

DISCRIMINATION PROHIBITED--Title VI of the Civil Rights Act of 1964 states: "No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Therefore, the programs of financial assistance for the handicapped, like every program or activity receiving financial assistance from the Department of Health, Education, and Welfare, must be operated in compliance with this law.

# MENTAL RETARDATION ACTIVITIES

OF THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE JANUARY 1971

U. S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Office of the Secretary
Secretary's Committee on Mental Retardation
Washington, D.C. 20201

#### FOREWORD

This report describes the current mental retardation program activities of the Department of Health, Education, and Welfare.

On October 30, 1970, President Nixon signed into law the Developmental Disabilities and Facilities Construction Act (P.L. 91-517) to expand and extend a number of significant mental retardation programs administered by the Department. Implementation of the provisions of the law will be undertaken during the current year.

Existing programs of the Department have made a very real contribution to our efforts to combat the problem of mental retardation. The following highlights illustrate some of the progress made in 1970:

More than 33,000 mentally retarded persons were rehabilitated in 1970 through the Federally-administered Vocational Rehabilitation Program. This represents an increase of 3,000 over the previous year.

Approximately 44,000 mentally retarded children and their families received services provided by clinics supported by the Maternal and Child Health Service.

More than 150,000 mentally retarded children were enrolled in special education programs supported in part by Federal funds, primarily through Title VI(B)"Education of the Handicapped Act".

To date 370 mental retardation community facilities construction projects have been approved. These projects upon completion will serve an estimated 95,000 retarded persons.

The challenges presented by this handicap continue to press for attention. The efforts of the Secretary's Committee on Mental Retardation will be directed to improving our programs to insure for mentally retarded children and adults the greatest possible benefit.

(Mrs.) Patricia Reilly Hitt Assistant Secretary for Community and Field Services

January 29, 1971

# MENTAL RETARDATION ACTIVITIES OF THE U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, 1970

Table of Contents	Page
Forward	iii
Table of Contents	v
Introduction	
Coordination of Mental Retardation Programs	vii
Summary of Mental Retardation Activities	x
Membership of Secretary's Committee on Mental Retardation	xiv
Mental Retardation Activities of the Department	
Assistant Secretary for Administration	1
Health Services and Mental Health Administration	9
National Institutes of Health	25
Office of Education	32
Social and Rehabilitation Service	47
Social Security Administration	66
Food and Drug Administration	70
Appendices:	
A. Obligations for Mental Retardation Programs Fiscal Years 1970-1972	71
B. Work Group on Income Maintenance	76
C. Development of Income Maintenance to the Mentally Retarded from Social Security Benefits	77
D. Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517)	78
Subject Index	Ω.5

#### COORDINATION OF MENTAL RETARDATION PROGRAMS

Coordination is probably the most crucial factor in successful administration of mental retardation programs. This is so because mental retardation cannot be confined to any one health, education, rehabilitation or welfare program or any single disciplinary group. A total program must include a wide range of activities designed to confront the problems of mental retardation simultaneously from many vantage points.

During the 1970 fiscal year, over \$550 million was obligated by the Department of Health, Education, and Welfare for mental retardation programs. These programs cover most aspects of the retarded person's life. They range in diversity from maternal and infant care to income maintenance for the aged retarded. Many agencies of the Department administer programs which affect the mentally retarded; it is extremely important that these efforts be focused and targeted so as to prevent duplication and gaps in program services.

The 1962 Report of the President's Panel on Mental Retardation recognized the importance of coordination both at the national and local levels. The Report further endorsed the concept of a Departmental committee composed of agency representatives advising the Secretary on activities related to mental retardation. The concern of the Panel resulted in the strengthening of the Secretary's Committee on Mental Retardation in 1963. The Committee had previously been known as the Departmental Committee on Mental Retardation, since its establishment in March of 1955.

Over the next several years the mental retardation program of the Department was expanded and extended. In 1968, in a move designed to make the Secretary's Committee more responsive to prevailing needs the Secretary reconstituted the membership of the Committee. The membership of the Committee had previously been composed of middle level agency personnel. Through the new action the membership was altered and now included the top level executives of the Department with the Under Secretary serving as Chairman. In addition, Regional Office Staff were also assigned to coordinate mental retardation Regional activities.

The mission of the reconstituted Secretary's Committee on Mental Retardation remains the same; i.e., the responsibility for coordination of the Department's program and activities affecting the mentally retarded.

In October 1969, the Under Secretary established a Program Advisory Committee to serve as a resource tool to the Secretary's Committee on Mental Retardation. The Program Advisory Committee has been assigned specific tasks which are designed to improve the coordination of mental retardation programs in the Department.

A comprehensive report evaluating the Department's overall mental retardation program is being prepared by Dr. Donald Stedman, Consultant to the Secretary's Committee on Mental Retardation. This

report will be completed in 1971 and implemented in fiscal year 1972. This will require cooperation of all Departmental agencies. The Program Advisory Committee is especially suited to this type of assignment.

The newly enacted Developmental Disabilities and Facilities Construction Act of 1970 (P.L. 91-517), requires coordination in the Office of the Secretary because of the inter-agency involvement in the programs that can be supported under this authority. Recently the Assistant Secretary for Community and Field Services established a Departmental coordinating committee for this purpose chaired by the Executive Director of the Secretary's Committee on Mental Retardation.

Public Law 91-517 includes two disability areas not previously of primary concern in the field of mental retardation; epilepsy and cerebral palsy. The Secretary's Committee on Mental Retardation has recently been involved in working with the Epilepsy Foundation of America and the United Cerebral Palsy Associations, Inc. The Act also emphasizes the need for services to mentally retarded in poverty areas. This concern will be one of the major thrusts of the Secretary's Committee on Mental Retardation. Cooperation of national voluntary and professional organizations will be enlisted, as well as relevant Department mental retardation programs. (See Appendix D)

The Secretary's Committee on Mental Retardation has provided extensive consultation to the Navajo Indians in the development of a mental retardation service facility on the reservation.

The Committee has assisted in coordination of the Department's support for mental retardation university-affiliated facilities. Several recent meetings with the Directors of these facilities have been sponsored by the Secretary's Committee.

A conference on lead poisoning occurred in February 1971, under the sponsorship of the Secretary's Committee on Mental Retardation. Major voluntary and professional organizations in the area of mental retardation were represented. Although continuing responsibility for this program area will be assumed by voluntary and professional organizations, SCMR involvement will still be required.

The Secretary's Committee on Mental Retardation maintains a distribution list of over 10,000 names of persons and organizations which receive the Committee's and agencies' publications in the area of mental retardation. The Committee has also represented the Department at national meetings of the American Association on Mental Deficiency, the National Association for Retarded Children, and the Council on Exceptional Children. Publications and information were provided by the Committee staff to delegates at the end of these meetings.

Specifically, the Secretary's Committee is responsible for the following activities:

- a. Serving the Secretary in an advisory capacity in the consideration of Department-wide policies, programs, procedures, activities, and related matters.
- b. Serving in an advisory capacity for the Department as a whole with respect to inter-Departmental programs and activities, and related matters.
- c. Functions as a means for coordination and evaluation of the implementation of the recommendations made by the President's Panel on Mental Retardation and the President's Committee on Mental Retardation in the final reports to the President.

The Regional Office Mental Retardation Coordinators have the responsibility to: assure that interagency review and consultation takes place on proposals and applications relevant to more than one agency; serve as a focal point for interested persons or organizations seeking information or consultation on Department mental retardation programs; and provide the Secretary's Committee on Mental Retardation with information on implementation of mental retardation programs in the States.

There are four subcommittees of the Secretary's Committee on Mental Retardation. They are charged with investigating and reporting periodically on activities related to their area of concern. The subcommittees are as follows: Training, International Activities, Mental Retardation Abstracts, and Research.

The staff of the Secretary's Committee on Mental Retardation serves as a focal point for information on all aspects of the Department's mental retardation program. It also acts as a center for the referral of requests for professional and technical consultation to the appropriate agencies. This activity is carried on in cooperation with the Department's Regional Offices and agency representatives in Washington.

#### SUMMARY OF MENTAL RETARDATION ACTIVITIES

The mental retardation activities of the Department have been arranged according to the following categories: preventive services, basic and supportive services, training of personnel, research, construction, and income maintenance.

## Preventive Services

Preventive services are defined as those services rendered as a part of programs designed to reduce the incidence of mental retardation. The major programs in this area are administered by the Maternal and Child Health Service, Health Services and Mental Health Administration. Maternity and Infant Care Projects support programs which provide necessary health care to prospective mothers in high risk populations. By January 1971, fifty-five such projects were in operation. Grants which support screening programs for phenylketonuria (PKU) and other metabolic diseases also are awarded by the Maternal and Child Health Service. As of July, 1970, forty-three States had enacted laws related to PKU, most of them making screening for this disorder mandatory. During the past year, approximately 90 percent of the total registered live births in the 50 States and the District of Columbia were screened.

#### Basic and Supportive Services

Basic and supportive services are defined as those services rendered to or for persons Who are mentally retarded.

State health departments, crippled children's agencies and State welfare agencies use funds administered by the Maternal and Child Health Services for programs designed to: increase the health and welfare services available to the retarded, enlarge existing mental retardation clinics by adding clinic staff, increase the number of clinics, begin evaluations of children in institutions, extend screening programs, provide treatment services for physically handicapped retarded youngsters, increase inservice training opportunities, and provide homemaker and other care services for the mentally retarded.

The mentally retarded receive a variety of services through the vocational rehabilitation program supported by the Rehabilitation Services Administration: medical diagnosis, physical restoration, counseling and testing during the rehabilitation process, assistance in job placement and follow-up to insure successful rehabilitation.

The Health Services and Mental Health Administration, in conjunction with the Division of Mental Retardation, Rehabilitation Services Administration, Social and Rehabilitation Service, support projects for the retarded which have service components of well integrated comprehensive health programs.

The Division of Mental Retardation through its initial staffing grant program is able to provide part of the initial cost of professional and technical personnel in the operation of new facilities or new services in existing facilities for the retarded. The total appropriation to implement the program was approximately eleven million dollars for fiscal years 1969 and 1970.

In addition, the Division of Mental Retardation also supports two programs directed at improving the quality of State institutional care and treatment for the mentally retarded. These programs are the Hospital Improvement and Hospital Inservice Training Programs.

The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P. L. 88-164) was amended October 30, 1970, by the Developmental Disabilities Services and Facilities Construction Act of 1970 (P. L. 91-517). The new Act was designed to provide the states with broad responsibility for planning and implementing a comprehensive program of services and to offer local communities a strong voice in determining needs, establishing priorities and developing a system for delivering services. The scope of the present program broadened to include not only the mentally retarded but also persons suffering from other serious developmental disabilities originating in childhood, including cerebral palsy, epilepsy and other neurologically handicapping conditions. The Division of Mental Retardation is currently developing guidelines for the Administration of this Act. The amount appropriated by Congress to implement this new legislation is \$11,215,000 in fiscal year 1971. \*

With the enactment of the Elementary and Secondary Education Act of 1965 (P. L. 89-10) and its subsequent amendments, has come a number of new programs and services for the mentally retarded. The mentally retarded have especially benefitted from the provisions of Title VI of the aforementioned act, which provides opportunities for local school districts to develop new and creative programs for all handicapped children. The amendments of 1969 (P. L. 91-230), signed into law April 13, 1970, consolidated all legislation relating to education of handicapped children in Title VI. The Bureau of Education for the Handicapped in the Office of Education administers Title VI, which is now referred to as "The Education of the Handicapped Act."

# Training of Personnel

Training programs form an integral part of most of the mental retardation programs of the Department. These programs include support of professional preparation in the following areas: research training in the basic and clinical biological, medical and behavioral sciences; training of professional personnel for the provision of health, social and rehabilitative services for the mentally retarded; inservice training of workers in institutions for the mentally retarded; teachers and other education personnel related to the education of mentally retarded children; and training of personnel in physical education and recreation for the mentally retarded and other handicapped children.

<sup>\*</sup> See Appendix D

#### Research

The National Institute of Child Health and Human Development in the National Institutes of Health, will support mental retardation research and research training grants to an estimated amount of over eleven million dollars in fiscal year 1971. The National Institute of Neurological Diseases and Stroke, the National Institute of Allergy and Infectious Diseases, and the National Institute of Arthritis and Metabolic Diseases, among other Institutes of the National Institutes of Health, also contribute to mental retardation research. These contributions directly or indirectly extend the efforts of the Mental Retardation Branch of the National Institute of Child Health and Human Development.

The Division of Research, in the Bureau of Education for the Handicapped of the Office of Education now supports five Research and Development Centers. Improvement in instructional procedures should be realized through the combined efforts of these Centers along with programmatic research. New systems of dissemination are being built upon the foundations already developed by the Instructional Media Centers and a system of Regional Resource Centers currently being developed. Engineering technology, programmed instruction, and the "systems approach" to education will occupy a major place in the Division's activities. With an appropriation of \$19,700,000 (actual obligations \$15,157,670), the Division supported 135 projects in 1970.

The Rehabilitation Research Branch Program of the Division of Research and Demonstrations in the Office of Research and Demonstrations of the Social and Rehabilitation Service supports a substantial program of research on problems of rehabilitation of retardates. Areas covered include evaluation of aptitudes and abilities, analysis of jobs which the retarded can perform, opening of new occupational areas for the retarded, improvement of counseling techniques, development of new methods of training and job adjustment and evaluation of facilities and programs to assist the transition of the retardate from the institution to community participation. Current programs of research and demonstration are increasingly concerned with new approaches to retardation in ghetto areas, and especially in model city neighborhoods. Emphasis is placed on the coordination and focusing of all relevant community agencies on the problems of the retarded. The Research and Training Centers Division continues to sponsor three Mental Retardation Research and Training Centers. These centers conducted 56 research projects in 1970. They are continuing to seek out the cause of retardation, to assess the potential for education and rehabilitation, to develop training and remedial programs, to ascertain their actual learning and socialization difficulties, and to develop methods to more adequately motivate the retarded for work. The appropriation for the three Centers was \$1,075,000 in fiscal year 1970.

Research grants administered by the Maternal and Child Health Service support projects directed toward the evaluation of programs and improving the development, management and effectiveness of maternal and child health and crippled children's services. Some examples of support areas during fiscal year 1970 include studies of the epidemiology of mental retardation in a rural county, sensory integrative processes and learning disorders, children with congenital rubella, perinatal casualty reports, galactosemia screening, and sensory motor activity in the neurologically handicapped child.

#### Construction

The university-affiliated facility and the community facility construction programs are administered by the Division of Mental Retardation, Rehabilitation Services Administration, Social and Rehabilitation Service.

University-affiliated facilities for the mentally retarded provides for training of physicians and other professional personnel vitally needed to work with the mentally retarded. Nineteen applications have been approved and funded under this program. The Developmental Disabilities Services and Facilities Construction Act of 1970 (P. L. 91-517) extends this program until 1973 and provides for the inclusion of persons with developmental disabilities other than just mental retardation. A new section provides for demonstration and training grants to cover costs of administering and operating these facilities.

To date, 370 projects for the construction of community facilities for the mentally retarded have been approved. The facilities constructed under this legislation will include a variety of services: diagnosis, treatment, education, training or care of the mentally retarded, including sheltered workshops.

#### Income Maintenance

The Social and Rehabilitation Service administers the five Federally-supported public assistance programs. These programs assist children who are deprived of parental support or care, the needy aged, the medically indigent aged, the needy blind, and the permanently and totally disabled. Mental retardation itself is an eligibility factor only in the category of aid to the permanently and totally disabled. (See Appendix).

The Social Security Administration administers a program which contributes to the maintenance of the mentally retarded through the payment of monthly benefits to eligible individuals. (See Appendix)

## Membership of

# THE SECRETARY'S COMMITTEE ON MENTAL RETARDATION

1970

Mr. John G. Veneman, Chairman Under Secretary

Mrs. Patricia Reilly Hitt, Vice Chairman Assistant Secretary for Community and Field Services

Dr. Roger O. Egeberg Assistant Secretary for Health and Scientific Affairs Dr. Vernon E. Wilson Administrator of Health Services and Mental Health Administration

Dr. S. P. Marland, Jr. Commissioner of Education

Dr. Robert Q. Marston Director of National Institutes of Health

Mr. Robert M. Ball, Commissioner Social Security Administration

Mr. John D. Twiname Administrator of Social and Rehabilitation Service

Dr. Charles C. Edwards, Commissioner Food and Drug Administration

Dr. Edward F. Zigler, Director Office of Child Development

## Staff of THE SECRETARY'S COMMITTEE ON MENTAL RETARDATION

Mr. Wallace K. Babington Executive Director

Mr. Richard A. Lippke Deputy Executive Director

Julie A. Burney Staff Assistant Betty M. Schmidt Secretary

Eileen R. Zeitz Student Research Assistant

#### ASSISTANT SECRETARY FOR ADMINISTRATION

#### OFFICE OF CHILD DEVELOPMENT

#### Introduction

In July 1969, the Office of Child Development (OCD) was established in the Office of the Secretary of HEW to serve as a point of coordination for Federal programs for children and youth, and to act as a national advocate of services for children. Although a major concern of the agency is the preschool child, OCD also plans and develops programs for all children and youth and their families.

The Office of Child Development has two chief bureaus: The Children's Bureau and the Bureau of Head Start and Early Childhood. The Children's Bureau, formed in 1912, was transferred to OCD from the Social and Rehabilitation Service of HEW. Head Start, a comprehensive program for disadvantaged preschool children, was launched by the Office of Economic Opportunity in 1965 and delegated by that agency to OCD in September 1969.

While OCD does not directly operate any programs for the mentally retarded, the agency has an overall advocacy and leadership responsibility for all children, including children with mental retardation. In line with this responsibility, the Office of Child Development may plan and recommend programs to deal with mental retardation; develop standards and guidelines for such programs; and provide technical assistance to States and public and private agencies in efforts to help mentally retarded children and youth. OCD also works cooperatively with the President's and Secretary's Committees on Mental Retardation, the SRS Division of Mental Retardation, and other HEW agencies.

#### A. Children's Bureau

# 1. Basic and Supportive Services

Members of the Children's Bureau staff participated in the preparation of standards developed by the Child Welfare League of America in the fields of adoption, foster family care, day care, child protection and other services for children, including the handicapped and mentally retarded. Children's Bureau specialists continue to assist in the interpretation, updating, dissemination and monitoring of these standards. Children's Bureau specialists travel throughout the country to provide technical assistance and expertise in the planning and development of services for children, including the mentally retarded as well as other handicapped youngsters.

An important OCD objective is to increase the number of adoptions of mentally retarded children by helping to locate the kind of adoptive parents who can give a great deal to such children and can assist them in reaching their maximum potential. A specialist on

adoptions on the staff of the Standards Division of OCD works with social agencies across the country in this effort and speaks to many groups on the subject.

Social agencies are becoming increasingly aware that mentally retarded children can bring happiness to couples whose performance expectations are realistic and who are patient, tolerant, and interested in giving rather than receiving. Children who are mildly retarded are being placed for adoption with couples who, knowing about the handicap, are willing to accept the child as their own.

In homes where they receive care and love, mildly retarded children show improved learning abilities. Studies have indicated that as adults these adopted children achieve at higher levels than would have been predicted from the intellectual, educational or socioeconomic level of their biological parents. As a result, adoption agencies are broadening their definition of an adoptable child and now include the mentally retarded child. While it is often time-consuming and costly to find the right adoptive parents, the effort is very worthwhile, because the benefits to the child are immeasurable.

At a conference held by the American Association on Mental Deficiency in May 1970, Children's Bureau specialists presented papers on the needs of mentally retarded children and on various child welfare programs designed to meet their needs, including foster family care, group care and adoption.

The staff of the Standards Division of the agency has also been concerned about unnecessary institutionalization of mentally retarded children. They help State and local public agencies and private organizations develop quality foster family care services as an alternative for these children.

Another area of concern of the Office of Child Development is that of licensing day care and other child care facilities which serve mentally retarded youngsters. Licensing helps insure the physical and psychological safety of these children and encourages the creation of developmental programs by child care services to meet their special needs.

In January 1971, OCD collaborated with SRS and NTMH in convening a seminar for representatives of HEW agencies at which an unusual advocacy project for mentally retarded children developed in Syracuse, New York, was reviewed. The project, sponsored by the University of Syracuse, Division of Special Education and Rehabilitation, stimulates established local agencies to plan or expand services for mentally retarded youngsters, especially those with multiple handicaps, and also operates several services of its own. At the seminar, representatives of the Syracuse project described the development of their program to Central Office and Regional HEW participants and also to members of two New York State agencies. This Syracuse project has applied for HEW National and Regional grants.

#### 2. Research

The Research and Evaluation Division of the Office of Child Development will consider applications for research and demonstration programs concerned with children who have handicapping conditions.

#### 3. Publications

OCD acts as a forum for the exchange of information for parents and the professional community. The Children's Bureau publishes a number of publications for the public dealing with the problems of the retarded child. These publications, prepared under the supervision of the Children's Bureau staff, are published by the U. S. Government Printing Office. Among these publications are: "The Mentally Retarded Child at Home: A Manual for Parents," "The Mentally Retarded Child: A Guide to Services of Social Agencies," "Selected Reading Suggestions for Parents of Mentally Retarded Children," and "Research Relating to Mentally Retarded Children,"

<u>Children</u>, an interdisciplinary journal published by OCD for the professions serving children, features many articles on retardation, such as research reports and articles on health, education and social services for mentally retarded children, including adoption and foster family care for these children.

#### B. Head Start

The nationwide Head Start program for disadvantaged preschool children, which is administered by the Office of Child Development, does not have any special centers for the mentally retarded. However, according to Bureau of Census data for 1969 collected on a sample of Head Start children, 1.3 percent of the children in the full-year program for 1968-69 and 1.4 percent of the children in the 1969 summer program were categorized as having a learning problem or mental retardation. Total Head Start enrollment was 217,000 in the full-year program for Fiscal Year 1968-69 and 447,000 in the summer 1969 program. As a result of participation in Head Start, which has a recommended ratio of one teacher and two aides to every 15 children, it can be expected that many of these children with learning or retardation problems will show noticeable improvement.

# SURPLUS PROPERTY PROGRAM

The Office of Surplus Property Utilization, within the Office of the Assistant Secretary for Administration, carries out the responsibilities of the Department under the Federal Property and Administrative Services Act of 1949, as amended, which makes surplus Federal real and personal properties available for health and educational purposes. The properties which become available under this program are those that have been determined by the General Services Administration as no longer having any further Federal utilization.

Surplus personal properties generating at Federal installations in the United States, Europe and Southeast, Asia, are screened to determine those which may be needed and usable by eligible institutions throughout the country in conducting health and educational programs. Properties determined to have such need and usability are allocated by the Department of Health, Education, and Welfare for transfer to State Agencies for Surplus Property which have been established in all States. These State agencies secure the properties, warehouse them, and make the distribution to eligible donees for health and educational uses within their respective States. The only costs to the eligible donees are the handling and service charges which are assessed by the State agencies.

In the case of real properties which have been determined to be surplus to Federal needs, notices of their availability are sent to potentially eligible applicants, either by the State agencies or the Regional Representatives for Surplus Property located in our ten Regional Offices. Real properties available for removal from their site for relocation are conveyed by agreement of sale with restrictions as to the use of the facilities which run for a period of 5 years. These properties are conveyed with a 95 percent public benefit allowance discount applied against the sales price. Land, or land and buildings together with other improvements, are conveyed by deed which contains restrictions as to use for a period of 30 years. These properties are conveyed with public benefit discount allowances ranging from 50 to 100 percent applied against the sales price. The only other costs to eligible transferees are "out of pocket" Federal costs, i.e., appraisals, surveys, etc.

Schools for the mentally retarded are eligible to acquire surplus real and personal property. In the case of personal property, such a school must be operated primarily to provide specialized instruction to students of limited mental capacity. It must be tax-supported or nonprofit and exempt from taxation under Section 501(c)(3) of the Internal Revenue Code of 1954. It must operate on a full-time basis with a staff of qualified instructors for the equivalent of a minimum school year prescribed for public school instruction of the mentally retarded. It must also demonstrate that the facility meets the health and safety standards of the local governmental body.

An applicant for real property must be a State, or a political subdivision or instrumentality thereof; a tax-supported educational or public health institution; or a nonprofit educational or public health institution that has been held to be exempt from taxation under Section 501(c)(3) of the Internal Revenue Code of 1954. Its proposed program of use must be fundamentally for an educational or public health purpose; i.e., devoted to academic, vocational or professional instruction, or organized and operated to promote and protect the public health. Real property may be put to a joint use, namely, for the training of the mentally retarded as well as the physically handicapped. Conveyances have been made for hospital use where, as a part of the total program, portions of the facility are used for the treatment and training of the mentally retarded.

Available personal property may range anywhere from a nail to an electronic computer. Many items have never been used before. Real properties may consist of all types of buildings which are removable, land with or without structures and other improvements such as utility lines, sewer and water systems, etc.

Pamphlets giving more detailed information as to eligibility of organizations for both surplus real and personal property, as well as additional information in connection with the Surplus Property Utilization Program, along with a directory of the State Agencies for Surplus Property and the ten Regional Offices of the Department, may be obtained from the Office of Surplus Property Utilization, Department of Health, Education, and Welfare, Washington, D. C. 20201.

The following are examples of real properties conveyed under the program for use in aiding the mentally retarded.

The State of Missouri passed legislation authorizing the State Department of Education to establish and operate State schools for mentally retarded in any county or in a district comprised of two or more counties. One of the first of these schools was established on 4.95 acres of land with 9 buildings, we conveyed for this purpose, at the surplus O'Reilly General Hospital, Springfield, Missouri. The facility is a day school for a maximum enrollment of 90 children.

The Arizona Children's Colony obtained 30 acres of land at the Davis Monthan Air Force Base in July 1967 as a site for the new "Mental Retardation Center at Tucson." Plans are to construct 6 buildings initially, including 3 residential units. These buildings will provide residential care facilities for approximately 84 residents and day care facilities for 150 to 200 people in the Tucson area, many of whom were cared for far from their homes. In addition, the facilities will provide space for a preschool program for children not yet determined to be retarded, vocational training and rehabilitation therapy, consultation services, and, in cooperation with the University of Arizona, training and research. Future plans are to enlarge the Center into a facility which will have approximately 200 beds for residents and space for 300 to 400 day care persons.

The former Sunmount Veterans Hospital Reservation, Tupper Lake, New York, consisting of 111 acres of land improved with 44 buildings and installed equipment, was conveyed to the State Department of Mental Hygiene to provide a complete program of care, treatment, education, and rehabilitation of mentally retarded children and adults. The State first took over the hospital under a permit agreement in 1965, and the majority of the staff remained to operate the new program. Nurses were assigned to the three operating State schools for orientation courses in the care of the mentally retarded. Upon their return to Tupper Lake, the first group of patients was transferred to the new facility. Since that time, this 506-bed hospital has been operated to serve mentally retarded persons of all ages, drawn from the five upstate New York counties.

The State of Florida has undertaken the establishment of a system of Sumland Training Centers throughout the State for the training of its mentally retarded children. Plans call for 10 of these Centers which will have a capacity of approximately 1,000 resident students each. One of these Centers which serves the northwest section of the State, has been established at Marianna on 372.67 acres of land with 65 buildings, formerly the Graham Air Force Station, through our Surplus Property Utilization Program. Most of the personal property for the operation of this facility was conveyed with the real estate.

The Warren City School District, Warren, Ohio has initiated a novel program for learning incentive for slow learning pupils of intelligence quotients between 50 and 79. Through the Surplus Property Program, the School District obtained 76.4 acres of land and 10 buildings from the Youngstown Family Housing Annex, Trumbull County, Ohio. There are farm ponds, vocational shops, and programs for conservation and horticulture. An experiment in providing summer garden plots for these pupils was significantly successful.

The State of Georgia obtained the former Veterans Administration Domiciliary in Thomasville, consisting of 207 acres of land and 131 buildings, with a bed capacity of 400 to 800, for the care and rehabilitation of the mentally ill and retarded. Another site of nearly 200 acres at the former U. S. Penitentiary Honor Farm near Atlanta has been conveyed for a Regional Mental Hospital for the rehabilitation and training of the mentally ill and retarded.

In 1966, the State of Ohio received the former Veterans Administration Hospital at Broadview Heights, near Columbus. Now known as the Broadview Center for the Mentally Retarded, inpatient service was begun in 1968. During the year, 580 persons applied for service. Of this number, 115 were admitted to the hospital unit. It is expected that the Center will have a capacity for 250 inpatients, in addition to its large outpatient load, with future expansion to 600.

Other States also have programs for the mentally retarded, using Federal surplus real and personal properties. The Department conveyed 34.39 acres of land and 47 buildings, formerly the Lufkin Air Force Base, Lufkin, Texas, to the Texas State Hospital and Special

Schools for a resident unit to accommodate between 1,000 and 1,500 retarded children. Louisiana received 537 acres with modest improvements at the Belle Chasse Navy Ammunition Depot, New Orleans, as a site for a State unit serving this area for day treatment or resident training and care of the mentally retarded. The State of Kansas has renovated the Winter Veterans Administration Hospital, comprising 225 acres and 195 buildings, for the treatment and care of some 300 to 400 mentally retarded children.

Two outstanding programs for the mentally retarded are operated in Prince Georges County, Maryland. One, operated by the Prince Georges County Association for Retarded Children, is located on approximately 6 acres of land, formerly a part of Andrews AFB, and is known as the Melwood Agricultural Training Center. Two greenhouses have been built, as well as an Administration- Floral Design Shop. and Cement Products Shop. The boys learn to work in greenhouses, to landscape and do field and ground work and to do the heavy work, such as making cement garden equipment; and the girls concentrate on design, and the more asthetic products fashioned from fresh and artificial flowers. The other program is operated by the Prince Georges County Board of Education on 5.7 acres of land at Silver Hill, Maryland, formerly a Weather Bureau test site. A modern, comprehensive school has been constructed, which has been designed to meet the individual needs of trainable children. It includes the very latest in equipment, a competent and dedicated staff, and supervised playground. The educational program of this, the Hillcrest Heights Special Education Center, is considered to be an outstanding one in the area of special education. Visitors continue to observe the operation, and there is an excellent program of parent education and public relations. Enrollment as of September 1970 was 172 students.

Some school districts include classes for the mentally retarded in the same facilities with other educational programs. In August 1968 three quonset buildings, located on 2 acres of land at the Naval Reserve Training Center, Woonsocket, R. I., were conveyed to the City of Woonsocket. These buildings, which were joined together, are divided into 30 classrooms and offices, and house various special educational programs and services, including those for the mentally retarded. One program teaches homemaking to girls, and another provides teenagers an opportunity to become acquainted with the world of work outside the home, and to develop skills and attitudes which enable the child to become occupationally competent.

Smaller areas, such as former Post Office buildings and sites and Nike sites, have been converted into schools and training centers. The former Post Office at Carlisle, Pennsylvania, is now a school, operated by the Cumberland County Association for Retarded Children; Lake County, Ohio, has converted the former Post Office at Willoughby into a school for the retarded; and portions of Nike sites at Needham, Massachusetts, and King County, Washington, are now used in the care and training of the mentally retarded.

Through June 30, 1970, 5,108 acres of land and 779 buildings have been transferred to institutions for use in programs serving the mentally retarded. These properties originally cost the Government \$44,417,527, and had a fair market value of \$17,031,273 at the time of transfer.

Schools for the mentally retarded operated by State and local agencies of government as well as many non-profit schools operated by Mentally Retarded Associations or Cerebral Palsy Associations are major users of surplus personal properties acquired through the State agency distribution center of their State. During FY 1970, surplus personal properties having an original acquisition cost of 280 million dollars were donated to eligible public health, educational and civil defense donees in the States. Representatives of schools for the mentally retarded should establish their school's eligibility with their State agency and make regular visits to their State agency distribution center (s) to inspect available properties and select items needed by their school.

# HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION

#### Introduction

The Health Services and Mental Health Administration provides leadership and direction to programs and activities designed to improve physical and mental health services for all the people of the United States and to achieve the development of health care and maintenance systems adequately financed, comprehensive, interrelated, and responsive to the needs of individuals and families in all socioeconomic and ethnic groups.

More specifically, the Health Services and Mental Health Administration collects, analyzes, and disseminates data on births, deaths, disease incidence, health resources, and the state of the Nation's health. It plans, directs, and coordinates a national effort to improve the physical health of all Americans and provide care and treatment for physically ill persons.

# I. Preventive Services

A. Prevention of Organically-Based Mental Retardation

#### Rubella Immunization

The 1964-1965 rubella epidemic was the most extensive in the United States since 1943. Estimates of morbidity with this usually mild exanthematous illness are striking. Of particular importance is the large number of children (20,000) estimated to have been born with congenital rubella syndrome. The total estimated direct and indirect cost of the 1964-65 epidemic is \$1.5 billion. The three greatest estimated costs are for special educational services, institutional care for retarded rubella babies, and direct medical care of children with congenital rubella syndrome.

The goal of rubella control programs is to prevent congenital rubella syndrome by vaccinating children, the primary reservoir of infection. The realization of this goal will provide immeasurable humanitarian benefits accrued from reduced suffering, economic savings from reduced health care costs, and savings in educational time and funds lost through school absenteeism.

The Immunization Branch of the Center for Disease Control, Atlanta, Georgia, is providing the leadership in the national rubella control program. Grant assistance has been provided to 53 States and Territories and 20 local health departments, mainly in major metropolitan areas, serving 100 percent of the Nation's population. A total of 28 million doses of rubella vaccine has been administered in the United States through December 1970; 20 million of these were administered through public programs. The Immunization Branch has collaborated with health

agencies in providing: (1) well-trained qualified personnel who engage in (a) planning, organizing, and promoting activities in connection with rubella immunization programs, (b) intensive public informational, educational, and motivational activities, (c) maintaining intensive epidemiologic and laboratory surveillance, (d) immunization level surveillance, and (e) use of jet injector and other immunizing equipment; and (2) rubella vaccine to be used in protecting susceptible children.

## Measles Immunization

The Center for Disease Control, State and local health departments, and other public health agencies, through the measles immunization program, almost eliminated this once common childhood disease in 1968. However, the number of cases now being reported is twice as many as last year at this time, and four times as many cases as in 1969.

From 1963, when measles virus vaccine first became available, through 1970, 43.1 million doses of vaccine were distributed in the United States. Reported cases of measles have dropped from an average of 450,000 in prevaccine years to 23,000 in 1968 and 25,000 in 1969. By the end of 1970, 47,000 cases had been reported, and measles was breaking out all over the U. S. During the record low years of 1968 and 1969, measles-associated encephalitis, mental retardation, and deaths diminished significantly. Although it is too early to tell, these have undoubtedly doubled in 1970 over the low levels of 1968.

There are still many areas in the U. S. where high immunity levels to measles have not been achieved. For measles to be eradicated in the U. S., the total proportion of immune children will need to be increased from the present 72 percent level to over 90 percent immune. This will have to be perpetually maintained at this high level in all segments of our population regardless of their economic, social, or geographic location. At that point, measles encephalitis with its associated mental retardation should cease to exist, and measles will no longer be a public health problem.

#### INDIAN HEALTH SERVICE

The prevention of mental retardation caused by organic factors is best accomplished by continuous, comprehensive, and high quality medical care of pregnant women and their offspring throughout the prenatal, intrapartum, and postnatal periods. The Indian Health Service, through its efforts to provide high quality, comprehensive medical care to its beneficiaries, is reducing the incidence of organically-based mental retardation as well as the wide variety of other diseases and conditions in mothers and infants which the state of the art in medicine now makes at least partially controllable.

The Indian Health Service provides comprehensive medical care during the prenatal, intrapartum, and postnatal periods. This includes both outpatient and inpatient care for the mother and her newborn child.

In the 47 Indian Health Service general hospitals which operate obstetrical services, comprehensive prenatal and neonatal care is given specifically to reduce the incidence of mental retardation. Phenylketonuria (PKU) tests are performed on newborn infants, and infants with a depressed apgar score or who are born prematurely are further evaluated for PKU or other evidence of brain damage.

Where genetic counselling is indicated the Indian Health Service attempts to provide it.

The Indian Health Service has increased the number and frequency of maternal clinics for Indian mothers during the prenatal period and has also expanded its measles and rubella immunization programs for Indian and Alaska Native children, to help prevent the measles encephalitis which has a high residual of brain damage of which mental retardation can be one of several adverse consequences, and the congenital malfunctions brought about by rubella during the first trimester of pregnancy.

Otitis Media, one of the major health problems among the children in the Indian and Alaska Native population, is currently under study in an effort to identify causal factors and to program preventive and corrective measures.

The Indian Health Service continues to develop its PKU blood screening program concurrently with the development of laboratory facilities by States in which their facilities are located. Individual Indian Health Area Offices cooperate with State and local health departments and regional offices in planning mental retardation programs made possible through Federal grants-in-aids funds. The Indian Health Service through its initiation of a nurse-midwifery program in Alaska and another one in Arizona, is fully utilizing all possible health staff in the prevention of mental retardation through improved care of expectant mothers and newborn infants.

Recent studies have indicated the value of child-spacing as a measure to prevent mental retardation. An active family planning program is conducted by the Indian Health Service. Family planning assistance, as one phase of the health and welfare continuum is much broader than birth control and includes infertility serfices as well as the promotion of responsible parenthood. In this broad concept it is implemented in the Indian Health Service. Since the inception of the family planning program in fiscal year 1965, 36,300 female Indian beneficiaries have been provided with birth control services (47% of female Indian beneficiaries 15-44 years of age). In fiscal year 1970, 14,256 women were rendered birth control services with 29,000 visits to physicians.

# B. Prevention of Functionally-Based Mental Retardation

As part of the ongoing comprehensive health program on Indian reservations, mental health projects include prevention, detection, treatment, and planning for functional mental retardation. The Indian Health Service is cooperatively working with Head Start programs throughout all of its areas.

#### II. Basic and Supportive Services

# A. Foreign Quarantine Program, Center for Disease Control

Mental Retardation is one of the conditions specified in the Immigration and Nationality Act causing an alien to be considered ineligible to receive a visa except under waiver. The intent of the waiver provision

of the law is to keep families together, and the mentally retarded person is eligible only if certain close family relationships exist with someone already legally admissible. The program is responsible for the review of findings in such cases and the decision on waiverability and on the suitability of proposed care.

For those mentally retarded aliens admitted to the United States, the Public Health Service reviews arrangements for treatment in this country. A record is then kept covering the first 5 years of the individual's treatment in this country, which must be provided in institutions, special facilities, or by specialists approved by the Public Health Service. Semiannual reports showing kind of treatment and progress made are required and kept on file at the Foreign Quarantine Program, Center for Disease Control, Atlanta, Georgia 30333.

# B. Medical and Social Services for American Indians

Medical services and medical social services are provided either directly, under contract, or through State Crippled Children's Services to all Indian beneficiaries discovered to be mentally retarded.

Because of cultural barriers and transportation problems, casefinding continues to be a major problem in this area.

# III. Professional Preparation

# A. Indian Health Training Programs

The Indian Health Service conducts physician residency training programs in pediatrics in its hospitals in Phoenix and Anchorage. This includes clinical training in the prevention, diagnosis, treatment, and rehabilitation of mental retardation.

The Indian Health Service continues to provide both in-service and out-of-service training in maternal and child health nursing to ensure continuity of service from hospital to home and community. An average of 12 nurses are trained each year. The Indian Health Service continues to develop and use coordinated teaching guides for hospital and public health nursing personnel, designed as aids in teaching good health practices to maternity patients and their families.

# B. Education and Training Efforts by the Federal Health Programs Service

Coping with mental retardation among its legal beneficiaries is only one of the many health responsibilities for which Federal Health Programs Service personnel must be prepared; nevertheless, several aspects of the Bureau's training program are clearly relevant and important to the attack on mental retardation.

Post-graduate training programs in Public Health Service Hospitals include rotating internships, and residencies in internal medicine and obstetrics which involve maternal and pediatric clinical training and the diagnosis and treatment of mental retardation as it arises in the patient population. Research training is conducted in metabolism and endocrinology, disciplines basic to some forms of mental retardation.

#### C. Training Efforts of the National Institute of Mental Health

The President's Committee on Mental Retardation recommends "greatly expanded" support and increased effort "... to attract scientists and professional specialists in education, the medical and behavioral sciences and related fields into research and service ..." Since the Inservice Training Program in Mental Retardation has been transferred from the Institute, the National Institute of Mental Health supports no training program specifically focused on the field of retardation. A number of programs, however, incorporate some emphasis on the area. Residency training in basic and child psychiatry, for example, includes education in mental retardation as a standard part of the curriculum. Also, training in psychiatric social work and other behavioral science areas includes field or classroom work in mental retardation.

The training programs vary widely in mission and content. Psychiatric residencies include training in intake, diagnostic, and evaluative studies of the retarded, as well as psychotherapeutic work with the emotionally disturbed retarded and their families. Pre- and post-doctoral training in clinical and school psychology includes instruction as well.

It should be noted that the subject of retardation is an element in all under-graduate nursing education and in most of the curricula integrating psychiatric and behavioral science concepts.

In summary, mental retardation is a multifaceted program area which incorporates many of the Institute's focal concerns such as the study and remediation of learning difficulties, cultural deprivation, and the enhancement of optimal development. The breadth and ramifications of mental retardation research make it critical to the extension of knowledge in the mental health field.

# IV. Research and Development Activities

# A. Research Related to Organically-Based Mental Retardation

A pilot project conducted by the Indian Health Service in cooperation with the Bureau of Indian Affairs utilizes an interdisciplinary approach to identify both organically and functionally retarded children. The medical, psychological and sociological screening of these children will provide a diagnostic basis for determination of required medical treatment and specialized curriculum to meet individual learning needs.

A study recently completed on the Whiteriver Reservation showed a correlation between cultural and social problems and incidence of prematurity, which frequently accompanies mental retardation.

Also completed recently was a five-year study of American Indian Congenital Malformations, carried out jointly by the Indian Health Service and the Human Genetics Branch of the National Institute of Dental Research. The study supplies data that helps to evaluate congenital defects in relation to total health status of the Indian. It also helps to identify high frequencies of specific defects due to causes which can be remedied, and makes possible racial comparisons of congenital defects which are of basic genetic interest in trying to determine the etiology of these defects.

A long-term study of a group of 643 Alaskan Eskimo children born between 1960 and 1962 is continuing under the joint sponsorship of the Arctic Health Research Laboratory and the Indian Health Service. A report on the growth, morbidity and mortality of these children presented at the American Public Health Association meeting in 1968 provided significant information on the health status of these children applicable to the prevention of mental retardation.

### B. Research Concerning Functional Mental Retardation National Institute of Mental Health

Over the past decades, the National Institute of Mental Health (NIMH) has supported a broad range of research and training projects in the field of mental retardation. In the past several years, new and reorganized agencies within the Department of Health, Education, and Welfare have enlarged their programs in mental retardation, absorbing a variety of NIMH efforts - particularly in the areas of demonstrations, inservice training and basic research in child development. Summarized below are those research and training programs which remain as part of the Institute's overall mental health mission.

In the report MR 68: The Edge of Change, the President's Committee on Mental Retardation recommends "... intensification of research in the social and other behavioral sciences ..." to isolate and define social and cultural factors in mental retardation (p. 25). The current NTMH research effort in retardation is consonant with this recommendation, falling into three categories: (1) studies of learning, with careful attention to the special learning problems of the retarded; (2) analyses of the effects of cultural and social deprivation; and (3) studies of the behavioral and biological aspects of retardation which relate to mental health and illness.

In the area of learning, investigators are conducting a variety of analyses of the learning process as it operates among the mentally retarded, with a view toward identifying those interventions and those techniques which may facilitate the learning process. Such variables as attention span, capacity for retention, distortions of perception and visual discrimination are being scrutinized to increase the retardate's ability to absorb and profit from his experiences, and to facilitate his intellectual and social development. A specific goal of this work is to develop improved teaching methods. For example, automated teaching techniques are being used in several studies, focusing on programmed learning to develop reading and other skills. Although a number of programs involve attempts to help already damaged children, a primary emphasis overall is the prevention of retardation in high risk populations.

In studies of cultural and social deprivation, investigators are defining the role of poverty, inadequate schooling and community disorganization in causing or contributing to various forms of mental retardation. The aim here is to provide new training and educational approaches for culturally handicapped children; to teach improved child-rearing practices to parents in deprived areas; and to modify attitudes of fear and rejection of the mentally retarded among those who are themselves economically and culturally deprived. Approaches range from broad inter-disciplinary efforts to establish controlled therapeutic settings, to the development of skills such as operant conditioning among those who attempt to teach the retarded self-sufficiency, self-control, and social adjustment.

In studies of behavioral and biological aspects of retardation, investigators are concerned with developing improved techniques for diagnosing and treating those psychological and physical abnormalities found among the retarded. A major issue here is the degree to which emotional factors contribute to retardation - the role of psychopathology and personality disorganization in the retardate's patterns of functioning. As in the case of such disorders as schizophrenia, the relative contribution of biological, social, and psychological factors remains to be accurately defined.

# C. Ecological Investigations Program

The Ecological Investigations Program of the Center for Disease Control conducted a follow-up study in Hale County, Texas, on the residual neurologic effects of western encephalitis. Twenty-three cases, from 1963 to 1966, and 23 matched controls underwent extensive neurologic, psychologic, and intelligence testing to ascertain the presence of abnormalities, particularly with reference to learning ability. Preliminary results indicated that at least five of the western encephalitis cases had residual brain damage.

## V. Construction

# A. Community Mental Health Centers--Construction and Staffing

Public Law 91-211, Community Mental Health Centers Act, Amendments of 1970, authorizes the NTMH to share in the cost of construction of new facilities for a community mental health center or the requisition and renovation of existing facilities. Grants are also made to community mental health centers to meet part of the cost of compensating professional and technical personnel providing new services. To be eligible for either construction or staffing grants an applicant must present a plan for providing a program of at least five essential services, namely, inpatient, outpatient, partial hospitalization, emergency, and consultation and education. These must be offered in a comprehensive and integrated fashion to the center's community, defined as a catchment area of 75,000 to 200,000 persons. These centers, in which the mentally retarded are eligible to receive treatment and services, serve as the nucleus of the National Mental Health Program.

Working in unison with other facets of national programs in mental retardation and mental health, the NTMH assists states and communities to achieve comprehensive treatment in the community for all who need it. Prevention of mental illness in the community is one of the major objectives of the centers.

Since the passage of the Community Mental Health Centers Act, the NIMH has supported the development of 420 community mental health centers in 50 states, the District of Columbia, and Puerto Rico. The services and programs of many of these centers extend to and include mentally retarded persons. More than half the states have enacted community mental health services legislation which encourages simultaneous development of community mental health and mental retardation services usually under the auspices of a county or multi-county MH-MR Board.

At the close of fiscal year 1970, 260 centers were operational. When all 420 centers are open, augmented and improved services will be available to 57 million Americans.

Many center programs have special relevance to children. More than half of the centers in operation include some kind of specialized services for children; 8 percent have an identified mental retardation service. Other data from centers operating in 1968 show that in terms of direct service, school age children are being serviced in numbers at least as great as their proportion of the total population would warrant.

# B. Health Facilities Planning and Construction Service

Since 1958 approximately 29 million dollars have been approved and funded through the Health Facilities Planning and Construction Service (Hill-Burton program) to some 80 projects for the construction of facilities for the mentally retarded. Two more applications for funds have been approved during the first half of the current fiscal year.

In addition, the HFPCS assists the Social and Rehabilitation Service (SRS) in administering the programs providing construction grants for community facilities for the mentally retarded and university-affiliated facilities for the mentally retarded under Title I, Part C and Part B, respectively, of the Community Mental Health Centers and Mental Retardation

More specifically, SRS reviews and approves the initial or grant approval stage of the applications for the programs concerned, and at the same time the HFPCS regional offices provide consultative recommendations to SRS in respect to the initial stage of the application. After this stage is approved by SRS, the HFPCS assumes responsibilities for administering subsequent project management by approving the ability of the project sponsor to provide his share of the capital needed to construct the facility and by approving the title to the site or other site interest.

#### VI. Other Activities

# A. Partnership for Health

Public Law 91-515 expanded and extended through Fiscal Year 1973 the authorities contained in Sections 314(a), (b), (c), (d), and (e) of the Public Health Service Act, as amended by P. L. 89-749 and P. L. 90-174. Grants under Section 314 are administered through the DHEW Regional Offices.

- 1. Section 314(a) authorized formula grants to States for comprehensive health planning, which would include planning for mental retardation, among other physical, mental, and environmental health concerns.
- 2. Section 314(b) authorized project grants for comprehensive areawide health planning (including planning for mental retardation). Public and nonprofit private agencies and organizations are eligible to apply for such support.
- 3. Section 314(c) authorized project grants for training, studies, and demonstrations in health planning. Public and nonprofit private organizations and agencies are eligible to apply for such support.

- 4. Section 314(d) authorized formula grants to States for public health and mental health services. States must allocate at least 15 percent of their grant funds to their mental health authority. Mental retardation programs may be supported in accord with a State's plans for health services or mental health services.
- 5. Section 314(e) authorized project grants for health services development. Public or nonprofit private agencies, institutions or organizations are eligible to apply for such support. Mental retardation projects (including related training) should be for service components of well-integrated comprehensive health services programs, applications for which will be given highest priority.

#### B. Maternal and Child Health Service

## Historical and Legislative Base

The Maternal and Child Health Service (MCHS) was a part of the Children's Bureau until September 1969, when it was transferred to the Health Services and Mental Health Administration. MCHS thus traces its concern with mentally retarded children and their families back to 1912, when the Children's Bureau was founded. In its first 6 years the Bureau produced three major studies which dealt with mental retardation.

In 1935 the Social Security Act authorized annual Federal grants to States for maternal and child health and crippled children's services; these grants have been and continue to be administered by MCHS. The Social Security Act also afforded MCHS an opportunity to aid the States in developing demonstrations and special programs in areas of health where there were gaps in service.

As recently as 1954, maternal and child health activities on behalf of mentally retarded children and their families were extremely limited. Many local public health nurses were reporting children in their caseloads suspected of mental retardation, but for the most part they had few or no resources for establishing a diagnosis. By age groups, the greatest gap in available services was in relation to infants and preschool children. It appeared that many of 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 appropriation and earmarked \$1 million specifically for special projects serving this group of children. The Appropriations Committee also expressed the hope that an additional million dollars which was to be distributed among the States on a regular formula basis would be used to implement services for the mentally retarded.

Amendments to the Social Security Act in 1963 increased the authorization and resulted in increased appropriations both for special projects for mentally retarded children and in the amount of regular formula funds designated for this purpose. The 1963 amendments also authorized special maternity and infant care projects in low-income areas; these are described in more detail, under Preventive Services.

The 1965 amendments to the Social Security Act included the provision of grants for the training of professional health personnel to work with crippled children, particularly the mentally retarded and those with multiple handicaps.

The 1965 amendments also made available project grants to provide comprehensive health services to children and youth of preschool and school age (Children and Youth Projects), particularly in areas with concentrations of low-income families. The appropriation for this program for fiscal year 1966, the first year, was \$15 million. The appropriation for 1971 is \$43.8 million. As of January 1971 there were 59 projects serving more than 400,000 children.

The Child Health Act of 1967, a part of the Social Security Act amendments of that year, made provision for the following: (1) increased authorizations for child health under Title V; (2) services for reducing infant mortality and otherwise promoting the health of mothers and children; (3) family planning services; (4) continuation of the project grant programs for maternity and infant care and for comprehensive health services for pre-school and school-age children; (5) new dental health service projects; (6) emphasis on early identification of health defects of children; and (7) broadening of the scope of research and training authorizations. Reducing the incidence of mental retardation and improving care to mentally retarded children are among the objectives of these provisions.

# I. Preventive Services

# A. Maternity and Infant Care Projects

The report of the President's Panel on Mental Retardation in 1962 emphasized the interrelationships of lack of prenatal care, prematurity, and mental retardation. In 1963 the Maternal and Child Health and Mental Retardation Planning Amendments authorized grants for the Maternity and Infant Care Projects. These projects provide comprehensive health care to prospective mothers in low-income areas who have, or are likely to have, conditions associated with childbearing which increase the hazards to their health or that of their infants and who would not otherwise receive needed care because of low-income or other reasons beyond their control. Health care is also provided for premature and other infants at risk.

State health departments, local health departments, with the consent of the State health department, and other nonprofit agencies may receive these project grants. The grants pay for up to 75 percent of the cost of projects.

For 1971 the appropriation is \$38.6 million; 55 projects were in operation as of January 1971. In fiscal year 1970 an estimated 128,000 maternity patients were admitted, 107,000 new patients received family planning services, and 42,000 infants received health care in these projects.

Under the authority of the 1967 amendments, a program of special projects to give expert care to high risk infants has been initiated. These projects will provide intensive care for the newborn in hospitals capable of high quality care - usually teaching hospitals associated with schools of medicine. For fiscal year 1970 the appropriation was \$450,000; the same amount has been appropriated for 1971. Five projects have been approved.

The 1967 amendments extended the program of Maternity and Infant Care Projects until June 30, 1972, after which they become a part of each State's health services plan. The legislation continued the intent to help reduce the incidence of mental retardation and other handicapping conditions caused by complications associated with childbearing, and in addition called for services for helping to reduce infant and maternal mortality.

# B. Phenylketonuria and Other Metabolic Diseases

A major emphasis in the prevention of mental retardation within the past few years has been in relation to phenylketonuria (PKU). This inborn error of metabolism has in the past been responsible for one 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 can usually be prevented. MCHS has been working with State health departments in developing and trying out various screening and detection programs, developing the necessary laboratory facilities, and assisting States in providing the special diet and follow-up programs for these families.

Although such programs may be initiated without a legislative requirement, in many States laws have been enacted on this subject. By July 1970, 43 States had such laws, most of them making screening for PKU mandatory. The 43 States are:

Alabama	Illinois	Missouri	Oregon
Alaska	Indiana	Montana	Pennsylvania
Arkansas	Iowa	Nebraska	Rhode Island
California	Kansas	New Hampshire	South Carolina
Colorado	Kentucky	New Jersey	Tennessee
Connecticut	Louisiana	New Mexico	Texas
Florida	Maine	New York	Utah
Georgia	Maryland	North Dakota	Virginia
Hawaii	Massachusetts	Ohio	Washington
Idaho	Michigan	Oklahoma	West Virginia
	Minnesota	Nevada	Wisconsin

During the past year, approximately 90 percent of the total registered live births in the 50 States and the District of Columbia were screened. This screening effort by the States, supported through MCHS, turns up approximately one confirmed case for every 16,000 live registered births. Annually about 225 infants born to families in which no previously known sibling with PKU had been delivered are being detected, subsequently confirmed as having PKU, and treated.

Interest continues to increase in metabolic diseases other than PKU that lead to mental retardation. MCHS is continuing to support a study of the clinical application of screening tests to detect galactosemia, maple syrup urine disease, and histidinemia. Also, support is being given to studies of new approaches to broader screening methods which would make available a battery of automated tests for detecting metabolic diseases.

#### C. Lead Poisoning

In the area of prevention, increasing attention is being paid to lead paint poisoning. Despite present-day manufacture and use of lead-free paint for interior purposes, many children become mentally retarded or suffer other damage from ingestion of chips of lead-containing paint from walls and woodwork in old, dilapidated housing. Two publications, "Lead Poisoning in Children" and "Childhood Lead Poisoning, an Eradicable Disease," addressed to public health workers, have been prepared; they suggest a program of prevention, casefinding, and follow-up of cases. Twenty-two of the Children and Youth projects report that lead poisoning is a problem in their project areas. Twenty projects reported that they had screened children for lead poisoning in 1969. Of these, 17 projects screened 3,584 children, of whom 85 were eventually diagnosed as having lead poisoning. Forty-one children were still being treated by the end of the year. Three other projects screened an additional 47,067 children in mass screening programs and reported 397 diagnosed as having lead poisoning with 187 still under treatment at the end of the year.

# D. Immunizations

The prevention of epidemics such as the rubella outbreak of 1964 through adequate and appropriate immunizations is a major interest of the MCHS program in mental retardation. Many of the estimated 20,000 babies born with birth defects resulting from that outbreak are showing evidence of mental retardation and will add to the burden of care of already overtaxed services for the retarded. States are encouraged to use MCHS funds to complete the immunization of children against rubella. MCHS is encouraging the States to develop a routine maintenance level effort in this area as part of the continuing MCHS basic immunization program, which reaches several million children each year.

# E. Malnutrition and Mental Retardation

There is growing evidence that the adequacy of nutrition during fetal life and early infancy may affect intellectual and behavioral development as well as physical growth. Recognition of this led the National Academy of Sciences' Committee on Maternal Nutrition to recommend that in the determination of food policies on the basis of physiological need, high priority be given to infants, children, adolescents, and pregnant women.

Many women, infants, and children do not have access to an adequate supply of food due to lack of income and other related socioeconomic factors. To improve the food supply for these groups, the Maternal and Child Health Service and the United States Department of Agriculture have continued to cooperate in programs such as the Supplemental Food Program. In August 1970, nearly 165,000 persons (including about 29,000 infants, 107,000 preschool children and 29,000 mothers), compared to 56,000 in August 1969, participated in this program.

#### F. Familial Mental Retardation

Approximately 20 percent of the children seen in the special clinical programs (described below) are labeled as having "Familial Mental Retardation," which usually is associated with deprivation and poverty. The conditions which spawn the problems of these children are to a large extent

the same ones which generate many other health and social problems. Amelioration in most instances is beyond the range of direct effectiveness of a clinic staff by itself, and depends upon massive community efforts, in which the clinic staffs are participating.

# II. Basic and Supportive Services

# A. Casefinding and Screening

The importance of <u>early</u> detection and casefinding has continuously been stressed as a major focus of the MCHS program for mentally retarded children. The fact that on a State and local level the same organizational unit (MCH) administers the mental retardation clinics and some sizeable organized screening programs (vision screening for some 10 million children, and hearing screening for 6 million children in 1969) permits easy use of these screening programs for casefinding for mental retardation. The fact that earlier detection is occurring is demonstrated by the earlier ages at which children are being seen in the special clinical programs. In 1970, 30.6 percent of the children seen in the clinical programs were under 5 years of age and 76 percent were under 10 years of age.

# B. Clinical Services

Support of clinical services for mentally retarded children is one of the most important uses for MCHS mental retardation funds. The services provided include diagnosis, evaluation of a child's capacity for growth, the development of a treatment and management plan, interpretation of findings to parents, and follow-up care and supervision. By the end of fiscal year 1969 there were 235 special mental retardation community clinics. Of these, 150 were supported in whole or in part by MCHS funds and were serving approximately 43,000 children and their families. Incomplete reports for fiscal year 1970 indicate that while there has been no real growth in the number of clinical programs, the existing clinics have increased their capacity to serve patients (117 reporting clinics served over 44,000 patients and their families).

# C. Crippled Children's Services

Since enactment of the Social Security Act in 1935, the Federal Government, through MCHS, has assisted the States in providing services to crippled children. Because of limited appropriations and restrictive definitions of conditions cared for, relatively few mentally retarded children were included in these programs prior to 1963. The enactment of the 1963 amendments, providing for increased funds for the Crippled Children's Program and for the earmarking of some of the funds specifically for mentally retarded children, resulted in removal of legal and administrative restrictions on serving physically handicapped retarded children, in broadening the definition of crippling conditions, and inclusion of services which had not hitherto been given. Some children who would formerly have been turned away are now being given services.

An important use of the increased funds available for mentally retarded crippled children is in providing corrective care for institutionalized retarded children, such as orthopedic services.

As a result of the broadening of the scope of crippled children's services, a number of clinics for multiply-handicapped children have been developed in an attempt to demonstrate the kind of staff and service provisions it would take to meet the total needs of these children through a single clinical setting.

In 1969 over 45,000 children with diagnoses of various forms of mental retardation received medical services in the Crippled Children's Program. The 1967 amendments to the Social Security Act require that State plans for crippled children's services provide for more vigorous efforts to screen and treat children with disabling conditions. This provision should result in an increase in the number of mentally retarded children identified and treated.

# D. Cytogenetic and Biochemical Laboratory and Genetic Counseling Programs

MCHS funds earmarked for mental retardation are also being used for cytogenetic and biochemical laboratory services. Project grants have been approved which establish such programs as extensions of clinical services at hospitals or medical schools. Projects include chromosome analysis and diagnosis of various medical conditions which may be genetic in origin and result in mental retardation. On the basis of these analyses, counseling may be given to parents seeking advise on genetic questions. These laboratories also provide continued monitoring of patients with metabolic diseases. Training of necessary professional personnel to deliver these services is also an important aspect of many of these projects. During fiscal year 1970, 21 special laboratory programs of this type were supported by MCHS. They provided chromosome studies on approximately 4,500 patients and their families with a known or suspected genetic problem. Of the patients served, some 70 percent were under one year of age, 9 percent were from 1 to 4 years of age, 5 percent from 5 to 9, and 16 percent over 9 years of age. Approximately 18 to 20 percent of these families came from low-income minority groups.

The biochemical components of these laboratory programs processed some 90,000 specimens to check for a variety of conditions. Genetic counseling, based on these cytogenetic and biochemical laboratory findings, combined with comprehensive clinical evaluations, was provided to most of the families.

# E. Dental Programs

The demonstration of good dental care and services to the mentally retarded is an integral part of each of the University-Affiliated Centers described below. Many of the special clinical programs provide such services for their patients. In addition, during fiscal year 1970, State MCH programs had budgeted \$234,992 and State Crippled Children's Programs had budgeted \$194,782 specifically for dental care and service for mentally retarded children. This is far from meeting the need. It is hoped that

the development of projects providing comprehensive dental health services for children from low-income families, authorized by the 1967 Social Security Amendments, will meet the dental needs of handicapped children in the project areas.

# III. Training of Personnel

Training activities for health services in the field of mental retardation, assisted by MCHS funds, have encompassed many approaches. Support of training staff at institutions of higher learning, grants for fellowships and traineeships, support of institutes, conferences, and inservice training programs were included in these efforts. Consultation on the broadening of existing professional curricula to include aspects of mental retardation, arrangements for student experiences in mental retardation clinics, and the preparation and distribution of professional informational materials and guides also represented a major portion of activities directed towards training.

During fiscal year 1970 a portion of MCHS funds earmarked for mental retardation was used to support 43 long-term trainees in mental retardation from the fields of medicine, genetics, clinical psychology, speech and hearing, and social work. Several hundred professional workers were given short-term training in concepts of service to retarded children and their families.

In addition, most of the \$9 million available for training under Section 511 of the Social Security Act was utilized for grants to 15 institutions of higher learning in support of multidisciplinary training programs (University Affiliated Centers) in mental retardation. Through these grants some 679 faculty and staff positions, representing some 540 manyears, and 202 long-term traineeships in a variety of disciplines were supported.

# IV. Research

A program of grants for research relating to maternal and child health and crippled children's services was authorized by the Maternal and Child Health and Mental Retardation Planning Amendments of 1963. As stated in this legislation, the program is one of

"...grants to or jointly financed cooperative arrangements with public or other nonprofit institutions of higher learning and public or other nonprofit agencies and organizations engaged in research or in maternal and child health or crippled children's programs, and contracts with public or nonprofit private agencies and organizations engaged in research or in such programs, for research projects relating to maternal and child health services or crippled children's services which show promise of substantial contribution to the advancement thereof."

The basic purpose of the program is to make a contribution toward the improvement of the health of mothers and children of the nation. In

consonance with that objective, the program aims to improve the general usefulness and effectiveness of maternal and child health and crippled children's services. Some examples of support areas relating to mental retardation during fiscal year 1970 include studies of the epidemiology of mental retardation in a rural county, sensory integrative processes and learning disorders, children with congenital rubella, perinatal casualty reports, galactosemia screening, and sensory motor activity in the neurologically handicapped child.

# V. International Activities

The Maternal and Child Health Service through its International Office has been participating in a variety of international efforts relating to mental retardation since 1961. These have included the interchange of experts and scientists, the dissemination of publications and materials, and the support of and participation in a number of international seminars and conferences.

P. L. 480 funds, available to this office since 1962, have been utilized to support nine projects in mental retardation to four countries --Poland, Yugoslavia, Pakistan and Israel. These projects have focused chiefly on the development of screening programs for newborn infants, management techniques for children with inborn errors of metabolism, studies of the incidence of metabolic disorders and genetic defects, various levels of retardation in selected populations, studies of institutional care, and the impact of corrective care of associated physical handicapping conditions on the functioning level of retarded children. These programs in general have permitted demonstrations and studies which could not readily be carried out in the United States, but which provide some valuable information about approaches we might take in our own programs. Of even greater importance is the impact these projects have had in stimulating the development of new services and preventive measures in the area of mental retardation in the participating foreign countries. A lasting channel of communication has also been established with these countries through which data and information continue to flow.

## NATIONAL INSTITUTES OF HEALTH

#### Introduction

As the primary health research and research support arm of HEW, the National Institutes of Health recognizes its responsibility to help provide solutions to the problems of the estimated 6 million mentally retarded in this country. This disorder affects not only the afflicted but also the members of their families and society in general who must bear the direct and social costs involved. Mental retardation is a major health, social, educational and economic problem. It is estimated that the number of retarded increases each year by approximately 126,000 patients. Medical progress has resulted in obstetricians and pediatricians being able to deliver and prolong the lives of many retarded babies so that the number of surviving affected individuals is increasing. This leads to larger requirements for resources of all kinds to manage and assist the patients and their families.

The biological bases of mental retardation are many and varied. Aberrant intellectual development may result from hereditary causes such as inborn errors of metabolism (phenylketonuria is an example); meiotic or mitotic chromosomal abnormalities (mongolism or Down's syndrome, which may also be hereditary); endocrine dysfunction (cretinism); and severe protein-calorie deficiency during pregnancy or infancy may result in inadequate central nervous system development. It is also known that the conditions of poverty, lack of good perinatal care, chronic and debilitating diseases, poor sanitation, broken or inadequate homes, insufficient or non-existent medical care, and inadequate educational opportunity result in incidence and prevalence of mental retardation at rates 7 to 10 times higher than the average estimate of 3 percent for the population as a whole.

Biomedical research now in progress has provided clues concerning the basic mechanisms involved in a number of diseases causing mental retardation. An increasing number of genetically determined conditions can now be diagnosed in utero. Management of these cases in utero is the subject of research in a number of research centers. Progress in the application of these preventive and corrective approaches frequently involve legal, religious and social issues which determine, in many instances, the management approach taken. Resolution of these issues will need to consider the prospects in behavioral and educational research where research progress is contributing significantly to the correction and amelioration of the problems of life adaptation in existing retardates.

The National Institutes of Health encourages and supports research and research training in order to acquire basic information about the causes of mental retardation. Adequate knowledge of etiology will facilitate development of preventive techniques, which is the ultimate goal of these endeavors.

Where primary prevention is not attainable, amelioration of human suffering and reducing the consequences of mental retardation to those affected, their families and society as a whole becomes a secondary goal. Using research grants for individual and program projects, research training grants to institutions of higher learning, fellowships and research career development awards to qualified individual scientists, and contracts to qualified institutions as well as the sponsorship of scientific conferences, the NIH is supporting a broad research effort in the biological, clinical and behavioral sciences. The Mental Retardation Branch of the NICHD alone is supporting over 130 research and research training grants, awards and contracts in the various aspects of mental retardation. The estimated total outlay for support of mental retardation research and training by the NICHD alone for FY 1971 is over \$11 million.

The National Institutes of Health efforts to prevent, cure, or ameliorate mental retardation emanate from at least five of the Institutes. Primary responsibility resides in the National Institute of Child Health and Human Development (NICHD), which recognizes the importance of this subject to such a degree that an entire branch, one of five in its extramural program, is devoted exclusively to development and support of mental retardation research and research training. The activities of three of the Institute's four other branches are also frequently of significance to the MR problem. Three branches of the Institute's intramural program have as their responsibility the conduct of mental retardation research. The Children's Diagnostic and Study Branch emphasizes research on problems of diagnosis and evaluation while the Behavioral Biology Branch and the Laboratory of Biomedical Science conduct research in the neurophysiological, electro-physiological, biochemical, metabolic and molecular aspects of mental retardation.

Other Institutes of the National Institutes of Health also contribute to the nation's research efforts to resolve the problem of mental retardation. Among these are the central nervous system research of the National Institute of Neurological Diseases and Stroke (NINDS), the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of Arthritis and Metabolic Diseases (NIAMD), all of which directly or indirectly extend the efforts of the Mental Retardation Branch of NICHD.

## I. Training of Personnel

It is clear that while research is making progress in supplying information to clinicians of all kinds, a great deal more research remains to be done. A broad attack embracing all the biomedical sciences from fundamental molecular biology through biochemistry, neurophysiology, genetics, epidemiology, pathology, obstetrics, pediatrics on through psychology, sociology and special education must be continuously maintained if the ultimate goals of maximum prevention, cure and amelioration are to be attained. This means training of competent investigators with deep knowledge of their primary field plus indoctrination into the special problems of research in the area of mental retardation.

# A. National Institute of Child Health and Human Development (NICHD)

The need for more research workers in all fields and disciplines, with primary interest in mental retardation, remains critical. Research training grants which provide support for student stipends, faculty salaries, and necessary equipment and supplies for teaching and research are the primary mechanisms used for stimulating additional training. Nineteen mental retardation research training grants, totaling \$1,177,000, are being supported by NICHD in FY 1971. While substantial, this effort will still fall short of supplying the anticipated requirements for trained scientists. These training grants provide training in basic biomedical research, clinical research and behavioral research. In addition to trainees directly involved in receiving stipends from these programs, a large number of other scholars also benefit from the existence of the specific programs through participation in seminars or courses and use of facilities established for or by the training program. Trainees range from Masters Degree candidates through post-doctoral trainees with several years of professional experience.

On an individual basis 10 research fellows are being supported. Research career development and research career awards totaled 10 in FY 1971. The fellowship and research career development awards cover basis biology, clinical medicine, and behavioral studies.

## B. National Institute of Neurological Diseases and Stroke (NINDS)

While the training program of the National Institute of Neurological Diseases and Stroke is not specifically and exclusively directed towards mental retardation, it is directed toward the development of clinical neurologists and competent research scientists in the fields associated with the diseases of the nervous system. These disciplines provide the basic tools required for any serious attack on the problem of organically-based mental retardation. Particularly important are the Institute programs for the training of pediatric neurologists, who are very often required to make the initial diagnosis of mental retardation. Training programs in speech pathology and audiology are fundamental to therapy in the mentally retarded and receive strong support from the Institute. These programs have had to be drastically cut in FY 71 because of budget cuts, and no new training programs started.

## II. Research

# A. National Institute of Child Health and Human Development (NICHD)

National Institutes of Health supported research covers nearly the whole spectrum of biological and clinical research disciplines and a great many of the behavioral ones as well. In recognition of the complexity of the disease entities involved, efforts have been made to stimulate multifaceted and interdisciplinary attacks on the

problem. The appropriate support mechanism for such research is the program project grant. About 30 such grants (including core support for the Mental Retardation Research Centers) are currently active. In all, 107 research grants (including program grants) and 6 contracts are currently active. Of these, approximately 70 percent of the research grants are in biomedical research and 30 percent in the behavioral research areas in terms of dollar amount. A large fraction of current biomedical research support is devoted to cytogenetic and tissue culture investigation of genetic defects including inborn errors of metabolism and mongolism.

Progress has been reported this year in extending the use of amniocentesis material as a source of diagnosis of additional inborn errors of metabolism. The use of cells derived from amniotic fluid for tissue culture supplies material for research into the mechanism of the errors of metabolism. It is expected that ultimately, the diagnosis in utero will not necessarily be the end point since elucidation of mechanism will eventuate in development of methods for therapeutic intervention.

Another encouraging trend is the increasing interest of several investigators, supported by the National Institute of Child Health and Human Development, in the effects of the various disease agents on the central nervous system. For instance, a group of investigators have measured the effect of excess phenylalanine on the concentrations of several lipid compounds involved in formation of the myelin sheath of normal brain neurones. The excess phenylalanine was found to slightly reduce the concentration if administered less than three weeks after the birth of the baby rats. A related series of experiments by colleagues of these investigators demonstrated that excess phenylalanine also interfere with protein synthesis in the brain by disaggregating the responsible polyribosomes into smaller units which are not capable of synthesizing protein. This effect was seen in the brain but not the liver and again only very early in the life of the rat. The significance of this research is that it provides a better understanding of how one agent may act to produce mental retardation and also act as a model for furnishing clues for designing experiments to investigate the effects of other causative agents, particularly inborn errors of metabolism.

In a clinical approach, a group of investigators at another Mental Retardation Research Center studied the consequences of convulsions during the first 3 weeks of life in humans. The convulsions were found to be due to metabolic disturbances, birth injury to the brain, anoxia, and congenital malformation of the brain. At 4 years of age more than 28 percent of the children showed neurological deficits usually associated with mental retardation and nearly 20 percent had died. It was determined that early electroencephalography could be used along with diagnostic infusion of suspected metabolites to identify the source of the problem and to indicate what preventive measures are necessary.

An epidemiological study conducted in Aberdeen, Scotland since 1962, and partly funded by NICHD, culminated this year with the publication of a monograph. The main thrust of the report is that there is a very strong association between low occupational level of the father, large family size, overcrowding and poor housing. The entire surviving birth cohorts of 1952, 1953, and 1954 were studied (except for a tiny percentage who moved away) at age 8 to 10. The authors found a significant excess of mildly subnormal children contributed by the lower social classes. This was not true of severely retarded children. The authors also found that perinatal complications such as pre-eclamptic toxemia, low birth weight, shortened gestation, complications of delivery and poor condition of the baby occurred significantly more frequently in the mentally subnormal children than in the comparison population. Although there are some methodological problems with the study (most of which the authors recognize) the monograph represents a most thorough epidemiological investigation which clearly illustrates the significance of circumstances antecedent to birth which can affect the intellectual development of human beings.

Contracts are being used to sponsor research where staff has observed a particular need which can be met best by specifying and guiding the research to be done. Two examples of this are the contracts set up to investigate the effect of protein and other supplements on the mental and physical development in young children when the supplement is supplied during pregnancy. One of these contracts covers work in a rural area in South America, the other in a large disadvantaged urban population.

Scientific conferences as a means of accelerating the diffusion of new research information, for stimulating interest in a neglected field, or for focusing on an area ripe for exploitation, or to obtain a fresh evaluation of existing research are often sponsored by the NICHD. Two such conferences occurred in Fy 71. A "Seminar of Research in Language of the Retarded" was jointly sponsored with the MRRC at Kansas. This conference, the first in an anticipated series of Center Conferences, covered a significant area since language deficiency is common to all the retarded. Another conference, "Perspectives in Human Cytogenetics in the Next Decade," served the purpose of synthesizing the cytogenetics research information of the past decade. The conference served the further purpose of identifying research opportunities and requirements for the coming decade.

At the Federal level the NICHD has primary responsibility for assisting MRRC administrations with the development and operation of their programs of research and research training in the field of mental retardation and related aspects of human development. When fully operational it is anticipated that the centers will carry the major research thrust of our nation's efforts to combat mental retardation. This year two more MRRC's (both in Massachusetts)

completed construction and occupied buildings provided under authority of Part A, P.L. 88-164, for a total of 9 centers operational in their own buildings. The Construction program is, therefore, nearly complete, with the last to be completed center occupied early in FY 1972.

The research activities of the centers are many and varied. Several of the centers are working on the problem of mental retardation associated with depriving life circumstances. The center at Kansas is making notable progress in methods utilizing local people, especially mothers, in creating or improving the conditions under which the intellectual development of children is stimulated. Methods of constructive intervention to prevent or minimize poverty-linked retardation are under way and others are being planned at the Peabody Center. Studies with the same aims are under way or planned at the University of North Carolina where ways of preventing retardation in the disadvantaged through the use of psycho-social intervention are underway. The staff of the University of Wisconsin Center is currently deeply concerned with rehabilitative methods as well as biomedical research on metabolic disorders such as phenylketonuria. At the University of Washington Center, the staff is planning an interdisciplinary, longitudinal research program to relate medical, biochemical, electrophysiological and other events during pregnancy with the neurological sequelae observed in infants and children. This will make possible elucidation of the role of events or processes occurring during gestation, birth and the neonatal period, which can result in mental retardation, and, hopefully, will assist in finding preventive or therapeutic measures.

## B. National Institute of Neurological Diseases and Stroke (NINDS)

The National Institute of Neurological Diseases and Stroke sponsors research in mental retardation when mental retardation appears as a symptom, complication or sequela of some disease of the central nervous system. Consequently, a large number of research projects supported by the NINDS can be said to be relevant to mental retardation research, although the interest of the scientist may be in the study of some particular phase of disease rather than in mental retardation directly. The research projects involved use nearly all of the scientific disciplines to some degree.

One of the Institute's major efforts which has great interest for mental retardation research is a collaborative project with 14 cooperating institutions investigating the prenatal, perinatal and postnatal factors relating to the development of children. The "Collaborative Study in Cerebral Palsy and Other Neurological and Sensory Disorders in Infancy and Childhood" is following the offspring of more than 50,000 mothers from early pregnancy through labor and delivery until the children are at least through the first year of school.

This program was started in 1959. The gathering of data has been completed for pregnancies, deliveries and on all children through the age of one year. About 40 percent of these children are now age seven, and are completing their examination schedule. Concurrent evaluations indicate that about 77 percent of the eligible children have actually been examined at the age of seven. Of the remaining children, half of them have been lost to the study, but efforts are being made to find them.

These data are now being continually analyzed and reported. Three volumes of the collected reports from this study have been published. The first from 1963 through June 1969 and the next two a year each from July 1 to June 30 of the following year. Currently, a collected bibliography is issued quarterly. These are available from the Perinatal Research Branch, NINDS, Wiscon Building, Room 708, Bethesda, Md. 20014.

Research into inborn metabolic errors is being supported in order to discover how early these diseases appear and when to begin treatment. There are more than 200 known metabolic abnormalities of which no more than 6 may be amenable to present therapeutic approaches. The biochemistry of these diseases and the relationship of the biochemical activities to brain function are being studied. These studies, which are directly relevant to the development of mental retardation, are identifying the enzyme defects which are specific for the various diseases. Research is beginning to see if substitution therapy can be developed.

The early diagnosis of mental retardation is frequently extremely difficult. The Institute continues to support programs for the refinement of diagnostic techniques. The problem of minimal brain dysfunction is undergoing re-evaluation to assess the current status of, and to, apply advanced techniques to this difficult area.

Mental retardation often follows hydrocephalus and brain tumors in childhood. Development of appropriate surgical or pharmacological therapy remains an objective of the Institute. The Institute is also supporting programs which investigate the mechanisms involved in meningitis or meningoencephalopathy to determine proper preventive and therapeutic approaches.

The study of maldevelopment and malfunction of the brain because of nutritional deprivation is being pushed on several fronts. Some of these involve the clinical evaluation of brain development and diet while others are related to the biochemistry of the development process. This is an expanding and promising field of research.

#### OFFICE OF EDUCATION

#### Introduction

Programs dealing with handicapped children in the Office of Education have been placed under the administrative direction of the Bureau of Education for the Handicapped. This is consistent with the efforts of the Office of Education to provide maximum educational programming for all children. The Bureau is responsible for supervising and implementing current and new legislative authorities to provide funds for projects and programs relating to the education, training and research of handicapped children and youth. These children include those who are mentally retarded as well as those who are hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled, or other health impaired and require special education.

The overarching goal for Federal efforts in the area of education for the handicapped is to equalize educational opportunities for handicapped children. Less than 40 percent of the nation's more than six million school-aged handicapped children receive needed special education services. Federal funds for the education of the handicapped currently average less than \$30 per child.

The main issues surrounding the Federal role in education for the handicapped are:

- 1. How can the limited available Federal resources be used in a catalytic and stimulative manner to bring quality educational services to the greatest proportion possible of the unserved 60 percent of the target group?
- 2. What is the best use of Federal resources in preventing identifiable handicaps from becoming serious disablements in school and adult life?
- 3. What educational techniques and methods can be developed, introduced and adopted to insure handicapped children job skills to enter adulthood with a high probability of participating in society in a meaningful manner?

Six objectives have been adopted for the Federal programs for education of the handicapped:

- 1. By 1976, assure that at least 60 percent of the handicapped children are adequately served by educational agencies. An increase of 250,000 children must be receiving services each year 1972-76 if this objective is to be achieved.
- 2. By 1973, develop programs and models, and in other ways assist in the prevention of disabling handicaps through relevant early education for 25 percent of all potentially handicapped preschool age children. The Bureau hopes to expand to 60, operating demonstration and model centers in 1971.

- 3. By 1976, develop and promote the installation or adaptation of relevant vocational education models leading to adequate career training and job opportunities for all handicapped youth. While the Bureau does not control the 10 percent set aside for the handicapped under the Vocational Education Act of 1968 (approximately \$30 million is the FY 1972 proposed set aside), BEH is carrying on research and experimentation in vocational education to complement the State allocation of funds.
- 4. By 1976, provide systems and resources so that significant and relevant educational materials are readily available to all teachers of handicapped, so that at least 60 percent of the handicapped children will be served. This objective is reflected in the FY 1972 budget by a continued investment in Media Services of \$6 million and continuing support of Regional Resource Centers at \$3,550,000.
- 5. By 1976, in cooperation with the Bureau of Educational Personnel Development, increase the number of trained personnel (subprofessional and professional) so that 60 percent of the handicapped children have adequate instructional and supportive services. We estimate that 15,000 new, special education teachers enter the field each year. If the goal of equalizing educational opportunities for handicapped children is to be achieved, 30,000 new special education teachers per year will be needed.
- 6. By 1973, develop programs and practices that demonstrably change the attitudes of educational professional, lay personnel, and employers towards greater acceptance and increased realization of the potentials of handicapped children and youth. In FY 1972, as in 1971, \$500,000 will be expended directly in a public information and recruitment campaign.

The challenge and urgency of its overriding goal infuses the Bureau with an atmosphere of dynamism reflected in the drive and commitment of its total staff. The primary tool of the Associate Commissioner for effecting the Bureau-wide concentration upon the achievement of this goal is the Office of Program Planning and Evaluation. This Office serves the Associate Commissioner as a facilitator and advocate of "accountability" in special education. It assists officers of BEH in the setting of national program objectives. It establishes evaluation procedures to "track" the impact of Federally-sponsored programs; and it attempts "Federal Responsiveness" through its efforts at mutuality of planning. That is, the OPPE attempts dialogue with special education decision-makers throughout America in articulating common goals, objectives, strategies, and unified action. The PPE unit also attempts to regularly assess the field for relevant planning data.

In order to efficiently implement the program and carry out the Federal mandate, the Bureau is administratively organized into three major divisions under the Office of the Associate Commissioner. In addition to the already mentioned Office of Program Planning and Evaluation, the

Associate Commissioner's office includes an Executive Office, and an Information and Reports Office. Each of the three major Divisions -- Training, Educational Services, and Research -- functions as an integral element in the total Bureau program for handicapped children. The following pages describe the functioning of each division as it relates specifically to mentally retarded children.

## I. Division of Training Programs

#### A. Purpose

The Division of Training Programs initiates, maintains, and improves programs for the preparation of professional leadership and teaching personnel to educate handicapped children. Divisional programs which are designed to implement this purpose are two-fold in their attack, in that they must provide: (1) classroom supervisory, consultative, and administrative personnel for State and local special education programs; and (2) personnel for higher education institutions responsible for preparing administrative and classroom personnel. The Division of Training Programs in an effort to effectively implement training programs for the mentally retarded has organized a Mental Retardation Branch. This Branch, one of three in the Division, is responsible for the coordination and administration of all programs in the area of mental retardation.

#### B. Need

As more States legislate mandatory education for handicapped children the major problem faced in implementing such legislation is an acute shortage of qualified personnel. According to data received from the State Plans submitted by State education agencies under Title VI, ESEA, for fiscal year 1969 approximately 446,000 teachers and other personnel were needed to provide educational services to all handicapped children then identified. Approximately 130,000 or 29 percent of the preceding personnel were needed in the area of mental retardation. Still, only 64,600 or 49 percent of the latter number needed for the education of the mentally retarded were employed in 1969, and many of these persons lacked full certification. If general turnover rates applicable to the education profession are applied, approximately 8 percent of the special education teachers will leave the field each year. At current rates of preparing professional personnel in mental retardation more than twenty years will be needed to close the gap between supply and demand, if all other variables remain constant.

As a result of the teacher shortage, approximately two-thirds of the more than six million handicapped children of school age are not receiving the special educational services they require. Many of the established programs are actually of minimal quality, because they have been started with less than fully qualified personnel. This current deficit, as in the past, not only retards the systematic growth of special education, but simultaneously requires the majority of our nation's handicapped children to accept an education program inappropriate to their needs. Similarly, college and university personnel so essential to the preparation of teachers are also in short supply. For academic year 1970-71, approximately 200 new faculty members were needed; however, less than one half of this number was available.

## C. History

In 1958, Public Law 85-926 was passed by Congress authorizing an appropriation of \$1 million per year for the preparation of professional personnel in the education of the mentally retarded. This initial piece of legislation was directed at preparing college and university personnel to staff the then existing programs, and much needed new programs for preparing personnel to work with the handicapped in State and local school systems. Between academic years 1959-60 and 1963-64, 692 graduate fellowships were granted to 484 individuals. The majority of these individuals became college and university professors while others became State and local special education leadership personnel. In fact, a recent survey made of the above fellowship recipients indicated that approximately 75 percent of all programs in mental retardation at colleges and universities are directed or coordinated by these individuals.

A study conducted in February of 1964, of 245 former P. L. 85-926 fellowship recipients revealed that over 90 percent of them were engaged in the field of special education, including the mentally retarded, and about 70 percent were engaged primarily in the field of mental retardation. Sixty-eight of the 245 former fellows indicated that they were currently employed by a college or university, 80 were employed in an administrative or supervisory capacity (19 of these were employed by State educational agencies), and 54 returned to the classroom as teachers of the mentally retarded.

On October 31, 1963, P. L. 88-164 was signed into law. Section 301 of this Act amended P. L. 85-926 to: (1) expand the program to include not just the area of mental retardation, but also the areas of the visually handicapped, deaf, crippled and other health impaired, speech and hearing impaired and the emotionally disturbed; (2) allow for the preparation of teachers and other specialists in addition to leadership personnel at the graduate level; (3) extension downward into the senior year undergraduate levels; and (4) increase the monies authorized for these purposes.

Public Law 85-926 was further amended with the passage of Public Law 89-105 and 90-170. These amendments expanded and extended the program through fiscal year 1970, authorizing appropriations of \$29.5 million for fiscal year 1967; \$34 million for fiscal year 1968; \$37.5 million for fiscal year 1969; and \$55 million for fiscal year 1970. On April 13, 1970, Public Law 91-230 was signed into law, effective June 30, 1970. Title VI of this law consolidates all of the prior legislation relating to the handicapped children which the Bureau of Education for the Handicapped administers. Title VI of Public Law 91-230 is referred to as "The Education of the Handicapped Act."

These appropriated funds have been used as stipends for students as well as to support colleges, universities, and State education agencies with the cost of instruction. Since P. L. 85-926 was passed in 1958, approximately 30,000 fellowships and traineeships have been awarded to individuals preparing to work with mentally handicapped children. This includes both short-term and full academic year awards. Table I gives a summary of the awards made in mental retardation since the passage of P. L. 85-926.

Table I - Awards made in the area of mental retardation since the passage of P. L. 85-926 (Fiscal Years 1960 through 1970)

Fiscal Year	Number of Traineeships & Fellowships	Number of Higher Education Institutions Participating	Number of State Education Agencies Participating	Total Amount Obligated
1960	177	16	23	\$985,222
1961	164	18	41	993, 433
1962	160	20	46	997,000
1963	163	19	48	996,433
1964	2,357	108	50	6,419,332
1965	2,506	153	50	6,569,815
1966	3,110	162	52	7,658,002
1967	3,816	177	53	8,891,072
1968	4,521	177	53	8,493,668
1969	6,366	193	53	9,382,084
1970 1971**	6,171	200	55	10,391,341

\*\* Appropriations will be approximately equivalent to fiscal year 1970 (awards not available at time of this report)

The number of individuals being trained in mental retardation under this grant program is significant. The improvement and expansion of the many teacher-training programs in mental retardation throughout the Nation -- resulting directly and indirectly from the grant program -- will, in the long-run, be of even greater significance. Evidence suggests that the support grants which accompany traineeships and fellowships have enabled a great many of the currently participating colleges and universities to add staff, expand the course offerings, and better supervise the observation and student teaching experiences of the students. The total number of students benefiting from these program improvements at the various colleges and universities will, in most instances, far exceed the number of students who are on a fellowship or traineeship.

It is readily apparent that the "old" P.L. 85-926 program, and its major amendment, P.L. 88-164, has enabled a great number of colleges and universities to develop and/or expand their teacher-training programs in mental retardation. A current analysis of the more than 250 institutions requesting funds in the area of mental retardation indicates that more than 170 of them have on their faculties former fellows who received training under Public Law 85-926.

Under current conditions, it will be years before there will be a great reduction in the gap between the number of trained teachers and "leadership personnel" in the area of mental retardation who are needed and the number who are available. However, Public Law 85-926 -- prior

to and since the amendments by Section 301 of Public Law 88-164 -- has provided the necessary beginning in the effort to close this gap. It is expected that Public Law 91-230 will continue these efforts.

- D. Related Program Activities
- 1. Training of Physical Educators and Recreation Personnel

With the passage of P.L. 91-230 the legislation established by P.L. 90-170, Title V entitled "Training of Physical Educators and Recreation Personnel for Mentally Retarded and Other Handicapped Children," was incorporated in the "Education of the Handicapped Act." The present program, Section 634, Part D of this bill is now entitled "Training of Physical Educators and Recreation Personnel for Handicapped Children."

In fiscal year 1970, the Bureau of Education for the Handicapped through the Division of Training Programs awarded a total of \$300,000 to fifteen universities and colleges to assist in providing professional training in physical education and recreation for the handicapped. Funds were provided for planning and minimal student support for graduate students in fifteen institutions.

In addition to the above awards a special study institute award was given to the American Association for Health, Physical Education and Recreation to develop guidelines for professional preparation programs in physical education and recreation for the handicapped. A series of three regional institutes were conducted in the latter part of 1970 with approximately 120 physical educators and recreation specialists participating.

Appropriations for fiscal year 1971 are expected to be approximately \$700,000. Forty-two applications for Fiscal Year 1971 funds requesting assistance in planning, program development, prototype and short courses were received. Awards had not been made prior to the completion of this report.

## 2. Special Institutes

Six Special Study Institutes were funded in August, 1970, in the area of Mental Retardation to bring together the leading special educators from institutions of higher education and from the State level to determine future direction and standards for doctoral programs training leadership personnel in mental retardation. Personnel from universities with doctoral level programs already in existence and universities desiring to implement doctoral level programs were represented, as well as State and local education Agency personnel. The universities are the producers of teacher-educators, who in turn train the teachers, while the State and local educational agencies represented the consumers. This combination was felt to be particularly useful in defining the competencies expected of the classroom teacher, and of the teacher educator.

These six Special Study Institutes were conducted on a regional basis in Texas, Oregon, Illinois, Georgia, Colorado and Virginia. The University of Virginia is in the process of consolidating the findings of the six Institutes. This report should be available in the summer of 1971.

#### E. Cooperative Activities

The Division of Training Programs in an effort to utilize all resources in the provision of quality educational programs for all retarded children has entered into cooperative funding or working arrangements with other personnel training programs in the Office of Education and the Social and Rehabilitation Service. The following are three examples of the Division's cooperative efforts:

## 1. University Affiliated Facility Program

The Division of Training Programs in cooperation with the Division of Mental Retardation of the Social and Rehabilitation Service provided support monies to special education components in seventeen university affiliated facility programs for fiscal year 1970. The extent of the Division's support ranged from approximately \$20,000 to \$30,000 with a total expenditure of \$440,000.

The Division supports a special educator on the university affiliated facility core faculty. The special educator is responsible for instructing medical students, psychologists, social workers, and other related medical personnel as well as students majoring in special education. He serves to effectively integrate special education concepts into the overall interdisciplinary training program of the university affiliated facility.

The institutions receiving support through this program for fiscal year 1970 were; Georgetown University; University of California at Los Angeles; Johns Hopkins University; University of Indiana; Miami University (Florida); Ohio State University; University of Cincinnati; University of Tennessee (Memphis); Children's Hospital (Harvard); University of Oregon; University of North Carolina; University of Alabama (Birmingham); Utah State University; University of Wisconsin; Georgia Retardation Center (Georgia Department of Public Health); University of Kansas; and the University of Michigan.

#### 2. Teacher Corps

The Teacher Corps and the Division of Training Programs are jointly supporting a teacher corps program administered by the Chicago Consortium. Specifically, the Division jointly provides funds for the support of four teacher corps teams (six post-undergraduate level teachers) who receive instruction in special education of the mentally retarded. Concurrent with their instruction, the teacher corps team members will be working with inner city disadvantaged children within the public schools of Chicago. Emphasis on selection of interns will be directed toward minority groups.

 Bureau of Educational Personnel Development (Education Professions Development Act - P. L. 90-35)

The Bureau of Educational Personnel Development and the Bureau of Education for the Handicapped have agreed to cooperate in the funding of programs which provide special education training to regular educational personnel who are working with handicapped children. Approximately 15 percent of the funds available under Part C and D of the above Act will be used in programs to train regular educational personnel, such as

counselors, educational technology specialists, and teachers and administrators who have an interest or need to become more knowledge-able regarding the problems of the handicapped.

The major responsibility for fulfilling this commitment rests with the Special Education Training Branch in the Division of School Programs. Priority is placed on projects for training decision-makers and change agents such as school administrators, supervisors, teachers of teachers, and State education agency personnel, who may influence the behavior of regular classroom personnel in dealing with the individual learning and behavior problems of handicapped children. Emphasis is placed on the prevention of severe learning problems, particularly for disadvantaged children. In fiscal year 1970, the Special Education Training Branch supported 43 projects in 27 states for the training of approximately 5,000 persons, many of whom were for personnel dealing with mentally retarded children. Colleges and universities conducted 36 of these projects, 5 were conducted by local school districts, and 2 by State education agencies. A special feature of the program is the Special Education Leadership Training Institute, which trains project directors, assists in the development of new projects, and evaluates the entire program by evaluating selected projects.

In addition, other BEPD programs do support some projects which involve the training of educational personnel to deal more effectively with the problems of handicapped children. These include the Early Childhood Program, Educational Administration Program, Career Opportunities Program, Vocational-Technical Education Program, and the State Grants Program to meet immediate critical shortages of teachers and teacher aides.

When one considers an earlier statement made in this publication to the effect that approximately 60 percent of all handicapped children are not receiving specialized educational intervention, it becomes quite obvious that this cooperative agreement will have great impact on improving services for the handicapped. The program, when fully implemented will facilitate greater cooperative interactions between regular and special educators. This will ultimately pave the way to maximum educational programs for all handicapped children.

## F. New Programs - Special Projects

Training programs to be truly effective must reflect the growth and evolution of special education programs brought about through expansion of research and service activities. Effective training programs must be flexible and provide for systematic modification of their approaches. Proven traditional approaches to training should be retained but every opportunity to blend the old approaches with new directions as increased knowledge and experience becomes available should be encouraged.

To provide a means for developing new models the Division of Training Programs administers a Special Projects Grant Award Program. The purpose of this program is to plan; to test new models of training; and to evaluate

the effectiveness and efficiency of these new models in preparing personnel to work with handicapped children. These grants are designed to provide the wherewithal for the field of special education to develop, implement, and test new approaches for the preparation of personnel to meet current and projected needs in the education of handicapped children.

There are two types of grants within the special projects award program: planning and prototype (including evaluation). Planning grants will be utilized to provide funds for the support of personnel, travel, and other costs necessary for developing a detailed plan for the implementation of a prototype.

Prototype grants will be utilized to implement and test new training approaches. Successfully implemented prototype grants which provide viable approaches to training will be placed into the regular award program for future funding and disseminated to other training agencies throughout the United States for replication. During fiscal year 1970 thirty institutions of higher education participated in this program. Grants ranged from \$3,829 to \$256,494. Approximately \$381,000 was expended for programs relating to mental retardation.

# G. Future Goals

The goals of the Division of Training Programs are to:

- Increase the number and quality of professional personnel for education of the handicapped with special attention to early childhood education, vocational education and the urban and rural poor.
- 2. Increase the amount and quality of technical assistance to agencies and institutions training professional personnel.
- 3. With State Departments of Education effect comprehensive planning for the training of personnel in special education.
- 4. Develop a systematic data collection program upon which to monitor current efforts and to base future efforts.
- 5. Produce informative materials concerning the education of handicapped children and the training of professional personnel.
- Systematically evaluate current programs preparing special education personnel.
- Effectuate qualitative evaluation of all current programs preparing personnel in mental retardation.

## II. Division of Educational Services

#### A. Purpose

The Division of Educational Services provides direct support to handicapped children through services at the classroom and intermediate levels. The Division offers support to State, regional, and local programs to assist in developing and maintaining leadership in the education of handicapped children.

## B. Historical Development

Public Law 85-905, the Captioned Films for the Deaf Law, was passed by Congress in 1958 to provide entertainment films for the deaf. This law has subsequently been amended by  $P.L.\ 89-715$  in 1962 and P.L. 89-258 in 1965 to allow for training, research, production and distribution of educational material for use by deaf children. In December 1967, this authority was again expanded to include educational services to all categories of handicapped children through the 1967 amendments to the Elementary and Secondary Education Act. The most recent amendment, P.L. 91-61, passed August 20, 1969 authorizes the establishment of a National Center on Educational Media and Materials for the Handicapped. The Center will provide a comprehensive program of activities to facilitate the use of new educational technology with the handicapped. The Media Services and Captioned Films program is as of January 1971 managed from this Division in conjunction with the 13 Special Education Instructional Materials Centers that were founded as a demonstration project within the Division of Research.

Public Law 89-313 was passed by Congress in November 1965, which extended the benefits of Title I of the Elementary and Secondary Education Act to handicapped children in State-operated and State-supported programs.

During recent years, as local facilities for the handicapped have increased, State schools have found the composition of their resident populations changing from the mildly handicapped to large percentages of children who are severely mentally retarded, and those who have serious handicaps in addition to mental retardation. Model and pilot programs for these types of children have been conducted under P. L. 89-313 in many States.

These funds have enabled institutions and agencies to develop programs for children who have not previously been considered capable of responding to educational or rehabilitative services. The results in many instances have been encouraging and special educators and staff in residential institutions and day classes have raised their levels of expectations for such children. While this program has had a relatively limited funding, significant results have been realized, especially in terms of planning for comprehensive services. Monies allotted under P.L. 89-313 for handicapped children were \$15.9 million for Fiscal Year 1966, \$15.1 for Fiscal Year 1967, \$24.7 for Fiscal Year 1968, \$29.7 for Fiscal Year 1969, \$37.5 for Fiscal Year 1970, and \$46.1 for Fiscal Year 1971. In Fiscal Year 1969, 63,605 mentally

retarded children were assisted under this program at an expenditure of \$14,379,663; in Fiscal Year 1970, over 64,000 mentally retarded children have benefited under this program at an expenditure of almost \$22,000,000.

During 1970, Public Law 91-230 incorporated the former Title VI-A of the Elementary and Secondary Education Act, into Part B of the Education of the Handicapped Act. This program is a State plan program which provides support to local education agencies through their State Departments of Education. While the law authorized \$200 million for both FY 1970 and FY 1971, only \$29.2 million was appropriated for FY 1970 and \$34 million for 1971.

The 1968 amendments to Title III of the Elementary and Secondary Education Act provide that, beginning in 1969, 15 percent of the funds be expended for programs to demonstrate innovative solutions to critical problems in American education as they pertain to handicapped children.

In Fiscal Year 1969, 75 percent of the Title III funds were administered by the States and 25 percent were administered by the U. S. Commissioner of Education. About \$17 million of the State-administered funds and \$6 million of the U. S. Commissioner's funds were set aside for the handicapped. All of the Title III funds for Fiscal Year 1970 were administered by the States, about \$16 million of which were set aside for the handicapped. In Fiscal Year 1971, 85 percent of the Title III funds are being administered by the States and 15 percent are being administered by the U. S. Commissioner. About \$17 million of the State-administered funds and \$3 million of the U. S. Commissioner's funds are being set aside for the handicapped.

The Vocational Education Amendments of 1968 provide that at least 10 percent of each State's allotment for basic grants must be used for programs for persons who are handicapped, including persons who are mentally retarded or seriously emotionally disturbed. This provision of the Act became effective in Fiscal Year 1970 and will be continued under the newly entitled "Vocational Education Act of 1963." The apportionment allotted to the handicapped was \$23,000,000 in Fiscal Year 1970 and \$32,174,771 in Fiscal Year 1971. It is anticipated that a substantial percentage of these monies will be utilized for the mentally retarded. The States are reported to be working on prevocational and work experience programs for the mentally retarded in State institutions and public schools.

P. L. 91-230 (formerly P. L. 90-247) provides for the development of regional centers and services for deaf-blind children under Part C, Title VI "Education of the Handicapped Act." The appropriation for 1970 was \$2 million and was used to continue support of eight regional centers to provide direct services for deaf-blind children and their parents and to fund two new centers to plan services for deaf-blind children in their region. The law permits use of the funds for deaf-blind children with additional handicaps, including those who are mentally retarded.

The Handicapped Children's Early Education Program (P.L. 91-230, Part C formerly P.L. 90-538) supports the establishment and operation of model preschool and early education projects designed to demonstrate a variety of effective approaches in assisting handicapped children during their early years. These projects will be distributed strategically throughout the country and the long-range objective is to provide visible, accessible models so that public schools and other agencies may replicate their programs. For Fiscal Year 1970, \$3 million was granted to 41 projects: (23 operational projects were funded at approximately the \$100,000 level; 4 combined planning-operational projects about the \$40,000-60,000 level; and 14 planning projects at about \$25,000 each).

### C. Impact on Mental Retardation

Programs will have a significant and far-reaching impact upon education and rehabilitation of mentally retarded individuals. Through such direct support programs Title VI (aid to local programs), P.L. 89-313 (aid to State programs), more extensive and comprehensive programs will develop which will include the utilization of the latest teaching techniques and educational technology. Media Services and Captioned Films for the Deaf with expanded responsibility should provide for an opportunity for State and local programs to take advantage of educational materials, media, and equipment especially designed to meet the needs of the handicapped. Certainly the newly established interest in early education programs for the handicapped will have major impact on mental retardation. This is especially so in the case of those youngsters from culturally disadvantaged areas who greatly need early stimulation. Without such stimulation, it is highly probable that many of those youngsters might become special education candidates.

#### D. Current Activities

Under the State Plan programs, forty percent of the 115,035 children served by this program during FY 1969 are mentally retarded. It is estimated that a similar number of children received direct services during FY 1970. Approximately 37 percent of the \$24.5 million expended in projects during FY 1969, was spent for special educational and related services for the mentally retarded.

These programs have led to an interest in comprehensive planning. The Division plans to work with State and project personnel to develop long-range plans and evaluation procedures during 1970. These activities are serving the special educational and related needs of retarded children through such programs as pre-school, elementary, and secondary education projects which may include: curriculum enrichment, expansion, improvement; summer school programs; preschool and school readiness programs; physical education and recreation; prevocational and vocational training; inservice training of teachers; and improved diagnostic services.

## E. Future Goals

The goals of the Division of Educational Services are to:

1. Provide significant support monies to both State-supported and

local educational programs to assure quality education for all handicapped children.

- 2. Provide intermediate services such as comprehensive educational diagnostic resource centers on a regional base to provide services for handicapped children and their families. In addition to direct services to children, these centers will provide consultative services to State and local educational agencies to assure the latest available information from research with respect to the learning process.
- Provide wherever needed comprehensive regional programs for severely multiply handicapped children such as deaf-blind children.
- 4. Provide through media services the research, production, and distribution of specially designed materials and programs for educational technology for handicapped children. To provide training in the use of media for teachers of the handicapped.
- 5. Provide through Instructional Material Centers and Regional Media Centers educational management and information systems.

## III. Division of Research

#### A. Purpose

The Division of Research promotes and supports research and related activities which show promise of leading to improvement in educational programs for handicapped children. Support is available for research, dissemination, demonstration, curriculum, and media activities, and for support of Regional Resource Centers.

## B. History

The program now administered by the Division of Research was initiated during Fiscal Year 1964 with an appropriation of \$1 million authorized under Title III, Section 302 of Public Law 88-164. The scope and flexibility of the program have been extended through amendments to this basic authorizing legislation in Public Law 89-105, Public Law 90-170, Public Law 90-247 and Public Law 91-230. Table II provides data on the authorizations, appropriations, obligations, and number of projects supported under this program.

Table II - Division of Research Historical Data							
Year	Authorization	Appropriation	Actual Obligations	Number of Projects			
1964	2,000,000	1,000,000	999,739	34			
1965	2,000,000	2,000,000	2,000,000	53			
1966	6,000,000	6,000,000	5,994,231	133			
1967	9,000,000	8,100,000	8,049,041	127			
1968	19,500,000	11,100,000	10,794,113	<b>13</b> 5			
1969	21,750,000	13,600,000	13,593,786	1.60			
1970	28,000,000	19,700,000	15,157,670	135			
1971	29,500,000	18,850,000					

#### C. Impact on the Problem of Mental Retardation

It is difficult to assess the direct impact of research activities since the lag between the discovery of new knowledge and consequent changes in educational practices obscures the picture. However, some information on the impact of the program is available. As of the end of Fiscal Year 1969 approximately seventy final reports of research monitored by the Division of Research had been made available to practitioners in the field. Many of these research projects have also resulted in other publications in the professional literature. Although the systematic collection of data on the actual implementation of research findings from these projects is just beginning, there are many instances in which these findings have had a direct impact on programs for the mentally retarded.

## D. Current Activities

The Division currently supports a wide range of activities relating to the education of mentally retarded children. One of the most visible of these is the network of Instructional Materials Centers for handicapped children. Although serving teachers of all the handicapped, these centers have a major commitment to mental retardation. The Instructional Materials Centers, 13 in all, are scattered across the country to serve specified regions. The primary objective of each center is to keep teachers of handicapped children aware of new developments in educational materials. The centers are evaluating existing materials as to their relevance to the handicapped and assisting in the development of new materials. Since the 13 centers are connected as a network, any information located in one center is immediately available to all other centers.

The Comprehensive Research and Demonstration Center for Handicapped Children, now under construction at Teachers College, Columbia University, similarly has a major emphasis on the problems of the retarded, although at the same time relating to the educational problems of many categories of handicapped children. This center represents a major investment of research funds, both for construction and operation, in an attempt to develop an intense effort in this area of education. Under the Regional Resource Center program, each center should provide a bank of advice and technical services upon which educators in a region could draw in order to improve the education of handicapped children. The primary task of a Center would be to focus on the special education problems of individual handicapped children referred to it. Each Center should provide testing and educational evaluation of the child, and in the light of this evaluation could develop a program of education to meet the child's particular requirements. Working closely with the handicapped child's parents and teachers, each Center could then assist the school (or other appropriate agency) in providing this program, periodically reexamining and reevaluating the program, and making any adjustments which are necessary to keep the program responsive to the educational needs of the handicapped child. Four Regional Resource Centers were funded in FY 1969. These centers are located in Eugene, Oregon; Las Cruces, New Mexico; New York, New York; and Des Moines, Iowa. Two additional Regional Resource Centers were funded in FY 1970 and are located in Salt Lake City, Utah and Harrisburg, Pennsylvania.

Other research activities now under way are attacking problems of teaching and learning with the mentally retarded. One such project has suggested that time spent in learning to learn can make a significant difference in the performance of retarded children. Other projects are developing and testing new curricula for the retarded.

## E. Future Goals

The history of research on handicapped children suggests that minimal gains are obtained by spreading research monies too thinly. Many of the most important problems in education require a massive effort if solutions are to be found in time to help today's children. The Division of Research now supports five Research and Development Centers to focus on the more difficult problems of evaluation, communication, instructional procedures, etc. of handicapped children. Through the combined efforts of Research and Development Centers and programmatic research, definite improvement in instructional procedures may well be realized within the next several years.

At the same time, systems of dissemination are being evolved which will facilitate the acceptance of these new models by local school administrators. The new systems of dissemination are being built upon the foundation already developed by the Instructional Materials Centers and a system of Regional Resource Centers currently being developed.

As more funds for research become available, engineering technology will more and more become a part of research supported by this Division. This development has been made possible by the amendment permitting the use of contracts as well as grants for research and development activities. Engineering technology, programmed instruction, and the "systems approach" to education will occupy a major place in the Division's activities in the years to come.

#### SOCIAL AND REHABILITATION SERVICE

## Introduction

The Social and Rehabilitation Services (SRS) was established August 15, 1967, by the Secretary, Health, Education, and Welfare to join under a single leadership the Department's income support programs for needy Americans and the social and rehabilitation programs such as mental retardation.

Six of the eight major components of SRS, Administration on Aging; Assistance Payments Administration; Community Services Administration; Medical Services Administration; Office of Planning, Research and Training; and the Rehabilitation Services Administration have major responsibilities in the area of mental retardation.

#### The Administration on Aging

# 1. Older Americans Act - Title III, Community Grant Program

Title III of the Older Americans Act of 1965, as amended, provides for funds from the Administration on Aging to stimulate the establishment of a single agency in each State to be responsible for Statewide planning, coordination, and evaluation of State activities and programs in aging, and for community service projects. Once the Governor has designated such an agency and the State plan has been approved, grant awards are made to the State. One type of grant is made to States to develop local projects for planning, coordination, evaluation, training, and administration of aging programs. Another type of grant is made to States for community projects. The States, in turn, make grants to public and non-profit private agencies for (1) community planning and coordination of programs in aging; (2) for demonstration of new programs or activities beneficial to older people; (3) training special personnel for such programs; and (4) establishment of new or expansion of existing programs, including senior centers.

For example, "Senior Citizens Conducting Programs for the Mentally Retarded Aged" a Title III project in Boulder Montana has 134 elderly retarded in the program. Seventy-three mentally retarded aged were helped by the program to move into Foster homes. A Title III project in the District of Columbia "Foster Grandparents for Institutionalized Retardates" provides financial assistance and an emotionally satisfying interpersonal experience for older District of Columbia residents at the District of Columbia Children's Center.

In these projects the elderly individuals are forming a bridge between the community and the institutions, and bringing new attitudes and understanding on mental retardation to the community.

### 2. The Foster Grandparent Program

The Administration on Aging administers the Foster Grandparent Program. The primary objectives of this program with regard to the field of mental retardation are: (1) to utilize the services of qualified older people to minimize the negative effects of institutionalization upon the social,

emotional, and intellectual growth and development of children under 18 years of age who reside in State institutions for the mentally retarded or attend special education day care centers; (2) to develop additional opportunities for older people to become involved in child-development programs throughout the United States in cooperation with public and private agencies; (3) to alleviate poverty and isolation among elderly people by bringing them within a socially productive sphere of involvement; and (4) to establish the concept of the foster grandparent service as an integral part of programs for the mentally retarded.

In December 1970, there were 68 Foster Grandparent Programs in 40 States and Puerto Rico. About 4,300 foster grandparents serve 8,600 children each day and over 20,000 children a year. They serve in 183 institutional settings. Over half the foster grandparents work with retarded children in 75 different institutions and day care settings. More than 120 communities are affected by the program and many more have expressed an interest in developing a program. However, funds are not available for expansion of the program.

Foster grandparents provide two hours of individual attention to each of two children daily, and usually serve five days a week. Foster grandparents do not relieve institution staff of routine care tasks. The work of the foster grandparents is entirely child-related; they serve on a one-to-one basis and provide personal attention and individual care to children. Prior to serving children, foster grandparents receive no less than 40 hours instruction by qualified program and institution staff. This orientation covers aspects of concern to the well being of older people (biological and psycho-social aspects of aging, social security, medicare, housing, etc.) as well as orientation to the type of children to be served and the role of foster grandparents with the children. Continuous in-service training sessions are also conducted.

Administrative staff of institutions for the mentally retarded report that children show improvement in self-care skills and motor skills. Evaluations of individual Foster Grandparent Programs conclude that, based on the projects studied, the program is a viable one which has great potential for further growth. The findings of a two-year study of the program at the Denton State School, Denton, Texas, conducted by Dr. Hiram J. Friedsam and Mr. H. R. Dick, North Texas State University, concludes:

"No matter how fleeting the contact or how limited the carryover, the program does enrich the lives of the children it touches, and anyone who is familiar with institutions for retarded children will not judge this to be a minor success."

## Assistance Payments Administration

Assistance Payments Administration's primary responsibility is to make grants to States for Public Assistance under the Social Security Act passed in 1935, and amendments thereto. Old-Age Assistance, Aid to Families with Dependent Children, Aid to the Blind, and Aid to the Permanently and Totally Disabled, and Emergency Welfare Assistance constitute the public assistance programs in which Federal financial participation is available to help needy individuals who also may be mentally retarded, by supplying financial aid through State-administered or State-supervised public welfare programs.

# 1. Maintenance Payments

Mentally retarded persons constitute about 15 percent of all recipients receiving money payments under the Aid to the Permanently and Totally Disabled program. In addition, the 1967 amendments to the Social Security Act provided for payments to needy persons who are disabled and in need of institutional care. In fiscal year 1972, it is estimated that the Federal share of money payments to an average monthly number of 155,000 recipients under this program whose primary disability is mental retardation will be \$108,000,000.

#### 2. Intermediate Care Facilities

As of March 1970, ten States reported having licensed distinct parts of institutions for the retarded as intermediate care facilities, and five other States were interested in using the intermediate care facilities program under the Aid to the Permanently and Totally Disabled program for the mentally retarded. In fiscal year 1972, it is estimated that the Federal share of payments to such facilities will amount to \$8,700,000.

## Medical Services Administration

The Medical Services Administration (MSA) is the agency responsible for the administration of medical assistance programs under Title XIX of the Social Security Act (Medicaid).

There is no specific legislation under Title XTX for the care of the mentally retarded. However, the mentally retarded who meet State's eligibility requirements for the medical assistance program may receive the same benefits in terms of medical care, as any other recipient. The amount and scope of medical services depends on the individual State plan.

Statistics for the number of patients and money spent during fiscal year 1970 are not available. It is known that fourteen States and the District of Columbia are making claims through Title XIX for payments of care in hospital or skilled nursing units in State institutions for the mentally retarded. States making claims for funds are New York, Pennsylvania, Maryland, Georgia, Illinois, Wisconsin, Kansas, Oklahoma, Texas, Utah, California, Oregon, Vermont, and Virginia. It is estimated that \$100,000,000 in Federal funds are being used annually by these States for mental retardation support.

A few States also claim Title XIX funds for care of the retarded in nursing homes outside the State institutions. Connecticut and Missouri reported such claims, and it is probable that other States make use of similar facilities.

#### Community Services Administration

The Community Services Administration is the newest organizational unit of the Social and Rehabilitation Service, having been established in October 1969. It carries the responsibility for the provision of Social Services under the Public Assistance and Child Welfare titles of the Social Security Act.

## Family and Child Welfare Services

Community Services Administration administers child welfare service funds authorized by Title IV-B of the Social Security Act, as amended, for the purpose of cooperating with State public welfare agencies in establishing, extending and strengthening child welfare services. These funds are allocated

to States on a formula basis. The appropriation for fiscal year 1971 is \$46 million. Although none of these funds are earmarked especially for serving the retarded, mentally retarded children are provided services. Child welfare services which can benefit the mentally retarded and their families include; parent counseling, homemaker services, day care services, foster family care, care in group home, adoption services, services to unmarried mothers, and certain institutional pre-admission and aftercare services.

At the present time, all State public welfare programs provide some child welfare services for mentally retarded children. By conservative estimates of the Community Services Administration, 43,000 mentally retarded children receive child welfare services from public welfare agencies.

The Social Security amendments of 1967 authorize grants under Title IV-A of the Social Security Act to State public welfare agencies for providing services to families and children receiving Aid to Families with Dependent Children and to former and potential recipients at the option of the States. Federal funds are authorized to pay for 75 percent of State costs. This program, administered by the Community Services Administration, will bring increased attention to the special needs of the estimated 306,000 AFDC children who are mentally retarded and to the family conditions in which mental retardation is often rooted.

Following are examples of developments related to the extension and improvement of family and child welfare services to mentally retarded children and their families:

A mental retardation specialist, during the four years since he was first employed by a State public welfare agency, contributed substantially to the development of services and facilities, including specialized foster family care, from which retarded children and their families benefit. In addition, he has been instrumental in improving coordination among the State's programs for the retarded.

A State on the basis of its experience in providing the range of child welfare services through a special unit for the retarded in one locality, is now extending increased child welfare services to retarded children and their families in other areas of the State. In another State, the school of social work has a mental retardation field instruction unit located in a county public welfare department. According to the Director of the county agency, this unit, which receives the support of the Community Services Administration, benefits the county in addition to providing a learning experience to the students. Increased services rendered by the students to the county's mentally retarded and their families is one benefit. The Director also points out that the unit's emphasis on problems connected with mental retardation has served to "sharpen up all the (agency's) workers to give this particular problem more attention."

Several States report that with the support of a child welfare worker, and assistance provided through this service in utilizing other community resources, parents often are able to keep their retarded children at home and keep their families intact. One agency through group counseling has assisted parents not only to better meet the needs of their retarded children but also to take action aimed at development of additional community programs for the retarded.

Another State public welfare agency describes its new homemaker service project as a "real success." This project provides 32 itinerant homemakers who specialize in serving families of retarded children. Through homemaker services, an over-burdened mother can be relieved of the constant and full

responsibility for the day-to-day care of her retarded child. Frequently, she acquires new skills which help her in better home management as well as in her special problems with child care.

Another important service provided by several State public welfare agencies to assist mentally retarded children and their families is day care services. Day care services offer both constructive experiences for some retarded children and necessary help and relief for their parents. This service often may be the key factor in determining whether a child can remain with his family. In one State, the number of licensed daytime activity centers for the retarded has quadrupled, from 21 to more than 80, in about a five-year period. The State child welfare agency licenses these centers. With concern for quality in their day care programs for the retarded, some States have given special attention to the development of standards and to training of day care personnel. The value of stronger linkage between the day care center and the family is also receiving increased attention in many of these programs.

Some children who must be cared for outside their own homes can profit from close interpersonal relationships and respond to the stimulation of foster family life. Short-term foster care at intervals or during periods of crisis may enable a retarded child's family to provide adequately for him at home for the most part. For other retarded children, foster family care permits long-term benefits of family life and community living. Foster family care would be the plan of choice for many children who have been placed inappropriately in large residential facilities. In fact, some States are giving attention to the "exchange" of children between institutional and child welfare services programs to assure more appropriate services for particular children.

Family and child welfare services also may have preventive aspects in relation to mental retardation. For example, day care or foster care for children from certain deprived homes may be preventive services.

Homemaker services may be preventive in nature when brought into play with some expectant mothers who need relief from the physical demands of caring for other children. Protective services can reduce child abuse as a cause of mental retardation. Services to unmarried expectant mothers can assure utilization of proper prenatal services.

Family and child welfare workers also are in a key position with regard to early casefinding, assistance with obtaining proper diagnosis, and providing continuity of planning and services consistent with the needs of the individual retarded child and his family.

In spite of the efforts and potential of family and child welfare services, which have been cited, numbers of retarded children and their families need and could profit from such services not now available. Professionally skilled staff, new programs, and extension of those in existence are needed. The continuing emphasis on community services as a means of combatting mental retardation will place increasing demands on family and child welfare agencies.

# Office of Planning, Research and Training

#### 1. Research and Demonstrations

The Office of Planning, Research and Training carries on a substantial program of research on problems of rehabilitation of retardates. Areas covered include evaluation of aptitudes and abilities, analysis of jobs which the retarded can perform, opening of new occupational areas for the retarded, improvement of counseling techniques, development of new methods of training and job adjustment and evaluation of facilities and programs to assist the

transition of the retardate from the institution or other sheltered environment to community participation. The 1965 amendments to the Vocational Rehabilitation Act recognized in particular the needs of retardates by providing up to eighteen months of services during which the individual is evaluated for employment potential. These amendments also recognized the need for continuing care and study in the form of provision for improved workshops for retardates and other handicapped persons.

The Social Security Amendments of 1968 have focused attention on the necessity for research on retardation as a function of cultural deprivation. Current programs of research and demonstration are, therefore, increasingly concerned with new approaches to retardation in ghetto areas, and especially model city neighborhoods. Rehabilitation techniques already developed through research are being extended to problems of the hard core welfare client.

Emphasis is placed on the coordination and focusing of all relevant community agencies on the problems of the retarded. Projects in five different cities have demonstrated ways of most fruitfully bringing together the services of agencies involved in programs for the retarded. An additional study evaluated the efforts of one of these coordinated services programs.

A variety of community based projects demonstrating involvement of community resources for training of retarded and for their transition to the wider community are the results of recent research efforts. For example, a substantial number of work study programs for retarded adolescents have been sponsored by State Division of Vocational Rehabilitation jointly with local school boards, parent organizations, private schools, and State departments of education. These projects were based on prototypes developed in the vocational rehabilitation research and demonstration program.

This office has also conducted energetic programs to place the retarded in a wide variety of civil service jobs. The District of Columbia, Department of Vocational Rehabilitation and George Washington University have completed a follow-up study of the first 2,000 mentally retarded workers placed with the Federal government throughout the country to determine how effective the program has been and how to improve and expand it to State governments as well.

Many retarded leaving an institution do not have a home nor family to which to return. The Elwyn School, Elwyn, Pennsylvania completed a demonstration of a program designed for adult retardates who had no home but were considered good candidates for discharge into the community. The program consisted of pre-discharge evaluation, a social and vocational remedial education program, halfway house activity concurrently with pre-industrial exploratory work experience, job placement, arrangements for independent living in the community and long-term follow-up to assist the retarded person in his solution of emergent problems.

A noteworthy project conducted by the Arkansas Rehabilitation Service at the Benton Unit, Arkansas State Hospital, accepted for service a random sample of all chronic older retarded in the hospital disregarding the retardates' age, length of institutionalization, presence or absence of work history, previous education, or severity of accompanying disabilities. It was found that 46% of the older retarded, with provision of adequate evaluation and work adjustment services, could be trained vocationally, rehabilitated and moved to full or partially-supporting employment outside the hospital.

The University of Hartford completed a project demonstrating that certain kinds of management in State mental hospitals, behavior of hospital personnel and different types of interrelationships between ward attendants and the retarded, have profound effects upon the retardates' abilities to learn and to respond to training programs.

The most significant recent research and demonstration development for the retarded is a set of six projects carried out jointly by the National Urban League, Family Services Association of America and the National Association for Retarded Children. These are demonstrating in model city neighborhoods new and more effective ways to reach culturally deprived and disadvantaged families with essential services for members of the families who may be retarded.

# 3. Training for Child Welfare Services

States are urged to provide educational leave for the training of child welfare staff. Grant-in-aid funds may be used for this purpose. All States have structures for a staff development program, including orientation, inservice training, and educational leave. These programs contribute to the overall increase of child welfare staff which is better able to service the mentally retarded.

The 1967 amendments of the Social Security Act provided an avenue for augmenting the supply of trained child welfare workers by establishing grants for child welfare training projects. This program provides grants to public and other nonprofit institutions of higher learning for special projects for training personnel in the field of child welfare, including traineeships to students. Training for child welfare services to the mentally retarded and their families is included in this program.

# 4. Child Welfare Research and Demonstration Grant Program

The Child Welfare Research and Demonstration Grant Program, authorized by the Social Security Amendments of 1967, provides financial support for special research or demonstration projects in child welfare which are of regional or national significance, and for special demonstration of new methods for child welfare.

Since community support is vital to improvement of child welfare services, an important function of several projects is to develop support through interpretation and communication of the problems that many children face, ranging from shattered families to mental retardation.

Projects relating to mental retardation which have been completed include: (1) a demonstration to test the feasibility and value of foster home care for deprived mentally retarded children; (2) a demonstration, training, and service project designed to test the feasibility of training and using skilled personnel as aides to professional personnel in caring for retarded children in the areas of homemaking and child care, physical medicine and nursing care, speech therapy, play activity, and auxiliary maternal care; (3) a study of specialized foster home care for deprived mentally retarded children; (4) a study of existing laws and their administration applicable to children suffering from mental disorders, including their commitment, care, and guardianship; (5) a study to evaluate the effectiveness of group therapy for retarded adolescents; and (6) a study of the value of homemaker services in families with a mentally retarded child under 5 years of age.

# 5. Older Americans Act - Title IV Program

Title IV of the Older Americans Act authorizes grants or contracts for research and demonstration projects of national or regional interest and value. Under Title IV, a demonstration project grant was awarded to the Community Service Society of New York and was conducted on Staten Island in the recruitment, training, placement and retention of older people as volunteers in community service. Of the 300 volunteers, with an average age of 70, 130 served at the Willowbrook State School, a 6,000 bed institution for the mentally retarded of all ages.

53

Thirty-nine of the volunteers have been working at Willowbrook more than  $2\frac{1}{2}$  vears.

Volunteers serve from 4 to 6 hours one or two days a week and perform such functions as feeding and playing with babies and young children, helping in the school rooms, and in the occupational therapy programs, sewing, stamping garments, and repairing toys and furniture in the shops. In addition, a group of women mend clothing for the School at the Stapleton Senior Center, and a folk dance group from another center visits the School once a week to teach dancing to teenage residents of a specially selected ward. Although Title IV support ended during the year, the project is continuing at Willowbrook.

## 6. Rehabilitation Research and Training Centers

In fiscal year 1970, the Office of Planning, Research and Training administered 19 Rehabilitation Research and Training Centers for mental retardation, 8 of which are in distinct organizational and physical entities providing a continuing framework for psychological, social, vocation and rehabilitation, research and training, and at least on a demonstration basis, a comprehensive program of evaluation, training, counseling and placement of the mentally retarded individual. Three Mental Retardation Research and Training Centers are currently sponsored by the Social and Rehabilitation Service: the University of Wisconsin, the University of Texas, and the University of Oregon.

The research conducted by these centers encompasses many aspects of the rehabilitation process, from onset to training and placement of the retarded individual. It is broadly directed to a wide range of psychosocial, vocational, or other fields of rehabilitation, and also to specific problems in the many aspects of rehabilitation of the retarded.

The training program of these Centers provides training of all types, long-term as well as short-term, professional, technical, and for all categories of students, graduate or undergraduate, working in the medical, health-related or other professions engaged in rehabilitation. The program provides training in such areas as the principles of rehabilitation of the retarded and the special problems related to individual or groups of educational, psychosocial, vocational, and medical and other disciplines in the practice of rehabilitation. In all instances, training has been based upon a defined, organized program of instruction designed for undergraduate and graduate students, interns, and professional workers in the field of rehabilitation. Selected sub-professional workers have also been trained.

Further research is being conducted to seek out the cause of retardation, to assess the potential for education and rehabilitation, to develop training and remedial programs suited to the needs of the retarded, and to ascertain the actual learning and socialization difficulties encountered by the retarded. Also being emphasized is the development of adequate motivation for work in the retarded through family, school, and community resources.

The centers are directing attention to, and advancing understanding of behavior modification techniques in a variety of settings, the learning and socialization processes, psycho-social testing, work adjustment and vocational rehabilitation procedures. Such studies will hopefully bring about new know-ledge not previously available, to be utilized in preparing the retarded for productive, independent living. This research will also be helpful in planning and developing remedial and rehabilitation programs for the disadvantaged and culturally deprived in becoming more self-sufficient.

The Rehabilitation Research and Training Centers in FY-1972 will train new personnel to enter the fields of rehabilitation and also advance the training of experienced personnel so that the vital knowledge they gain can be used to implement new and better services for handicapped and disadvantaged persons. Research environments will be improved so that new knowledge and skills can be developed to solve existing problems. These centers already have considerable impact on the State Vocational Rehabilitation programs and other State service agencies and this will be further strengthened. Center personnel will work closely with State agencies staffs, coordinating training activities with them so that the greatest effort will be aimed toward the areas needed most by the States. The training of medical and paramedical personnel and community volunteers in conjunction with the State agencies will have an important influence on the communities from which they come.

In addition, the Centers will share a significant role in the provision of rehabilitation and employment services to the disadvantaged and poverty stricken in rural and urban settings. Each Center will provide rehabilitation research and training directed to the achievement of success in effectively serving the impoverished disadvantaged, and dependent, with emphasis upon the improvement of services for self care.

Specific research projects will focus on such high priority areas as improved work adjustment methods for motivating and training the dependent or potentially dependent for employment, new physical restoration techniques for increasing mobility potential of the severely handicapped, and factors effecting the etiology and acquisition of cultural deprivation and mental retardation in inner city populations.

Training activities of the Centers will prepare medical and other rehabilitation related professionals and supportive personnel to work with disabled welfare and other poverty stricken citizens, to recognize characteristics important in the planning and coordination of rehabilitation services. The use of both sub-professionals and volunteers will be increased during 1972.

#### 7. International Activities

The Office of Planning, Research and Training, Division of International Activities, is the focal point for the development of all SRS international activities. These include program operations in social welfare, vocational rehabilitation of the physically handicapped and the mentally retarded designed to supplement and complement domestic programs and to strengthen relationships with other countries as well as to further U.S. foreign policy goals. Activities in the fields of maternal and child health and crippled children's services, formerly included in the program of the Division, were transferred to the International Office, Maternal and Child Health Services, Health Services and Mental Health Administration in October 1969.

A major segment of the international program has been the development and support of cooperative research and demonstration projects in certain foreign countries. This program, financed with U.S.-owned foreign currencies derived from the sale of agricultural commodities, was initiated by the Vocational Rehabilitation Administration in 1961. A vital adjunct to these research activities is the interchange of experts program authorized under the International Health Research Act. As a result of this authority, the Social and Rehabilitation Service has arranged for the interchange of scientists and experts engaged in research between the U.S. and countries participating in this cooperative program.

55

As an example, the University of Texas Mental Retardation Research and Training Center is in the process of completing a comparative study of the administrative structure of work-study programs conducted throughout the United States jointly by State vocational rehabilitation and special education agencies. They have also completed a study of the effectiveness of computer-assisted instructional methods of teaching certain basic skills necessary for independent money management including transfer of learning to simulation tasks in which the study was required to make purchases and count change in a simulated shopping situation. Of prime significance is their in-depth longitudinal follow-up of retarded young adults in Central Texas soon to be completed. This study should be particularly significant since one-fourth of those studies were Mexican-American and will include an analysis and comparison along ethnicity lines.

The University of Oregon Research and Training Center is involved in such research as:

- 1. Socio-cultural ecology of upper level mental retardation.
- An investigation of the post-high school vocational adjustment of educable retardates.
- 3. Development of a model for evaluating the relationship between Educable Mentally Retarded high school programs and the socio-vocational success of terminated pupils.

The Milwaukee High-Risk Population research program conducted by the University of Minnesota Research and Training Center contributed significant new survey data pertinent to the Epidemiology of "cultural-familial" mental retardation. The new data extended previously reported survey data which indicated that the high prevalence of retardation found among disadvantaged population groups is accounted for, largely, by a relatively small proportion of the population involved. The data suggest a rather remarkable congruence of maternal and paternal intelligence where low maternal intelligence is involved; the data suggested further, a significantly increased percentage of low-IQ mothers of newborns in both the below CA 20 and over CA 35 groups with a resultant substantially increased total family size. Data from the family rehabilitation program extend their optimism (although still cautious) that this experimental approach may prove effective in preventing "cultural familial" mental retardation.

Also at the University of Wisconsin Research and Training Center, the results obtained in the research and related activities of the Laboratory of Applied Behavior Analysis and Modification have provided an experimental basis for new rehabilitation practices with mentally retarded clients who present unusually difficult behavior problems. The staff is enthusiastic about the implications of these findings and feel that continued pursuit of the behavior theory approach will result in a fully developed technology of rehabilitation practices for use with the mentally retarded client who previously had been dismissed from rehabilitation programs as being dependent adults.

In the area of training, 32 short-term courses attended by 1,465 trainees were sponsored by the three Mental Retardation Research and Training Centers. These included training for rehabilitation counselors, physicians, special education personnel, nurses, parents, attendants, and others in specific rehabilitation techniques leading to employment of the retarded.

Since the beginning of the research and demonstration program in 1961, 18 projects in various aspects of mental retardation have been approved by the Division of International Activities. The range of research interest is very broad encompassing both medical and non-medical projects as well as clients of all ages. Types of projects that are now in progress include the experimentation with new techniques for evaluating, training and placing mentally retarded and investigations on the medical, psychological, social and cultural aspects of mental retardation. During the past 10 years, projects dealing with mental retardation were approved in India, Israel, Pakistan, Poland, Tunisia, and U.A.R.

Under the Interchange of Experts Program, investigators on some of the mental retardation projects have been brought to the United States for consultation and observation. During May and June of 1970, for example, two investigators on a research project concerned with rehabilitation of the mentally retarded in Warsaw, Poland, observed programs and research in this field and consulted with specialists in the United States under this program.

#### Rehabilitation Services Administration

The Rehabilitation Services Administration is responsible for a broad range of programs designed both for the provision of diagnostic, treatment, and rehabilitation services for the mentally retarded, and for the support of special facilities and activities to expand and improve national resources for serving the mentally retarded. These programs include the State-Federal vocational rehabilitation program, as well as special project grants for the expansion and innovation of vocational rehabilitation services; the improvement of State residential institutions and sheltered workshops for the mentally retarded; the planning and construction of rehabilitation facilities and sheltered workshops, the construction and staffing of specialized community facilities, and the construction of university affiliated facilities for the mentally retarded; and training for professional, supportive and technical personnel already engaged or preparing to engage in occupations in the care and rehabilitation of the mentally retarded.

These diverse activities are unified by the common goal and objective of assisting mentally retarded individuals to achieve and maintain the maximum personal, social, and economic competence of which they are capable. Underlying these activities is the continuing concern for expanding the opportunities and resources available to the more severely mentally retarded.

#### 1. Vocational Rehabilitation Services

Under the public rehabilitation program, grants are made to State vocational rehabilitation agencies to assist them in providing rehabilitation services to mentally and physically disabled individuals who have substantial employment handicaps and who can reasonably be expected to be rehabilitated into gainful employment. Among the services provided by State vocational rehabilitation agencies are comprehensive medical, psychosocial and vocational evaluation; physical restoration; counseling; personal adjustment, prevocational and vocational training; maintenance and transportation during the rehabilitation process; placement in suitable employment; services to families of handicapped people when such services contribute substantially to the rehabilitation of the handicapped client; recruitment and training services to provide new careers for handicapped people in the field of rehabilitation and other public service areas; and follow-up services to assist handicapped individuals to maintain their employment.

Recent years have seem dramatic advances in the provision of vocational rehabilitation services to the mentally retarded. The retarded now comprise

nearly 13% of the people rehabilitated from all categories of disability by the State-Federal program of vocational rehabilitation. In 1971, about 37,800 retardates were rehabilitated.

Basic to the vocational rehabilitation effort has been the growing reliance on counselors and other vocational rehabilitation staff who work exclusively with retarded clients. This specialized staff may be assigned to local vocational rehabilitation offices, schools, institutions, sheltered workshops, or other facilities serving the mentally retarded. By concentrating their attention on the mentally retarded clients, these counselors are successfully developing rehabilitation plans based on the special problems of the retarded, and are able to be broadly responsive to the needs of both the client and his family. As special vocational rehabilitation and facilities for the retarded continue to be developed and expanded, the number of specialized counselors within State vocational rehabilitation agencies is expected to increase.

The specialized vocational rehabilitation staff working with the mentally retarded has been particularly effective in the development of cooperative vocational rehabilitation—school programs designed to assist the retarded young person make a satisfying transition from school to work. These cooperative school programs are found in many communities through the country and have greatly strengthened both special education and vocational rehabilitation efforts with the mentally retarded. The cooperative program structure varies from State to State, and the variety of approaches is extraordinary. In some States, program administration is Statewide and in others there are individual agreements with individual school districts. Some programs function only to serve the mentally retarded, while other include youth with all kinds of disabilities. In some States, only vocational rehabilitation and special education are administratively involved, while other representation includes vocational education.

Most cooperative arrangements have brought about the development of vocationally oriented curricula within the schools. All of them, however, provide for a comprehensive evaluation of the retarded young person's vocational rehabilitation potential; the provision of personal adjustment and pre-vocational training; counseling; on-the-job training and work experience; job placement, follow-up and related vocational rehabilitation case services.

The number of retarded young people enrolled in cooperative vocational rehabilitation work-study programs is increasing steadily as new programs are developed. These cooperative programs have proven themselves effective in reducing the school dropout rate of retarded youngsters and have provided a technique for continuous service to youngsters during the school years when they are best able to benefit from them.

Another emphasis of State vocational rehabilitation agencies have been the establishment of rehabilitation facilities, such as comprehensive rehabilitation centers, evaluation centers, occupational training centers, workshops, half-way houses, and other specialized facilities serving the mentally retarded. Such a rehabilitation facility may be established by State rehabilitation agencies, by the State agency in cooperation with other public or private agencies.

State vocational rehabilitation agencies may assist in the construction of rehabilitation facilities in a variety of ways. They may construct new buildings; alter, expand or renovate existing buildings; purchase necessary equipment; and provide initial staffing support. In all cases, State or private financial resources must be used to match Federal funds.

The program for Federal employment of the mentally retarded has been an outstanding success, with 7,200 placements in 143 different job titles at Federal installations across the country. The retention rate for these retarded employees has been far superior to that of other employees in similar jobs; and the program has become a part of the permanent personnel policy of the U.S. Civil Service Commission. State vocational rehabilitation agencies play a highly important role in this program in that they certify all retarded applicants as job-ready.

Special project grants for the innovation and expansion of vocational rehabilitation services have been utilized to extend and improve State rehabilitation agency efforts for the mentally retarded. Innovation grants provide the means for State agencies to develop new programs and techniques in order to adapt to changing needs, while expansion grants are designed specifically to increase the number of people rehabilitated by the State agency.

Under the Innovation grant program, a project has provided pre-vocational training for the mentally retarded at the Roswell (New Mexico) Vocational Evaluation and Adjustment Center. A rehabilitation facility has been developed at the Boulder River School and Hospital (Montana) under an Innovation grant; this is serving both residential and non-residential retardates in the region. Other Innovation grants have supported the development of an evaluation unit for the visually handicapped retardate at a State institution in Pennsylvania, and the establishment of a vocational center at the Idaho State School and Hospital for the Mentally Retarded.

An Expansion grant has supported the cooperative development of a rehabilitation program by the New Orleans Association for Retarded Children and the Dr. Russell L. Holman Vocational Center for Retarded Girls. Another grant of this kind has been utilized in the State of Washington to underwrite expansion of a Yakima workshop into a box factory to provide employment for mentally retarded persons. The Expansion grant program has also supported the growth of sheltered workshops for the retarded in Alaska, Indiana, Louisiana, Massachusetts, Nebraska, Oregon and Pennsylvania.

Within an extensive program of rehabilitation facility improvement, the Rehabilitation Services Administration administers Facility Improvement grants designed to upgrade the services of sheltered workshops and other facilities by supporting such activities as the employment of additional staff, technical consultation, staff development, and the purchase of equipment.

During fiscal year 1970, 155 Facility Improvement Grants totaling \$3,900,000 were awarded to rehabilitation facilities, many of which were affiliated with local associations for retarded children. Facility Improvement Grants were also awarded to residential institutions for the mentally retarded to improve their sheltered workshop programs.

Other rehabilitation facility improvement activities are (1) a program of technical assistance consultation to provide workshops and other facilities with special consultation services in such areas as workflow, safety engineering; contract procurement, and vocational evaluation and adjustment; and (2) projects to share in the cost of providing training services for handicapped individuals in public or nonprofit workshops and rehabilitation facilities. Federal financial participation in the Training Services grant program may assist in the cost of such services as training in occupational skills, work evaluation, work testing and the provision of occupational tools and equipment necessary for training purposes and job tryouts.

During fiscal year 1970, Training Services Grants totaling \$5,860,000 were awarded to 41 rehabilitation facilities serving the mentally retarded as well as other disabled persons.

#### 2. Mental Retardation

The Mental Retardation Amendments of 1967 (P.L. 90-170) which amended P.L. 88-164 initiated a services support program to stimulate and aid local communities in responding to the unmet needs of the retarded by providing grants to pay for part of the initial cost of professional and technical personnel in the operation of a new facility or a new service in existing facilities for the mentally retarded. The authority for new grants under this support program expired June 30, 1970, and was replaced on October 30, 1970, by a broadened services support program P. L. 91-517 "The Developmental Disabilities Services and Facilities Construction Act of 1970."

Approximately eleven million dollars was appropriated under P.L. 90-170 in fiscal year 1969 and 1970 to implement the program. Of the amount awarded 50 percent was used to support projects serving residents of model cities. During this time a total 459 individual projects were approved, which were sponsored by local and nonprofit community organizations or by public agencies to benefit over 119,000 retardates. Grants are made on a declining basis for 51 months, the grant may not exceed 75 percent of the cost, 60 percent for the next year, 45 percent for the third year, and 30 percent for the last 12 months.

#### a. Community Facilities for the Mentally Retarded

The community facilities construction program authorized under Title I, Part C of the "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963" (P.L. 88-164) which was amended October 30, 1970, by the Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517) provides Federal grants to States to assist in the construction of specially designed public or other nonprofit facilities for the diagnosis, treatment, education, training, or personal care of the mentally retarded, including sheltered workshops which are part of a facility providing comprehensive services. The program is administered at the State level by an officially designated State agency. Participation in the program requires the development of a State plan for the construction of community facilities for the mentally retarded based on an inventory of needed additional services and facilities. Construction projects are approved in accordance with the provisions of the State plan.

As of December 1970, 370 projects have been approved. Ninety-eight facilities are completed and in operation, and 110 additional facilities are under construction. These facilities will provide care and treatment for approximately 95,000 retarded persons. The estimated total cost of these projects is over \$217 million with an estimated Federal share of over \$74 million.

The program has widespread impact on community efforts to meet the needs of the retarded. Public and voluntary agencies demonstrate increasing interest in participating in the construction program, and community leaders and professional personnel are combining efforts to stimulate sponsorship of needed facilities. Despite accomplishments to date, there is still great need for additional services and facilities. State plans indicate that services should be provided for about one million additional retarded individuals. Special consideration was given in programming and allocation of grant funds to urban and rural poverty areas.

# b. University-Affiliated Facilities for the Mentally Retarded

The University-Affiliated Facilities for the Mentally Retarded program assists universities or affiliated facilities for the mentally retarded in the construction of special facilities capable of demonstrating exemplary care, treatment, education and habilitation of the mentally retarded. In University-Affiliated facilities comprehensive services are provided; specialized personnel are trained; or new techniques of specialized services are demonstrated.

The primary purpose of this program is to provide facilities for the interdisciplinary training of physicians and other professional and technical personnel in the field of mental retardation. Among the professional disciplines represented in these facilities are medical personnel, dentists, nurses, speech and hearing therapists, nutritionists, physical therapists, occupational therapists, rehabilitation specialists, special educators, psychologists, social workers, recreational specialists and chaplains. Each facility is encouraged to conduct a comprehensive interdisciplinary training program so that each discipline involved in the care and rehabilitation of the mentally retarded may be fully familiar with the contributions of the other disciplines.

The law was amended in 1967 (P.L. 90-170) to provide grants for the construction of university affiliated facilities which include programs for persons with other neurological handicapping conditions related to mental retardation and for research incidental or related to activities conducted within the facility.

The amendments of 1970 (P.L. 91-517) extended the program until 1973 and provide for the University Affiliated Facilities program to include persons with developmental disabilities. A new section was added to provide Demonstration and Training grants to cover costs of administering and operating these facilities. Priority will be given to applicants with arrangements for junior colleges to participate in these programs.

Because of the complexity of the university-affiliated program, individual planning grants are available. Such individual grants may not exceed \$25,000 nor more than 75 percent of the planning costs.

Approved projects for the construction of university-affiliated facilities for the mentally retarded are: Children's Rehabilitation Institute, Reisterstown, Maryland; University of Colorado, Denver, Colorado; Walter E. Fernald State School, Waltham, Massachusetts; Children's Hospital Medical Center, Boston, Massachusetts; Georgetown University, Washington, D. C.; University of California Neuropsychiatric Institute, Los Angeles, California; University of Alabama Medical Center, Birmingham and Tuscaloosa, Alabama; Indiana University Medical Center, Indianapolis, and Bloomington, Indiana; University of North Carolina, Chapel Hill, North Carolina; University of Tennessee, Memphis, Tennessee; New York Medical College, New York, New York; Georgia Department of Public Health, Atlanta, and Athens, Georgia; University of Oregon, Portland, Oregon, and Eugene, Oregon; University of Miami, Miami, Florida; Utah State University, Logan, Utah; the University of Kansas, Lawrence, Kansas City and Parsons, Kansas; University of Wisconsin, Madison, Wisconsin; and Ohio State University, Columbus, Ohio, and the Children's Hospital, Cincinnati, Ohio.

c. Project Grants for Rehabilitation of the Mentally Retarded

The program of Project Grants for Rehabilitation of Mentally Retarded is administered by the Division of Mental Retardation, Rehabilitation Services Administration, of the Social and Rehabilitation Service. Any questions or

requests for clarification should be directed to the appropriate  ${\tt DHEW}$  Regional Office.

The purpose of project grants administered by the Division of Mental Retardation under the provisions of Section 4(a)(1) of the Vocational Rehabilitation Act, as amended by the Vocational Rehabilitation Amendments of 1968, is to pay part of the cost of organized, identifiable activities which are undertaken to contribute to the rehabilitation of mentally retarded individuals generally not eligible for vocational rehabilitation services. Grants provide for expansion or establishment of programs serving the mentally retarded, application of new techniques for rendering services, coordination of resources and information, and for increasing the number and types of specialized personnel working with the retarded.

The activities undertaken should stimulate the development, and encourage the utilization of community facilities and services for the mentally retarded such as:

- (1) Establishment of special services for the diagnosis, treatment, training, or care of the mentally retarded;
- (2) Demonstration projects in the rehabilitation of the mentally retarded; or;
- (3) Training, including inservice training and education of personnel in all fields or disciplines which contribute to the rehabilitation of the mentally retarded, through the provision of training, teaching, or traineeship grants.

Projects may include, but are not limited to, activities such as the following:

- (1) Utilization of newly developed techniques and methods that have been found to be effective in the rehabilitation of the mentally retarded.
- (2) The extension of mental retardation programs and activities to areas of urban or rural poverty.
- (3) The initiation or expansion of programs for mentally retarded individuals with special problems such as multi-handicapped adolescents or mentally retarded adults who might not be eligible for vocational rehabilitation services or mentally retarded children who cannot profit from available educational or vocational rehabilitation programs.
- (4) The initiation, expansion, and extension of present rehabilitation services in order to serve additional numbers of mentally retarded persons.
- (5) Special training of personnel in disciplines or occupations contributing to the rehabilitation of the mentally retarded.
- (6) Student Work Experience and Training (SWEAT) to provide a guided work experience program to help young people learn about career opportunities in mental retardation while serving the retarded.

In fiscal year 1970, 46 service projects in 27 States received support under this program. They serve retarded persons of all ages and degrees of handicap, largely and more severely retarded or multiply handicapped. A variety

of services are being provided: Pre-school centers, activity programs for multi-handicapped adults, a variety of programs for inner-city inhabitants and for persons in rural areas.

Forty-three training grants were awarded in fiscal year 1970. They provide short and long-term training of administrators and program directors, social workers, speech pathologists, judges, medical students, psychologists, citizen advocates, dentists, physical therapists, nursing home personnel, and others; one will develop training materials dealing with the Human Rights of the retarded; another is concerned with the retarded youthful offender; while others are concerned with poverty and retardation.

Students were hired for summer work with retarded persons in 72 projects in 35 States, the District of Columbia and Puerto Rico.

#### d. Hospital Inservice Training

The Hospital Inservice Training grants have been designed to provide a means for increasing the effectiveness of employees in State residential institutions for the mentally retarded.

Eighty-two State residential facilities are receiving a total of \$1,659,358 through the Hospital Inservice Training program and are translating the rapidly expanding body of knowledge about practices in the care of the mentally retarded into more effective services.

Hospital inservice training has been broadly defined to include: preservice training, job-related training, inservice training, continuing education, special training and technical training needed to introduce new methods, and training of personnel which will result in an improved quality of care for the mentally retarded residing in institutions.

Because personnel such as attendants, houseparents, aides, and others in similar personnel categories comprise the major portion of those rendering direct care to institutionalized retardates, the first major area of grant support was extended to these personnel. Grant support is available for inservice training of all professional, sub-professional, and technical personnel who have direct responsibilities for resident care and training.

Every State residential facility for the mentally retarded is eligible to participate in this program. The maximum grant to a single institution may not exceed \$25,000 in any one year. These grants can be made for a period of up to five years and are renewable.

There are four general types of training supported by inservice training grants to institutions for the mentally retarded: (a) initial on-the-job training for employees; (b) refresher, continuation, and other special job-related training courses; (c) continuation training for technical and professional staff to keep them informed of new developments in their fields which can be translated into more effective patient service; and (d) special instructor training for staff with inservice training responsibilities aimed at providing a cadre of personnel to continue and extend the institutional training program.

The content of the training programs includes general instruction in the areas of mental retardation; child growth and development; nursing care skills; patient-staff relations; human behavior; intra-staff relations; supervisory skills; communications skills; and adjunctive therapy skills.

Consultation is given to the institutions which have received grants to assist them in making the best use of training opportunities. Technical

information and professional consultation is being provided to the remaining State institutions for the mentally retarded in order to enable them to qualify for similar grants.

#### e. Mental Retardation Hospital Improvement

The Mental Retardation Hospital Improvement Grant Program is designed to assist State institutions for the mentally retarded to improve their care, treatment, and rehabilitation service. The program is specifically focused on the demonstration of improved methods of services and care, as opposed to research exploration or the development of new knowledge.

Only State residential institutions for the mentally retarded are eligible to apply for these grants. These State institutions are defined as those residential facilities under the administrative direction of State agencies responsible for such institutions. The maximum amount of support, including direct and indirect costs, that an institution can receive under this program for any one budget period (usually 12 months) is one hundred thousand dollars (\$100,000). Individual projects are normally approved for no more than a five year period. Projects are planned in response to high priority needs in relation to the overall institution plan and are directed toward the ultimate improvement of resident care throughout the institution.

An analysis of the current Hospital Improvement projects shows that a majority of the projects is focused on specialized services for residents who will require long-term care and treatment. A number of these projects involve retardates functioning at the severe and profound levels of retardation; some involve residents with multiple handicaps; and a few are concerned with aged residents. Demonstration projects for these more severely retarded and dependent residents are emphasizing personal development by means of self-care training, socialization experiences, intensive medical diagnosis and treatment, and opportunity for improved speech.

A number of projects have focused on special program areas, such as prevocational training for adolescents, and programs of treatment, training, and social habilitation. Other projects provide a diversified range of improved services, such as placement preparation, speech therapy, medical-physical diagnosis and treatment, recreation services, social-vocational habilitation, diagnostic study with improved records and program planning and use of the unit system, all of which enhance the development of an institution-community continuum of services.

The Mental Retardation Hospital Improvement project grant program was initiated in 1964 as an extension of the Mental Health project grant program. In fiscal year 1970, 90 projects in 86 State institutions for the mentally retarded received awards. They constitute approximately 50 percent of the rapidly increasing number of eligible institutions who are included in the program.

Major emphasis in this program during the next year will continue to be placed both on the extension of coverage to those institutions not yet involved in the program and on the development of long-term collaborative efforts by the staffs of the institutions receiving grants, their State mental retardation agencies, and the Rehabilitation Services Administration. Such collaboration is being developed so that project experience in solving problems of institutional care of the mentally retarded may be assessed and shared to ensure that improved methods and techniques can be widely disseminated.

The coordination of institutional programs with community service programs and Statewide comprehensive planning activities remains an important objective of the Mental Retardation Hospital Improvement Program.

#### f. Collection and Dissemination of Information

Mental Retardation Abstracts is a specialized mental retardation abstracting and information service published by the Division of Mental Retardation, Rehabilitation Services Administration, Social and Rehabilitation Service. Specifically, this service is designed to meet the needs of investigators and other workers in the field of mental retardation for comprehensive information about new developments and research results and to foster maximum utilization of these results.

Mental Retardation Abstracts is published quarterly under contract with the American Association on Mental Deficiency who collects all the current literature on mental retardation, writes informative abstracts, indexes the literature and compiles annotated bibliographies on various topics.

Special annotated bibliographies have been prepared on: (1) Programmed Instruction with the Retarded; (2) Literature for Parents; (3) Application on the Stanford-Binet and Wechsler Intelligence Scales with the Mentally Retarded; (4) Nursing and Mental Retardation; (5) Family Care and Adoption of Retarded Children; (6) Psychotherapy with the Mentally Retarded; (7) Recreation for the Retarded; (8) Counseling Parents of the Mentally Retarded; (9) Sheltered Workshops for the Mentally Retarded; (10) Films on Mental Retardation; (11) Psychopharmacological Therapy with the Mentally Retarded; (12) Electroencephalographic Studies Relating to Mental Retardation; (13) Hydrocephalus; (14) Mental Retardation and Religion; (15) A Selected List of Teaching Materials Regarding Mental Retardation for Faculty of Schools of Social Work; (16) Architectural Planning for the Mentally Retarded to Remove Barriers and Facilitate Programming; (17) Inservice Training in Institutions for the Mentally Retarded; (18) Behavior Modification of the Mentally Retarded; (19) Dental Care for the Mentally Retarded; (20) Malnutrition and Mental Retardation; (21) Research and Learning with the Mentally Retarded; (22) Education and Psychological Services for the Mentally Retarded Deaf.

Review articles and critiques have been prepared on: (1) Mental Retardation: Definition, Classification, and Prevalence; (2) Research on Linquistic Problems of the Mentally Retarded; (3) Attendant Personnel: Their Selection, Training and Role; (4) Research on Personality Disorders and Characteristics of the Mentally Retarded; (5) Effects of Severely Mentally Retarded Children on Family Relationships; (6) Factor Analysis and Structure of Intellect Applied to Mental Retardation; (7) Counseling Parents of the Mentally Retarded; (8) Genetic Aspects of Mental Retardation; (9) Instrumental Learning in Mental Retardates' (10) Vocational Rehabilitation of the Mentally Retarded: The Sheltered Workshop; (11) Relationships between Educational Programs for the Mentally Retarded and the Culturally Deprived; (12) A Decade of Research on the Education of the Mentally Retarded; (13) Application of Operant Conditioning Techniques to Institutionalized Severely and Profoundly Retarded Children; (14) Adaptive Behavior: A New Dimension in the Classification of the Mentally Retarded.

The abstracts and annotated bibliographies appear in the quarterly journal <u>Mental Retardation Abstracts</u>, and may be obtained through subscription directly from the Superintendent of Documents.

#### SOCIAL SECURITY ADMINISTRATION

#### Purpose

The basic purpose of the social security program is to provide cash benefits to replace, in part, earnings that are lost to individuals and families when earnings stop or are reduced because the worker retires, dies, or becomes disabled, and to provide health insurance protection to persons 65 and over. The program is contributory, it is self-supporting, benefits are wage-related, and entitlement to benefits is an earned right.

#### Historical Development

In 1935, when the original social security law was passed, the program was to have provided only retirement benefits to aged workers. In 1939, benefits for dependents and survivors were added and benefits became payable in 1940. Protection against long-term total disability -- not only for disabled workers, but also for adult sons or daughters (who became disabled before age 18) of disabled, retired, or deceased workers--was provided by the 1956 amendments. In 1965, health insurance benefits for the aged were added. The 1967 amendments provided benefits for disabled widows and widowers age 50 and over. Since 1949, there have been six general benefit increases in recognition of the fact that prices and wages have gone up, and legislation now under consideration by Congress would provide further increases.

#### Economic Impact

Mental deficiency is a major factor in more than 65 percent of cases involving dependents or survivors who have been continuously disabled since childhood. It is the primary diagnosis in about half of all childhood disability cases. In fiscal year 1970, an estimated 168,000 mentally retarded adults disabled in childhood and 8,000 mentally retarded workers received \$156 million.

The regulations contain guides as to the level of severity required in disability cases involving mental retardation. These regulations (published in 1968) have the effect of law and are available to the public and the medical community.

The number of mentally retarded children under age 18 who receive payments as dependents of retired, disabled, or deceased workers is unknown, since their benefits are payable regardless of disability.

Under social security's "Childhood Disability" provisions, lifetime monthly payments can be made to a person age 18 or over who has been disabled by mental retardation—or other impairments—since childhood. In many cases, the monthly benefits enable the retarded childhood disability beneficiary to be cared for at home instead of in an institution. Furthermore, as more and more retarded people outlive their parents, the program offers reassurance to fathers and mothers who know that financial help for their disabled child will be forth coming even after their death. (About half of the childhood disability beneficiaries are over 35 and 25 percent of them are over 45.) If the parents are dead, a relative who has demonstrated a continuing interest in the beneficiary's welfare, a welfare agency, or a legal guardian may be chosen as representative payee to handle the benefit funds and plan for using them in behalf of the beneficiary. A representative payee receives social security benefits in trust for the beneficiary and, as a trustee, is held accountable for the way in which he uses the benefits.

Health insurance benefits under the social security law are available to any individual, including a mentally retarded individual who is 65 or over and who meets certain necessary conditions. Therefore a mentally retarded individual 65 years of age who has contracted an illness or suffered an injury is, like any other person in this age group, protected under the health insurance program. However, the health insurance for the aged program specifically prohibits reimbursement under the law for expenses incurred for personal care designed primarily to aid an individual in meeting the activities of daily living and which do not require the continuing attention of trained medical or paramedical personnel. Therefore, an aged mentally retarded person whose only deficiency is mental retardation requiring general institutional care, e.g., vocational training, help in the activities of daily living, and so forth would not be receiving the type of care covered under the Medicare program.

# Activities and Achievements

All district offices of the Social Security Administration maintain a referral service to other programs and services of both public and private agencies and organizations. Giving information about these programs and agencies is an essential part of the Social Security Administration's service to the public. The service is provided to beneficiaries as well as to non-beneficiaries and applicants who inquire about services not provided by the old-age, survivors, disability, and health insurance program. Disabled persons applying for disability benefits under social security are promptly referred to the Rehabilitation Services Administration to the end that the maximum number may be rehabilitated into productive activity or to a level of self-care. Working relationships have also been established with all agencies and institutions that work with mentally retarded children, so that proper referrals may be made to district offices.

During 1970, the Social Security Administration launched a new program instituting biennial on-site reviews in State mental hospitals and schools for the retarded.

The program focus is an in-depth examination of the way in which these institutions are managing social security benefits on behalf of patients who receive their checks through an institutional official serving as "representative payee."

The program has the following objectives:

 To ascertain the nature of institutional policies applicable to the beneficiaries for whom the institution serves as payee.

- 2. To examine the personal and financial situation of a sample of such beneficiaries in each institution, and to make personal contact for brief interview with sample beneficiaries, unless medically contraindicated.
- 3. To evaluate both the State policies and their demonstrated application in the light of the Administration's policies for benefit use geared to beneficiary needs and individual planning.

The observations and conclusions resulting from a State review are, after analysis, communicated to the State Commissioner for his use in the development of improved practices in the State's system. The findings will also serve as a basis for SSA program and policy evaluation. In this way, it is expected, the on-site approach will strengthen relationships with the States, improve their understanding of their responsibility for optimum use of benefits when serving as representative payee, and open new channels for the discussion of problems and practices affecting the well-being of all beneficiary-patients in State mental institutions.

SSA has participated in the employment of the mentally retarded since the inception of the employment program in 1964. It has also tried, through the coordinator for employment of the handicapped, to generate interest in the program of private employers and other Federal agencies. Experience has demonstrated conclusively that the retardate can perform excellent work in basically routine positions when placement is carefully selected or the job re-engineered to the level or degree of his handicap. The ultimate goal in recruiting and hiring the mentally retarded is to assist in their rehabilitation to a productive life. In SSA, retardates are successfully performing in such positions as mail and file clerk, messenger, operators of printing, xerox, and card reader machines. Recently, SSA has experimented with the color coding of file cabinets and cartridges of microfilm, an area of work which requires a very high degree of accuracy. To date, the retardates have performed their duties in an excellent manner.

Retardates are performing so well many have been promoted to grades GS-2 and GS-3. At least two have qualified on a competitive examination and have been converted to status appointments, and several have received superior accomplishment awards.

In the area of public information, a new leaflet, "Mental Illness and Social Security Disability Benefits," is being developed in cooperation with the National Institute of Meutal Health. The leaflet is designed to provide people disabled by mental disorders or deficiencies (or their families) with information about social security benefits they may be entitled to. It will be printed in quantity and distributed through regular NIMH channels, through community mental health centers, through State and Federal mental hospitals, and to professional workers in the field.

Another leaflet, "Birth Defects and Social Security Disability Benefits" (SSI-95), was printed in 1970 and distributed to local affiliates of the National Foundation--March of Dimes. More than 150,000 copies of this leaflet have already been provided to National Foundation affiliates. In addition, the Social Security Administration provided State rehabilitation agencies and State agencies responsible for mental retardation programs with supplies of the basic disability program pamphlet, "If You Become Disabled."

These publications have as their focus a specific disease or condition orientation, rather than the traditional program approach. As such, they have considerable value to the families of the mentally retarded.

The color film, 'Where There Is Hope," which tells of the social security benefits available for the adult child, continues to be distributed through district offices for theatrical and general showing. It is also offered to State associations for retarded children. It depicts teenagers and older people at work in a sheltered workshop in Washington, D. C., diagnosis and therapy at the John F. Kennedy Institute in Baltimore, and the trial work period of a beneficiary in Greensboro, North Carolina.

The 1967 Survey of Institutionalized Adults conducted by the Social Security Administration collected basic information on the socio-economic characteristics of mentally retarded and other disabled persons aged 18 and over in institutions such as homes and schools for the mentally and physically handicapped, mental hospitals, chronic disease and other long-term hospitals. Data was obtained from institutional records and from relatives and guardians. The survey focused on types of care, cost of care, sources of payment, economic resources of the patient and his family, and his social relationships with family and friends. The handling of the institutionalized person's economic resources by administrators (including the institution) and payees was also examined. A report published in November 1970 ---The Severely Disabled in the Institutionalized and Noninstitutionalized Populations, 1966"--includes demographic data on persons aged 18-64 in institutions for the mentally retarded. Other reports on demographic characteristics, financial administrators, costs and payments, types of care, and social relationships will be published during 1971.

#### FOOD AND DRUG ADMINISTRATION

The Food and Drug Administration is concerned with preventing mental retardation that might follow the use or misuse of drugs or hazardous substances. The special age of concern is the reproductive age. The vulnerable periods are those specifically of embryonic, fetal, and infant life. Dosage levels considered safe in older infants may be potential causes of permanent brain damage in the prenatal or newborn age group which possess immature mechanisms of detoxification of these drugs. Infants cannot handle drugs as well as adults because of lack of development of an enzyme system.

Mental retardation can be defined to limit it to the impairment of the learning ability, or extended to include the lack of emotional response. Whether or not mental retardation is defined to include mongoloids, persons suffering from degenerative diseases such as Parkinsonism, institutionalized mental patients, or others, FDA is concerned with the use or abuse of drugs intended to prevent or treat such conditions. Much of the work in this area is so specialized that it is performed by individual investigators rather than by drug companies.

In the Bureau of Drugs, the Office of Scientific Evaluation monitors the investigational use of new drugs in early testing phases. Animal experimentation is required to prove a new drug safe and effective before that drug may be tested on human beings. Observations of adverse effects of new drugs are reported within the surveillance system of the administration.

FDA expects investigators to set up metabolic methodology on new entities, at least to attempt to develop functional toxicology and biochemical toxicology, relating experiences of one species to those of another, eventually to experiences of man.

The Food and Drug Administration also is concerned with the treatment of mental retardation. Special diets and drugs may or may not be effective. Regulatory action is taken against drugs or devices that are represented to be useful in the prevention or treatment of mental retardation but in fact have no such beneficial effects.

Surveillance by the Food and Drug Administration also covers any untoward effect of chemical entities used in foods, drugs, cosmetics, or household chemicals. These data are acquired in close liaison with many hospitals, with the American Medical Association, the World Health Organization, the pharmaceutical industry, and with other health, education, and welfare agencies. This information is catalogued, retrieved, and evaluated by means of an advanced data processing system.

# APPENDIX A

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

# Obligations for Mental Retardation Activities

Fiscal Years 1970-1972 (Thousands of Dollars)

ACTIVITY	1970	1971 Revised Budget Est <b>im</b> ate	1972 Budget Estimate
HEALTH SERVI	CES AND MENT	AL HEALTH ADMINISTRAT	FION
Services			
Comprehensive Health Planning and Services	525	-0-	-0-
Maternal and Child Health and Welfare	12,990	12,990	12,990
Total, Services	13,515	12,990	12,990
Training			
Mental Health Research and Services	441	438	400
Comprehensive Health Planning and Services	50	-0~	-0-
Maternal and Child Health and Welfare	14,765	16,965	1 <b>9,</b> 336
Total, Training	15,256	17,403	19,736
Research			
Mental Health Research and Services	600	-0-	-0-
St. Elizabeth's Hospital	-0-	-0-	-0-
National Health Statistics	-0-	-O <b>-</b>	-0-
Maternal and Child Health and Welfare	1,842	1,600	1,600
Total, Research	2,442	1,600	1,600
Construction			
Hill-Burton	-0-	-0-	-0-
Total, Construction	-0-	-0-	-0-
Other			
Mental Health Research and Services (Abstracts)		-0-	-0-
Total, Other	-0-	-0-	-0-
TOTAL, HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION	31,213	31,993	34,326

ACTIVITY	1970	1971 Revised Budget Estimate	1972 Budget Estimate
	NAL INSTIT	UTES OF HEALTH	
Training Neurology and Stroke Activities	6,171	6,241	4,676
Child Health	1,471	1,579	1,431
Total, Training	7,642	7,820	6,107
Research Neurology and Stroke Activities Child Health	4,795 9,089	5,195 10,609	4,974 11,879
Total, Research	13,884	15,804	16,853
TOTAL, NATIONAL INSTITUTES OF HEALTH	21,526	23,624	22,960
<u>O</u> F	FICE OF ED	UCATION	
Services Title I, ESEA, Educationally deprived children	33,000	35,600	35 <b>,6</b> 00
Title III, ESEA, Supplementary centers Education for the Handicapped Act, Part B Education for the Handicapped Act, Part C, Section 623 Vocational Education Act, Part B	3,650	4,900	4,900
	9,200	10,160	10,160
	590 11 <b>,</b> 500	860 11 <b>,</b> 500	950 11,500
	57,940	63,020	63,110
Training Education for the Handicapped Act, Part D Education Professions Development Act	10,391	10,500	10,500
	1,400	1,400	1,400
Total, Training	11,791	11,900	11,900
Research Cooperative Research Act Education for the Handicapped Act, Part E	76		
	1,602	1,420	1,600
Total, Research	1,678	1,420	1,600
Other Library Services and Construction Act	<u>15</u>	30	30
Total, Other	<b>1</b> 5	30	30
TOTAL, OFFICE OF EDUCATION	71,424	76,370	76,640

ACTIVITY	<u>1</u> 970	1971 Revised Budget Estimate	1972 Budget Estimate
SOCIA	L SECURITY	ADMINISTRATION	
Income Maintenance			
Estimated Benefit Payments from Trust Funds Trust Fund Obligations In-	143,000	165,800	176,800
curred to Adjudicate Claims of Beneficiaries	2,100	2,400	2,500
Total, Income Maintenance	145,100	168,200	179,300
TOTAL, SOCIAL SECURITY ADMINISTRATION	145,100	168,200	179,300
SOCIA	L AND REHA	SILITATION SERVICE	
Services Rehabilitation Services and Facilities:			
Basic State Grants	54,500	67,400	74,100
Innovation	223	28	-0-
Expansion Grants	108	108	144
Facility Improvement Grants	3,600	3,600	3,400
Formula Grants for the Developmentally Disabled	-0-	5,608	5,608
Services for the Develop- mentally Disabled	20,172	19,495	18,975
Total, Rehabilitation Services and Facilities	78,603	96,239	102,227
Grants to States for Public Assistance:			
objila Halfana o madaaa		1/	1.7
Child Welfare Services Medical Assistance	100,000	100,000	100,000
Total, Grants to States for Public Assistance	100,000	100,000	100,000
Special Programs for the Aging:			
Foster Grandparents Program	5,800	5,900	5,000
Title III Community Grant Programs	100	100	50
Total, Special Programs for the Aging	5,900	6,000	5,050
Total, Services	184,503	202,239	207,277

ACTIVITY	1970	1971 Revised Budget Estimate	1972 Budget Estimate
Training			
<del>.</del>			
Rehabilitation Services and Facilities:			
Vocational Rehabilitation Services for the Develop-	1,282	1,200	290
mentally Disabled Health Services Activities	3,359 113	4,080 -0-	4,600 -0-
Total, Rehabilitation Services and Facilities	4,754	5,280	4,890
Research and Training:			
Research and Training Centers <u>2</u> /	902	950	950
Total, Research and Training	902	950	950
Total, Training	5,656	6,230	5,840
Research			
Research and Training:			
Research and Demonstra- tions <u>3/</u> Social and Rehabilitation Activities Overseas (Speci	1,216	1,071	695
Foreign Currency Program)	300	200	400
Total, Research	1,516	1,271	1,095
Construction	v		
Rehabilitation Services and Facilities:			
Formula Grants for the Developmentally Disabled Construction of University	-0-	5,607	5,607
Affiliated Facilities	-0-	1,591	-0-
Construction of Community Service Facilities	16,870	9,628	-0-
Rehabilitation Facilities and Construction Grants	123	900	-0-
Total, Rehabilitation Services and Facilities	16,993	17,726	5,607
Total, Construction	16,993	17,726	5,607
Income Maintenance Grants to States	79,200	96,000	116,700
	·		
	79,200	96,000	116,700
Total, Income Maintenance	•		

ACTIVITY	1970	1971 Revised Budget Estimate	1972 Budget Estimate	
	OFFICE OF T	HE SECRETARY		
Secretary's Committee on Mental Retardation	(111)	(110)	110	•
President's Committee on Mental Retardation	580	550	650	
Total, Office of the Secretary	580	550	760	
GRAND TOTAL, ALL FUNDS	557,711	624,203	650,505	

<sup>1/</sup> Data not available.
2/ Includes Child Welfare Training Programs.
3/ Includes Child Welfare Research and Demonstration and Special Programs for the Aging, Title IV, Research and Demonstration.

#### APPENDIX B

#### Work Group on Income Maintenance

There was a preliminary meeting of the Work Group on Income Maintenance on January 21, 1971 in the offices of the Secretary's Committee on Mental Retardation. Present at this meeting were representatives from Social and Rehabilitation Service and Social Security Administration.

One of the purposes of this meeting was to determine the basis for data used to calculate estimates of the numbers of mentally retarded individuals among public assistance recipients.

As a result of this meeting, the National Center for Social Statistics, Social and Rehabilitation Service, prepared a statement indicating extent of mental retardation among public assistance recipients. Their statement is summarized as follows:

- On the basis of a survey in 1967, it is conservatively estimated that 4.6 percent of all Aid to Families with Dependent Children recipient children are mentally retarded. It is also estimated that at least 9 percent of the incapacitated fathers are mentally retarded.
- 2. On the basis of a survey in 1962, 14.7 percent of all Aid to Permanently and Totally Disabled recipients were reported as having "mental deficiency" as the primary diagnosis, and 2.9 percent were reported as having mental deficiency as the secondary diagnosis.
- 3. On the basis of a survey in 1962, it is conservatively estimated that 5.1 percent of all Aid to the Blind recipients were mentally retarded.
- 4. Results of the 1970 Adult Survey covering the Aid to the Blind, Old Age Assistance, and Aid to the Permanently and Totally Disabled categories will be available soon after July 1971. This study will identify (based on medical examination) mental retardation as either the primary or the secondary disabling condition for the Aid to the Permanently and Totally Disabled recipients, and will report the caseworkers judgement as to whether an Old Age Assistance or Aid to the Blind recipient had a special learning disability or mental deficiency.

The Secretary's Committee is planning to prepare a <u>Programs for the Handicapped</u> giving more specific information about the data utilized in determining the extent of mental retardation among public assistance recipients.

#### APPENDIX C

Development of Income Maintenance to the Mentally Retarded from Social Security Benefits

# Childhood Disability Beneficiaries

A childhood disability beneficiary is an adult with a childhood disability who is awarded dependents' benefits as a disabled son or daughter of an insured worker who has retired, died or is disabled. Persons with disabilities since childhood must meet the same criteria on severity of disability as do workers who receive disability benefits. Mental deficiency is a major factor of about 65 percent of the childhood disability beneficiaries. The total amount of benefits paid from trust fund to childhood disability beneficiaries is a matter of record. The estimate of benefit payments to be paid in the future from trust funds are made by the Actuary each year. Trust fund obligations incurred to adjudicate claims of childhood disability beneficiaries are determined from unit cost data for units handling this work load.

#### Determination of the 65 percent ratio

In the processing of disability claims, international diagnostic codes are used to identify the disease or disorder. These codes are accumulated for every year to show the number and percentage of allowances by diagnostic group and primary diagnosis. Prior to 1966 the international codes were used plus social security added some of their own primary codes to the international codes to identify claimants with mental deficiencies in connection with other diseases or disorders. Starting in 1966 international codes were used exclusively in coding diagnoses to make social security data compatible with data on disability from this country and abroad. Because of this change it has been necessary to calculate the number of mentally retarded in other than the primary diagnosis.

The method used to determine how many mentally retarded now receiving benefits is to use primary diagnostic code in childhood disability allowances for prior years in conjunction with the studies made by the Office of the Actuary on changes to the childhood disability rolls. The percentage of childhood disability claimants with mental retardation, allowed in the eleven years statistics are available, has remained constant, and the makeup of the benefit rolls has remained stable. The figures currently being used are for 1957-1967. The 1968 data on childhood disability allowances will be available in about 6 months.

#### Other Benefits

Because of the insured requirements to receive benefits as a disabled worker, very few mentally retarded draw insured workers' disability benefits. When a person receives dependent's or survivor's benefits, other than disability benefits, there is no statistical data obtained or needed as to mental retardation. Eligibility to benefits for minor children, widows, widowers, parents, and spouses have no relationship to mental retardation. Therefore, no attempt has been made to estimate the amount of benefits paid to the mentally retarded in these categories and no amount was included in Appendix A.

#### APPENDIX D

# DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT Public Law 91-517

President Nixon signed into law the Developmental Disabilities Services and Facilities Construction Amendments of 1970 on Friday, October 30, 1970. This new legislation significantly expands the scope and purposes of the Mental Retardation Facilities Construction Act of 1963, as amended, and marks a new phase in the Federal Government's efforts to provide a better life for all mentally retarded and other developmentally disabled citizens. It is designed to provide the states with broad responsibility for planning and implementing a comprehensive program of services and to offer local communities a strong voice in determining needs, establishing priorities and developing a system for delivering services.

Title I of P.L. 91-517 replaces existing authority (Part C, Title I, P.L. 88-164) to aid in the construction of community facilities for the mentally retarded with a combined formula and project grant program covering both construction of facilities and the provision of services to persons with developmental disabilities. The scope of the present program is broadened to include not only the mentally retarded but also persons suffering from other serious developmental disabilities originating in childhood including cerebral palsy, epilepsy and other neurological handicapping conditions. It is estimated that 8.7 million children and adults - or 1/24 of the nation's population - suffer from developmental disabilities. Of this number, approximately six million are mentally retarded, one million are epileptics, 700,000 suffer from cerebral palsy and one million from other neurological handicaps originating in childhood (other than blindness and deafness). In the case of serious developmental disabilities, it is quite common for an individual to be afflicted with two or more overlapping conditions. In general, the more serious the disability, the more likely that the individual will be multiply handicapped.

The new legislation also extends the present authority to construct university-affiliated facilities for the mentally retarded (Part B, Title I, P.L. 88-164) through June 30, 1973, and authorizes a new project grant program to cover the costs of administering and operating demonstration facilities and interdisciplinary training programs in such facilities (Title II, P.L. 91-517).

#### MAJOR PROVISIONS

Grants to the States for Planning, Administration, Services and Construction of Facilities

Existing authority to construct community mental retardation facilities is replaced by a broad new federal-state grant-in-aid program to assist the states in developing and implementing a comprehensive plan for meeting the needs of persons with developmental disabilities. States may use these funds to construct facilities, provide services, support state and local planning, administration and technical assistance, train specialized personnel and develop and demonstrate new service techniques.

\$60 million dollars is authorized to be appropriated for this program in fiscal year 1971, \$105 million in FY 1972, and \$130 million in FY 1973.

#### State Allotments

State allotments under the program will be calculated on the basis of population, need for services and financial need of the state. However, each state will receive a minimum of \$100,000 per year.

After FY 1971, the minimum state allotment will be increased when the level of annual appropriations rises above the authorization level for FY 1971. The percentage increase in the minimum allotment will be identical to the percent by which the appropriations in that fiscal year exceeds the FY 1971 authorization level.

In determining a state's need for services the Secretary of HEW is authorized to take into account the scope and extent of services specified in the state plan. Funds allotted to a state which are not used may be reallotted to another state by the Secretary in accordance with a specified formula.

Funds allocated to a state for construction remain available for two fiscal years. However, if a state's plan calls for construction of a particular facility and the federal share of the costs will exceed the state's construction allotment for that fiscal year, the funds may remain available for a total of three fiscal years. This provision will allow a state with low annual construction allotments to pool its allotments for three years in order to obtain funds for a single construction project.

A state may apportion grant funds among two or more state agencies in accordance with each agency's responsibilities for carrying out the state plan. In many states more than one state agency plays a significant role in delivering a comprehensive array of services to the mentally retarded and other developmentally disabled persons. The purpose of this provision is to permit each state to tailor its state plan to most efficiently carry out the purposes of the program.

Title I funds may be combined with other state or federal funds provided the benefits to the developmentally disabled are proportional and the non-duplication clause in Section 140 is observed (see page 6).

The Secretary of HEW is authorized to set aside up to 10 percent of appropriated funds for project grants of special national significance. The federal share of the cost of such projects will be up to 90 percent.

#### State Plan Requirements

In order to qualify for federal assistance under the new formula grant program, a state must submit an acceptable state plan. This plan must include:

-- Provision for the establishment of an adequately staffed state planning and advisory council. The council must include representatives of each principal state agency, local agencies and non-governmental organizations concerned with services to the developmentally disabled; at least 1/3 of the council must

consist of consumer representatives. The council must review and approve the state plan at least annually and submit necessary modifications to HEW. The Secretary of HEW, however, may waive the requirement for appointment of an advisory council during FY 1971.

- -- Designation of the state agency or agencies to administer the plan and a single state agency to administer all construction funds. (The Secretary may waive these requirements during fiscal year 1971).
- -- A description of the current status of statewide facilities and services available to the developmentally disabled including services provided under related federal programs (including education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, comprehensive health, and mental health). The plan must indicate how grant funds will be used to complement and reinforce existing programs.
- -- Assurances that federal funds will not be used to supplant state funds, that a portion of such funds will be made available to local public and non-profit private agencies, and that the state government will participate to a reasonable degree in the cost of carrying out the state plan.
- -- Provision for services to mentally retarded persons, specification of other categories of disabilities (as approved by the Secretary) to be covered under the plan, and a description of the quality, extent and scope of services to be provided to eligible persons.
- -- Assurances that all services meet federally-established standards. (The Secretary may waive this requirement during FY 1971).
- -- Provision for special financial and technical assistance to poverty areas.
- -- A description of the methods to be used in assessing the effectiveness of efforts under the state plan.
- -- A construction plan based on a statewide inventory of need including funding priorities for such construction projects.
- -- Specification of the percentage of the state allotment to be used for construction of facilities. However, in no case may a state use more than 50 percent of its annual allotment for construction. In addition, the Secretary is authorized to limit the percentage of a state's allotment which may be used for this purpose.
- -- Assurances that other administrative requirements related to the expenditure and control of federal funds, maintenance of records, submission of required reports and provision for an adequate hearing will be met.

#### National Advisory Council

P.L. 91-517 authorizes the establishment of a National Advisory Council on Services and Facilities for the Developmentally Disabled effective July 1, 1971. The purpose of the Council is to advise the Secretary on regulations and to study and evaluate programs conducted under Title I of P.L. 91-517. The Council does not duplicate the functions of the President's Committee on Mental Retardation or the Secretary's Committee on Mental Retardation, neither of which is associated with a specific operating program of the Federal Government.

The Council will consist of twenty members who are not full time employees of the Federal Government. Members must be selected from among leaders in the field of service to the mentally retarded and other persons with developmental disabilities including leaders of state and local government, institutions of higher education, and organizations representing consumers of services. At least five members must represent state or local public or non-profit private agencies responsible for services to developmentally disabled persons. In addition, five members must represent the interests of consumers of such services.

Council members will be appointed by the Secretary of HEW to fouryear terms except that five of the initial appointees will serve for three years, five for two years, and five for one year. The Secretary of HEW will designate one member to act as Chairman of the Council.

The Council is authorized to engage necessary technical assistance and the Department of Health, Education, and Welfare is required to furnish secretarial, clerical and other staff assistance to the Council. Members will be reimbursed for days spent on Council business.

# Payment to States for Planning, Administration and Services

States with an approved plan under Title I will be reimbursed in advance for the federal share of non-construction expenses. These funds may be used to support a full range of planning, direct service, administration, technical assistance, training and demonstration costs associated with serving the developmentally disabled.

The federal matching percentage for expenditures under this new federal-state program is 75 percent during FY 1971 and FY 1972, and 70 percent during FY 1973 except for projects in areas of urban and rural poverty where a state may qualify for 90 percent federal matching during the first two years of the project and 80 percent during the third year.

For purposes of determining the federal share of the cost, expenditures by local jurisdictions and non-profit groups will be regarded as state expenditures. However, as noted above, a state must participate reasonably in the cost of providing services called for under the state plan.

#### Approval of Construction Projects

Existing statuatory provisions governing the approval of construction projects are largely unchanged in P.L. 91-517. The maximum federal matching ratio for construction grants remains 90 percent in poverty areas and  $66\ 2/3$  percent in other areas.

#### Regulations

As soon as practical the Secretary is required to issue regulations prescribing: (a) the kinds of services which may be provided under a state plan and the categories of persons to whom such services may be offered; (b) standards regarding the scope and quality of services provided under a state plan; (c) the general manner in which a state must determine priorities for services and facilities based on type of services, categories of persons to be served, and type of disability (with special consideration being given to urban and rural poverty areas); and (d) general construction standards.

#### Definitions

The term "development disability" is defined in the Act as "a disability attributable to mental retardation, cerebral palsy, epilepsy

or another neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals . .." In addition, the disability must have originated before the individual reached age eighteen and have continued or be expected to continue indefinitely. Finally, the disability must constitute a substantial handicap to the individual in question.

The term "services for persons with developmental disabilities" means "specialized services or special adaptations of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with such a disability . . . " The Act spells out the following services which are included in the definition: diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling of the disabled individual and his family, protective and other social and socio-legal services, information and referral, follow-along services, and transportation necessary to assure delivery of services to persons with developmental disabilities.

#### Effective Date

Title I of P.L. 91-517 applies to all funds appropriated by Congress after June 30, 1970. However, funds appropriated before that date for construction of community facilities for the mentally retarded remain available for obligation during FY 1971. In addition, funds for continuation of staffing grants awarded prior to June 30, 1970, will not be affected by the new legislation.

#### Nonduplication

As in most federal grant programs, federal funds may not be used for matching purposes in obtaining other federal grants. However, the former prohibition against using public health service construction funds to build retardation facilities while P.L. 88-164 funds are still available has been eliminated.

# Construction of University Affiliated Facilities

Title II of P.L. 91-517 extends the university affiliated facilities construction program for three additional years. \$20 million is authorized for this purpose in each of fiscal years 1971, 1972, and 1973. The federal share remains unchanged at 75 percent of the eligible costs of the construction project.

The new legislation also expands the purposes of the university affiliated program to include other developmental disabilities beside mental retardation. In addition, the term "clinical training" is

replaced by the term "interdisciplinary training" to emphasize the cross-disciplinary nature of the university affiliated training program.

Since this program was originally authorized in FY 1963 the federal government has assisted in the construction of eighteen university affiliated centers. These centers provide an excellent setting for interdisciplinary training of the wide range of professional specialists needed to diagnose and care for the developmentally disabled. In addition, university affiliated facilities serve as a focal point for testing and demonstrating the latest techniques and concepts in serving the developmentally disabled.

# Demonstration and Training Grants

Title II adds a new project grant authority to cover the costs of administering and operating demonstration facilities and interdisciplinary training programs for personnel needed to render specialized services to individuals with developmental disabilities. Funds under this new authority are designed to upgrade and improve programs in university affiliated facilities. Authorizations for the program are \$15 million in FY 1971, \$17 million in FY 1972, and \$20 million in FY 1973.

Only colleges, universities and non-profit agencies operating university affiliated facilities are eligible to apply for project grants under this new program. Priority must be given to applicants who have made arrangements for junior college participation in the project. The Federal share of the cost of all projects will be 100 percent of the approved grant.

# Maintenance of Effort

A new section is added to Part B requiring that all applications for construction, demonstration and training grants be supported by reasonable assurances that the grant will not result in any decrease in the level of state, local and other non-federal support.

#### AUTHORIZATIONS FOR APPROPRIATIONS, 1971-1973

Public Law 91-517, "Developmental Disabilities Services and Facilities Construction Act"

Millions of Dollars				
	Fiscal Years			
	1971	1972	1973	Total
Title I				
Grants to the States for Planning, Administration, Services and				
Construction of Facilities	60.0	105.0	130.0	295.0
Title II				
Construction of University Affiliated				
Facilities	20.0	20.0	20.0	60.0
Demonstration and Training Grants	15.0	17.0	20.0	52.0
Total	95.0	142.0	170.0	407.0

Adoption, 1-2 Appropriations, 16, 18, 27, 33, 35-38, 41, 44, 50, 62 Assistance Payments Administration, 48 Bibliographies, 65, 68-69 Biological Bases, 25, 31 Birth Control, 11 Center for Disease Control, 9-10 Cerebral Palsy, 30 Community Mental Health, 15-16, 49, 52, 60 Community Services, 49 Congenital Malformations, 13, 22 Construction, 15, 30 Crippled Children's Program, 21-22 Cultural Deprivation, 14 Cytogenic and Biochemical Programs, 22 Day Care, 2 Deaf-Blind, 42 Dental Programs, 22 Detection, 21 Disease Control, 11 Education and Training, 12-13 Emotional Factors, 15 Epidemiology, 29 Family and Child Welfare, 49, 53 Films, 69 Food and Drug Administration, 70 Foreign Quarantine Program, 11-12 Foster Grandparents, 1, 47-48 Foster Parents, 1 Genetic Counseling, 22-23 Grants, 15, 17, 23-24, 27-28, 40, 59 Head Start, 3 Health Services and Mental Health Administration, 9 Homemaker Service, 50 Hospital Inservice Training, 63 Immunization, 9-11, 20 Indian Health Service, 10, 12-13 Intermediate Care, 49 International, 24, 55 Lead Poisoning, 20 Learning Processes, 14 Maintenance Payments, 49 Malnutrition, 20 Maternal and Child Health, 21-22, 24 Maternity and Infant Care, 18 Measles, 10 Medicaid, 49 Medical Services Administration, 49

```
Mental Retardation Abstracts, 69
Metabolic Diseases, 19, 22, 25
National Institutes of Health, 25
   National Institute of Child Health and Human Development, 27, 29
   National Institute of Neurological Diseases and Stroke, 27, 30
National Institute of Mental Health, 2, 14-15
Neurological Diseases, 27-28
Office of Child Development, 1, 3
   Children's Bureau, 1
   Bureau of Head Start and Early Childhood, 1, 3, 14
Office of Education, 32
   Division of Training Programs, 34
   Division of Educational Services, 41
   Division of Research, 44
Office of Surplus Property Utilization, 4
   Qualifications, 5
   Real Property, 4-8
   Surplus Property, 4-8
Older Americans, 53
Otitis Media, 11
Personnel Training, 23, 27
Perinatal Research, 31
Phenylketonuria, 10-11, 19, 25
Poverty, 20
Prenatal Factors, 25
President's Panel on Mental Retardation, 18
Preventitive Services, 9-11, 15, 17-18
Public Law, 16, 35, 42-44, 60-61
Publications, 3, 69
Rehabilitation Services Administration, 57, 61
   Vocational Rehabilitation Service, 57
   Mental Retardation Hospital Improvement, 64
Research, 3, 11-14, 23, 27, 44
Rubella, 9-10, 20
Senior Citizens, 47
Social Deprivation, 14
Social Rehabilitation Service, 2, 16, 47
   Administration on Aging, 47
   Assistance Payments Administration, 48
   Division of International Activities, 55
   Medical Services Administration, 49
   Office of Planning, Research and Training, 51
   Rehabilitation Research and Training Centers, 54
Social Security, 17, 50, 52, 66, 68
Social Security Administration, 66
Special Studies Institutes, 37
Stroke, 27, 30
Teacher Corps, 38
Teaching Methods, 14, 38
Training, 13, 34, 37-39, 53, 62, 63, 45, 56, 61
University Affiliated Programs, 38, 45, 56, 61
Vocational Rehabilitation, 58
```

# DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE WASHINGTON, D.C. 20201

OFFICIAL BUSINESS





U. S. DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
Office of the Secretary
Secretary's Committee on Mental Retardation
Washington, D. C. 20201