

Rep. John E. Fogarty
American Association on Mental Deficiency
Newport, Rhode Island, Oct. 19, 1960

I was very pleased when Dr. Smith invited me to be with you this evening because I have had a long and active interest in the cause to which you are devoted. During my score of years as a representative of the good people of Rhode Island in Congress, and as chairman of the House subcommittee on labor, health, education, and welfare appropriations, I have been privileged to participate in the attack upon the grave problems of mental deficiency.

As dedicated professionals you appreciate the possibilities of reducing mental retardation that are indicated by general scientific advances in recent years. As a delegate to the World Health Assembly, I had the privilege of supporting the "Bill of Rights" for exceptional children. As Chairman of the subcommittee of Congress concerned with this, I am grateful for the opportunity to put this humane policy into practice by helping to initiate and to expand our Government's programs to combat mental retardation and to rehabilitate our retarded children and adults.

For years few handicapping conditions were as neglected as mental retardation. Only in recent years has there been a concerted effort to meet the problem. Your group typifies the change in the old, hopeless attitude that long stifled progress. Fortunately, today there is greater knowledge, and greater motivation, toward meeting and overcoming the problems presented by retardation.

An increased birth rate, a decrease in infant deaths, and a longer life span have caused a rise in the number of mentally retarded persons. Current estimates are that of more than four million children

born annually in the United States, about 3 percent (126,000) will never achieve a 12-year old's intellect; 0.3 percent (12,600) will remain below the 7-year level; and 0.1 percent (4,200), if they live, will be completely helpless. It is estimated that there are 5 million retarded persons in our country.

Of the total retarded, only 4 percent are in State hospitals or schools. The cost to the States is one-quarter billion dollars annually. We do not know the cost of maintaining the 5 percent who are in private institutions. Nor do we know the cost borne by individual families and local communities of the special care for the 91 percent who are not institutionalized. It is unlikely that any other form of disability in this country equals impairment of mental ability, in its toll of economic uselessness and human misery.

Associations such as yours provide inspiration to those professional people engaged in the many medical, social, educational, and economic programs arising from physically and mentally crippling conditions. You are the voice of the public prompting the local, State, and Federal legislatures. You are the public's conscience bestirring our people to support greater efforts to control the disability and to aid the handicapped.

Congress has responded to the public's growing demands. In cooperation with State, local, and private agencies, the Federal government is engaged in a campaign against mental retardation and similar chronic

disorders on a broad front. Numerous services and programs are helping these persons function better and are thereby decreasing the effects of mental subnormality.

Most of the Government's programs on retardation are administered by the Department of Health, Education, and Welfare. These programs provide services for the retarded; they prepare professional personnel; and they provide for medical research and scientific studies.

In all of these activities the Federal Government cooperates with voluntary organizations and State agencies through grants, publication of special reports, technical consultation services, and information services.

Under Federally aided programs, vocational rehabilitation service now is available to the retarded on the same basis as it is to other handicapped persons. The Office of Vocational Rehabilitation is constantly studying ways of evaluating individual capacity and equipping the retarded for gainful employment.

Using the information and techniques furnished by the Government, state agencies expect to rehabilitate more than 2,000 retarded persons during this year. The Federal Government's cost share of this project is \$1,500,000.

Your Association cooperated with the Office of Vocational Rehabilitation and the Office of Education in a mental retardation project which produced a much-needed manual, entitled Preparation of Mentally Retarded Youth for Gainful Employment.

Only 25 percent of the retarded children and youth in the Nation are receiving the special education they require. We need 65,000 teachers qualified to train all the retarded children. This is four times the number now available. Two years ago, for the first time, Congress enacted a law (Public Law 85-926) to provide this instruction. The law, which I was privileged to sponsor in the House, provides \$1 million for recruitment of college instructors to train teachers of the retarded, and for supervision of special educational programs.

Under this law, last year the Office of Education made grants to colleges and universities and established 100 fellowships to train supervisors for work in State and local educational programs. It was the first Federal aid specifically for special education for the retarded.

In addition to education and rehabilitation, some help in defraying living needs is supplied by the Social Security Administration's Children's Bureau, its Bureau of Old Age and Survivors' Insurance, and its Bureau of Public Assistance.

The Children's Bureau collects information on the needs of retarded children, makes technical consultation available to the States, ^{and aids} ~~furnishes~~ demonstration projects through grants. Since 1957 the Maternal and Child Health appropriation has contained annually \$1 million dollars earmarked as grants for special projects for retarded children. Smaller grants were made available by the Crippled Children's Services and Child Welfare Services. Recent amendments to the Social Security Act (Public Law 86-778),

include increased funds for maternal and child welfare. This will permit an expansion in the number of child welfare workers, with more workers equipped through special training to help the retarded.

Amendments to the Social Security Act in 1956 and 1957 made it possible for the Bureau of Old Age and Survivors Insurance to make benefit payments to disabled children of such recipients. These benefits include payments beyond the age of 18 if the disability began before the person reached 18. The mentally retarded are heavily represented among those who qualify for children's benefits based on disability.

These are only some examples of how the Federal Government, working with many private agencies, voluntary organization, and state governments, supports services to the mentally retarded in the way of health and welfare programs, vocational guidance, special education, and other needed assistance.

The problem of mental retardation is being approached in another-- and very vital--way. Congress has marshaled substantial resources behind a massive research effort to discover the causes of retardation and to find methods of prevention. I think we all recognize that the ultimate hope lies with medical research.

In the Department's Public Health Service, the primary responsibility for the research programs rests with two of the seven National Institutes of Health at Bethesda.

When Congress established a National Institute of Neurological Diseases and Blindness a decade ago, it launched a national research attack on disorders of the nervous system, including mental retardation.

Many of you know about the Institute's exciting 10-year project in which it is collaborating with 15 other research institutions in a unique study of 50,000 mothers and their children. This study will follow the participating mothers from pregnancy through delivery and their children from the moment of birth until age six.

The big hope is to discover what things go wrong during pregnancy, childbirth, or early in a child's life that may trigger mental retardation and other chronic neurological disorders. Information that comes from this study is expected to disclose causes not yet known, or even suspected.

Besides causes originating during pregnancy and infancy, medical investigation of retardation follows four other major avenues: studies in heredity; investigation of jaundice, asphasia and injury to the newborn; detection of biochemical ailments causing the disorders; and the relation of encephalitis and other early infection to the condition.

Perhaps you are familiar with some of these developments in research:

It has been found that jaundice of the newborn infant, or kernicterus ^{+ other para-natal} once caused 1 percent of admissions to institutions for the mentally defective. This condition is being combatted by exchange transfusion replacing the baby's blood.

Cretinism is being prevented by counteracting the mother's iodine deficiency during pregnancy, or by giving the baby thyroid hormone if it is born with a defective thyroid gland.

A simple mass screening test has been developed to detect phenylketonuria, ^{P.K.U.} an inborn metabolic error that allows an excess amount of phenylpyruvic acid to build up in the body and cause mental retardation.

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A simple diet, eliminating certain proteins, has been developed to alter the output of this acid. Similar biochemical defects are being treated by therapeutic diets, and hopes are that more disorders causing mental retardation may also be amenable to dietary treatment.

In heredity studies, mongoloids were found to have 47 chromosomes instead of the standard 46, suggesting an irregularity in the human egg before it is fertilized.

These scientific findings have focused research upon the 10-year perinatal project.

The National Institute of Neurological Diseases and Blindness has other important projects concerning mental retardation besides its long-term collaborative one. In its own laboratories, the Institute is working on microscopic and chemical studies of the brain and central nervous system. Examination of the brains of children and adults known to have been mentally retarded is tremendously important to uncovering new clues to the answers neurophysiologists are seeking.

These observations in human adults and children are being paralleled by animal experiments in which deliberate efforts to produce a mentally retarded animal have been undertaken. For example, in the perinatal project in Puerto Rico, infant monkeys have been subjected to asphyxia. These animals, when severely afflicted, suffer from cerebral palsy. In milder states, they exhibit a clear-cut state of mental retardation. This information enables researchers to direct their studies toward similar causative conditions in humans.

Important research related to exceptional children is also being done by the National Institute of Mental Health. This Institute is studying parent-child relationships and other environmental conditions among normal children in order to discover the conditions which promote or impede emotional and intellectual development. Similarly, it is doing research on cerebral metabolism in normal and abnormal individuals in order to gather basic data about the causes of mental defect. It is supporting a study of 600 pairs of twins, one or both of whom have been in an institution for mental deficiency, in order to learn more about the genetic aspects of retardation. Both Institutes, in fact, support a great deal of research in mental deficiency.

In addition, the National Institute of Mental Health has done much to encourage more widespread scientific and professional interest in retardation. Your own Association is a splendid example. Since 1956 it has received a grant for a special project to help it serve more effectively as a clearinghouse for scientific information. The result has been to give the field much needed professional support and channels of communication of new research findings.

About 50 separate research projects in or immediately related to mental retardation are now being supported by the Institute at an annual rate close to one-and-a-half million dollars. The rate of support depends primarily on the number of applications of suitable scientific quality. A sharp increase in approved applications has occurred in recent years.

The National Institute of Mental Health is helping to develop and expand community and institutional programs for the retarded. It also

supports the direct training of psychologists and other professional workers, so that they may acquire special competence in dealing with exceptional children.

These programs by no means indicate everything going on in the expanding mental retardation research activities of the two Institutes. But they do suggest some of the divergent areas in which scientists look for the answers.

I can remember that a little more than 10 years ago less than a million dollars a year was being invested in research into mental retardation by all sources in the Nation. Compare this to ~~more than~~ ^{NEARLY} ~~\$11 1/2~~ ^{20 Million} million dollars which the two Institutes alone estimate they will spend this year on research and allied programs concerning mental retardation. The desire of the people, of course, to deal with a complex health problem has given great impetus to this mounting tempo of research endeavor.

The past decade has brought an increasing public interest in promoting the health of all our people and in combatting mental retardation. Federal legislation has been the mainstay of many services for the retarded. In cooperation with the States, the Government led in rehabilitating what had been regarded as useless lives; it encouraged education of those citizens earlier believed incapable of learning; it helped lessen the economic dependency of man on local and state institutions.

The Government also signalled a continuing crusade against an undiscerned foe. It is using every known tool of medical and scientific research to ferret out more of the reasons for retardation and to eradicate them.

Many facts known which we did not know 10 years ago, many more welfare workers and more educators and researchers have been trained and are now working on the problem.

And--not the least--a growing number of dedicated persons such as you and your fellow professional volunteers are helping to improve the welfare of the retarded. With an increasing number of trained social workers, administrators, teachers, and scientists, we may confidently hope that our joint efforts will eliminate the risk of retardation for future generations.

I want to wish you success in your endeavors, and I can assure you that I, for my part, will continue to pursue our common goal.