

REMARKS OF CONGRESSMAN JOHN E. FOGARTY AT AMERICAN LEGION  
AND AUXILIARY CHILD WELFARE CONFERENCE, JOHNSONS HUMMOCKS,  
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You have done me an honor today in asking me to speak to you, and you have given me pleasure, as well, in naming a topic that is very close to my heart.

The problem of the handicapped child are sympathetically recognized by practically every thinking adult in this country. But unfortunately, we have a plethora of persons who either give lip service to the idea of better programs for handicapped children, or simply remain in neutral... neither for or against; and we have a dearth of citizens like yourselves who are not only able but willing to act in behalf of tomorrow's generation of adults.

Indeed, you are to be congratulated for having recognized the need and for giving of your time and skills to alleviate some of the unhappy conditions that exist for our handicapped children. Some of you are working in this field because you are concerned, conscientious parents; and all of you are working as responsible, aware citizens.

I believe that one of the most encouraging developments in recent years is the increasing numbers of groups like yourselves throughout the country: volunteer organizations dedicated to various phases of child welfare--education, health, rehabilitation, and recreation.

I am proud to say that I, too, am able to work for this same cause in my capacity as a legislator, representing this 2nd District of Rhode Island in our Congress. For a good portion of my twenty two years as a lawmaker, I have had the responsibility and the privilege of being the chairman of the Subcommittee on Appropriations for the Department of Health, Education, and Welfare. In this capacity I have become familiar with the diseases and the disabilities that kill and cripple our children. I have knowledge of the Federal, State, and local programs that have been established to help our handicapped. I have learned many facts about the important role of medical research in attacking these diseases and disabilities. And -- perhaps the most satisfying to me -- I have had the privilege and

opportunity of helping advance our country's attack on these problems by urging broader Federal support of medical research and training for workers in these areas.

I am happy to say that our present administration is very much concerned with the health of its future citizens, and has taken an active role in providing leadership for the creation of new programs on behalf of child welfare.

Two specific instances are particularly interesting: the first is the Center for Research in Child Health which has been set up within one of the Divisions of the National Institutes of Health. The Center will have responsibility for directing a program 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 concerning research in these fields; and will administer broad collaborative research programs and act as a national service center for such programs.

The establishment of this Center, it seems to me, is one of the most vital and progressive steps taken by our Government in the past decade to further the cause of child welfare. I trust that the Center will one day be part of a new Institute, in addition to the seven other National Institutes of Health, which will be devoted to the study of problems of human development from birth through old age.

The second significant development of particular interest to us in this discussion today, and one which presents further evidence of the present administration's interest in the problems of handicapped children, is President Kennedy's recently-organized Panel on Mental Retardation.

The President has asked the Panel to conduct a review and make recommendations with regard to the following:

1. Personnel necessary to develop and apply new knowledge--which means that more physicians, nurses, social workers, educators, psychologists, and other trained workers are needed.

2. Major areas that offer the most hope, and the means, the techniques, and the private and governmental structures necessary to encourage research in these areas.
3. Present programs of treatment, education, and rehabilitation.
4. Relationships between the Federal Government, the States, and private resources in their common efforts to eliminate mental retardation.

Just a few weeks ago, the Secretary of Health, Education and Welfare, Abraham Ribicoff, established a committee within his agency to assist the President's Panel and to coordinate all departmental activities in the field of mental retardation. This action, and others that will be stimulated by the President's leadership, will help to bring together a closer bond and freer communication the efforts of all levels of government, as well as of voluntary and professional organizations, many scientific disciplines, and thousands of private individuals.

Now I want to focus my discussion on the two principal aspects of help to handicapped children -- rehabilitation and research.

The Children's Bureau was charged by Congress 50 years ago to investigate and report "upon all matters pertaining to the welfare of children and child life among all classes of our people."

This it has done, and is doing admirably, I feel. The scope of the Children's Bureau has grown to encompass such programs as infant and material mortality studies, nutritional surveys, mothers' aid, juvenile delinquency, and services for handicapped children. The Bureau gathers and reports facts, publishes pamphlets, sets up standards of care for special groups of children, awards grants to public agencies, and assists the States in developing community organization of services for children generally.

The Bureau's policy of cooperation with voluntary child health and welfare agencies makes its services available to hundreds of such organizations.

In recent years, for example, the Bureau has won increasing acceptance of its principle that the best type of treatment for a handicapped child requires a team of professional workers -- physician, nurse, psychologist, medical social worker, physical therapist, teacher, and others who can pool their knowledge and skills.

The Children's Bureau not only helps the States to reach more children with more and better services; it also works with universities providing training in medicine, nursing, social work, physical therapy, nutrition, and in developing courses to equip professional workers for these services to handicapped children.

Now I would like to focus on just one of the many kinds of handicaps that afflict millions of our children today -- mental retardation. Up to 20 years ago, little effort was made on behalf of mentally retarded children. Many did not survive long, and those who did were either kept quietly at home or were cared for in one of the 75 State-operated institutions. Then, during the baby-boom in the 1940's, the number of mentally retarded increased along with the population.

Parents organized to learn how their afflicted children could be helped, and it soon became apparent that they had come to grips with an almost universal problem. With Federal assistance, this program has developed into a wide range of special rehabilitation activities in 50 States as a part of their public health activities; clinical services in 46 States; and 50 specialized clinical teams. Over 25,000 public health nurses have received some training and orientation in mental retardation and in assisting families to care for such cases at home; and about forty-five hundred medical students, residents, and interns have been trained in the newer concepts and approaches to mental retardation.

In our own city of Providence there is one of a new and, I hope, growing type of organization called a sheltered workshop. Here, people who are mentally retarded are trained to help themselves -- to work, to do simple tasks and simple assembly jobs subcontracted from local firms. For the first time in their lives, these people perform useful work and receive pay for it.



They have gained respect in their own eyes, and in the eyes of their families and the community. The Providence sheltered workshop, which is now receiving funds from the Vocational Rehabilitation Program, supports 30 people, 10 of whom have come from the State institution. The case of one particular girl struck me as a dramatic illustration of the good work of this program -- the girl 23 years old, left her house for the first time in 20 years, and left it, furthermore, to earn a weekly sum of money through her own efforts.

I have been increasingly concerned with the impact of mental retardation on the families of the afflicted persons, and I was happy to be able to give material assistance recently to a statewide service of counseling and referral. Today, the program is jointly sponsored by the State council on community services and the State association for the mentally retarded. It channels parents to the facilities in the Rhode Island area which can help their children, and--equally important--it attempts to give the parents valuable insight into what they can and cannot expect of their

child and his development. The program is designed to help expectant mothers, as well, in preparing for the problem of retardation if it should happen. This program, although it is relatively new, has already won the interest and support of the National Institute of Mental Health.

Vital as this problem of mental retardation is, there are other types of handicap that demand our attention as well. For example, more than 8 million Americans of all ages suffer from speech or hearing impairments. A child burdened with such a disability is very likely to be, at the least, retarded in his efforts to learn to communicate. In many cases, the child also suffers emotionally and socially. The help of trained speech and hearing specialists is desperately needed for these people, and especially for the children. Such specialists provide services in elementary and secondary schools, hospitals, and community centers. At present, there are only about 2,000 certified speech and hearing specialists and 5,000 noncertified specialists. A minimum of 20,000 trained specialists are needed--and needed urgently --

to properly diagnose, train, and rehabilitate these 8 million handicapped individuals. Just last month, I introduced a bill into the House of Representatives providing for a grants-in-aid program to assist our colleges and universities in the training of such specialists.

Thus far, we have been discussing some of the programs developed to help the mentally retarded. But I am sure you will agree wholeheartedly with me that the ultimate answer to the problem of the handicapped must come from research. The problem of determining the causes and means of preventing disabling conditions is extremely complex and difficult, as I am sure you realize. Various combinations of biological, psychological, social, and environmental factors determine an individual's development, and provide a wide variety of possible causes of disorders and malformations. However, medical research has already had success in discovering some of the reasons for this condition, and in finding ways to prevent or treat it. In addition, a large-scale attack has been launched to get at the roots of the other causes.

Some individuals suffer from what are termed "inborn errors of metabolism." Metabolism, as the scientists describe it, is the process by which the body converts food, air, and water into energy and growth. Perfect health results from the perfect functioning of the tremendously complex machinery of the body. In some cases a baby may be born with a slight metabolic error -- say, for instance, that one of the hormones fails to function. The results of this may be unnoticeable -- or may be serious enough to lead to brain damage and mental retardation.

I would like to mention briefly just one of these disorders -- galactosemia. An infant born with this condition lacks the proper enzyme to convert galactose, the sugar in milk, to glucose, the common sugar of the blood. The baby is unable to tolerate milk, and if the condition is not diagnosed, the child will lose weight, suffer liver damage, cataracts, brain damage, and an early death. Scientists at the National Institutes of Health discovered the cause of this condition, devised a simple test to detect it, and a diet to counteract it.

Now I want to tell you about an exciting and far-reaching program developed by the National Institute of Neurological Disease and Blindness, another of the seven National Institutes of Health. Its aim is to identify those 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.

Teams of scientists in 15 hospitals throughout the country are cooperating by using uniform and comparable approaches to the study of expectant mothers from early pregnancy through labor and delivery, and are examining the children periodically from the time of birth through early school age. By the end of last year, about 23 thousand mothers and 17 thousand children were involved in the project, and eventually the figure will reach 50 thousand mothers and their children.

It is far too early to reach any conclusions from the data that have been accumulated, but several interesting patterns have begun to develop. For example, there is an indication that the incidence of neurological disorders among these infants and children may be higher than was expected.

In addition, the scientists have found an association between cigarette smoking and decreased weight of the infant at birth, which is an important factor in brain damage and death in infancy. And, interestingly, the decrease in weight at birth was found to be proportional to the number of cigarettes smoked daily by the mother.

Additional studies by the NIH scientists in Bethesda and by research investigators working under grants from the Institute include studies of chromosomes 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 newborn infants.

Finally, I would like to make the point that there are many diseases -- communicable diseases -- that very often leave children with lifelong handicaps. For example, most of us have had measles, and we expect that our children will get the disease some time during their early years. We think of measles as representing a week or so of illness, followed by a short period of limited activity for the child. What we don't often

realize is that thousands of children in this and other countries die year after year of the disease or its complications. And a good many more suffer, as a result of measles, such complications as pneumonia, impairment of hearing and sight, or brain damage.

A good many man-years of research have gone into the experimental vaccine that has recently been proved effective, and a number of medical scientists here and abroad have contributed to the sum of knowledge that made the vaccine possible. Two types of vaccine -- live virus and killed virus -- are now being tested extensively through the combined efforts of hospitals, county medical societies, university medical schools, pharmaceutical houses, and the U. S. Public Health Service. I am confident that this combined effort, of cooperation among scientists, and of whole-hearted participation among local, governmental, and industrial groups will soon pay off in the form of a vaccine that is not only effective in measles prevention but completely safe as well. The availability of a safe and effective measles vaccine will be another milestone in the crusade

for better health. But its availability will simply serve as another challenge -- a challenge to continue the cooperation that joins individual citizens and voluntary groups such as yours with professional organizations, State agencies, and the Federal government to make certain that the new knowledge, new vaccines, and improved drugs are effectively applied to achieve -- as the President said -- individual and national dignity.