

An address by Representative
John E. Fogarty at the Annual
Meeting of the Connecticut
Association for Retarded Chil-
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NEW OPPORTUNITIES FOR THE MENTALLY RETARDED

It is a pleasure for me to meet with you here in Connecticut tonight, for it gives me two opportunities that I think will be meaningful to all of us.

To begin with, it is good to return to New England, after all these hectic months in Congress in Washington. It is especially good to come into Connecticut to meet with this Association. Here I feel something of a sense of renewal, because this State has long been in the forefront of the battle against mental retardation. You have developed excellent State training schools and hospitals: Southbury Training School in particular has been outstanding in research and in evolving new approaches to institutional care. And in 1959, your State became one of the first to set up an Office of Mental Retardation with a State Department of Health.

From this State have come men who have made impressive contributions to our knowledge of mental retardation and its treatment, men like Eric Sandahl and Dr. Grover Powers. And this Association itself is an example of the effectiveness of private effort, working in close harmony with State government, in achieving better services for the mentally handicapped.

To be here, then, is an opportunity for me. It is always good for a Federal legislator to come close to one of the sources of inspiration which helps us at the Federal level to move in the proper directions.

The second opportunity--and this one will be of much greater interest to you parents and teachers of the mentally retarded--is to tell you of the latest developments in this field where for so long we have been surrounded by darkness. We are opening a new front in what I call our alliance to conquer mental retardation. I say "new front," for though the problems posed by mental retardation are as old as man's history, the broad-scale attack now being mounted is almost unbelievably recent in development.

And what has been done in this brief time is, I firmly believe, only a prelude of 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, through 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. As it is implemented we will move from the concept of the large custodial 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 the efforts Connecticut is making, efforts which bear great promise as an approach to the care of the retarded. These efforts, of course, are the establishment of regional residential centers for the mentally retarded. Other States are moving along the same lines, with some direction and assistance from the Federal level.

That we have been moving in the proper direction has been confirmed only recently. Our actions will be highlighted this month when a report to President Kennedy is 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 to be submitted in a few days, many weeks 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 report, too, will be of great satisfaction to those of us who have been interested in the field for so long, because, as I see the report, it gives a definite vote of confidence in the advances we have made and the directions in which we are headed.

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 a number of 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 just last 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 vital interest to all of us. Let me show you just how vital by 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.

When the groundswell of public opinion began to rise on behalf of our nation's health problems--including those of mental retardation--it came from every side. With mounting intensity, the voices of parents, educators, civic and religious leaders demanded a full-scale attack, a demand that was unmistakable. Responding to the voice of the people, we in Congress in 1946 passed the National Mental Health Act, and two years later established the National Institute of Mental Health.

Meanwhile, across the country parents were joining together, united by their common determination to improve the lot of their handicapped children. By 1950 there were some 50 parent groups. That year, representatives from these organizations in thirteen States met to establish the National Association of Retarded Children.

In 1951, the John P. Kennedys of Trumbull led in the establishment of a center at Bridgeport. During that same year, there was another Kennedy with me in the House of Representatives--John Fitzgerald Kennedy of Boston, who has since moved up in government echelons--when we approved the foundation of the National Institute of Neurological Diseases and Blindness.

And so in just a few short years, a series of potent weapons had been forged in the fight against mental retardation. Yet we were just beginning.

Just how far we still had to go was deeply impressed upon me in 1955 when I met with the Parents Council for Retarded Children of Rhode Island. These parents told me of the immense problems they faced in trying to obtain adequate medical services and educational opportunities for their children. They made me realize how little actually was being done.

Subsequently my interest in the problem was heightened when I read the speech on mental retardation given by His Eminence Richard Cardinal Cushing, then Archbishop of Boston, dedicating St. Coletta School at Hanover, Massachusetts.

When hearings on the 1956 appropriations bill began in Washington before the Appropriations Subcommittee of which I am chairman, I looked into the matter and found that no Federal funds had been allocated specifically for mental retardation.

The report of the Committee that year urged a Federal program to meet the needs of retarded children. For this purpose, we earmarked \$750,000 over the budget requests of the Institute of Neurological Diseases and Blindness and the Institute of Mental Health.

Each year since then the Committee and the Congress have steadily increased their support of such programs. Today we are spending more than \$28 million for this purpose at the Federal level, not including about

\$52 million in disability and survivors' benefits paid by the Social Security Administration.

What is the current status of the battle against mental retardation?

We are on the move on many fronts. Through the two Institutes, the causes of mental retardation are under determined attack. Research into prevention and treatment has been stepped up and some encouraging advances have been scored. Funds allocated by these Institutes for mental retardation have increased from almost nothing to about \$20 million at the present time.

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 recall for you tonight 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.

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.

Through the Office of Vocational Rehabilitation, work is being carried on in conjunction with State rehabilitation agencies. Typical is the project underway here in Connecticut through the Bureau of Vocational Rehabilitation in cooperation with both Southbury and Mansfield. The aim is to tie in local rehabilitation facilities more closely with the institutions to provide community related services that will carry over beyond the institution and into the community. To this end, more use is being made of community rehabilitation centers and workshops for pre-vocational evaluation and training. Personal-adjustment training, on-the-job training facilities, and employment opportunities are being emphasized. The idea here is the achievement of a better job-community adjustment for the mentally retarded, helping them move out of the institution into the community and facilitating their employment. It is estimated that at least 5,400 mentally retarded persons will be rehabilitated through programs carried on at the State level during 1963.

Another aspect of the campaign focuses on improving the level of professional training for educators to teach the retarded. Public Law 85-926, resulting from legislation I introduced into the Congress, set up a teacher training program in 1958. At present some 25 colleges are participating. Programs for retarded children are being directed by specially prepared educators recruited for the program in all but three of our States.

We are trying both to bolster the quality of professional training and to increase the number of teachers available to work with retarded children. In both areas, the amount of money being spent has climbed upward in the last few years.

Through programs carried on by the Children's Bureau and the Bureau of Family Services of the Social Security Administration, special clinics for the mentally retarded have been established across the country. There are now 97 such clinics, 64 of them developed through the programs of these two bureaus.

The Children's Bureau is working with State health departments to develop screening, detection and diagnosis methods for infants and families with phenylketonuria, responsible for one percent of the population in our State institutions for the mentally retarded. A large-scale study to determine the accuracy of a new blood test developed for newborn infants is now underway by this bureau.

Through the Bureau's programs, more than 25,000 public health nurses have been given some training in mental retardation and in assisting families in the home care of mentally retarded children. And 14 medical schools are using the special clinical services to retarded children as the basis for training of medical students, residents and interns.

There are many other programs and 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. In this area, the establishment of regional residential centers for the mentally retarded here in Connecticut bears great promise as an approach to the care of the retarded.

These small community facilities on the outskirts of thickly populated areas minimize the danger for many children in long-term institutionalization and separation from home and family. Those of us most closely concerned with the care of the retarded are watching your progress with interest, including the already operational New London facility and the second center now underway in New Haven.

We see this as a cooperative community approach that can spell rich dividends, both in helping families more easily keep their children at home and in giving the retardate the full advantage of the community's educational, medical, consultative, and social facilities.

As I understand it, services will include residential care for the severely and moderately retarded, halfway houses, and sheltered workshops, as well as day-care programs for pre-school children and for school-age retardates unable to meet the criteria for admission to public school classes.

You have reason to be proud of the example set by your State in establishing these regional centers. They reflect an intense concern here with the development of better facilities for the retarded. It is a concern shown not only in your excellent training schools but also in the development of other community services.

And so it goes. We know, however, that no effort can succeed without enthusiastic public support--which most often is expressed and implemented by voluntary organizations such as the National Association and your

Association here in Connecticut. The need for research, prevention, care, and rehabilitation can be satisfied only with the cooperation of a sympathetic public.

This 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 Americans must be aware of the necessity of our fight. And the best place to begin, as we have seen, is here at home.

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 we can now begin to promise them as the result of the coordinated efforts of all of us.

The opportunities I have had here tonight have been deeply gratifying to me. And I would like to close by expressing my conviction that some day the world for the mentally retarded will closely resemble that at Southbury, which was so warmly described by Eunice Kennedy Shriver in her recent Saturday Evening Post article.

She said: "Here for once, at Southbury, the mentally retarded were participating as human beings, with all the privileges of work and play that the nonretarded enjoy."

With determined parents and others like those of you in this Association, we can attain that goal.