

Each year the Office of Mental Retardation Coordination prepares a detailed report on the Department's mental retardation programs for submission to the House of Representatives Subcommittee on Appropriations. A copy of the 1972 report entitled "Mental Retardation Programs of the Department of Health, Education, and Welfare" is available free of charge upon request from the Office of Mental Retardation Coordination, Department of Health, Education, and Welfare, 330 Independence Avenue, S.W., Washington, D.C. 20201.

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# OFFICE OF MENTAL RETARDATION COORDINATION

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## FOREWORD

This publication describes the current mental retardation program activities of the Department of Health, Education, and Welfare. Over \$800,000,000 for mental retardation related programs will be obligated by the Department during the coming fiscal year.

The Federal commitment to preventing mental retardation and combating the effects of this disability continues to grow. On November 16, 1971 President Nixon asked that all Americans join him in commitment to two major national goals:

To reduce by half the occurrence of mental retardation in the United States before the end of this century

To enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community

In January of this year, Secretary Richardson moved to strengthen the Department's ability to coordinate our varied and diverse Federal programs serving the mentally retarded. This was accomplished by the establishment of the Office of Mental Retardation Coordination in the Office of the Secretary. This unit is responsible for the coordination and evaluation of mental retardation activities and serves as a focal point for Department-wide policies related to this field.

Every effort will be made during the coming fiscal year to meet challenges put forth by President Nixon and to continue the development of a unified, dynamic Federal mental retardation program.



(MRS.) PATRICIA REILLY HITT  
Assistant Secretary for  
Community and Field Services

April 25, 1972

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## 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 problem of mental retardation simultaneously from many vantage points.

During Fiscal Year 1972, an estimated \$735 million will be 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 remained the same; i.e., the responsibility for coordination of the Department's programs and activities affecting the mentally retarded.

On January 25, 1972, the Secretary of Health, Education, and Welfare directed the establishment of the Office of Mental Retardation Coordination. This new unit replaces the Secretary's Committee on Mental Retardation and will be responsible for the duties formerly assumed by that Office. Specifically, the Office of Mental Retardation Coordination is responsible for the following activities:

- Serves as a means of coordination and evaluation of the Department's mental retardation activities.
- Serves as a focal point for consideration of Department-wide policies, programs, procedures, activities and related matters relevant to mental retardation.
- Serves in an advisory capacity to the Secretary in regard to issues related to the administration of the Department's mental retardation programs.
- Serves as liaison for the Department with the President's Committee on Mental Retardation.

There will be two coordinating committees under this new Office: Steering Committee: Consists of representatives of the Office of the Assistant Secretary for Health and Scientific Affairs, Social and Rehabilitation Services, Health Services and Mental Health Administration, National Institutes of Health, and Office of Education. This group will be responsible for advice and consultation in the implementation of the Office functions. Mental Retardation Interagency Committee: Consists of representatives of all mental retardation operating programs. Its functions will be to provide a means of communication, information exchange and program development for agency staff concerned with Federal mental retardation activities.

The Secretary has also directed that an interagency coordinating committee be established in each of the Department's Regional Offices. At the present time, the Regional Offices are served by a mental retardation coordinator, located in the Office of the Regional Director. The new committee will be the responsibility of that staff member.

The Office of Mental Retardation Coordination will place special emphasis on coordination of the implementation of the President's proposals to reduce mental retardation, and to minister more effectively to those affected by this problem. To carry out this mandate the Committee plans to evaluate the impact that the Department's mental retardation programs have on the mentally retarded in local communities, to ascertain the extent of coordination of these programs, and to obtain recommenda-

## **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. Grants which support screening programs for phenylketonuria (PKU) and other metabolic diseases also are awarded by the Maternal and Child Health Service. Forty-three States have 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 and crippled children's 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, extend screening programs, provide treatment services for physically handicapped retarded youngsters, increase inservice training opportunities, and provide 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 Developmental Disabilities, Rehabilitation Services Administration, Social and Rehabilitation Service, supports projects for the retarded which have service components of well-integrated comprehensive health and mental health programs.

The Division of Developmental Disabilities 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. On December 28, 1971, the Division of Developmental Disabilities issued proposed regulations for the administration of this Act. They are still in the process of being evaluated in light of comments received prior to final issuance.

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.

## **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 \$16 million in fiscal year 1972. The National Institute of Neurological Diseases and Stroke, 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 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. 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. 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.

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. 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.

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 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 construction program is administered by the Division of Developmental Disabilities, Rehabilitation Services Administration, Social and Rehabilitation Service.

This construction program is authorized under P.L. 91-517, the Developmental Disabilities Services and Facilities Construction Act of 1970, which supplants in part and expands the old mental retardation law of 1963 to allow for grants to States for planning, construction, administration, and services for the mentally retarded, cerebral palsied, epileptic, and other neurologically disabled individuals. University-affiliated grants are made also to cover the costs of administration and operation of facilities and for the training of physicians and other professional personnel vitally needed to work with the mentally retarded.

As of June 30, 1971, 439 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. The estimated total cost of these projects is over \$252 million with an estimated Federal share of \$105 million.

### **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.

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.

## 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 (SRS) 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 Committee on Mental Retardation, the Office of Mental Retardation Coordination, the SRS Division of Developmental Disabilities, and other HEW agencies.

### I. CHILDREN'S BUREAU

#### Research and Evaluation Project on Institutional Improvement

The Office of Child Development is financing a \$76,000 grant to the Human Interaction Research Institute, Los Angeles, California, for developing strategies to improve child caring institutions. One third of the

institutions studied are public and voluntary institutions for mentally retarded children. Site visits have been made to three outstanding institutions for retarded children; their successes noted; and efforts will be made to replicate these successes in other institutions for retarded children.

### **H.R. 1 Standards for Child Caring Institutions**

H.R. 1 includes provision of \$150 million for State agency provision or purchase of foster care for children, including foster family and institutional care for mentally retarded children. The Office of Child Development is preparing standards that could be used by SRS Community Services Administration in administering the Act.

### **National Association of Private Residential Facilities for the Mentally Retarded**

OCD participates on the Board of Advisors for an SRS-RSA-DDD project implemented by the National Association which is attempting to gather comprehensive data on services provided by private residential facilities for the mentally retarded.

### **Social Protections for Children in Public Institutions**

The Office of Child Development is preparing a plan for implementing reform in public institutions for children through a system of regular study and evaluation similar to the licensing system for private institutions for children. One fourth of the thrust in this area will focus on public institutions for mentally retarded children. Legal suits may be included to facilitate legislative changes to enable public institutions to comply with some form of annual or other regular evaluation and improvement.

### **Publications**

A day care manual for the handicapped entitled *Serving Children with Special Needs* is a joint effort of the Office of Child Development, the Bureau of Education for the Handicapped, and the President's Committee on Mental Retardation. The manual is intended as guidebook for directors and staff of day care programs who are or may wish to include some children with special needs in their program, and as a guide to parents of these children in selecting a day care resource.

*Children Today* is 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.

## II. HEAD START

The research coordination efforts of the Office of Child Development includes examining present and planned research activities of the agencies of the Interagency Panel on Early Childhood Research and Development to identify overlapping or duplicating projects, determining gaps in research, sharing information on future plans, and exploring procedures for designing interagency research.

In the area of mental retardation the Office of Child Development through its Information Secretariat has contributed to the coordinating efforts of the agencies within broadly outlined research areas such as the developmental process; effect of primary environmental influences; the effect of community and broader social programs; the global approach and combined and comparative effects; research and methodology; and the study of research planning and dissemination.

The Office of Child Development has been moving increasingly toward the goals of serving handicapped children which had been the policy of Head Start since its inception. That policy states that handicapped children must be given consideration for admission to Head Start classes in the same manner as any other child who meets the economic criteria.

Head Start is developing a new program information system which will help to improve the quality of the program for all children, and especially handicapped or retarded children whose special needs must be recognized and individually met.

The Office of Child Development is now actively developing a collaborative program with the Bureau of Education for the Handicapped to integrate the resources of BEH's 70 Handicapped Children's Early Education Program projects into a number of local Head Start programs. In order to provide appropriate services for a Head Start child who may be emotionally disturbed, OCD is now arranging active collaboration between the Office of Child Development and the National Institute of Mental Health to integrate the resources of NIMH's Community Mental Health Centers into local Head Start programs in the CMHC catchment areas.

## 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. 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.

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

- To assure that every handicapped child is receiving an appropriately designed education by 1980 (75% by 1977).
- To assist the States in providing the appropriate educational services to 75% of the handicapped by 1977.
- To assure that by the year 1977, every handicapped child who leaves school has had career educational training that is relevant to the job market, meaningful to his career aspirations, and realistic to his fullest potential.
- To assure that all handicapped children served in the schools (75% by 1977) have a trained teacher competent in the skills required to aid the child in reaching his full potential.
- To secure the enrollment of 750,000 (75%) preschool aged handicapped children in Federal, State, and local educational and day care programs.

## **I. DIVISION OF TRAINING PROGRAMS**

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 designated 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.

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 traineeships 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 traineeship recipients indicated that approximately 75 percent of all programs in mental retardation at colleges and universities are directed or coordinated by these individuals.

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; and (3) extension downward into the senior year undergraduate levels.

Public Law 85-926 was further amended with the passage of Public Laws 89-105 and 90-170, which expanded and extended the program through fiscal year 1970. Title VI of P.L. 91-230 consolidated all of the prior legislation relating to the handicapped children which the Bureau of Education for the Handicapped administers.

Since P.L. 85-926 was passed in 1958, approximately 30,000 traineeships have been awarded to individuals preparing to work with mentally handicapped children.

### **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."

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.

#### **University-Affiliated Facility Program**

The Division of Training Programs, in cooperation with the Division of Developmental Disabilities of the Social and Rehabilitation Service, provided support monies to special education components in seventeen university-affiliated facility programs for fiscal year 1971.

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.

#### **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 Parts C and D of the above Act will be used in programs to train regular educational personnel, such as counselors, educational technology specialists, teachers and administrators who have an interest or need to become more knowledgeable regarding the problems of the handicapped. Most such projects will operate under the new Educational Renewal strategy. The Educational Renewal strategy is designed to develop mechanisms whereby local schools can receive Office of Education discretionary resources in a comprehensive, long-term plan geared to meet their particular needs.

#### **New Programs—Special Projects**

To provide a means for developing new models the Division of Training Programs administers a Special Projects Grant Award Program.

crippled or in some way health impaired. At present, it is estimated that less than 40 percent of these children are in educational programs designed to provide for their unique learning characteristics.

As part of a comprehensive effort to demonstrate innovative approaches to solve the needs of handicapped children, Title III of the Elementary and Secondary Education Act as amended in 1968, mandated that 15 percent of its project funds be set aside for special education programs for the handicapped.

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 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.

### III. DIVISION OF RESEARCH

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.

The program now administered by the Division of Research was initiated during fiscal year 1964 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.

The Division currently supports a variety of research and related activities relating to the education of mentally retarded children. A major applied research program is involved in a number of studies on the effects of teacher behavior on pupils, and on ways of establishing desired teacher behaviors. Another major program is investigating methods of optimally matching learning characteristics of retarded children with various teaching methods and environments. A comprehensive program of curriculum development activities is currently being supported by the Division. The correlated program includes projects on reading, mathematics, social

studies, physical education, academic readiness, and science, each designed to produce both curricula and teaching materials for educable mentally retarded children. An additional project is developing social living and prevocational training materials designed for trainable children.

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 re-examining and re-evaluating the program, and making any adjustments which are necessary to keep the program responsive to the educational needs of the handicapped child.

Additional efforts of a more general nature have important implications for retarded as well as other handicapped children. One of the most critical projects currently being supported is investigating the re-integration of handicapped into regular education programs.

Through fiscal year 1971, funds under the Library Services and Construction Act, Title IV-A, are for the purpose of establishing and improving State institutional library services. Residential schools for the handicapped, including the mentally retarded, may be included in a State plan if these schools are operated or substantially supported by the State. Funds may be used for providing books and other library materials as well as other library services to students in such residential schools under an approved State plan.

This program has acted as a stimulus to the States to expand, initiate and integrate library services as an important component in the educational development of the State institutions for mentally retarded. Library services have been established where none existed and existing services have been expanded and worn collections have been updated to include multi-media materials and equipment carefully selected to meet the needs of the mentally retarded.

Beginning in fiscal year 1972, the Library Services and Construction Act provides library services to State institutionalized persons and physically handicapped persons under Title I.

## **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 through the development of services to promote and sustain physical health, and provide care and treatment for physically ill persons. Similarly, it strives to improve mental health by developing knowledge, manpower, and services to promote and sustain mental health, prevent mental illness, and treat and rehabilitate mentally ill persons.

### **NATIONAL INSTITUTE OF MENTAL HEALTH**

The National Institute of Mental Health supports a limited range of research and training projects in the field of mental retardation. Although these programs have largely been transferred to other agencies, many of the ongoing activities of the National Institute of Mental Health relate directly or indirectly to mental retardation. For the Fiscal Year 1971, forty-nine research and training grants, primarily focused on mental retardation, exceeded \$3,000,000.

### **Research**

Major research projects directly related to the field of mental retardation include studies of cognition and the learning process; the development of educational techniques and the evaluation of treatment modalities; identification of psycho-social variables.

## **Training**

For the Fiscal Year 1971, the Institute supported 126 training programs in mental retardation for the mental health disciplines, including continuing education. Programs range from residency training of psychiatrists to those for clinical psychologists, child psychiatrists, psychiatric social workers, psychiatric nurses, special training for pediatricians, internists and general practitioners, and new career workers. The programs are intensive as well as comprehensive, varying in design according to the orientation and associated facilities of the sponsoring institution.

## **MATERNAL AND CHILD HEALTH SERVICE**

Maternal and Child Health Service programs designed to meet the needs of children with mental retardation or developmental delay have demonstrated continued growth in three major areas: 1. Basic health and supportive services; 2. Preventive services; and 3. Training of personnel to deliver these services.

Through programs supported with earmarked portions of MCH and CC funds, States are demonstrating both the unique and specific contributions which can be made on a State and local level in evolving balanced services for retarded children and those handicapped children who show a developmental lag.

Through the mechanism of basic formula and special project grants, new and better ways of meeting need and delivering care have been demonstrated. Because of the demonstration nature of the programs, they do not provide total services for an area or community.

### **I. BASIC HEALTH AND SUPPORTIVE SERVICES**

#### **Maternal and Child Health Services**

Section 501, Title V, Social Security Act, authorizes annual formula grants to the States to extend and improve health services for mothers and children, especially in rural areas.

These are basically programs to improve nutrition, prevent ill health and infectious disease, safeguard the period around pregnancy, and minimize health hazards by identifying them as early as possible. State maternal and child health programs included some of the following services for fiscal year 1970:

- Maternity services to 529,000 mothers.
- Well Child Conferences, serving 1,473,800 children.

- Hospital inpatient care for 44,000 infants born prematurely.
- Nursing services to 2,391,000 children.
- Dental treatment for 736,392 children.
- Vision screening for 8,996,000 children.
- Audiometric testing for 5,816,000 children.
- Dental screening for 2,472,000 children.
- Children received over 15 million basic immunizations.

### **Crippled Children's Services**

Section 501, Title V, Social Security Act, authorizes annual formula grants to the States to find children who are crippled or who are suffering from conditions leading to crippling, and to provide them with medical, surgical, corrective and other services.

A total of 491,855 children, or slightly more than 6 out of every 1,000 children in the population, received physician's services under State crippled children's programs in 1970. Nearly 34 percent of the children seen were new patients.

Children between 5-9 years of age comprised the largest users of the program (30.1 percent), with the next largest groups those between 1-4 years (25.7 percent) and 10-14 years (22.9 percent).

Congenital malformations accounted for a fifth of all conditions noted, and more than 18 percent of the children served were reported to have multiple conditions.

### **Clinical Services**

Clinical services for mentally retarded children operating in all but three States include diagnosis, evaluation of a child's capacity for growth, the development of a treatment and management plan, interpretation of findings and counseling of parents, and follow-up care. Mental retardation clinic services were provided for over 60,000 children through 243,000 clinic visits in 154 clinics supported by MCHS funds during FY 1971.

Children are being seen at these special clinics at an earlier age as a result of multiple screening procedures carried out by the State maternal and child health programs. Approximately 30 percent of the children seen in clinical programs were 5 years of age or under, and 3 out of every 4 children seen were under 10 years of age.

New patients numbered 28,000. These clinical programs fulfill a major function of "unlabeling" children referred as mentally retarded. Slightly over 8,500 children were found not to be retarded.

## **Multiply-Handicapped Children's Clinics**

Ten specialized clinical programs for multiply-handicapped children provide comprehensive services for children with a multiplicity of handicapping conditions including mental retardation. They are models for the type of staffing and services required to meet the total needs of children in a single setting.

## **Genetics Program**

Projects supported with earmarked CC funds provided cytogenetic and biochemical laboratory services as extensions of clinical services at hospitals or medical schools. On the basis of these analyses, counseling is given to parents seeking advice on genetic questions.

## **II. PREVENTIVE SERVICES**

### **Maternity and Infant Care Projects**

Section 508, Title V, Social Security Act, authorizes grants for projects to help reduce the incidence of mental retardation and other handicapping conditions caused by complications associated with child-bearing and to help reduce infant and maternal mortality by providing necessary health care to high-risk mothers and their infants.

Maternity and Infant Care projects were located in 35 States, the District of Columbia and Puerto Rico. While more than 60 percent of the Maternity and Infant Care projects serve cities of 100,000 or more, projects are also located in rural and urban-rural populations in such States as Alabama, Georgia, Florida, Arkansas, Idaho and others. All the projects serve localities which have shown higher infant and maternal mortality rates than the Nation as a whole.

According to provisional data, a total of 141,000 new maternity patients were admitted to the M & I projects during FY 1971, representing a 9.6 percent increase over 1970, with about 60 percent of women admitted for care being black.

### **Inborn Errors of Metabolism**

Phenylketonuria (PKU), an inborn error of metabolism, has in the past been responsible for 1 percent of the population in the State institutions for the mentally retarded. By detecting families with the condition and by providing young infants with the condition with a special diet, mental retardation usually can be prevented. MCHS works with State

health departments in developing the necessary laboratory facilities and assisting States to provide special diets and follow-up services for these families.

During the past year, approximately 90 percent of the newborns in the 50 States and the District of Columbia were screened. This screening effort by the States turned up approximately one confirmed case for every 16,000 live registered births.

MCHS is continuing to support a study of the clinical application of screening tests to detect galactosemia, maple syrup urine disease and histidinemia. Support is also being given to studies of new approaches to broader screening methods which would make available a battery of automated tests for detecting metabolic diseases.

### **Lead Poisoning**

In addition to activities planned by the Bureau of Community Environmental Management under authority of P.L. 91-695, the States, supported by Maternal and Child Health Service grants, continue to carry out a considerable program of identification, treatment and management of children with lead poisoning.

### **Rubella**

Many of the babies born with birth defects resulting from the rubella outbreak of 1964 and 1965 are showing evidence of mental retardation or other handicaps. States are encouraged to use MCHS funds to complete the immunization of children against rubella as part of the national campaign spearheaded by the Center for Disease Control.

## **III. TRAINING**

Under Section 511, Title V, Social Security Act, grants are made for the training of personnel in health care and related services for mothers and children, particularly mentally retarded children and children with multiple handicaps.

Training activities are also supported by funds authorized under Sections 503 and 504 of Title V for projects which may contribute to the advancement of maternal and child health and crippled children's services.

### **University-Affiliated Centers**

The program designed to provide comprehensive multidisciplinary training of specialists who will work with the handicapped and retarded



## **CENTER FOR DISEASE CONTROL**

### **Rubella Immunization**

In 1964 and 1965 a major rubella epidemic occurred in the United States, and was responsible for the birth of approximately 20,000 children with congenital rubella syndrome. The economic cost from this pandemic is estimated to be \$1.5 billion. Most of these costs were for special educational services, institutional care for retarded rubella babies, and direct medical care for the diagnosis and treatment of children with congenital rubella syndrome.

Following the licensure of a live rubella virus vaccine in 1969, the Center for Disease Control provided the leadership in coordinating a nation-wide rubella immunization program supported by Federal grants. The initial emphasis was placed upon immunizing young school age children, who are the primary reservoir of rubella virus and most responsible for its spread in the community. Further vaccination of preschool children and of susceptible non-pregnant postpubertal women is recommended.

More than 70 percent of the primary target group has now been immunized against rubella. Total rubella immunizations as of December 31, 1971, now approximate 32 million. Over 25.1 million of these were administered in public immunization programs.

The number of reported cases of rubella has declined substantially each year since introduction of vaccine.

### **Measles Immunization**

The number of measles cases reported during the 1970-1971 epidemiological year exceeded 77,000 and was almost double the number reported in 1969-1970. Data from the 1970 U.S. Immunization Survey indicated that the measles immunization level had decreased from its 1969 level.

During 1971, funds were redirected permitting the Center for Disease Control to support State and local health agencies in measles control programs. As a result, the distribution of measles vaccine increased significantly during 1971. A total of 6.0 million doses were distributed in 1971, the largest number for any year since 1967 and a 23 percent increase over 1970. The Center for Disease Control distributed more than 3 million doses of measles vaccine in 1971.

This increase in measles vaccine distribution coincided with a decrease in the incidence of measles. The number of reported measles cases during the first 16 weeks of the 1971-1972 epidemiological year decreased 42 percent from the number reported during a similar time period one year ago.

In addition, data from the 1971 U.S. Immunization Survey indicated that the immunization level against measles increased significantly from its 1970 level. This increase was most striking among preschool age children residing in poverty areas of large cities, where the level of immunization increased by more than 18 percent in one year.

There are still many areas in the United States where satisfactory immunity levels to measles have not been achieved. For the disease to be controlled in the United States the immunity level should be increased to 80-90 percent for all preschool and young school age children and sustained at that level. When this has been achieved, measles will no longer be a major public health problem and measles encephalitis with its associated mental retardation should occur only rarely, if at all.

### **Western Encephalitis**

The Center for Disease Control conducted a follow-up study in Hale County, Texas, on the residual serologic effects of western encephalitis. The study consisted of extensive serologic, psychologic, and intelligence testing to ascertain the presence of abnormalities, particularly with reference to learning ability. The results show that 12 of 35 persons with western encephalitis suffered residual brain damage. Nine of the 12 cases with sequelae were less than one year old and eight had moderate or severe brain damage. Three of these required institutional care and three others were almost totally disabled. This indicates a high risk of severe brain damage for any children under one year of age who have western encephalitis. The estimated long-term cost for a single epidemic year of encephalitis in Hale County exceeds \$300,000.

### **Quarantine Activities**

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 Center for Disease Control is responsible for the review of findings in such cases and the decision on waiverability and on the suitability of proposed care. Care is provided by specialists or by appropriate public or private facilities.

For those mentally retarded aliens admitted to the United States, the Public Health Service reviews arrangements for care in this country. Semiannual reports showing the level of care and progress are required and kept on file at the Center.

## **INDIAN HEALTH SERVICES**

### **Prevention of Organically-Based Mental Retardation**

The prevention of mental retardation caused by organic factors is best accomplished by continuous, comprehensive, and high quality medical care of 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.

The Indian Health Service provides comprehensive medical care during the prenatal, intrapartum, and postnatal periods.

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.

Where genetic counseling 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.

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.

An active family planning program is conducted by the Indian Health Service. Nineteen percent of the Indian women ages 15-44 were provided family planning services in 1971.

### **Indian Health Training Program**

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.

### **HEALTH CARE FACILITIES SERVICE (HILL-BURTON PROGRAM)**

Mental retardation facilities have been eligible for and have received construction assistance from the Hill-Burton program since its inception

twenty-five years ago. Up until the passage of the "Mental Retardation Facilities Construction Act" (1963)—P.L. 88-164, Title I, the Hill-Burton program was the primary source of Federal assistance for retardation construction. Since the advent of the specific construction programs for retardation facilities, the Hill-Burton program has been acting primarily as a backup resource for construction aid. As of June 30, 1971, a total of 90 retardation facilities have been constructed. Hill-Burton personnel in both the regional H.E.W. offices and in the State Hill-Burton agencies have provided expert consultation to the retardation facility programs and to many retardation project sponsors or potential sponsors.

# 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. The search for solutions embraces investigations into the causes, means of prevention, and methods for amelioration of mental retardation. The solutions are concerned with biological, psychological and social factors, acting singly and in interaction, as these shape the course of individual development over the life-span.

Because of the magnitude and complexities of the problem of mental retardation, it is not unexpected that two Institutes at the National Institutes of Health have a major and direct interest in this problem and give wide support to research and training activities in this field. These are the National Institute of Child Health and Human Development and the National Institute of Neurological Diseases and Stroke. Moreover, fundamental research conducted by other Institutes and Divisions of the National Institutes of Health contribute substantially, though less directly, to the ultimate resolution of the problem.

The National Institute of Child Health and Human Development's activities are authorized by the Public Health Service Act, as amended, Sec. 301 (c), 308, 394, 402(d), 412(g), 422(c), 433(a), and 444. National Institute of Neurological Diseases and Stroke activities are authorized by the Omnibus Research Act, P.L. 692, Sec. 431 and Sec. 432, 81st Congress, Act 1, 1950, as an amendment to PHS Act, P.L. 410, 78th Congress, 1944.

## 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 continually main-

tained 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.

#### **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. 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 pre-doctoral candidates through post-doctoral trainees with several years of professional experience.

In addition, fellowship and research career development awards cover basic biology, clinical medicine, and behavioral studies.

#### **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 competent clinical and basic 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 research training in pediatric neurology, the specialty 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.

## **II. RESEARCH**

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

The National Institute of Child Health and Human Development sponsors research over a broad range from almost every branch of the

physical, biological, psychological, social and clinical sciences. These investigations are concerned with the etiology, epidemiology, pathophysiology, diagnosis, prevention and amelioration of mental retardation. Of primary Institute concern are fundamental inquiries into the causes and means of preventing mental retardation through research into the biological and behavioral processes which may be influential in the development of this disorder. The Institute's research attack on this complex disorder is implemented through a program of research grant support, the creation and support of special research facilities and resources, the dissemination of scientific information through support of scientific conferences, and contract support of research designed to accomplish specified research objectives.

The attack on mental retardation has been strengthened by the development of twelve special research facilities. These Mental Retardation Research Centers were designed to conduct broad interdisciplinary research and to move promptly to apply the results in service programs to prevent mental retardation or help those already afflicted.

These twelve centers provide the major research thrust of our Nation's efforts to combat and prevent mental retardation and related disorders of human development. All but one of the centers have completed their construction and nearly all are fully operational. Collaborative and interdisciplinary research and research training programs are evolving as laboratory space is occupied and scientific exchange is enhanced.

NICHD-supported scientists are making progress in a wide variety of investigations. These include:

- Intensive study of metabolic abnormalities in storage disorders which has made prenatal diagnosis and therapeutic abortion possible.
- Study of dietary therapy in PKU indicating it must start in the first three weeks of life and may be discontinued after average treatment time of 50 months.
- The development of a screening instrument for early detection of handicapped children which may be used by health aides in poverty areas.
- Studies in intrauterine undernutrition and the nutritional status of migrant children.
- A simple, quick, and accurate method to identify each human chromosome will make diagnosis of chromosomal defects more precise.
- Kidney transplantation may provide a possible means of controlling certain inborn errors of metabolism.
- The development of an automated system of chromosomal analysis using computer technology.

- Modification of available measures and development of new procedures to assess the relationship between hearing impairment and language disability.

The National Institute of Child Health and Human Development disseminates scientific information through scientific conferences. Institutes were held on Antenatal Diagnosis, Human Sexuality and the Retarded, and Methodological Approaches to the Study of Brain Maturation and Its Disturbances.

### **National Institute of Neurological Diseases and Stroke (NINDS)**

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 Perinatal Research Project of the NINDS has made and recorded detailed observations on some 58,000 pregnancies. Most of the surviving children have been given a series of tests until eight years of age, or at least through the first year of school.

The study is producing information about the distribution of characteristics such as serum immunoglobulin levels, the consequences of elevated neonatal bilirubin levels, the distribution of physical and intellectual measurements, and the frequency of certain abnormal conditions. The importance of low birthweight as a determinant of perinatal death, neurologic abnormality, and intellectual development has been one of the study's key findings to date.

Some 500 papers have come out of the study, which was begun in 1959, and the first major publication, a volume entitled *The Women and Their Pregnancies*, will be out within the next few months. A second major volume, also in preparation, will describe the infants, their nursery characteristics, and medical and developmental events during the first year of life.

Among the 1,500 genetic disorders which can afflict man are the inborn errors of metabolism usually due to a missing or faulty enzyme. Of the approximately 200 known inborn errors of metabolism—many of which cause severe mental retardation and often early death—about 40 can now be diagnosed before birth by tests on the amniotic fluid and its cells.

Although only a small number of these disorders are amenable to therapy, many of them are preventable through genetic counseling because prenatal diagnosis and carrier detection are possible.

All of the nine known lipid storage diseases, for example, can be



## **SOCIAL AND REHABILITATION SERVICE**

### **Introduction**

On August 15, 1967, the Social and Rehabilitation Service was established by the Secretary, Department of Health, Education, and Welfare, to join under a single leadership income support programs for needy Americans and the social and rehabilitation programs, including services for the mentally retarded.

Five of the eight major components of the Social and Rehabilitation Service have responsibility for providing income maintenance, medical services, social services, and rehabilitation services for the economically, physically, and mentally handicapped. These bureaus and offices administer the legislation concerned with the care and provision of services for retardates and their families as follows: Assistance Payments Administration, Social Security Acts, Titles I; IV, Part A; X; and XIV; Medical Services Administration, Social Security Act, Title XIX; Community Services Administration, Title IV, Parts A and B; Office of Planning, Research, and Training, Title VII, Section 707 and Title XI, Sections 1110 and 1115; Rehabilitation Services Administration, the Vocational Rehabilitation Act of 1965, as amended, the Developmental Disabilities Services and Facilities Construction Act of 1970, and various other Acts or portions of Acts such as the Public Health Service Act, concerned with the health and welfare of the mentally ill or retarded. Following is a description of the Social and Rehabilitation Service's efforts on behalf of the mentally retarded.

### **ASSISTANCE PAYMENTS ADMINISTRATION**

The Assistance Payments Administration has primary responsibility for grants to States for public assistance programs under the Social Security Acts, Title I, Old-Age Assistance; Title IV, Part A, Aid to Families with Dependent Children and Emergency Welfare Assistance; Title X, Aid to the Blind; Title XIV, Aid to the Permanently and Totally Disabled. It is in the program of Aid to the Permanently and Totally Disabled that Federal financial participation is available to help needy individuals who also may be mentally retarded through State-administered or -supervised public welfare programs.

Mentally retarded persons eligible for money payments under the "Aid to the Permanently and Totally Disabled" program account for about 16 percent of all APTD recipients.

### **MEDICAL SERVICES ADMINISTRATION**

The Medical Services Administration administers Title XIX of the Social Security Act as amended—Grants to States for Medical Assistance Programs—popularly called Medicaid. Mentally retarded individuals receive the same benefit in medical care as any other medical assistance recipient. The amount and scope of the services depends on the individual State plan.

Sixteen States and the District of Columbia make claims through Title XIX for care in hospitals or skilled nursing units in State institutions for the mentally retarded. Nine States also claim funds for medical services to the mentally retarded in skilled nursing homes outside of State institutions.

The 1971 amendments to the Social Security Acts rescinded Section 1121 of Title XI of the Acts, and transferred the responsibility for Intermediate Care Facilities to Title XIX, Section 1905. Section 1905 specifies that Intermediate Care Facilities shall be available for the mentally retarded or persons with related conditions if the facility provides health or rehabilitative services. It also specifies that care shall be provided for the mentally retarded in public institutions—an intermediate care facility being defined as an institution which provides services less than a skilled nursing home, but is somewhat more than a boarding home.

### **COMMUNITY SERVICES ADMINISTRATION**

The Community Services Administration has responsibility for administering the Social Services program under Title IV, Part A, and Child Welfare Services under Title IV, Part B of the Social Security Acts.

The Social Services program provides services to families and children receiving Aid to Families with Dependent Children money payments and to former or potential recipients at the option of the State. Social services related to mental retardation may include day care services, foster care, protective services to reduce child abuse, as well as prenatal services to unmarried mothers.

The basic purpose of the Child Welfare Services program is to protect children from abuse, neglect, exploitation, or delinquency and to assure that they have an opportunity for normal development and an adequate home life. Mentally retarded children benefit from services provided. Child Welfare Services that are rendered to retardates and their families

include: parent counseling, homemaker services, day care services, foster family care, care in group homes, adoption services, services to unmarried mothers, and certain institutional pre-admission and after care services.

During fiscal year 1973, approximately 43,000 mentally retarded children will receive services under the Child Welfare Services program and 456,000 will receive services under the Social Services program.

#### **OFFICE OF PLANNING, RESEARCH AND TRAINING**

Accurate appraisal of the abilities of retardates is a crucial first step in the rehabilitation process leading to competitive employment, increased earnings and independent community living. As services are extended into ghetto areas to reach more and more of the functionally retarded whose handicaps derive from social and cultural deprivation, it becomes increasingly necessary to refine techniques of social, educational and vocational training most likely to help a retardate achieve full participation in the economic and communal life of the country. Precise evaluation of individual potentials and the effectiveness of various rehabilitation approaches is an equally important prerequisite for development of innovative patterns of service to the profoundly retarded.

Future projects will be concerned with improved delivery of services to retardates in Model City neighborhoods. A new emphasis will be on rehabilitation of the retarded delinquent. Community organization projects will demonstrate in several Model Cities ways of involving parents of retardates in the rehabilitation process.

Complementing domestic programs, international research in mental disabilities will emphasize projects dealing with non-institutional rehabilitation of the mentally retarded and the mentally ill.

This Office also administers selected demonstration projects that seek to coordinate community resources for the mentally retarded. Rehabilitation research and training centers for the mentally retarded provide for the diagnosis, evaluation, treatment and training, vocational counseling and placement of the mentally retarded.

#### **REHABILITATION SERVICES ADMINISTRATION**

The Rehabilitation Services Administration is responsible for a broad range of programs designed to provide rehabilitation services for the developmentally disabled including the mentally retarded. These programs cover support for planning, administration, services and the construction of community facilities through formula grants to States as well as support project grants designed to reduce the resident population in large State institutions for the retarded by making available specialized community

services and by increasing the use of generic services. Also included are grants for: core support of interdisciplinary training programs in university-affiliated facilities for manpower needed in care and treatment of the developmentally disabled; improvement of services in State residential facilities for those retarded who are appropriately placed; training of professional, supportive and technical personnel already engaged in occupations involved in the care and rehabilitation of the developmentally disabled; planning and construction of rehabilitation facilities and sheltered workshops; special projects for expansion and innovation of vocational rehabilitation services.

These diverse activities are unified by the common goal of assisting the developmentally disabled, including the mentally retarded, 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 opportunities and resources available to the substantially handicapped among the developmentally disabled.

## **I. DEVELOPMENTAL DISABILITIES**

### **Formula Grants to States**

The Title I, Part C of the Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517), which amended the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1973 (P.L. 88-164), authorizes formula grants to States for comprehensive planning, administration, services and construction for the developmentally disabled. The 1963 Act limited Federal support to facilities and programs for the mentally retarded. The 1970 Act extends support to include not only mental retardation but also cerebral palsy, epilepsy and other neurological conditions approved by the Secretary. The Developmental Disabilities Act calls for Federal, State and local governments and voluntary agencies to share responsibilities for establishing and maintaining programs that will enable the developmentally disabled to: (1) enhance their physical, intellectual, and social capabilities to the fullest extent possible; (2) gain emotional maturity commensurate with social and intellectual growth; and (3) attain whatever possible skills, habits, and attitudes essential to living a personally satisfying life.

The Act provides for the co-mingling of funds under this program with those of other State programs. This facilitates the development of comprehensive services through the combination and integration of efforts in both specialized and generic services of several State agencies representing diverse areas such as health, welfare, education and rehabilitation, yet not imposing a set pattern of services.

Comprehensive planning of needed services and facilities providing for more efficient and effective utilization of existing human and fiscal resources at all levels must be set forth in a State plan. New or innovative programs will be developed to fill gaps in existing services and to expand them so as to reach new groups of individuals. The goal is integration of services and resources to assist the developmentally disabled at all levels—State, regional, and local.

The State Plan must include a description of how other State-Federal programs provide for the developmentally disabled and how the new program will complement and augment, and not duplicate, these programs. At least 9 programs must be taken into account: vocational rehabilitation, public assistance, social services, crippled children's services, education for the handicapped, medical assistance, maternal and child health, comprehensive health planning, and mental health.

### **University-Affiliated Facilities for the Developmentally Disabled**

Under Title I, Part B of the Developmental Disabilities Services and Facilities Construction Act of 1970, the University-Affiliated Facilities for the Developmentally Disabled Program provides for Federal support for interdisciplinary training in institutions of higher learning as well as for the construction of facilities to house these programs. Multiple resources of Maternal and Child Health Service, Office of Education, and other State and Federal programs are utilized in support of training programs. University-affiliated facility grants may be made to cover the costs of administering and operating the facilities.

Among the professional disciplines trained 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 program so that each discipline involved in the habilitation and rehabilitation of the developmentally disabled may be fully familiar with the contributions of the other disciplines.

Approved projects for the construction of university-affiliated facilities for the developmentally disabled 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 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; Ohio State University, Columbus, Ohio; and the Children's Hospital, Cincinnati, Ohio. One additional center, University of Washington, Seattle, Washington, received funds from Title I, Part A of the Act.

### **Project Grants for Rehabilitation of the Mentally Retarded**

The purpose of project grants administered by the Division of Developmental Disabilities 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 increasing the number and types of specialized personnel working with the retarded.

The activities undertaken should be directed towards the goal enunciated by the President in November 1971 of reducing the population in residential institutions. In particular these would be directed toward reducing overcrowdedness by (a) finding alternative services for those inappropriately institutionalized; (b) preventing inappropriate admissions by serving the waiting lists; (c) preventing readmission through a variety of supportive services; (d) revitalizing rehabilitation programs for those appropriately placed in institutions with the goal of discharge as soon as possible; and (e) training institutional and community personnel to carry out the above activities.

### **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 eligi-

ble to apply for these grants. 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).

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. Demonstration projects for 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.

### **Hospital Inservice Training**

The Hospital Inservice Training program provides a means for increasing the effectiveness of employees in State residential institutions for the mentally retarded.

Because personnel such as attendants, house-parents, 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.

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.

### **Collection and Dissemination of Information**

*Mental Retardation Abstracts* is a specialized mental retardation abstracting and information service published by the Division of Developmental Disabilities, 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.

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

## II. 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, pre-vocational 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 seen dramatic advances in the provision of vocational rehabilitation services to the mentally retarded. The retarded now comprise about 14% of the people rehabilitated from all categories of disability by the State-Federal program of vocational rehabilitation. In 1972, about 43,700 retardates will be rehabilitated.

Another emphasis of State vocational rehabilitation agencies has been the establishment of rehabilitation facilities, such as comprehensive rehabilitation centers, evaluation centers, occupational training centers, workshops, half-day houses, and other specialized facilities serving the mentally retarded. Such a rehabilitation facility may be established by State rehabilitation agencies 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.

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. Expansion grants are designed specifically to increase the number of people rehabilitated by the State agency.

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.



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.

### **III. REHABILITATION TRAINING**

Rehabilitation training in mental retardation has focused on social work and rehabilitation counselor training by supporting field units in which student trainees could concentrate their practicum experience in work with this client population. Such grants also support field instructional faculty. Fiscal year 1972 expenditures reflect a phasing out of this type of training grant support in response to new SRS training grant policies and procedures which consolidate support for special focus training and basic training in the same professional field into a single grant. In addition to this form of support, the Rehabilitation Services Administration will continue in FY 1973 to support multidisciplinary programs in select teaching-research-service centers.

## **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 seven 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 1971, an estimated 175,500 mentally retarded adults disabled in childhood received \$173 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.

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. Reports on demographic characteristics, costs of care, and economic resources have been published, and a report on financial administrators will be published in the summer of 1972. A monograph summarizing all findings will be available in 1973.

## 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 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.

In the Bureau of Drugs, the Office of Scientific Evaluation monitors the investigational use of new drugs in early testing phases.

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.

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.

## SURPLUS PROPERTY PROGRAM

The Office of Surplus Property Utilization, within the Office of the Assistant Secretary for Administration and Management, 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 education 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.

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 non-profit 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 non-profit 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., de-

voted 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.

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.

Schools for the mentally retarded operated by State and local agencies of government as well as many nonprofit schools operated by Associations for the Mentally Retarded or Cerebral Palsy are major users of surplus personal properties acquired through the State agency distribution center of their State.

## Obligations for Mental Retardation Programs

Fiscal Years 1971-1973  
(Thousands of Dollars)

ACTIVITY	1971	1972 (Est.)	1973 (Est.)
<b>OFFICE OF EDUCATION</b>			
Services	\$ 67,820	\$ 74,610	\$ 77,354
Training	11,900	11,900	12,320
Research	1,420	1,600	1,664
Other	69	69	69
Total	\$ 81,209	\$ 88,179	\$ 91,407
<b>HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION</b>			
Services	\$ 13,148	\$ 19,739	\$ 21,479
Training	17,312	19,683	19,923
Research	2,299	2,299	2,299
Other	2,395	1,300	1,300
Total	\$ 35,154	\$ 43,021	\$ 45,001
<b>NATIONAL INSTITUTES OF HEALTH</b>			
Training	\$ 7,474	\$ 7,515	\$ 7,515
Research	18,397	21,524	22,835
Total	\$ 25,871	\$ 29,039	\$ 30,350
<b>SOCIAL AND REHABILITATION SERVICE</b>			
Services	\$206,918	\$240,346	\$347,950
Research	897	1,000	1,050
Training	5,424	5,188	5,007
Construction	16,383	6,109	4,886
Income Maintenance	97,000	114,000	132,000
Other	817	7,978	7,247
Total	\$327,439	\$374,621	\$498,140

# Obligations for Mental Retardation Programs

Fiscal Years 1971-1973  
(Thousands of Dollars)  
(Continued)

ACTIVITY	1971	1972 (Est.)	1973 (Est.)
<b>SOCIAL SECURITY ADMINISTRATION</b>			
Income Maintenance	\$175,355	\$194,597	\$208,838
<b>OFFICE OF THE SECRETARY</b>			
Office of Child Development Head Start	\$ 4,270	\$ 4,462	\$ 4,462
Office of Mental Retardation Coordination	(110)	115	118
President's Committee on Mental Retardation	550	635	635
	<u>\$ 4,820</u>	<u>\$ 5,212</u>	<u>\$ 5,215</u>
Total, Grants and Services	\$377,493	\$426,072	\$538,113
Total, Income Maintenance	\$272,355	\$308,597	\$340,838
<b>GRAND TOTAL</b>	<b>\$649,848</b>	<b>\$734,669</b>	<b>\$878,951</b>