

An address by Representative  
John E. Fogarty at the Annual  
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EQUALIZING OPPORTUNITIES FOR THE MENTALLY RETARDED



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I am happy to be here with you tonight at the conclusion of one of the most exciting and challenging weeks in the lives of those of us who are so vitally interested in the battle against mental retardation.

The excitement, of course, has been engendered by the Report submitted Tuesday by the President's Special Panel on Mental Retardation, a Report we have been looking forward to ever since President Kennedy appointed the Panel last October. The challenge is that which we face as a result of the Panel's findings and recommendations, as well as a result of the events which have transpired here in Chicago this week.

Personally, I am extremely gratified by the Panel's Report, which indicates that those of us who have been concerned in this field for so long have made definite advances and that the directions in which we are headed are good.

The Report makes it plain that to move forward toward what we hope will be the eventual elimination of retardation we must continue to expand our programs at the community level. On the other hand, it also strengthens my own convictions that there are areas where only the Federal Government can provide the necessary leadership.

To paraphrase an old cliché, mental retardation is no respecter of persons. The affliction, as all of us know, makes no distinction among families in its effects. It is truly democratic, striking the child born into humble circumstances equally as hard as the child whose parents are well able to afford the best in specialists and care.



This is where the role of Federal activities is so important. Individuals and private organizations have their roles, of course, but we cannot limit our advances to their accomplishments. For example, the President's Panel strongly recommends extended research in the biological and behavioral sciences, both generic and specific. To confine that research to the institutions and organizations that have the interest and the money to carry it out is foolhardy.

There are more than five million persons in the United States today who are classified as mentally retarded. Retardation, however, is not a single disease entity -- it is a syndrome arising from a single cause or a combination of causes, many of them not yet even understood. We cannot confine ourselves to searching for one cause or one cure at a time; we must keep our attack diversified to make as much progress as possible on the broadest possible front.

As I found in 1955, when our House Appropriations Subcommittee began making inquiries into the problem, little was being done in the area of mental retardation on a national scale. And yet the problem was a national one. For 1956 we appropriated funds above the budget requests of the National Institute of Mental Health and the National Institute of Neurological Diseases and Blindness with the specific request that they be used for research into retardation.

That was the beginning. Now we are spending nearly \$20 million a year through these two Institutes to support research. This activity is one that can only be coordinated at the Federal level; research support must be national in scope. For research findings, like items of interstate



commerce, transcend State lines. A discovery made in California must be made available to those whom it would benefit all across the country.

An outstanding example of research results which belong to the entire country came in last summer's dramatic announcement of the isolation of the virus which causes German measles. For years the search was carried on by scientists. Success finally was achieved through the efforts of two doctors at the National Institute of Neurological Diseases and Blindness. Their work involved the use of blood sera from five rubella outbreaks over the world -- one of them in Tahiti -- and much of the work was done at the Neurological Diseases Laboratory of Perinatal Physiology in Puerto Rico. Without Federal support of these activities we might well still be waiting for this advance which promises almost complete elimination of mental retardation in children whose mothers have German measles during pregnancy.

Another important example of Federally coordinated research is the extremely comprehensive and complex study by the Institute of Neurological Diseases which is trying to establish links between physical and mental defects in a child and the events of pregnancy. This is, of course, the Collaborative Project which by 1965 is expected to involve some 50,000 mothers and their children in representative parts of the country. Already the study has enrolled nearly 30,000 mothers and more than 20,000 children. Teams of medical and allied scientists at fifteen medical centers throughout the country are studying expectant mothers from early pregnancy through labor and delivery, and are examining their babies periodically from birth through school age.



Here again, only at the Federal level can such research be done so effectively.

Two other recommendations of the Panel carry our situation even farther. One Panel recommendation is for an extended, enriched and comprehensive program of special education in public and private schools closely coordinated with vocational guidance and specific preparation for employment or productive occupations through a planned workshop experience. It also calls for appropriate adult education for the mentally retarded who have not had the advantages of educational opportunities earlier, or who can profit by additional opportunities.

This recommendation leads into the other -- wherein the Panel recommends a realistic look at the serious problems of manpower as it affects the entire range of our concern. Among the suggestions are a stepped-up program of recruiting with fellowships, career teacher investigatorships, opportunities for medical students and those in other professions to observe and learn something at first hand about the phenomenon of retardation.

The entire problem here boils down to the need for trained personnel and the fact that no one institution can afford to train people to deal with all the problems of retardation. Persons being trained in the field must be mobile, able to attend those institutions which offer the type of training needed. Thus, for example, a university with special training interests and strengths cannot remain solely a local or State resource because it would be completely unrealistic to expect each locality or State to support all the specialties needed.



We are equalizing these opportunities for training through grants from the Institutes in the National Institutes of Health and through programs of other agencies within the U. S. Department of Health, Education, and Welfare. An example of this is the program designed to improve the level of professional training for educators to teach the retarded, a program which resulted from the law I introduced into the Congress. Some twenty-five colleges are now participating.

We are trying both to boost 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 mounted steadily 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 with phenylketonuria, responsible for 1 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 to detect PKU in newborn infants is now underway by the Bureau.

Through the Bureau's program, 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 fourteen medical



schools are using special clinical services to retarded children as the basis for training of medical students, residents, and interns.

As you can see, all these programs are in need of manpower -- manpower specifically trained for all of the areas involved in our great struggle to overcome retardation. Here the Federal Government must be responsible because the problems are nationwide in scope.

One other recommendation from the Panel calls for greatly improved care and facilities for care with emphasis on the home and the development and coordination of a wide range of community facilities. Special emphasis is to be given to "returning the institution to the community," suggesting as one alternative, regional centers providing diagnostic, day care, and parent counseling services to all in the region who need them.

This, of course, is the area where local, regional, and State organizations assume their primary role. For it is a basic truth that facilities and services for the retarded must be predicated on the retarded person's entire life cycle. For all the stages, different programs must be developed -- an approach which can and must be made by the community and the organizations working in the community.

I am particularly proud of two accomplishments in my own home State of Rhode Island, where our sheltered workshop is offering new opportunities to the retarded and where we can now offer dental care to the retarded. These programs could well be emulated in other States or areas.

But here, too, I can see the need -- I can see the absolute necessity -- for participation by the Federal Government. Many of our States have moved ahead with us in providing facilities and services for



the mentally retarded. Others, however, have fallen behind because the demands upon their resources are terrific, and it is an economic fact from which we cannot hide that State resources are not equal.

As a Federal legislator, serving in the Congress which represents all the people of this country, I believe that this inequality must be offset. Since the Federal Government stands as the government of all our people, it must exercise its responsibility to provide for all the people equally.

It is possible that not all States have done as much to help the mentally retarded as they could -- and with this approach, or lack of approach, I have scant patience. Still, simply because a State has not fulfilled its obligations is no reason for the Federal Government to shirk its responsibilities that are its alone.

Thus, in reviewing the recommendations of the President's Panel, we can see two areas of action lying ahead of us.

The first is to push basic and clinical research, seek to improve methods of diagnosis and evaluation, and stress preventive measures as well as our present knowledge permits. The second is 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.

These areas of action should involve all of us - parent, teacher, interested individual, group, organization, government. We stand as spokesmen for the mentally retarded who look to us for fulfillment of the promise of better things in the future. As individuals, however --



even as individual organizations - we cannot bring about this better future. We must move in concert. In addition to more activity at the local level, I feel that we must continue to expand national activities through Congressional action.

In this way, we can provide an equalization of opportunity for every mentally retarded child born into our society. Nor is what we are doing completely selfish. As we move more and more into areas of need for the retarded, the results we achieve can be of benefit to vast segments of our population.

Now, as a result of the Panel's Report, we have our blueprint for the future. The Panel has done its work well. The next step is for us to continue the job.

Striving together, we can be assured that equal opportunities for the mentally retarded are attainable goals. We have this week received the challenge. I say we can meet it.