REMARKS OF U.S. REPRESENTATIVE JOHN E. FOGARTY IN THE HOUSE OF REPRESENTATIVES IN SUPPORT OF HIS MENTAL RETARDATION BILLS, THURSDAY, JUNE 13, 1963 Health

HR 7033 Ward 6/19

In my opinion, Mr. Speaker, the Administration bill to combat mental retardation and improve mental health will not adequately do the job intended. The omnibus approach to this type of legislation has been found to be ineffective and subject to considerable objection and delay.

Because of this and after much study and consultation, I am today introducing for appropriate reference three separate bills confined solely to the area of mental retardation. These three bills, taken together, comprise the essential components of a unified and effective program to combat the problem.

The first of these three bills relates to a greatly increased maternal and child health and crippled children's program. The second concerns the construction of clinical and service centers for the mentally retarded in the community, and the construction of research centers and mental retardation facilities that are affiliated with university and medical school programs. The third contains provisions for the training of teachers of the mentally retarded and for research and demonstration projects relating to the education of mentally retarded children. I ask unanimous consent that the bills and a summary of them be printed in the Record at the end of my remarks.

Mr. Speaker, these bills contain many of the provisions in the bills previously introduced, to carry out President Kennedy's

mental retardation program.

The first of these three bills is, in fact, identical with the maternal and child health and mental retardation planning bill (H.R. 3386). My motive for introducing an identical bill is this: I wish to leave no doubt in anyone's mind as to where I stand in relation to the provisions of these bills. I am for these provisions, and I consider their adoption by this House to be of critical importance.

However, despite the similarities between the other two bills I am introducing today and the bills that were previously introduced, I consider the differences between these bills to be essential to the successful enactment of the President's general proposals and the implementation of his goals.

The essential differences are these:

Unlike H.R. 3689, entitled the "Mental Retardation Facilities Construction Act of 1963," my bill contains a separate title to provide grants for the construction of university-affiliated facilities for the mentally retarded. These grants are to be made whenever or wherever a university or medical school is ready to develop a suitable facility, quite apart from the readiness--or lack of readiness--of the State to develop community mental retardation facilities under the State formula mechanism described in H.R. 3689.

H.R. 3000, entitled the "National Education Improvement Act of 1963," is the Administration's omnibus education bill. It consists of six titles, and contains provisions for such educational matters as modern foreign language training and research, student work-study programs, public community libraries, and adult basic education. Of the 182 pages of the printed bill, less than four pages relate exclusively to the educational problems of the mentally retarded.

Mr. Speaker, I maintain that the educational problems of the mentally retarded are too important a matter to be buried in the center of an omnibus bill.

I would like, too, to reaffirm the fact that my interest in providing for appropriate educational opportunities for the mentally retarded has not decreased since I introduced in this House the bill which later became the Act of September 6, 1958 (Public Law 85-926) and which H.R. 3000 seeks to amend.

Mr. Speaker, I consider this a suitable occasion on which to refocus the attention of this House upon the goals of the President's proposals relative to mental retardation.

As stated in his Message of February 5, these include: (a) the prevention of the occurrence of mental retardation; (b) the providing of facilities and programs for research and for early diagnosis and continuous and comprehensive care, in the community, of those suffering from mental retardation; (c) the

restoration and revitalization of the lives of the mentally retarded in the community through better health programs and strengthened educational services; and (d) the reinforcing of the will and capacity of our communities to meet the problems of mental retardation, in order that the communities, in turn, can reinforce the will and capacity of individuals and individual families to meet these problems.

The President emphasized in this Message that if our Nation is to live up to its own standards of compassion and dignity and achieve the maximum use of its manpower, we must, as a Nation, seek to bestow the full benefits of our society on those who suffer from mental retardation.

Mr. Speaker, though the Congress and the Executive Branch have done much, in the past decade and a half, to help the mentally retarded, they have remained victims of the ancient but persistent belief that mental retardation is a hopeless, incurable affliction.

As a result of the persistence of this belief and the negative attitudes that accompanied it, this Nation has never launched a full scale attack on the problems of mental retardation.

Consequently, mental retardation continues as a major national health, social, and economic problem. Over five million persons are thus afflicted--twice as many as blindness,

polio, cerebral palsy and rheumatic heart disease combined.

Because, under our present system of care, many of our mentally retarded are not properly trained and educated to achieve their maximum productivity, the losses to our economy are great. In addition, States and localities spend over one-half billion dollars for care and services for the mentally retarded--for the 200,000 who are cared for in residential institutions, most at public expense, and for others of the 400,000 of the mentally retarded who require constant care or supervision.

Yet it may be said that for the five million Americans who suffer from some degree of mental retardation, our present system of care could better be called our system of "don't care."

In our public institutions for the mentally retarded, conditions are no better--they are sometimes worse--than they are in our State mental hospitals. But it is among the millions of retarded who remain in our communities that our "don't care" system has been most vicious.

Time and time again our dedicated scientists and professional workers have found these relationships functioning in our society: Where people are impoverished, there is poor health; where there is poor health, mental illness and mental retardation are prevalent. Where families are weak, community ties tenuous, educational and employment opportunities lacking, there you will find the mentally

retarded clustered. Among expectant mothers who do not receive prenatal care--a disproportionate number of whom reside in city tenements and rural slums--premature births occur two or three times as frequently as they do among women who receive adequate prenatal care; further, among premature infants, the incidence of birth defects and mental retardation is high.

In city tenements and rural slums, the intellectual blight that characterizes these neighborhoods is associated with the higher incidence of mental retardation found among school children coming from these neighborhoods.

Yet in our communities, rich or poor, urban or rural, we have done little to help the mentally retarded. Less than 30,000 mentally retarded individuals were served by our psychiatric outpatient clinics in 1959, and only 20,000 received clinical services in programs supported by the Children's Bureau in 1961.

Out of five mentally retarded school-age children, one is enrolled in special education programs in public schools. We need 75,000 specially prepared teachers to instruct the mentally retarded--we have less than one-third that number now.

These findings--and many others reported by the President's Panel on Mental Retardation--are the facts that undergird current proposals in this field. They indicate that if we are to prevent the occurrence of preventable mental retardation, we must allocate more resources for health, for education and training.

Furthermore, if we are to bestow the benefits of our society upon those who are already retarded, they must receive special services, in the community, that will actively foster the development of each individual's maximum capacity, and his maintenance in the community at the highest level of social responsibility of which he is capable.

If, as is apparent, providing adequate medical care to expectant mothers and their infants prevents mental retardation, then adequate medical care must be made available to each mother, and to each child.

If the mentally retarded need special educational opportunities, then we must make special efforts to insure that there are enough classroom teachers to instruct each mentally retarded child. For the retarded child does not differ from the normal child in his need to be properly educated for adult responsibilities.

If, as we know, many of the retarded will require special services over a long period of time, and that some of the more severely retarded will require a sheltering environment for an indefinite period of time, then provisions for these must be made in the community.

Mr. Speaker, time does not stand still for the mentally retarded while those who control his destiny quibble about what proportion of his total needs they are going to provide: whether

he will get 10 percent of the services he needs, or 25 percent, or 50 percent. The passage of time will make only more desperate the needs of the retarded that are not being met today. For it is <u>now</u> that the infant's mother needs care. It is <u>now</u> that the toddler needs a careful diagnostic workup. It is <u>now</u> that the child needs special education. And it is <u>now</u> that millions of the retarded need special facilities in their communities, near their own homes.

For a long time, I have known that the needs of the mentally retarded were great and complex. I have consistently brought these needs to the attention of this House. As Chairman of the Subcommittee of the Committee on Appropriations that annually considers the Administration's Budget for the Department of Health, Education and Welfare, I have, year after year, urged that adequate funds be appropriated to mount truly effective programs in this field.

The Appropriations Committee was pleased that the President gave this problem the recognition he did when he appointed the President's Panel on Mental Retardation. While that Panel made an excellent report, there are certain aspects of the problem that could have been given attention if the Panel had had a little more time. The following are a few exciting possibilities for new programs that appear to have been overlooked.

1. Perinatal Research

The report of the Panel makes reference to some of the early findings of the collaborative perinatal project of this

Institute. It points to some of its results as "illustrative of research findings which have led to prevention of a significant number of cases of mental retardation." However, the Panel makes no recommendation for continuation or extension of this important undertaking--an undertaking which has mobilized vast resources in 15 university centers, and has created a national resource with continuing capability for an organized and concerted drive against the causes of retardation, cerebral palsy, and other neurological and sensory disorders. The potential of this resource is largely unexplored, but numerous requests from many agencies indicate that this unique program is in a position to make broad contributions to many facets of the problem of mental retardation.

At the present time, a wealth of research information is already assembled in the collaborative project. The Institute is now exploring with other agencies the most profitable directions for the further extension of this program and should be in a position to present such a broad plan for fiscal year 1965.

2. Role of Viruses in Pregnancy

The Panel points out that a "number of viruses and other infectious agents have already been identified or are strongly suspected of producing damage to the fetal brain when the mother is infected during pregnancy." No specific recommendation for an attack on this problem is made, however.

Within the Institute's collaborative perinatal project, every woman is receiving serological examinations for the detection of viral infection. Preliminary studies show that about 7 percent of these women experience infection by a known virus during pregnancy. Within this program, the virus of German measles--an agent known to produce mental retardation--has been isolated. The human disease has been produced experimentally for the first time. The effectiveness of a vaccine has been demonstrated, and its usefulness in preventing fetal injury is under investigation in monkeys.

These studies should be extended to other viruses. The place to search for such viruses is in abortions or premature births because those agents which in mild instance cause mental retardation, lead to death and miscarriage of the fetus in severe cases.

The methods for culturing such viruses have now become routine, but they are laborious and time consuming. Such work does not provide challenge for the university-based scientist whose interest lies in the search for new approaches. It would be possible, however, through industrial contracts, to establish a large screening program to search for viruses among a number of specimens. Within such a program it is almost certain that additional viruses responsible for fetal injury would be found.

3. A National Neurosensory Instrumentation Center

Because of the complexity of the nervous system, the

development of precise instruments is an essential aid to investigation. For example, a statement frequently quoted is that "in 75 percent of instances of mental retardation no structural abnormality of the brain has been demonstrated." A thorough review of the literature suggests one probable explanation for this impression: brains of retarded individuals after death have not been studied with the precise methods required to demonstrate detailed and deep-lying deformities.

The studies of Dr. Windle and his associates in Puerto Rico indicate that asphyxiated newborn monkeys undergo extensive cell loss in the brain. Such loss, however, is demonstrable in later life only as a reduction in the number of cellular elements present. One cannot see what is absent, and without the use of precise cell-counting techniques, up to 25 percent of the neural elements of a nucleus of the brain may be lost without this being evident to the neuropathologist.

Studies in the Institute's Laboratory of Perinatal Physiology also indicate that the effects of such deleterious agents as asphyxia and kernicterus are highly selective, leading to serious impairment of some parts of the brain while sparing others. Exact quantitation of cell loss in various nuclei of the brain is thus essential if we are to understand the structural basis of the varied forms of intellectual impairment in mental retardation. However, the brain comprises several billions of nerve cells. It

has been the lifework of a few dedicated scientists to attempt such quantitative studies of even one or two specimens. However, technology has now reached the stage where much of this arduous task could be accomplished automatically by the use of instruments. The development of an automatic cell-counting microscope is now well within the realm of attainment. The specific technological problems which must be overcome in the production of such an instrument have been defined.

A central planning group, empowered to use grants or contracts to recruit the technical and industrial resources required, is need to make this possibility a reality. The availability of a cell-counting instrument to scan the brains of mentally retarded individuals dying of intercurrent diseases, and of animals with comparable experimentally induced neurosensory defects, would constitute a major contribution in our efforts to define with accuracy the organic abnormalities responsible for mental retardation.

Particular concern has been expressed regarding the complex problem presented by the blind and the deaf retarded. Especially where multiple handicaps are present, the mobilization of the individual's intellectual resources may be completely blocked by failure of communication. Fundamental investigations, well underway, are exploring the use of patterned sensory stimuli, applied to the skin by electronic devices, as a means of establishing a meaningful communication. In a similar way, Helen Keller learned the meaning

of sound through feeling with her fingertips the vibrations of the larynx of her teacher. The time is ripe for an all-out investigation of the various alternative sensory pathways through which visual and auditory information may be made available and meaningful to those whose normal channels are destroyed.

An even greater challenge exists in explorations directed toward the substitution of electronic divices for the eye and the ear--devices which might be keyed into the human nervous system directly in such a fashion as to provide substitute stimuli within the visual and auditory systems. The problems to be overcome are awesome but not insurmountable.

In vision, for example, one first must have precise knowledge of the coding process of the eye whereby the light impulse falling on the retina--composed of some 100 million computer cells--is converted into patterns of nerve impulses. When this knowledge is available, it will be necessary to develop computers and other instruments capable of interpreting the impulses. Finally, means must be found to key the coded messages into the nervous system in a way which will not destroy the delicate nerve fibers to be stimulated.

A committee of competent scientists is actively engaged in the consideration of this entire problem of substitutions for vision. The financial and logistical resources required to transform into reality the ideas of this committee, and of other

related groups, should be established within a national neurosensory service center.

4. A Cooperative Head Injury Study

The most common single cause of hospitalization of children is accident and injury. Of a group of injured hospitalized children, 30 percent were found to be suffering from injuries of the head and brain. Head injury is not ordinarily thought of as a cause of mental retardation. However, in approximately 10 percent of institutionalized retarded, a postnatal condition is held responsible for the retardation. Among these, a significant number result from head injury. Automobile accidents account for a large portion of such accidents, but sports, various play activities, and home accidents are also causes. As pointed out by the President's Panel, the obvious solution is prevention. However, as is the case with asphyxia, many of the serious permanent residuals of head injury appear to develop after the event during a postconcussion reactive phase. Therefore, effective management of this delayed reaction could materially reduce the severity of the permanent neurological damage in many instances of head injury.

A cooperative head injury program should investigate many problems: the logistical problems of providing prompt, definitive surgical management of accident victims from cities and highways; the fundamental characteristics of the reaction of the brain to injury; the classification and evaluation of the injured; and the

evaluation of the therapeutic measures now being carried out on a largely empirical basis.

5. Centers To Study Diseases Of The Nervous System in Infancy And Childhood

The problem of mental retardation is one of broad scope to which a diversity of skills and talents must be addressed. The Chairman of the President's Panel has made it clear that it has been the intent of that Panel to mobilize, for the attack on this problem, individuals having the widest possible variety of skills. Important among these is the scientist whose life is devoted to the study of the brain. The mobilization of the field of neurology to attack this vast problem requires a clear definition of the role and responsibility of clinical neurologists, neuropathologists, neurophysiologists, neurochemists, and neuroanatomists. The importance of this aspect of the problem of retardation requires that it receive specific focus. The development of centers specifically to study diseases of the nervous system in infancy and childhood, is essential if such people are to be drawn into active participation in research in this field.

It is believed that the above-mentioned special activities are in line with the thinking and objectives of the President's Panel and could appropriately have been included within their report.

This year we face an unprecedented opportunity. First, as a result of the work of the President's Panel on Mental Retardation, the facts regarding mental retardation have been clarified as never before. Second, the President of the United States, in an historic message to Congress, has used the weight of his great office to lead the Nation into better ways of dealing with the medical, social, and economic burdens caused by mental retardation. Third, the people have indicated by their response to the President's Message, that it is their will, as well as their desire, that the mentally retarded be given appropriate care, treatment, and education in their home communities.

I therefore urge that this great legislative body act on the opportunities currently available to us, and enact an effective mental retardation program.

I am submitting for the Record a summary of the three bills I now introduce.