

CONGRESS EMPHASIZES REHABILITATION RESEARCH

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INTRODUCTION

During the recently concluded 95th Congress, much legislative emphasis was placed by the Congress on research programs to aid the handicapped. The impetus for the emphasis was initiated by the House Committee on Science and Technology, under the leadership of the Committee Chairman Olin E. Teague (D-Tex.), the former Chairman of the House Veterans Affairs Committee. The Committee recognized that much was to be gained by directly applying this nation's vast scientific and technological expertise to the problems caused by disability and several legislative measures were adopted following the studies and recommendations of two consultant advisory Panels on Research Programs to Aid the Handicapped commissioned by the Committee. Both Panels were chaired by William A. Spencer, M.D., Director, Texas Institute for Rehabilitation and Research, Houston, Texas.

These consultant advisory Panels were comprised of clinicians, engineers, consumer organization representatives, and government research executives. Representing the Veterans Administration on the Panels were Wilfred Holsberg, Chief, Prosthetics Field Operations; Thomas F. Newcomb, M.D., then Assistant Chief Medical Director for Research and Development, and Vernon Nickel, M.D., Director, Rehabilitative Engineering Research and Development, each of whom played a key role by contributing expertise and knowledge to the final Panel recommendations.

Over the years many studies and reports indicated a critical deficiency in the completeness and extent, and the lack of overall direction in our nation's research programs to aid disabled persons. Recently, several prominent studies and reports cited the potential for

establishing a national research program, e.g., the National Academy of Sciences' report on "Science and Technology in the Service of the Physically Handicapped" (October 1976), the White House Conference on Handicapped Individuals (May 1977), Committee on Science and Technology "Report of the Panel on Research Programs to Aid the Handicapped" (April 1977 and March 1978), and the National Science Foundation-sponsored Texas Tech Study "Technology Assessment: Human Rehabilitation Techniques" (August 1977). These studies all had a profound impact and formed the basis for several legislative actions during the 95th Congress.

NATIONAL SCIENCE FOUNDATION

The National Science Foundation (NSF) Authorization Act for Fiscal Year 1979 (P.L. 95-434) authorized \$2 million for a handicapped research program in the Applied Sciences Research Applications Directorate of the Foundation. The NSF, throughout a number of its Directorates, is supporting a significant amount of select pioneering research projects (e.g., computerized, automated artificial limbs, electromagnetic stimulation and regeneration of bone, and nerve implant prostheses for nerve regeneration) and is exploring other problems of the disabled which indicate that much progress and great public benefit can be realized through federally-sponsored research projects which address the problems of the disabled.

These types of innovations require a multidisciplinary research approach which includes not only the natural sciences and engineering but the social (legal and economic) and medical sciences. The NSF has this expertise, the capability and the necessary organization in place to carry many of these successful basic projects through the applied research and feasibility phases, ensuring the timely availability of these efforts to the service delivery system and the disabled population.

The Congress is concerned that, too often, successful basic research projects lack the attention and further Federal assistance to carry them through the feasibility and implementation processes. Therefore, the Congress has directed the NSF's Applied Science and Research Applications Directorate to establish a science and technology program focused on the problems of the disabled. The Foundation has the coordinating mechanisms available to establish such a program and is directed to establish the program in a cooperative mode with the other Federal agencies dedicated to serving the disabled.

NATIONAL AERONAUTICS AND SPACE ADMINISTRATION

Following the recommendation of the consultant advisory Panel on

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Research Programs to Aid the Handicapped, the Congress increased the responsibility of the National Aeronautics and Space Administration (NASA) by amending the statutory NASA charter to include bioengineering for the handicapped. In P.L. 95-401, Congress declares that the general welfare of the United States requires that the unique competence of NASA in science and engineering systems be directed to assisting in bioengineering research, development, and demonstration programs designed to alleviate and minimize the effects of disability.

Although \$4 million was authorized to be appropriated for this activity in the original legislation, the final appropriation action cut deeply into the space program budget, and it is questionable at the time of this writing what bioengineering research NASA will be able to sponsor in Fiscal Year 1979.

NATIONAL INSTITUTE OF HANDICAPPED RESEARCH

Another major action which indicates Congressional interest and emphasis on rehabilitation research was the passage of H.R. 12467 (P.L. 95-602), initially introduced in the House of Representatives by Representative John Brademas (D-Ind.), Chairman of the Subcommittee on Select Education, Committee on Education and Labor and subsequently introduced by Senator Jennings Randolph (D-W.Va.), Chairman of the Subcommittee on the Handicapped, Committee on Human Resources. On November 6, 1978, the President of the United States signed H.R. 12467 into law. Besides the creation of a National Institute of Handicapped Research (NIHR), among other elements Public Law 95-602 also contains provisions for an Interagency Committee on Handicapped Research (ICHR) and a National Council on the Handicapped (NCH), major recommendations of the House Science Committee's Panel on Research Programs to Aid the Handicapped. These three elements are paramount for coordination and cooperation among the various Federal agencies involved with handicapped individuals and will maximize the utilization of our nation's vast scientific and technological resources in addressing the problems caused by disability.

The House Committee on Education and Labor committee report on this legislation explained that "research regarding the needs of handicapped people for greater independence demands the same quality of leadership and institutional visibility as research regarding disease prevention such as sponsored by NIH". Senator Randolph quite vividly explained that the "rehabilitation research program has long been recognized as the life's blood of new ideas for improving services to the disabled". In the Congressional debate that led to establishing the NIHR it was noted that the HEW rehabilitation research

budget for Fiscal Year 1978 was actually less than the budget for Fiscal Year 1967; in 10 years this budget dropped from \$32 million to \$31.5 million. This did not represent frugality on the part of Congress but a lack of leadership and commitment on the part of the previous administration. Senator Randolph went on to say that the NIHR may be the brightest star in the future of rehabilitation services.

This NIHR, headed by a Director appointed by the President (Executive Level V), will both finance and coordinate Federal research activities affecting the lives of handicapped people. Specifically, it is envisioned as a focal point to expand the scientific base of rehabilitation, improve the skills and knowledge of rehabilitation professionals in the most modern technology available, contribute to better analysis and planning in the rehabilitation field, and place research and development in the field of the handicapped on a more equitable standing with the best of research and development in the fields of medicine and education. The purposes of the NIHR are—

1. To provide for a comprehensive and coordinated approach to the administration and conduct of research, demonstration projects, and related activities for the rehabilitation of handicapped individuals, including programs designed to train persons who provide rehabilitation services and persons who conduct research;

2. To facilitate the distribution of information concerning developments in rehabilitation procedures, methods, and devices to rehabilitation professionals and to handicapped individuals to assist such individuals to live more independently;

3. To improve the distribution of technological devices and equipment; and

4. To increase the scientific and technological information presently available in the field of rehabilitation.

With these purposes in mind, the NIHR may very well extend to all disabled persons, through an expanded commitment and utilization of the latest research in freeing handicapped individuals from dependent, life-threatening, and life-shortening conditions. To promote this goal the Institute will be responsible for:

1. Conducting research with public and private organizations, and administering the research and training center program—

- a. research with private as well as public organizations;

- b. research in other rehabilitation services as well as vocational;

- c. research, including basic research when related to rehabilitation techniques and service;

- d. establish and support rehabilitation research and training centers;

- e. conduct research in the area of telecommunications systems;

- f. conduct a program of joint projects with the National Insti-

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tutes of Health, Health Services Administration, Administration on Aging, National Science Foundation, Veterans Administration, Office of Education, National Aeronautics and Space Administration, other Federal agencies, and private industry in areas of joint interest involving rehabilitation; and

g. conduct a program of research related to handicapped children and individuals who are aged 60 and over.

2. Disseminating information acquired through research funded by the NIHR to other Federal, State, and local public agencies and to private organizations engaged in research relating to rehabilitation or providing rehabilitation services;

3. Coordinating, through the Interagency Committee established by Section 203 of this Act, all Federal programs and policies relating to research in rehabilitation;

4. Disseminating educational materials to primary and secondary schools, institutions of higher education, and to public and private entities concerning how the quality of life of handicapped individuals may be improved.

5. Conducting an education program to inform the public about ways of providing for the rehabilitation of handicapped individuals, including information relating to family care and self care;

6. Conducting conferences, seminars, and workshops (including in-service training programs) concerning research and engineering advances in rehabilitation pertinent to the problems of handicapped individuals;

7. Taking whatever action is necessary to keep the Congress fully and currently informed with respect to the implementation and conduct of programs and activities carried out under this legislation;

8. Producing, in conjunction with the Department of Labor, the National Center for Health Statistics, the Bureau of the Census, the Social Security Administration, and other Federal departments and agencies, as may be appropriate, statistical reports and studies on the employment, health, income, and other demographic characteristics of handicapped individuals and disseminating such reports and studies to rehabilitation professionals and others to assist in the planning and evaluation of vocational and other rehabilitation services for the handicapped;

9. Scientific review through the Director of all research grants and programs over which he has authority by utilizing, to the maximum extent possible, appropriate peer review groups established within the NIHR and composed of non-Federal scientists and other experts in the rehabilitation field;

10. Development of a long-range plan for rehabilitation research which shall—

a. identify any research which should be conducted respecting

the problems encountered by handicapped individuals in their daily activities, especially problems related to employment;

b. determine the funding priorities for research activities under this program and explain the basis for such priorities, including a detailed description of any new types of research recommended for funding; and

c. specify appropriate goals and timetables for activities to be conducted under this program.

11. Promote, through the Director's cooperation among Federal departments through the Interagency Committee on Handicapped Research and consultation with Administrators of research programs with regard to design of research projects, results and applications; and

12. Take whatever actions appropriate to provide for a comprehensive and coordinated research program under this law; and that any person responsible for administering any such program shall, through the Interagency Committee, consult and cooperate with the Director in carrying out this program.

Through these program objectives the Institute will ensure that the practical products of basic research will ultimately be transferred and disseminated to the disabled themselves, thus providing great potential for improving their lives.

INTERAGENCY COMMITTEE ON HANDICAPPED RESEARCH

Another key element to this program is an Interagency Committee on Handicapped Research (ICHR). The ICHR must become an effective integrating agent to promote interagency cooperation, joint-funding and information dissemination of the latest in scientific and technological endeavors. In addition to the previously mentioned cooperative linkage with the NIHR, it will:

1. Promote coordination and cooperation among Federal departments and agencies conducting rehabilitation research programs by its interagency structure composed of the National Institute of Handicapped Research; Rehabilitation Services Administration; Office of Education; National Institutes of Health; Veterans Administration; National Aeronautics and Space Administration; Department of Transportation; National Science Foundation and such other members as the President may designate;

2. Identify, assess, and seek to coordinate all Federal programs, activities, and projects, and plans for such programs, activities, and projects with respect to the conduct of research related to rehabilitation of handicapped individuals; and

3. Submit a report to the President and to the appropriate committees of the Congress making recommendations as the Committee

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deems appropriate with respect to coordination of policy and development of objectives and priorities for all Federal programs relating to the conduct of research related to rehabilitation of handicapped individuals. In order to establish a close liaison and continuity of effort both Houses agreed that the Director of the NIHR would be the Chairman of the Interagency Committee, thus, emphasizing the Congressional intent of promoting cooperation among research entities.

NATIONAL COUNCIL ON THE HANDICAPPED

The final element, which will emphasize the importance of the research activities within the rehabilitation field with regard to disabled persons, is the National Council on Handicapped (NCH). With programs affecting disabled persons fragmented across many Federal departments and agencies, a balanced, comprehensive, cohesive program can be achieved only if governmental and private representatives work together on planning, directing, and coordinating the total national effort. To that end, it is imperative that handicapped individuals participate significantly in the program, both as working members of the organization and as members of the NCH. This government-consumer-professional-industry partnership will be embodied in the NCH with representatives of handicapped individuals, national organizations concerned with the disabled, providers and administrators of services to the disabled, individuals engaged in conducting medical or scientific research relating to the disabled, business concerns and labor organizations. The NCH will link the NIHR and other Federal agency programs and will be the primary vehicle for adequately communicating the needs of disabled persons at the highest levels of government.

The duties of the NCH shall be:

1. To establish general policies for, and review the operation of the NIHR;
2. To provide advice to the Commissioner of the Rehabilitation Services Administration (RSA) with respect to the policies of and conduct of RSA;
3. To advise the Commissioner of RSA, the appropriate Assistant Secretary of the Department of Health, Education, and Welfare (HEW) and the Director of the NIHR on the development of the programs to be carried out under P.L. 95-602;
4. To review and evaluate on a continuing basis all policies, programs, and activities concerning handicapped individuals and persons with developmental disabilities conducted or assisted by Federal departments and agencies including programs established or assisted under this Act or under the Developmental Disabilities Assistance and

Bill of Rights Acts, in order to assess the effectiveness of such policies, programs, and activities in meeting the needs of handicapped individuals;

5. To make recommendations to the Secretary of HEW, the RSA Commissioner, and the Director of the NIHR regarding ways to improve research concerning handicapped individuals, and the methods of collecting and disseminating the findings of such research, and make recommendations to facilitate the implementation of programs based upon such findings; and

6. To submit, beginning in 1980, an annual report to the Secretary of HEW, the Congress and the President to include (a) a statement of the current status of research concerning the handicapped in the U.S., (b) review of activities of RSA and NIHR, and (c) such recommendations respecting the items described in clauses (a) and (b) as the NCH considers appropriate.

Emphasis on rehabilitation research affirms the congressional intent to bring technological developments and their application to rehabilitation problems. Improving the management of research, technology development and applied engineering for the disabled, and developing a more comprehensive research program between Federal agencies interested in research for the disabled, will be priority missions under P.L. 95-602.

The National Institute of Handicapped Research will be charged with the delicate task of planning and implementing research and development strategies critical to the problems relating to disability and enlisting professionals with expertise which can be brought to bear in new ways on these problems. The NIHR is to develop, conduct, and coordinate an innovative research program which actively seeks solutions to the many and varied problems experienced by disabled persons. It has a broad mandate to coordinate Federal rehabilitation research programs and policies, conduct special studies, disseminate research findings, and inform the community—both professional and consumer—with regard to the latest developments in rehabilitation research and engineering.

From these several Acts of Congress, it is clearly seen that there is tremendous support and interest in the Congress for rehabilitation research. It is up to each one of us now to use these funding resources to exploit the latest scientific and technological advances in overcoming or alleviating the problems caused by disability.