Changes in Local Public and Residential School Programs

for the Mentally Retarded

Type of Schools	Enrollments	Number of States	Number of Local School Systems
<u>Local Public Schools</u>			
Enrollment, 1948	87,179	47	730
Enrollment, 1958	219,588	48*	3,102
Numerical gain	132,409	1	2,274
Percent gain	151.9	2	312.3
<u>Residential Schools</u>			
Enrollment, 1948	21,562	47	140
Enrollment, 1958	28,207	46	192
Numerical gain	6,645	-1	52
Percent gain	30.8	-2	37.1

* The total number surveyed.

As the table shows, there has been, within the last 10 to 12 years, a marked increase in the enrollments of mentally retarded pupils in special education facilities and there is reason to believe that this trend is continuing. Perhaps even more significant than the increase in enrollment is the increase in the number of school systems offering special educational opportunities for their mentally retarded pupils. The number of local public school systems providing such programs has quadrupled in the last 12 years. This and other trend developments are reflected in the recent publication "Exceptional Children and Youth: A Chart Book of Special Education Enrollments in Public Day Schools of the United States," issued by the Section on Exceptional Children and Youth.

Professional Preparation of Personnel in the Education of the Mentally Retarded

Although the Office of Education has for years given attention to the matter of professional qualifications of special educators to work with the mentally retarded, it was not until the passage of Public Law 85-926 that it was able to make substantial financial contribution to reducing the shortage of qualified special educators. It is estimated that

about 75,000 specially prepared teachers are needed if all the mentally retarded children and youth are to have access to suitable educational opportunities. On the basis of facts and estimates, it appears that only about 20,000 such teachers are now available. The most significant contribution toward alleviating this nationwide problem is the program developed under Public Law 85-296 "to encourage expansion of teaching in the education of mentally retarded children through grants to institutions of higher learning and to State educational agencies."

Since the time the program under Public Law 85-926 was initiated, a number of leading educators have been brought to the Office to advise on the administration of the Act. Although the law authorizes the use of funds for the training of classroom teachers as well as leadership personnel, the Office decided, on the basis of consultation, to place the emphasis, in the early years of the program, on the preparation of promising persons to occupy leadership positions to: (1) conduct programs in the training of teachers of mentally retarded (Section 1 of the Act); or (2) direct or supervise programs for retarded children in State educational agencies or local schools or local school systems (Section 2 of the Act).

The first impact of this program has already been felt throughout the Nation. Not only have promising individuals been recruited, but the quality of professional preparation and the procedures for selecting special educators are steadily improving. As more fellows prepared under the program assume positions of leadership, they will multiply their effectiveness and the full impact of the program will be even more deeply felt.

Under Section 1 of the law, twenty-five colleges are presently participating. Four of these, during the current year, received stimulation grants to enable them to strengthen their programs so that they will be in a position to receive fellowships as are the other twenty-one colleges.

Under Section 2 of the law, all but three of the States have participated in the program. This widespread use of fellowships by State departments of education has insured national recruitment.

Throughout the administration of this program, professional conferences have been called on such matters as the College and University Curriculums for the Preparation of Special Educators in the Field of the Mentally Retarded and Competencies Needed by Leadership Personnel in the Education of the Mentally Retarded.

Acquisition and Dissemination of Information and New Knowledge

The Office of Education conducts studies of both an opinion and fact-finding nature, encourages and contributes to the support of research,

and disseminates information on the education of the mentally retarded. Examples of recent studies are: "Special Education Enrollments in Local Public Schools: A Directory," "Education of the Severely Retarded," "Curriculum Adjustments for the Mentally Retarded," "Teachers of Children Who Are Mentally Retarded," "Preparation of Mentally Retarded Youth for Gainful Employment," and "The Retarded Child Goes to School." In addition to these more formal publications, the Office of Education has available for distribution bibliographies on the education of the retarded and curriculum guides.

The Office of Education also participates in a number of international activities designed to benefit the mentally retarded. One was representation at the Geneva conference sponsored by the International Bureau of Education of UNESCO. In preparation for this, the Office contributed a section on the education of the mentally retarded to the Geneva report. The Office was also represented at the London Conference on Scientific Study of Mental Deficiency. Specialists in the Office are continually in correspondence, and confer frequently with foreign educators interested in mental retardation.

The Office also conducts a number of multi-area activities which include the field of mental retardation. Examples now underway are "State Certification Requirements for Teachers of Exceptional Children," "College and University Programs for the Professional Preparation of Teachers of Exceptional Children," "State Legislation for Exceptional Children," and, in cooperation with the National Association of Local Directors of Special Education, a pamphlet on "Inservice Training Programs for Teachers of Exceptional Children."

The Office has also increased its efforts in cooperation with other groups to identify critical needs and to encourage investigators to undertake research which would throw new light on mental retardation. The Office staff is also increasing its emphasis on activities which will result in the application of research findings.

In addition to the foregoing work, there are two other resources in the Office of Education which have specific research functions in this field: one is the Cooperative Research Program authorized under Public Law 531, 83rd Congress, and the other is Title VII--Educational Research Media--of the National Defense Education Act.

Cooperative Research Program

The initial appropriation of \$1 million to the Cooperative Research Program, authorized under Public Law 83-531 in 1957, was made available with the request that approximately two-thirds be used to support research pertaining to problems in the education of the mentally retarded. Total Federal support through FY 1962 for all projects under the Program has been approximately \$22 million. About 20 percent, or somewhat over \$4 million has been given for research on problems in the field of mental retardation.

A total of 459 projects have been recommended to the Commissioner by the Cooperative Research Advisory Committee since the beginning of the program. Seventy-five, or approximately 16.5 percent, are concerned with educational problems of the mentally retarded. The 75 projects can be categorized into eight general problem areas. The area, number of projects, and a brief description of a representative problem that is or has been investigated in each follows:

Cognitive processes, six projects: An example of a type of problem in this area is one in which the investigators are studying how mentally retarded children differ from normal and gifted in their perception of form and meaning.

Communication, nine projects: One typical project has shown that for mentally retarded children the best language channel for learning is listening. This is especially true in the primary grades.

Counseling and guidance, four projects: Study is being directed toward an assessment of the attitudes of parents in order to determine what personality variables affect their attitudes, and what effect periodic counseling would have on those attitudes.

Education and training, 30 projects: A 4-year longitudinal study, still being carried on, is making comparisons of the mentally retarded children's mental, educational, and social development as a result of being in special or regular classes.

Identification and survey, three projects: A research project in this area reports on the number of mentally retarded children in one State and how other States might use the techniques that were devised for surveying and identifying mentally retarded children on a statewide basis.

Learning, 13 projects: The finding that mentally retarded children, as compared to normal children, have more fears and worries and the impact this has on motivation and performance on learning tasks is typical of the type of research projects in this area.

Measuring instruments, five projects: A research project in this area has resulted in a new test for measuring the hearing vocabulary and verbal intelligence of mentally retarded children from as young as 22 months to 18 years.

Miscellaneous, five projects: One project within this area is concerned with research design and methodology problems that must be accounted for in researching problems of educational significance in the whole field of mental retardation.

During the fiscal year 1962, four research projects significant to the education of the mentally retarded were initiated. In addition, a national seminar was held for the purpose of determining the status of research in the field of the mentally retarded and stimulating further

research effort. Outstanding scholars who have contributed significantly to research in the education of mentally retarded met for a period of 15 days. They proposed and developed major research designs in order to foster and stimulate more significant research.

Of the four research projects initiated in fiscal year 1962, one is a demonstration project which has as its major purpose the field-testing of research findings in a natural school setting. The demonstration project underway is based upon previous research of Dr. O. K. Moore of Yale University, who had found that pre-first-grade normal children can learn basic intellectual and inter-actional skills, e.g., to type, to print, to read, to take dictation, and to objectify their inter-actional experiences in the form of a dialogue prior to first grade. On the basis of these findings, Dr. Burton Blatt of Boston University is demonstrating the effects of placing familial retardates (those who do not have central nervous disorders) in a similar environment and using similar teaching techniques as were used by Dr. Moore with normal children. This approach is based on the notion that the learning of retarded youngsters may approach a normal level if they have an opportunity to learn under conditions which are not threatening.

A basic research project was initiated with Dr. Kai Jenson of the University of Wisconsin. This project is concerned with a study of factors influencing learning and problem solving behavior in the mentally retarded.

Another research project recently initiated is being conducted by Dr. Leslie F. Malpass and his associates of the University of South Florida. The major purpose of this study is to evaluate the usefulness of two automated teaching procedures ("teaching machines") for mentally retarded children. Both automated procedures will be compared with a standardized classroom instructional procedure in spelling and reading. The experimental procedures offer specific promise for teaching spelling and reading to retarded children who need such skills for minimally adequate self-maintenance in current society but who, too frequently, even in special education programs, do not gain such basic skills.

The social adjustment of mentally retarded children and its bearing on how these children learn in special and in regular classes is the problem under investigation in another research project currently underway. This study is being directed by Drs. John de Jung and Norris G. Haring of the University of Kansas.

Approximately two-thirds of the 75 research projects are completed at the present time. The seven following examples illustrate research findings and possible implications for the whole field of education of the mentally retarded.

1. Most standardized tests are difficult to use with severely (trainable) mentally retarded children because they are usually

heavily penalized by verbal, motor, sensory, and experimental handicaps. Therefore, the resulting low I.Q.'s are not too meaningful. It appears that the ideal test to employ in the study of mental deficiency would be one which investigates the ability to learn. Researchers at New York University have designed a test which evaluates the child in learning abilities. Results of this type of test can be used as a basis for evaluating the educability in severely retarded children.

2. Up to the present time no one has reliably demonstrated that educable mentally retarded children placed in special classes when they start to school develop mentally, academically, and socially at a more advanced rate than they might have had they continued in the regular grades. Past research has been fraught with faulty design, involving such problems as biased groups used for comparisons, small numbers of children studied, inadequate measures on the children and untrained teachers. The preliminary report of a 4-year study undertaken at the University of Illinois, one that has overcome many of these problems of research design, shows that the educable mentally retarded who have been in special classes for only 2 years are far ahead in social adjustment and considerably ahead academically as compared with their equals in regular classes. The impact the findings of this study may have on the total field of education in providing special classes may be one of the greatest breakthroughs in the area of the mentally retarded.

3. In developing educational programs for mentally retarded children great emphasis has been placed on motor tasks and rote memorization and little attention has been given to more complex mental processes such as the discovery of a principle. Available evidence appears to indicate that such an emphasis has oversimplified the abilities and limitations of mentally retarded children. An investigation at Syracuse University concludes that the rate of learning of mentally handicapped children in three types of direct learning performance--sensorimotor learning, rote learning, and the discovery of a principle--does not differ significantly from that of intellectually normal subjects with similar mental ages. It would appear that we are unnecessarily placing restrictions on the learning potential of the mentally retarded child by not taking advantage of the abilities he does possess in abstract reasoning and overemphasizing the abilities we assume he possesses in, for example, motor development.

4. Many individuals have assumed in the past that mentally retarded children do not have fears and become upset with failures and therefore have no worries. For example: "All he does is wash dishes, or dig ditches, or carry garbage, etc.; he doesn't have any real worries." Studies of Southern Illinois University have revealed that this concept about the mentally retarded is not true. It was found that the manifest anxieties (worries and fears) of mentally retarded children both in institutions and in special classes are significantly higher as compared with normal children. Recognition of the impact that worry and fear have on learning effectiveness in the classroom may well tend to foster a change in attitude toward the mentally retarded child by many teachers and in turn result in a higher level of accomplishment by the mentally retarded child.

5. The old adage that an individual who is not good at book learning is the one who is good with his hands has been refuted by researchers at the University of Wisconsin. They found that the motor retardation of the educable retarded child is greater than had been previously supposed. Their motor abilities are organized in much the same way as normal children and their development of these abilities is similar in growth pattern to normal children but at a lower level. These factors suggest that educable mentally retarded children profit by the same kind of motor experiences as normal children although much more patience will be required in setting the stage for learning. The most important implication of this study is that a well-planned program of physical education should assume an important place in the educational programs of the mentally retarded.

6. In teaching the mentally retarded the question invariably arises as to what particular method or methods would tend to increase the rate at which mentally retarded children learn. Certain facets of this question are being studied at the University of Illinois. The researcher is employing an automatic teaching device in teaching mentally retarded children in the area of the language arts. From this study will come programming principles based on sound learning theory to be used in future teaching of the mentally retarded through the use of autoinstructional devices. This type of aid will permit the teacher to spend more individual time with her students.

7. Research at San Francisco State College has devised a test which can measure the change in communicative effectiveness of mentally retarded children. It is now possible for both teachers and speech therapists to determine the level of communicative effectiveness of mentally retarded children. They can now incorporate the teaching of particular communicative skills with the daily life activities of the children by providing more experiences in the areas in which the children have been found to be weak.

Copies of all final reports of research projects supported by the Cooperative Research Program are sent to the Library of Congress. The Library, in turn, distributes the reports to approximately 60 subscribing libraries throughout the Nation. They are available through the inter-library loan system.

The monographs released by the Office of Education, and distributed by the Superintendent of Documents, U. S. Government Printing Office, are based on selected cooperative research program projects and activities. One of the nine that has been released to date is entitled "Motor Characteristics of the Mentally Retarded." The publication reports on a research project conducted at the University of Wisconsin. Six additional monographs are in the latter stages of printing, editing, and proofing. Twelve more monographs are planned for fiscal year 1963. Among these will be one summarizing all Cooperative Research projects concerned with mental retardation.

The exact number of articles based on cooperative research projects that have been prepared by the investigators and published in professional journals is unknown. It is known, however, that one project alone was the basis for 26 different professional journal articles. Information pertaining to the dissemination of research findings will be available in the near future and will be based on a survey of information secured from the principal investigators.

Another method of dissemination is the publication of the abstracts of completed projects dealing with the mentally retarded in the quarterly issues of the American Journal of Mental Deficiency.

Educational Media Research

Under the provisions of Title VII of the National Defense Education Act, approximately \$9 million has been granted to nonprofit institutions for support of research and experimentation in the educational uses of newer media of communication. Thus far approximately \$200,000 has been allocated for support of projects directly concerned with the mentally retarded. Discoveries from the other research projects will also apply to this group, particularly those which report findings suggesting new understanding of mental processes and abilities.

Three projects specifically involving the mentally retarded, their location and expected date of completion, are as follows:

1. The effects of mental retardation on film learning: A study to determine what types of instructional film experiences are meaningful to children with mental retardation, regularly enrolled in public schools (University of California at Los Angeles, September 30, 1961). (Final report has not yet been submitted.)
2. Automated programs for the instruction of arithmetic concepts to mentally retarded children (Partlow State School, Alabama, August 31, 1962).
3. The development and evaluation of a curriculum for educable mental retardates utilizing self-instructional devices or "teaching machines" (Edward R. Johnstone Training and Research Center, New Jersey, May 31, 1963).

A fourth project, completed by Grambling College, Louisiana, investigated the comparative effectiveness of three techniques of film utilization in teaching a selected group of educable mentally retarded children enrolled in public schools.

With the extension of the National Defense Education Act, the opportunity has been provided for the initiation of limited new programs of fundamental media research. The research should be useful in securing new knowledge which will in time provide teachers with new and more efficient techniques for educating the mentally retarded. Educators have long been interested in the problems of developing in the retardate

a felt need for learning and of finding means for facilitating the transfer of learning to life situations. There has been little investigation of the relationship of media to these problems. As a result, the range of instructional materials for the slow learner is relatively small, and the development of educational technology geared to this level of mental ability has been slow.

The findings of projects supported under the provisions of Title VII are widely disseminated for the benefit of the public schools and institutions of higher education in using new communications media to educate their students. The final report is distributed through the Library of Congress Documents Expediting Service to key libraries across the Nation and a copy is sent to each chief State school officer. The completed report is microfilmed and made available through the University Microfilm Service and an abstract of the report is published in a national educational research quarterly. Critical essays on appropriate groups of completed projects also appear in the research quarterly and special reports on groups of projects will be published.

E. OFFICE OF VOCATIONAL REHABILITATION

The Office of Vocational Rehabilitation assists the States in rehabilitating physically and mentally handicapped individuals so that they may prepare for and engage in remunerative employment to the extent of their capabilities, thereby increasing not only their social and economic well-being but also the productive capacity of the Nation. The Office also encourages and supports research (both national and international) and demonstrations in methods and techniques for improving and expanding vocational rehabilitation services to disabled persons; and provides professional training and instruction in technical matters relating to vocational rehabilitation.

Mentally Retarded Persons Who Could Benefit from Vocational Rehabilitation Services

It is estimated that there are from 60,000 to 90,000 persons, mostly children or adolescents, who are so severely retarded that they will remain, throughout their lives, completely dependent upon others. Vocational rehabilitation has little to offer them. They will always need custody; and, unless major medical discoveries are made, their vocational potential will remain extremely limited.

Another group of the retarded are born with about three times the above frequency and with a greater chance for survival. This group comprises about 300,000 to 350,000 children, adolescents, or adults who are much more capable than the first group. They can learn, and understand the meaning of danger. They can assist with their own care and in a protective environment can even undertake semi-productive endeavors. Their shortcomings become evident when they are called upon to understand the meaning of symbols as used in the written language. Present day evidence, in and out of institutional settings, shows that these people can learn many tasks when patiently and properly taught. The better their over-all emotional adjustment, the greater the likelihood that through rote memory they can acquire several job skills.

A third category of the mentally retarded--totalling some five million people--includes a substantial number of persons who, in a limited way, adjust to the demands of our society and take a positive place in our manpower pool.

While the number of persons in this third category in need of rehabilitation services is not known, several studies have revealed that, despite improved public school programs for the retarded, 25 to 40 percent of the educable groups coming out of those programs could not either be placed on jobs, or hold them if they were placed. Moreover, a significant number of the trainable group received no vocational training or job opportunities whatsoever. Traditionally the mentally retarded individual has been the target of ridicule and prejudice which has restricted all phases of his development. Inadequate

education and poor personal relationships have pushed him steadily down the scale of intellectual functioning.

It is the vocational rehabilitation of this third group to the point where they can take and hold a job that constitutes the focus of the Office of Vocational Rehabilitation program. Usually the retarded person referred to the rehabilitation agency has had no employment experience or a series of unsuccessful attempts on a job. His lack of skills and confidence further jeopardizes his opportunities in the labor market. These are some of the problems confronting the rehabilitation counselor--problems of community attitudes as well as those of the client himself.

Number of Mentally Retarded Persons Rehabilitated

The number of mentally retarded rehabilitated by the State rehabilitation agencies is increasing. It is expected that 5,400 will be rehabilitated in 1963 at an estimated expenditure of about \$3.5 million in Federal funds in addition to State funds. These totals compare with the estimated expenditure of about \$2.8 million in Federal funds in 1962 for the rehabilitation of about 4,400 mentally retarded, \$2.1 million in Federal funds in 1961 for the rehabilitation of about 3,500 mentally retarded, and an estimated \$1.6 million for the rehabilitation of 2,937 mentally retarded in 1960. (See table.)

Estimated number of mentally retarded rehabilitated by the State vocational rehabilitation agencies in fiscal years 1959 - 1963

Fiscal year ending June 30	Persons rehabilitated	
	Total ^{1/}	Mentally Retarded ^{2/}
1959	80,739	2,016
1960	88,275	2,937
1961	92,501	3,500
1962	100,000	4,400
1963	110,400	5,400

1/ Total rehabilitants, actual for fiscal year 1960; estimates for fiscal years 1961, 1962, and 1963, based on State budget estimates.

2/ Estimates based on the trend in the number and percent of rehabilitants for each group in fiscal years 1957-1959.

Extension and Improvement of Services to Mentally Retarded Persons

Projects to extend and improve rehabilitation services generally (made under Section 3 of the Vocational Rehabilitation Act) have substantially contributed to increasing the number of rehabilitations among the mentally retarded. A total of 16 projects concerned with the mentally retarded were supported in 1961.

Typical is the project in the State of Connecticut. This project has been developed by the Connecticut Bureau of Vocational Rehabilitation in close cooperation with the Southbury Training School and the Mansfield State Training School and Hospital, which are under the Office of Mental Retardation of the State Department of Health. A principal aim of this project is to tie in the use of local rehabilitation offices and other local facilities such as rehabilitation centers and workshops more closely with the two institutions.

Rehabilitation counselors assigned to the institutions work closely with the institutions and with local public and private groups and agencies to provide community-related services carried beyond the institutions to achieve successful job-community adjustment for mentally retarded. There has been increasing utilization of community rehabilitation centers and workshops for pre-vocational evaluation and training. Emphasis is being given to the development of personal-adjustment training, on-the-job training facilities and employment opportunities. This program is making it possible to move mentally retarded individuals out of the institution into the community and to facilitate their entrance into employment.

Research and Demonstrations

In view of the large number of persons who are retarded, we must develop more precise knowledge and skills for their treatment and training. Research is, therefore, needed in the social, psychological, and vocational aspects of their rehabilitation.

The research and demonstration grant program, authorized under the vocational rehabilitation legislation of 1954, is a major step in meeting this need. A total of 54 projects have been approved to date, of which 15 research and 23 demonstration projects are currently in operation.

Among the subjects covered by the research projects are special workshops, mental retardation aspects of community programs, employer attitudes, vocational training in a rural regional center, and transitional facilities through a half-way house. The remainder are devoted to specialized subjects such as predicting performance; assessing social adjustment based on job, personality and education; developing a social capacity scale; and ascertaining the effects of special training.

In July 1957, the Office of Vocational Rehabilitation began a program of demonstration projects to accelerate vocational rehabilitation services to severely disabled persons and to provide for prompt and widespread application of knowledge and experience acquired in the Office of Vocational Rehabilitation research grant program. The 31 demonstration projects approved through FY 1961 for the mentally retarded have been a vital factor in accelerating services for this group.

Training Courses for Rehabilitation of the Mentally Retarded

To apply overall the methodologies and skills developed through research and demonstration and to provide services to greater numbers of the retarded, the State Vocational Rehabilitation agencies need additional staff with special knowledge in the field. Of particular importance to the mentally retarded are the rehabilitation counselors, the psychologists, the social workers, and frequently the speech and hearing personnel. The Office of Vocational Rehabilitation supports long-term training programs to increase the supply of professional personnel and short-term training programs to increase the technical proficiency of existing rehabilitation personnel. In addition, regional workshops are conducted for rehabilitation counselors and others engaged in the rehabilitation of the mentally retarded.

III. THE PRESIDENT'S PANEL ON MENTAL RETARDATION

Establishment of the President's Panel

Today the problem of mental retardation is receiving attention from the highest levels of the Federal Government. In October, 1961, President Kennedy appointed a panel of outstanding physicians, scientists, educators, lawyers, psychologists, social scientists and leaders in the field to review present programs and needs, to ascertain gaps and any failure in coordination of activities, and to prescribe a program of action.*

The Task of the Panel

The President stated the task of the Panel as follows:

"We must undertake a comprehensive and coordinated attack on the problem of mental retardation. The large number of people involved, the great cost to the nation, the striking need, the vast area of the unknown that beckons us to increased research efforts--all demand attention.

"It is for that reason that I am calling together a panel of outstanding physicians, scientists, educators, lawyers, psychologists, social scientists and leaders in this field to prescribe the program of action. I am sure that the talent which has led to progress in other fields of medicine and the physical sciences can enlarge the frontiers of this largely ignored area.

"It shall be the responsibility of this panel to explore the possibilities and pathways to prevent and cure mental retardation. No relevant discipline and no fact that will help achieve this goal is to be neglected.

"The panel will also make a broad study of the scope and dimensions of the various factors that are relevant to mental retardation. These include biological, psychological, educational, vocational, and socio-cultural aspects of the condition and their impact upon each state of development--marriage, pregnancy, delivery, childhood, and adulthood.

"The panel will also appraise the adequacy of existing programs and the possibilities for greater utilization of current

*The complete statement of the President, A National Plan to Combat Mental Retardation, may be secured from the President's Panel on Mental Retardation, U. S. Department of Health, Education, and Welfare, Washington 25, D. C.

knowledge. There are already many devoted workers in this field, trained in diagnosis, treatment, care, education and rehabilitation. The panel should ascertain the gaps in programs and any failure in coordination of activities.

"The panel will review and make recommendations with regard to:

"1. The personnel necessary to develop and apply the new knowledge. The present shortage of personnel is a major problem in our logistics. More physicians, nurses, social workers, educators, psychologists, and other trained workers are needed.

"2. The major areas of concern that offer the most hope; and the means, the techniques and the private and governmental structures necessary to encourage research in these areas.

"3. The present programs of treatment, education and rehabilitation.

"4. The relationships between the Federal Government, the States and private resources in their common efforts to eliminate mental retardation.

"I am asking the panel to report on or before December 31, 1962."

Members of the Panel

The following persons were appointed by the President to serve as Members of the Panel on Mental Retardation:

Chairman

Dr. Leonard Mayo, Executive Director
of the Association for the Aid of
Crippled Children, New York City

Vice-Chairman

Dr. George Tarjan, Superintendent and
Medical Director of the Pacific State
Hospital in Pomona, California

Members

Judge David L. Bazelon
U. S. Court of Appeals for the
District of Columbia
Washington, D. C.

Monsignor Elmer H. Behrmann
Associate Secretary for Special Education in
the National Catholic Education Association
St. Louis, Missouri

Dr. Elizabeth Boggs
Research Chairman
National Association for Retarded Children, Inc.
New York, N. Y.

Dr. Robert E. Cooke
Professor of Pediatrics
The Johns Hopkins Hospital
Baltimore, Maryland

Dr. Leonard S. Cottrell, Jr.
Staff Social Psychologist
Russell Sage Foundation
New York, N. Y.

Dr. Edward Davens
Deputy Commissioner
Maryland State Department of Public Health
Baltimore, Maryland

Dr. Lloyd M. Dunn
Coordinator, Education for Exceptional Children
George Peabody College for Teachers
Nashville, Tennessee

Dr. Louis M. Hellman
Department of Obstetrics and Gynecology
State University of New York
New York City College of Medicine
Brooklyn, N. Y.

Dr. Herman E. Hilleboe
Commissioner of Health
New York State Department of Health
Albany, N. Y.

Dr. Nicholas Hobbs, Chairman
Division of Human Development
George Peabody College for Teachers
Nashville, Tennessee

Dr. William Hurder
Associate Director for Mental Health
Southern Regional Education Board
Atlanta, Georgia

Dr. Seymour Kety
Psychiatrist-in-Chief
Henry Phipps Psychiatric Clinic
The Johns Hopkins Hospital
Baltimore, Maryland

Dr. Joshua Lederberg
Department of Genetics
Stanford University School of Medicine
Palo Alto, California

Dr. Reginald Lourie
Director, Department of Psychiatry
Children's Hospital
Washington, D. C.

Dr. Oliver H. Lowry
Professor of Pharmacology
Washington University School of Medicine
St. Louis, Missouri

Dr. Horace W. Magoun
Department of Anatomy
University of California
School of Medicine
Los Angeles, California

Dr. Darrel J. Mase
Dean, College of Health Related Services
University of Florida
Gainesville, Florida

Mr. F. Ray Power
Director of Division of Vocational Rehabilitation
Charleston, West Virginia

Dr. Anne M. Ritter
Director of Psychological Services
Kennedy Child Study Center
New York, N. Y.

Dr. Wendell Stanley
Professor of Virology
University of California
Berkeley, California

Dr. Harold Stevenson
Director
Child Development Research
University of Minnesota
Minneapolis, Minnesota

Mr. W. Wallace Tudor
Vice President
Sears Roebuck & Company
Chicago, Illinois

Mr. Henry Viscardi, Jr.
President
Abilities, Inc.
Albertson, Long Island, New York

Mrs. Irene Asbury Wright
Speech Pathologist
Albany, Georgia

Dr. Ernest P. Willenberg
Director of Special Education
Los Angeles City Board of Education
Los Angeles, California

Consultant to the Panel

Mrs. Robert Sargent Shriver, Jr.
Vice-President, Joseph P. Kennedy Foundation
Member, Chicago Commission on Youth Welfare
and Board of Governors of the Menninger Foundation,
Topeka, Kansas

Financing the Panel

The President's Panel will be supported during fiscal years 1962 and 1963 by transfer of funds available to the National Institute of Mental Health and the National Institute of Neurological Diseases and Blindness.

Organization and Operation of the Panel

On the basis of suggestions made by Members of the Panel during its first meeting in October 1961, the Panel members were divided into two major but temporary groups, one dealing with research and the other with services. These groups delivered extensive reports at the second plenary session of the Panel in December 1961. On the basis of these reports, which outlined fundamental issues, goals, and problems in mental retardation and which recommended methods by which the Panel might best fulfill its mission, the Panel was divided into six task forces:

- I. Prevention (Clinical and Institutional)
- II. Education and Habilitation
- III. Law and Public Awareness

IV. Biological Research

V. Behavioral and Social Research

VI. Coordination

The Panel has emphasized its concern with new ideas and new theories for combating mental retardation. Its goal is not merely to make recommendations concerning the encouragement and coordination of existing efforts, but to recommend new methods of care and treatment, new directions for research, and new patterns of community organization to deal with the problem of mental retardation.

The Panel has also agreed that exchange of ideas and personnel with other countries would serve a number of important purposes in furtherance of the Panel's objectives. Exploration of the resources, patterns of service, and research in other countries will directly benefit the United States in devising means to wage war against mental retardation. At the invitation of President Kennedy, Dr. Osamu Kan, a leading Japanese authority in the field of mental retardation, visited the United States in December to participate in the work of the President's Panel.

IV. SELECTED PUBLICATIONS ON MENTAL RETARDATION OF THE
U. S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE^{1/}

Note: The publications listed below may be secured, at the prices shown, from the Superintendent of Documents, U. S. Government Printing Office, Washington 25, D. C., except for those preceded by an asterisk (*), which may be obtained without charge from the issuing agency.

PUBLIC HEALTH SERVICE

Mongolism: Hope Through Research. Public Health Service Publication No. 720, Health Information Series No. 94. 1961. 6 pp. 5 cents.

Research Highlights, Neurological and Sensory Disorders. Public Health Service Publication No. 842. 1960. 57 pp. 40 cents.

*Patients in Mental Institutions. Part I, Public Institutions for Mental Defectives and Epileptics; Part IV, Private Institutions for Mental Defectives and Epileptics. Public Health Service Publication No. 820. 1959. 46 pp. Part I, 27 pp. Part IV.

*Mental Retardation: A Selected Reading List. Public Health Service, Reference Guide No. 7. 1959.

OFFICE OF EDUCATION

Motor Characteristics of the Mentally Retarded. Cooperative Research Monograph No. 1. Francis, Robert J. and Rarick, G. Lawrence. 1960. 40 pp. 20 cents.

Education of the Severely Retarded Child: A Bibliographical Review. Williams, Harold M. and Wallin, J. E. Wallace. Office of Education Bulletin 1959, No. 12. 1959. 25 pp. 15 cents.

^{1/} This list is restricted to publications of the Department of Health, Education, and Welfare. Publications of private agencies and of State and local governments have not been included. Also excluded are reports which were financed, in whole or in part, with Federal funds, but published and distributed by some private agency or group. Information about such publications may be secured directly from the agencies concerned.

Teachers of Children Who Are Mentally Retarded. Mackie, Romaine P., Williams, Harold M. and Dunn, Lloyd M. Office of Education Bulletin 1957, No. 3. 1960. 97 pp. 45 cents.

The Retarded Child Goes to School. Williams, Harold M. Office of Education Pamphlet No. 123. 1960. 24 pp. 15 cents.

Preparation of Mentally Retarded Youth for Gainful Employment. A Study Sponsored Jointly by the U. S. Office of Education, the U. S. Office of Vocational Rehabilitation and the Project on Technical Planning of the American Association on Mental Deficiency. Office of Education Bulletin 1959, No. 28. 1961. 86 pp. 35 cents.

Exceptional Children and Youth: A Chart Book of Special Education Enrollments in Public Day Schools. Mackie, Romaine P. and Robbins, Patricia Peace. Office of Education Bulletin No. 35019. 1961. 14 pp. 15 cents.

Education of the Severely Retarded Child: Classroom Programs. Williams, Harold M. Office of Education Bulletin 1961, No. 20. 1957. 100 pp. 45 cents.

The Forward Look: The Severely Retarded Child Goes to School. Hill, Arthur S., Office of Education Bulletin 1952, No. 11. 1952. 54 pp. 20 cents.

Curriculum Adjustments for the Mentally Retarded: A guide for Elementary and Secondary Schools. Martens, Elise H. Office of Education Bulletin 1950, No. 2. 1957. 100 pp. 45 cents.

OFFICE OF VOCATIONAL REHABILITATION

Preparation of Mentally Retarded Youth for Gainful Employment. A Study Sponsored Jointly By the Office of Education, the Office of Vocational Rehabilitation and the Project on Technical Planning of the American Association on Mental Deficiency. Office of Education Bulletin 1959, No. 28. 1961. 86 pp. 35 cents.

Vocational Rehabilitation of the Mentally Retarded. Di Michael, Salvatore G. Office of Vocational Rehabilitation, Rehabilitation Service Series No. 123. 1950. 184 pp. 45 cents.

SOCIAL SECURITY ADMINISTRATION - Children's Bureau

The Child Who is Mentally Retarded. Children's Bureau Folder 43.
1956. 23 pp. 10 cents.

*Clinical Programs for Mentally Retarded Children. Hormuth,
Rudolf P. Children's Bureau. 1962. 33 pp.

*The Clinical Team Looks at Phenylketonuria. Children's Bureau.
1961. 30 pp.

*Four Surveys of Phenylketonuria High Risk Groups. Children's
Bureau. 1961. 14 pp.

Health Services for Mentally Retarded Children: A Progress
Report (1956-1960). Children's Bureau. 1961. 34 pp. 30 cents.

The Mentally Retarded Child at Home. Dittmann, Laura L.
Children's Bureau Publication 374. 1959. 99 pp. 35 cents.

The Mongoloid Baby. Children's Bureau Folder 50. 1960. 20 pp.
10 cents.

*The Nurse in Home Training Programs for the Retarded Child.
Dittmann, Laura L. Children's Bureau. 1961. 10 pp.

Phenylketonuria. Centerwall, Willard R. and Siegried A.
Children's Bureau Publication 388. 1961. 28 pp. 15 cents.

*The Public Health Nurse in Community Planning for the Mentally
Retarded. Hormuth, Rudolf P. Children's Bureau. 1957. 13 pp.

*Research Relating to Mentally Retarded Children. Clearing House,
Children's Bureau. 1960. 92 pp. 35 cents.

*The Role of Child Welfare in Mental Retardation. Begab, Michael J.
Children's Bureau. 1961. 13 pp.

*A Selected Bibliography on Phenylketonuria. Children's Bureau.
1961. 25 pp.

*Some Reading Suggestions for Parents of Mentally Retarded
Children. Children's Bureau. Revised 1961. 8 pp.