

An address by Representative
John E. Fogarty at the Annual
Meeting of the Canadian Associa-
tion for Retarded Children,
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OUR ALLIANCE TO CONQUER MENTAL RETARDATION

It gives me great pleasure to be here in Halifax with you tonight. It is gratifying to have this opportunity to meet personally with the members of this Association which has done so much in so short a time to focus public attention--and action--on the pressing problems of mental retardation.

But this opportunity is meaningful to me in a larger sense. For it is a very tangible symbol of the shared concern of our two countries in mounting an all-out attack against this affliction which has shadowed so many hearts and lives.

And in joining with you tonight I bring greetings from those of us in the United States who are, like you, enlisted in this great cause. We take heart and inspiration from the knowledge that the goals we seek are shared, and are being approached on many fronts and in many lands by dedicated and devoted colleagues.

I like to think that these two great countries of ours, whose patterns of friendly alliance in so many fields have given the world a shining symbol of brotherhood and cooperation, are also moving forward together on this new front--in an alliance to conquer mental retardation.

I say "new front"--for though the problem posed by mental retardation is as old as man's history, the broad-scale attack now being mounted is almost unbelievably recent in development.

It has been made possible by a new atmosphere of hope, where before there was a lack of hope. And where did that hope spring from? From the determined and dedicated efforts of persons such as yourselves

who, facing the magnitude of the problem, refused to despair but instead moved ahead. It sprang from research findings, fragmentary at first, but which when added together provided dramatic evidence that much could be done through research to control--and even prevent--many forms of retardation.

And just as faith and determination were essential ingredients in mobilizing research efforts, so the results of research inspired new hope. Together, these two great forces have succeeded in an incredibly short time--since World War II; even more precisely, during the last decade--in drastically changing the picture presented by this unhappy affliction.

And what has been done in this brief time, is, I firmly believe, only a prelude to what is to come.

The promise of advances in basic and clinical research which will decrease mental retardation offers no solution, however, to the families with loved ones who are retarded.

While cures and preventive measures are important to many thousands yet unborn, the rehabilitation of those who cannot benefit from cures because they came too late is of equal urgency.

Thus the attack on mental retardation must be two-pronged. As the scientists move forward toward understanding the causes of these abnormalities, so must communities create environments in which the mentally retarded--no matter at what level their capacity--have fullest

opportunity to develop, and lead productive, satisfying lives.

It has become increasingly evident that a variety of facilities and services must be planned for the total life cycle of the retardate, starting in the earliest weeks of life, and moving through nursery school years, childhood and adolescence, into adulthood. For all of these stages different programs must be developed. This approach to the problem of mental retardation can and must be made by the community-- and as it is implemented, we will move from the concept of the monolithic institution where many types of retarded are clustered together to a variety of smaller treatment centers and rehabilitative workshops geared to special needs.

In this connection, I am particularly happy to see that your theme for this year is "The community--a necessary member of the team." Though only a handful among us can take part in the approach to this problem being made in scientific laboratories, all of us can play important roles in advancing our cause through increased acceptance by the community of its responsibility toward the mentally retarded. Much of our recent progress has been as a result of such growing acceptance.

Happily, down this avenue lies our best hope for improvement; particularly for the vast majority of those mildly retarded children, adolescents and adults who are able to perform more adequately, adjust in a limited way to the demands of society, and play a more positive role as workers--when given proper support.

That this support is becoming more and more available for the retarded here in Canada is most evident through the work of your Association, whose growth has been little less than phenomenal. I think you will agree with me that much of your progress is a definite tribute to your past president, Laurie G. Hall, whose work we in the United States have watched with admiration.

We have also observed with deep interest the direction your Association has taken. Those of us in government are always pleased to see citizens' groups move into areas of leadership and action, to get something important accomplished, without sitting back and waiting for their legislators to act. You are getting much done in your community programs. The work of parents in the 209 local branches in the nine provincial associations for the mentally retarded in establishing education and training facilities to enable the retarded to make the very most of their abilities has given us in the United States a pattern to emulate.

Your Association is but four years old, yet its membership is more than 15,000; and many of the local programs now in effect are under the direct sponsorship of CARC provincial branches. There are special educational programs for the mildly retarded; special classes for the trainable retarded; and a growing number of sheltered workshops--whose success in harnessing the capacities of the retarded has been so dramatically demonstrated in the United Kingdom.

We have also watched with admiration your advances on the scientific front: the work of Dr. Murray Barr, of the University of Western

Ontario, and his studies of chromosomal abnormalities; Dr. Norma Ford Walker of Toronto's Hospital for sick children, and her work in genetics and retardation; Dr. Michael Partington, of Queen's University in Kingston, in retardation and metabolic errors; and Dr. William Cochrane of Dalhousie University in Halifax.

It is clearly evident to us in the United States that Canada is on the move, both in rehabilitative programs and in research. It is something of which you can be justifiably proud, especially since most of the progress has been achieved since the end of World War II--which seems such a short time ago to many of us.

The same holds true in the United States, where our efforts in behalf of the alliance against mental retardation since the war have gained in momentum during the past ten years. The actions and interest inspired by those of us with such a deep concern in the field were highlighted this month when a report to President Kennedy was submitted by a special Panel on Mental Retardation. The Panel, appointed by the President last fall, was asked to prescribe a program of action after reviewing current programs, needs, progress, and shortcomings.

This it has done, in a voluminous report which ^{is being} ~~was~~ submitted several months before the Panel's deadline. Such fast action on the part of the Panel--which is unprecedented among government committees, at least within my memory--shows that our citizens are eager to get on with the job we face.

The twenty-seven members of the Panel moved swiftly to their work following an initial meeting at the White House last October. Members organized task forces and assigned themselves to smaller aspects of the overall problem of mental retardation. Areas set up for specific study and recommendation included research; community facilities, including residential care and coordination of services; special education and rehabilitation, including preparation for employment; and legal problems. A number of outside advisors also worked with Panel members, who concentrated on these areas from the middle of December to the first of April.

Then began a period of travel, in this country and abroad, in an effort to assimilate the thinking of our own people and of those in other countries. During April and May, seven regional meetings were held, in the East, South, and West. Representatives from thirty-five States attended these meetings, and I was fortunate in being able to attend the session held in my own home State of Rhode Island. Panel members heard administrators, State officials, public school teachers, university faculty members, social workers, rehabilitation workers, and parents of mentally retarded children. These people reported on local, State, and regional accomplishments and problems, and presented recommendations for inclusion in the Panel Report.

Three missions were sent abroad during April to study methods of care for the retarded, and workshops and programs of special education. In June a mission headed by Dr. Seymour Kety, who recently rejoined the National Institute of Mental Health after a year at Johns Hopkins University, went to the Soviet Union to observe basic research there relating to the brain and the central nervous system, as well as the

work the Soviets are doing in the field of learning.

All through the months after its appointment, the Panel received many letters from over the country, many of them extremely thoughtful. Excellent suggestions were offered by a number of professional organizations. And the Panel was able to confer with key people, in and out of government, who will be able to help in carrying out or implementing its recommendations.

A progress report on the work of the Panel was made by Panel Chairman Dr. Leonard Mayo earlier this month. He said:

"As in the case of certain other conditions and disorders, the task confronting society insofar as mental retardation is concerned is two-fold: (1) to push basic and clinical research, seek to improve methods of diagnosis and evaluation, and stress preventive measures insofar as present knowledge permits; and (2) to substantially improve teaching and curricula and methods of rehabilitation to the end that the retarded may realize the highest degree of independence and productivity possible for them."

It may well be, as Dr. Mayo also pointed out, that one of the major recommendations concerning community services will be for the establishment of a Domestic Peace Corps to make up for the inadequacy of professionally trained personnel. Because this inadequacy is expected to continue far into the future, the Panel emphasizes the need for a corps of volunteers in every community.

It is very pleasing to me that the Panel, in addition to a strong emphasis on research and prevention, is aiming at comprehensive and improved services, including extended educational and vocational opportunities; a continuum of well-coordinated services available to all retarded persons; and community-centered, rather than isolated, services, such as regional

centers close to teaching and research facilities.

From this brief review, I am sure it is clear the report will be of great interest to all of us. I know that your Association is interested in the Panel's final report, because your officers have followed the progress of the Panel since it was first constituted.

Now, I would like to try putting the report and the actions which led up to it into historical perspective--which takes us back to the period just after World War II. At that time the push to solve our nation's health problems--including those of mental retardation--began. To those of us in Congress at the time, this emerging demand for better health services for all our citizens was unmistakable. The demands came from everywhere, and with relentless fervor. They came from dedicated professionals, educators, civic and religious leaders. The people spoke.

We in Congress listened, passed the National Mental Health Act in 1946, and established the National Institute of Mental Health two years later. Then in 1951, the National Institute of Neurological Diseases and Blindness was established. Also during this period a group of forty parents of retarded children met to form the National Association for Retarded Children. Thus we had the organizational framework to do battle with mental retardation, based on many of the actions and thinking of a number of pioneering individuals and groups who preceded us, some of them by many years.

In Congress we felt that what had been done was an achievement of note. But two events in 1955 helped prove to me that we had just barely begun our great adventure in the efforts to conquer our enemy. I became first deeply and personally concerned with mental retardation when I learned of the plight of the exceptional children in my own home state of Rhode Island. There I met with the Parent's Council for Retarded Children of Rhode Island, where the parents told me of how little was being done for their children, as well as the difficulties they had in obtaining proper medical care and educational opportunities for them. The second event, which showed me that the problem stretched across our country, was a speech on mental retardation presented by His Eminence, Richard Cardinal Cushing, then Archbishop of Boston.

When hearings on the 1956 appropriations bill began in Washington before the Appropriations Subcommittee of which I am chairman, I made inquiries and found that no Federal funds were specifically set aside for programs to combat mental retardation--though more than five million U. S. citizens suffer from this affliction. To get something started, our Committee appropriated funds over and beyond the budget requests of the Institute of Neurological Diseases and Blindness and the Institute of Mental Health specifically designating that they be spent on problems of mental retardation. Our Committee report that year said:

"So little attention has been paid to the problem (of mental retardation) that we have only the haziest notion of what percentage of unfortunate children, of at least as unfortunate parents, could be

helped medically and through educational techniques fitting their needs, so that they could lead useful and satisfying lives. We have an equally hazy notion of the causes of the problem.

Today, in the U. S., the National Institutes of Health serve as the focal point for collaboration in mental retardation research--with the Institute of Mental Health working on problems related to socio-economic conditions, emotional problems, psychosomatic and psychological factors, and with the Neurological Institute concentrating on the determination of causes of mental retardation and developing a program for prevention of retardation due to brain pathology.

Since 1956 my Committee and Congress have increased funds for these programs each year. During this fiscal year of 1963 we will spend nearly \$30 million at the Federal level on the problem of mental retardation--and that does not include disability and survivors' benefits paid by the Social Security Administration. We have been heartened and gratified by significant advances in treatment and prevention of mental retardation made by the two Institutes.

What are some of the research projects underway?

A mere recounting of them does little justice to the drama that is unfolding before us in this great battle that does, indeed, encompass all of life. For mental retardation--unlike the many communicable diseases which plagued our country for so long and which finally have all but succumbed to our public health medical weapons--is a malady that spans

the generations. Its first unsuspected effects can doom an unborn infant to a lifetime of subnormality. So our fight is one that must, of dire necessity, begin in the prenatal stages and continue without letup throughout the entire life cycle.

We are not always seeking a cure, though seek for cures we must. In addition, we are hoping to find methods of prevention. And, in areas where neither cure nor prevention can be achieved, we look for ways to enhance the attributes a retardate does have. I think you will agree with me that it is almost as exciting to see a person, whom we once called helpless and assigned to a life of custodial care, rise phoenix-like from the ashes of his affliction to attain at least a place in society where he can make some contribution--that is almost as exciting as the discovery of a single cure.

We must, however, keep our attacks diversified. This is one of the main areas recognized by the President's Panel. Because of that diversification I can tell you tonight about one of the most exciting discoveries of recent years--isolation of the virus which causes German measles. It is so exciting because very soon now we should be able to provide protection for many unborn children whose mothers will be able to acquire immunity before becoming pregnant.

As you know, for most of our population a rubella infection is fairly innocuous. For pregnant women, however, it can be tragic since rubella is known to result in infant mental retardation as well as other abnormalities. In our part of the world, in fact, estimates show that about

18 percent of the women who contract German measles during the first three months of pregnancy will bear defective children.

The rubella question has been such an intriguing one that many scientists the world over have been striving for a long time to isolate the virus. Success was achieved by two doctors working in the National Institute of Neurological Diseases and Blindness, and using blood sera from five rubella outbreaks to prove they had isolated the virus.

This achievement constitutes only one aspect of the work that is going on at the Institute of Neurological Diseases, where scientists also are studying embryological growth and development because in many cases retardation is evident from birth even without such mitigating causes as German measles. These scientists are investigating factors occurring during pregnancy which may have a harmful effect on the child.

Discovery that abnormalities of body chemistry can lead to retardation has pushed investigation in the chemistry of retarded persons, including the puzzling chromosome composition of mongoloids.

At the Institute's Laboratory of Perinatal Physiology in Puerto Rico--where much of the work was done on isolating the rubella virus--a free-ranging colony of monkeys has been established. Studies there have shown that cerebral palsy and mental retardation can be produced in animals as a result of lack of oxygen at the time of birth.

The Institute of Neurological Diseases also has undertaken one of the most comprehensive, complex, and challenging studies of its kind in

trying to establish links between physical and mental defects in a child and events of pregnancy. This is the Collaborative Project which eventually will involve some 50,000 mothers and their children in representative parts of the country and which is investigating those biological and medical factors operating between conception and birth that may be associated with various types of birth defects. Scientists have found, in one part of the study, that of all those infants who perform poorly on a psychological test when they are eight months old, one-third have shown evidence of lack of oxygen at birth or soon after. Already nearly 30,000 mothers and more than 20,000 children are enrolled in this long-term research venture.

Typical of the Institute of Mental Health's research is its wide array of projects in phenylketonuria. Biochemists are studying the metabolism of the child with PKU in relation to his total growth and development, as well as the action of the chemical which in excessive amounts causes retardation.

Other studies, supported by NIMH grants, are investigating the capacity of the retarded to learn, and the effects of institutionalization on both the retarded child and his family. In addition, the Institute is aiding the training of professional persons in the basic mental health disciplines--such as psychologists with special competence in mental retardation. Improved and expanded service programs are being developed for the retarded. A pilot project is underway in one state for diagnosing

and treating mentally retarded pre-school children, and the project already has suggested that many children who do not belong there are being committed to institutions for the retarded.

Other agencies also are active in the field of mental retardation. The Office of Vocational Rehabilitation this year expects to rehabilitate at least 5,400 mentally retarded through State rehabilitation offices.

In 1958, as a result of legislation which I am proud to have sponsored, the Office of Education established a program to train teachers to work with retarded children.

Other Federal programs have encouraged the establishment of special clinics for the mentally retarded. Today there are 80 such clinics in various States. The Children's Bureau has developed a screening program so that widescale detection of PKU can be accomplished through a diaper test, thereby making possible the control of this disorder by dietary means.

There are many, many other projects I might enumerate. But I think you can see from this brief sketch that the United States Government is moving ahead in this tremendously important fight against mental retardation. As a Federal legislator, however, I would like to emphasize that Government activities are bounded by the kind of support they receive from the public. Unless the people are behind us, Congressional efforts to promote progress--not only in mental retardation, but in any field--will be to little avail. It, therefore, gives me a great deal of satisfaction to observe the continuing expansion of activities and programs among

State legislative bodies, and professional, scientific, and citizens' groups.

For example, forty-eight States now have legislation providing for special classes for the mentally retarded in the public schools-- State programs which doubled in number in a single year. The National Association for Retarded Children has grown from its forty members in 1950 to a membership today of 50,000 with 1,000 local associations throughout all the States. Among private foundations contributing more than \$100,000 each year in the field of mental health, one-third of them are interested in mental retardation. An outstanding example of a foundation devoting its resources to the battle against mental retardation is, of course, the Joseph P. Kennedy, Jr. Memorial Foundation.

And so it goes. We know that no effort can succeed without enthusiastic public support--which most often is expressed and implemented by voluntary organizations such as the National Association in the United States and your Association here in Canada. The need for research, prevention, care, and rehabilitation can be satisfied only with the cooperation of a sympathetic public.

That is the underlying strength of an organization such as yours. For you can give not only impetus and direction to government programs, you can do much that government alone cannot do. Your educational activities must continue so that public interest can be heightened--all Canadians must be aware of the necessity of our fight.

In our two countries today there are more than six million mentally retarded persons who need our help. Although there are many problems left unsolved, the progress we have made shows us we cannot afford to slow our efforts. Through research, mental retardation is yielding up its secrets; through community action, mental retardation is losing its stigma.

Many of the retarded can look toward the future with hope--some of them we have already been able to give life in a much fuller sense; others are waiting for the breakthroughs that we can now begin to promise them as the result of the coordinated efforts of all of us.

The opportunity to join with you here has been deeply gratifying to me, and I return home heartened and inspired by the conviction that our alliance in the field of mental retardation brings ever closer the time when "the day breaks, and the shadows flee away."