

Congressman John E. Fogarty  
R.I. Association for Retarded Children  
June 3, 1962

It gives me great pleasure to be here with you again and to see so many familiar faces. I am particularly pleased to have this opportunity to talk to you about some of the impressive and encouraging work going on in a field that is of immediate concern to all of us here -- mental retardation.

As some of you know, I have just returned from a trip to Geneva, where I had the privilege of attending the Fifteenth World Health Assembly as an advisor to the U.S. delegation. This is the fourth such meeting of the Assembly that I have been able to attend, and it is always a memorable experience.

While I was in Geneva, I had the opportunity to talk to representatives of some 100 nations about the work being done in their countries to improve health. The World Health Organization has placed considerable emphasis on mental health during the past year, and I found all of these people to be particularly interested in hearing about the work being done in this field in the United States.

Most of all, they were interested in hearing about the work being done in this country by voluntary organizations such as your own. Such organizations are rare in most of these countries, and there was great interest in learning about what such groups had been able to accomplish.

You can imagine my pride at being able to point to the work being done right here in my own State and my own home town, Providence, by this organization in helping the mentally retarded and their families. I described the referral and counselling services which this group inaugurated--the sheltered workshop you are operating for 30 mentally retarded individuals--the new medical and rehabilitation center that has been added to the Ladd School--and your support and cooperation with State and Federal government organizations in obtaining the best possible care and assistance for the mentally retarded. I was happy to describe the support organizations such as yours have given for increased medical research into the problems of mental retardation, and some of the important discoveries that are already beginning to come out of research laboratories.

All of you, I am sure, have read about some of the outstanding scientific and medical discoveries that have been made during the past year. One which has received particular attention is the so-called "cracking of the genetic code." These discoveries are vitally important to all of us, for in its investigation of these life processes, science is revolutionizing our understanding of such disorders as mental retardation and its causes. Perhaps someday it will also make possible prevention or cure of these disorders.

For a good portion of my twenty years as a representative of the people of the 2nd District of Rhode Island in our Congress, I have had the responsibility and the privilege of serving as the chairman of the Subcommittee on Appropriations for the Department of Health, Education, and Welfare. Every year, as my committee has held hearings on the budget for the next ~~fix~~<sup>f</sup>iscal year, I and my colleagues have learned much about the important role of medical research in attacking the diseases and disabilities that kill and cripple so many children and adults in this country of ours.

In some cases, I am proud to say, I have had the privilege and opportunity of helping to advance our country's attack on a specific problem by urging broader support by the Federal Government for medical research and training for workers in a particular area.

Mental retardation is such an area. As you know, I have been deeply and personally concerned with the problems of mental retardation for a number of years. This interest was brought to a focus in 1955, when the plight of the mentally retarded children in Rhode Island and throughout our country was described to me in detail by the Parent's Council for Retarded Children of Rhode Island--the group out of which this present organization has grown. The President of the Council at that time was Arthur Trudeau, a friend of mine since school days. He and the other members of this group told me how little was being done in this area, and the difficulties they were facing in obtaining proper medical care and educational opportunities for their children.

When I subsequently learned, during the hearings on appropriations for the Department of Health, Education, and Welfare for the following year, that no Federal funds were specifically allocated to conquer mental retardation, and that in the National Institute of Mental Health only one scientist was working on the problem of mental retardation, I was deeply disturbed. The Committee's report for that year called for a Federal program designed specifically to meet the needs of retarded children. We backed up this directive by appropriating \$750,000 over the budget requests of the National Institutes of Mental Health and of Neurological Diseases and Blindness, and requested that these additional funds be devoted to exploring new approaches to problems of mental retardation.

For each succeeding year since then, the Committee and the Congress have seen to it that increased support was given these programs. And we on the Subcommittee have inquired closely as to the progress being made in this field.

For this reason, I have been particularly gratified by a number of developments which were reported to the Committee in March of this year, during the appropriations hearings for fiscal year 1963.

One of these, of course, was the cracking of the genetic code by a young scientist, Dr. Marshall Nirenberg, at the National Institutes of Health. This discovery has to do with the translation of part of the "genetic code," the hereditary information that controls formation of proteins by the cell. We already know that such diseases as

phenylketonuria and galactosemia--both of which can cause mental retardation--are due to a defect or omission in the hereditary information carried by the individual's genes. Investigators all over the country are already working to translate more of the code.

At these same hearings in March, we were also told about two major accomplishments in connection with the prevention of mental retardation.

One of these accomplishments is the discovery that a special diet will prevent mental retardation in children with phenylketonuria (PKU). It has also been reported that it may be possible to stop this special diet after the child has reached five or six years of age and the brain has matured sufficiently, without any subsequent brain damage or deterioration.

The second accomplishment is the development of a new blood test to monitor how completely milk and milk products are eliminated from the diets of children with galactosemia.

I am aware that these two types of mental retardation are very rare, but the prevention of mental retardation in even a very few children represents a tremendous savings to their parents, to their community, and to the nation--not to mention the heartbreak and tragedy which can be avoided. Moreover, the fact that mental retardation can, in some cases, be prevented will make it possible to gain more ready acceptance for new discoveries still to come.

Another far-reaching and exciting program which we have been following for some time is that developed by the National Institute of Neurological Diseases and Blindness to identify biological and medical factors operating between the time of conception and birth which may have a bearing on congenital defects of the nervous system, mental retardation, cerebral palsy, and congenital blindness and deafness.

This perinatal project, as it is popularly known, involves teams of scientists and physicians in 15 hospitals throughout the country who are using uniform and comparable approaches to the study of expectant mothers from early pregnancy through labor and delivery, and then are examining the children periodically from the time of birth through early school age.

More than 23,000 mothers and 17,000 children are already participating in this project. Eventually the figure will reach 50,000 mothers and their children. It may be 10 to 15 years before definite conclusions can be reached on the basis of the data being collected in this study, but several patterns have already begun to develop. In one of these, scientists have found an association between cigarette smoking and the decreased weight of the baby at birth, which is an important factor in brain damage and death in infancy. What is more, the decrease in weight at birth was found to be proportional to the number of cigarettes the mother smoked daily.

Among the other studies being conducted by NIH scientists in Bethesda and research investigators working under grants from NIH are studies on chromosome abnormalities in mongoloids and in patients with congenital malformations; biochemical and microscopic investigations of the brain and nervous system, and the effects of oxygen deprivation and jaundice in new-born infants.

While it is research discoveries from efforts such as these which more than ever justify the concentration of time, money and people on the study of the biological and medical causes of mental retardation--it is important also to help those children and the parents of those children who already have this disability.

Not very long ago, mental retardation was just something one didn't talk about. Parents with a mentally retarded child were ashamed to mention it. There was practically no research on mental deficiency, and an almost complete lack of training programs.

We've come a long way since then. At the present time we are spending close to \$25 million at the Federal level in the field of mental retardation. I have already mentioned some of the research being done by the Public Health Service through the National Institutes of Health. We now have a 10-year program for the training of teachers of the mentally retarded, and we have aided in the establishment of diagnostic clinics for the mentally retarded. There are 80 of these today, whereas there were none less than 10 years ago.

It was heartening for me to hear, in testimony before the Subcommittee, how much the States themselves have been doing in mental retardation. But I was particularly proud when the State of Rhode Island was given special mention for its program of counselling and referral services--a program which this organization inaugurated and has continued to sponsor in cooperation with the State council of community services. The National Institute of Mental Health is also assisting in this program now to a significant degree, and plans to do so for some time in the future, I was told.

The services to mentally retarded individuals and their families which this program provides are sorely needed in many States, and I feel confident that what you have been able to accomplish in Rhode Island will serve as a model in many other areas. This is a program, as you know, in which I have had a keen personal interest, and I am proud to have been able to assist it.

Today, 48 states have legislation providing for special classes for the mentally retarded in the public schools--twice the number of State programs that existed a decade ago. In 1950, not a single State required local school districts to provide for those mentally retarded who were not capable of receiving formal education, but who could be trained for a special vocation. At the present time, more than 20 States provide such training for these children.



It should be strongly emphasized that none of these efforts could have come about without the devoted and staunch support of groups such as yours. In many, many cases, it has been the group of concerned individuals who has started the ball rolling. Here in Rhode Island, your own group has done a truly outstanding job in the sheltered workshop you are sponsoring with the assistance of the Office for Vocational Rehabilitation. You are enabling 30 people--10 of whom came from the Ladd school--to earn money and to work for the first time in their lives. When you think that fully one-third of these individuals were in a State institution for the mentally retarded, this is a tremendously impressive achievement.

On the national level, the National Association for Retarded Children now has 50,000 members and 1,000 local organizations functioning in every State in the country. Yet, in 1950 at its organization meeting, just 40 parents of retarded children were present.

And of private foundations contributing over \$100,000 annually to the field of mental health, one-third are interested in the problems of mental retardation.

But this, although encouraging, is just a beginning. The problem of mental retardation is a long way from being licked.

I am therefore very gratified--as I am sure you are--by the leadership which President Kennedy has assumed in the area of mental retardation. The interest of the entire Kennedy family in this field is well known, and the foundation set up in memory of the oldest Kennedy son who was killed during World War II--the Joseph P. Kennedy Jr. Foundation--has already given approximately \$15 million to some 75 institutions around the country for work in the field of mental retardation. Only recently the Foundation made possible

the establishment at Stanford University of a new research center--the Joseph P. Kennedy Jr. Laboratories for Molecular Medicine.

President Kennedy's administration has already taken several steps toward stimulating new programs and new effort in the areas of mental retardation. One of the first of these was the establishment of a new Center for Research in Child Health, which has been set up within one of the Divisions of the National Institutes of Health. This Center will have the responsibility for directing a program designed to stimulate research in the basic biological, behavioral and clinical sciences related to health problems of childhood and adolescence. It will provide a central point for coordinating and disseminating information about research in these fields, and it will also administer broad collaborative research programs and act as a national service center for these programs.

It is possible that this Center will one day be a part of a new Institute, devoted to the study of problems of human development from birth through old age. A bill with this in mind has already been introduced into both the House of Representatives and the Senate.

With the appointment of a President's Panel on Mental Retardation in October of last year, the President set in motion a national effort to evaluate the current efforts and the future needs of this nation in the area of mental deficiency. Named as chairman of this Panel was Dr. Leonard W. Mayo, executive director of the Association for the Aid of Crippled Children. And as special consultant to the panel, the President named his sister, Mrs. Eunice Kennedy Shriver.

This Panel, some of whose members met here in Rhode Island last month, is now in the process of mapping an all-out attack on mental retardation.

Most recently--just two months ago, in fact--the Secretary of Health, Education, and Welfare, Abraham Ribicoff, established within his department a committee to work with and assist the President's Panel and to coordinate all departmental activities in the field of mental retardation. This action, and others which may be stimulated by the President's leadership, will help to bring together the efforts of all levels of government, as well as of voluntary organizations, professional organizations, many scientific disciplines, and thousands of private individuals.

A decade ago, few people felt that there was any reason for hope in the area of mental retardation. It was felt that nothing could be done and the whole problem was regarded with fatalism. Today, the attitude of fatalism is no longer justified. There is increasing interest and concern about doing as much as possible for those afflicted with this disability, and in supporting research into the causes of the retardation. Research has already shown that two so-called "hopeless" forms of mental retardation can be prevented. Research has shown that mongolism--one of the more common forms of mental retardation--is linked to chromosomal abnormalities. We are on the threshold of exciting new discoveries about the life processes which hold the <sup>key to the</sup> "how" and the "why" of mental retardation.

The road is certain to be long, and the way will be lined with difficulties and discouragement. But we have begun. And we shall continue our efforts to bring light into the many lives now darkened by the disability of mental retardation, and to prevent the darkening of the lives of others not yet born.

I pledge my own contributing efforts to insure that this movement will not falter.

Thank you.