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REPORT OF THE PANEL ON
PHYSICAL MEDICINE AND
REHABILITATION RESEARCH

*Ad Hoc Group of Consultants to the
Advisory Committee to the Director, NIH*

December 1989

Report of the Panel on Physical Medicine and Rehabilitation Research

Errata

Panel Member List should appear as:

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In Appendix B, page B-89, para. 2, line 1 should read:

The community of medical physiatrists appears eager to support

MEDICAL REHABILITATION RESEARCH

**A Report of the Panel on Physical Medicine
and Rehabilitation Research**

*Consultants to the Advisory Committee
to the Director, NIH*

National Institutes of Health
Bethesda, Maryland

December 21, 1989



The
University of Oklahoma
Oklahoma City Campus-Health Sciences Center

OFFICE OF THE DEAN
College of Medicine

Edward N. Brandt, Jr., M.D., Ph.D.
Executive Dean

December 19, 1989

Dr. William F. Raub
Acting Director
National Institutes of Health
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Dear Dr. Raub:

Please find enclosed the final Report of the Panel on Physical Medicine and Rehabilitation Research.

The Report sets forth the final recommendations of the Panel, which are based upon the testimony given by speakers on November 20, 1989, and the deliberations of the Panel on November 21, 1989. The conclusions are also based upon correspondence from public organizations concerned with physical medicine and rehabilitation research.

It was a pleasure to chair this Panel, and I trust the recommendations set forth in the report will be helpful to NIH in guiding policy decision in this area.

Sincerely,

Edward N. Brandt, Jr., M.D., Ph.D.
Executive Dean
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ENB/das

Enclosure

Panel on Physical Medicine and Rehabilitation Research

November 20-21, 1989

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Report of the Panel on Physical Medicine and Rehabilitation Research

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I. *Executive Summary*

The Panel on Physical Medicine and Rehabilitation Research was established by the National Institutes of Health (NIH) in response to legislative interest in medical rehabilitation research and the desire of the NIH to review comprehensively the needs and concerns of the medical rehabilitation research community. The Panel was constituted as an ad hoc group of consultants to the Advisory Committee to the Director, NIH, to receive testimony from the medical rehabilitation research community and other interested parties and organizations and to develop a report and recommendations for consideration by the Advisory Committee. The mandate of the Panel was to review and consider the concerns of the medical rehabilitation research community, to assess the current administration of rehabilitation research at the NIH, and to develop suggestions for approaches to assure continued progress in this area of research.

During public sessions on November 20 and 21, 1989, the Panel heard presentations of invited experts from the National Institute for Disability and Rehabilitation Research (NIDRR), NIH, the Centers for Disease Control (CDC), and the medical rehabilitation research community and received public testimony from other concerned organizations. In deliberations after these presentations, the Panel put forward the following recommendations:

1. That the Director, NIH, appoint a panel consisting of experts in rehabilitation research and persons with disabilities to define a research agenda with priorities, time lines to complete research, and dollars needed. Such a research agenda should include short- and long-term elements and a plan for developing a larger number of experts in rehabilitation research relative to the NIH mission.
2. That the mission of any rehabilitation administrative entity should be to foster research and research training in rehabilitation sciences and to promote all aspects of rehabilitation research within the mission of the NIH.
3. That the Director, NIH, work through appropriate channels to create a high-level transgovernmental entity to monitor and coordinate rehabilitation research in all Federal agencies, to identify unserved rehabilitation research needs and opportunities, and to stimulate programs in appropriate agencies to address these needs and opportunities.

4. That the NIH establish a National Institute of Rehabilitation Sciences reporting to the Director, NIH, to accomplish the mission defined [to foster research and research training in rehabilitation sciences and to promote all aspects of rehabilitation research within the mission of the NIH].
5. That a Center of Rehabilitation Sciences be created, either freestanding or integrated into an existing institution, to contain the following elements:
 - training grant authority,
 - gap-filling and cross-cutting award authority,
 - a long-range plan for rehabilitation research that can be implemented,
 - a central focus for rehabilitation,
 - an advisory body (to include people with disabilities), and
 - a way to coordinate and promote rehabilitation throughout the NIH.
6. That the Director, NIH, as an interim step, create an entity that includes the following elements:
 - a long-range plan for rehabilitation research that can be implemented,
 - a central focus for rehabilitation,
 - an advisory body (to include people with disabilities), and
 - a way to coordinate and promote rehabilitation throughout the NIH.

All of the recommendations were passed with the exception of Recommendation 4.

II. *Introduction*

The NIH has a significant investment in laboratory and clinical research aimed at improving the quality of life for persons with disabilities. Although some definitional problems involving physical medicine and rehabilitation research and medical rehabilitation research could affect NIH estimates of dollars expended in the area of rehabilitation research, in FY 1987, NIH support in this area amounted to \$102.1 million. Estimates for FY 1990 are placed at \$124.9 million. Research in this area is supported by 13 components of the NIH.

NIH convened the Panel on Physical Medicine and Rehabilitation Research to consider how best to ensure an enhanced scientific environment for research relevant to the rehabilitation sciences. The agenda for the meeting was designed to offer the expression of many different viewpoints on this issue. Following a series of presentations on the particular scientific and policy aspects of rehabilitation medicine and commentaries from interested organizations and scientific societies, the Panel held extensive discussion on the second day of the meeting. This report summarizes the Panel's deliberations and provides recommendations for consideration by the Advisory Committee to the Director, NIH.

III. *Background Leading to the Meeting of the Panel on Physical Medicine and Rehabilitation Research*

Legislative Interest in Medical Rehabilitation Research

During the 1988 reauthorization process, Representative Doug Walgren (D-PA) and Senator Edward Kennedy (D-MA) introduced legislation (H.R. 4013 and S. 2222, respectively) proposing a freestanding center for medical rehabilitation research within NIH. The 1988 House bill (H.R. 4013) was not acted upon, and the rehabilitation center provision in the Senate bill (S. 2222) was not included in the final NIH reauthorization legislation.

On July 24, 1989, Senator Kennedy introduced S. 1392, the Biomedical Research Act of 1989. Title II of the act would establish within NIH a National Center for Medical Rehabilitation Research to conduct and support biomedical research and research training, disseminate health information and research training, and support other programs with respect to the rehabilitation of individuals with physical disabilities resulting from diseases or disorders of the neurological, musculoskeletal, cardiovascular, or other physiologic systems. (On November 21, 1989, the second day of Panel deliberations, Representative Walgren introduced H.R. 3819, which designates that a medical rehabilitation research center be established within the National Institute of Child Health and Human Development.)

NIH Approach and Initiative

To respond to the concerns of the medical rehabilitation research community, as well as to the legislative interest in medical rehabilitation research, the NIH established an ad hoc panel of consultants to the Advisory Committee to the Director, NIH, to receive testimony from the medical rehabilitation research community

and other interested parties and organizations, and to develop a report and recommendations for consideration by the Advisory Committee to the Director, NIH.

The mandate of the Panel on Physical Medicine and Rehabilitation Research was to review and consider the concerns of the medical rehabilitation research community, to assess the current administration of rehabilitation research at the NIH, and to develop suggestions for approaches to assure continued progress in this area of research. Specifically, the Panel was to

- review the extent and nature of rehabilitation research at the NIH and ascertain its advancement under the current organizational structure;
- assess the degree to which existing mechanisms provide for coordination of research programs with those of rehabilitation research and suggest modifications as necessary to improve coordination; and
- identify the concerns and needs of the physical medicine and rehabilitation research community and solicit suggestions for enhancing the growth, development, and scientific productivity of medical rehabilitation research.

To launch this effort, a 14-member NIH working group was established to begin preparing for a conference to address the rehabilitation research issue. The group consisted of representatives from the institutes with major interest in the area of medical rehabilitation and members of the staff of the Director, NIH, and was chaired by a member of the Advisory Committee to the Director. An Executive Committee, consisting of the chairpersons of the working group and the Panel, along with an additional member of the Advisory Committee, selected the Panel members and approved the conference agenda.

The membership of the Panel, which met in public sessions on November 20 and 21, 1989, reflected a broad interest in medical rehabilitation research and related fields. Medical and biomedical engineers; basic biomedical and clinical scientists, including an orthopedist, a neurosurgeon, neurologists, and physiatrists; experts in the development and evaluation of prosthetic devices; representatives from physical therapy and the nursing profession; and psychologists were represented. Disabled consumers, representatives of disabled constituency groups, and parents with disabled children, as well as individuals familiar with disability rights, were also represented on the Panel.

More than 140 concerned organizations having an interest in medical rehabilitation research were notified about the meeting and invited to present public testimony. Oral testimony was given on behalf of 18 organizations at the November 20 session; an additional 5 organizations submitted written testimony for the record. On the second day of the meeting, also open to the public, the Panel began its deliberations and the drafting of its report.

IV. *Status of Medical Rehabilitation Research*

NIH Institutes

Briefing materials prepared for the Panel indicate that *each* of the NIH research institutes is directed by legislation to support research, investigations, experiments, demonstrations, and studies related to rehabilitation. A tabulation of *rehabilitation-related* research supported by the NIH also included in the briefing book showed actual FY 1988 and 1989 expenditures to be \$110.9 million and \$119.3 million, respectively (table 1 on page 8). Based on written statements and testimony presented to the Panel by representatives of each of the research institutes, the following activities were highlighted.

National Institute of Child Health and Human Development (NICHD) (\$24.1 million*)

Because disability in children can extend throughout life, the efforts of this Institute to prevent, treat, and rehabilitate are especially important. Early detection and treatment have traditionally been heavily emphasized. Especially important in early prevention is early detection of chromosomal anomalies that can now be assessed through amniocentesis and chorionic villus sampling techniques developed through NICHD-supported research. Phenylketonuria (PKU) and hypothyroidism can be detected very early in development and effectively treated, reducing many of the costly medical and behavioral problems that characterize these conditions if they are left untreated. The multiple systems research approach taken by NICHD-supported researchers recognizes the biological and behavioral complexities and the interactive nature of the controlling variables involved in mental retardation and learning disabilities. Restoring function by replacing or augmenting physical or cognitive impairments or

* Actual dollars supporting rehabilitation-related research in FY 1989.

Table 1
Rehabilitation-Related Research
Supported By NIH (\$ in Millions)

NIH Institute	FY 1987*	FY 1988 Actual	FY 1989 Actual	FY 1990 Estimate
NINDS**	\$ 30.4	\$ 12.1	\$ 10.6	\$ 10.6
NIA	15.7	9.7	10.5	10.8
NHLBI	2.0	2.0	2.2	2.3
NCI	6.3	6.5	9.6	10.0
NICHD	20.2	22.3	24.1	24.1
NIDR	4.7	5.0	7.9	8.0
DRR	11.8	10.7	10.3	9.7
NCNR	.6	1.3	1.3	1.4
NIAMS	2.1	17.8	18.6	18.9
NIDDK	5.1	5.0	3.6	3.6
NEI	2.8	2.2	1.9	1.8
NIGMS	0.4	0.2	0.2	0.2
NIDCD	—	16.1	18.5	23.5
CC***	—	—	—	—
TOTAL	\$102.1	\$110.9	\$119.3	\$124.9

*In FY 1987 the BIDs were asked to use the American Academy of Physical Medicine and Rehabilitation definition in identifying rehabilitation research. However, some institutes interpreted rehabilitation research more narrowly than others and, in some instances, the figures do not include the full range of research, demonstration, and education programs related to the management of diseases. For succeeding years, institutes were asked to report their outlays in this area with no specific instructions to use the Academy definition, but to report rehabilitation research and related research.

**NINDS figures for 1987 include outlays for deafness and communication that were later transferred to NIDCD.

***Research conducted by the Department of Rehabilitation Medicine (DRM) is a collaborative effort with the institutes. This effort is billed to individual institutes through the Management Fund formula. Consequently, institute figures above include DRM costs.

through modifying environmental living conditions has been emphasized through the NICHD's use of small business innovation research funds. Major pertinent research in genetic disease, infectious disease (especially recent work on HIV), disorders of infants, and injury to children and young adults provides intensive new research commitments with obvious major relationships to rehabilitation research.

National Heart, Lung, and Blood Institute (NHLBI)
(\$2.2 million)

A major portion of the Institute's research, demonstration, and education programs is directed at rehabilitation in its broad sense. Activities directed at a narrow definition of rehabilitation include research on exercise and respiratory muscle training (and other techniques as well) for patients with chronic obstructive pulmonary disease; comprehensive cardiac rehabilitation after myocardial infarction, coronary bypass, or other surgery; and varied imaging and quantitative physiological assessments with exercise stress to evaluate functional and work capabilities. Bioengineering aspects include development and assessment of portable oxygen sources, implanted defibrillators, prosthetic heart valves, vascular conduits, and artificial heart devices. Other areas of rehabilitation concern include coping after heart disease, self-management of long-term diseases (e.g., asthma, cystic fibrosis), smoking cessation effects on heart and lung disease, dietary modification for respiratory dysfunction, and control of cardiovascular risk factors. These activities involve a broad spectrum of methods from investigator-initiated research, Institute-initiated research, small business innovation research awards, clinical trials, and public education programs as examples of a spectrum of rehabilitation-related research efforts.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
(\$18.6 million)

Organ-oriented research has a strong relationship to both the basic science important to rehabilitative research and to pragmatic applications to patient disability and direct solutions for overcoming it. Studies of joint function of the elbow, wrist, fingers, spine, hip, knee, and ankle form a basic set of data critical to such rehabilitative applications as major joint replacement, cartilage allografts, studies of mechanisms of loosening, bone remodeling around porous implants, exercise-induced adaptations of muscle grafts, use of ultrasound treatment, radiation synovectomy, and innovative modes of therapy after joint surgery. Clinical and basic research in bone response to stress, strength training and bone density, effect of electric fields on fracture recovery, enzyme treatment effects on discs, and growth and remodeling in scoliosis are all intimately concerned with rehabilitative research. So, too, is muscle research on fatigue mechanisms, use of electrical stimulation in muscle rehabilitation, exercise-induced growth of muscle, and disuse atrophy. Similar research involves physiology and pathophysiology of ligaments and tendons.

Functional assessments range from modeling prosthetic gait to design of tasks and scales of patient function in disease. Outcome measures of physical capability in arthritic diseases in young and old include psychosocial evaluation as well.

National Institute of Neurological Disorders and Stroke (NINDS) (\$10.6 million)

Much of the NINDS basic and clinical research on head injury, spinal cord injury, stroke, and demyelinating and neuromuscular disorders is directly relevant to rehabilitation efforts. Most of these disorders result in profound disabilities of lifelong duration. The rehabilitation research efforts involve support of individual investigators, the business community, and groups working in large specialized centers. Major centers focus on spinal cord injury, head injury, and stroke. Basic and applied research into biochemical and physiological processes of brain injury in stroke and trauma have entered an era of novel and promising possibilities for future research. New research possibilities for dealing with human disease are now rapidly developing as a result of new technological advances, including magnetic resonance imaging (MRI), positron emission tomography (PET), and single photon emission computed tomography (SPECT). A wide variety of disorders, including language dysfunction, dementia, and movement and behavioral disorders, can now be systematically and sequentially assessed at structural and metabolic levels using these technologies. This accomplishment was previously impossible and is providing new knowledge useful in the care of the disabled population. The neural prosthesis program is actively involved with focal electrical stimulation, efforts to improve bladder and bowel control, visual prosthetics, and transduction of sound to cutaneous stimulation. Therapeutic cerebral stimulation and the potential offered by implantable microstimulators have opened up rehabilitative research in ways unimaginable in even very recent years. Rehabilitation research in both retraining and recovery utilizing computer programming techniques, voice simulation, and even pharmacological facilitation of spinal and cerebral function are the source of rehabilitative research that previously had seemed impossible. The incidence of depression and its treatment are still being explored with vital implications to removing disability.

National Institute on Deafness and Other Communication Disorders (NIDCD) (\$18.5 million)

The National Institute on Deafness and Other Communication Disorders supports rehabilitation research and research training related to hearing impairment; speech, voice, and language disorders; and disorders of balance. For FY 1990, an estimated \$24 million, about 20 percent of the NIDCD's total budget, will support rehabilitation research and research training. A good illustration of the Institute's involvement in rehabilitation research is its support of work on the

electronic inner ear, or cochlear implantation, for individuals who are profoundly deaf.

In its present stage of development, the so-called "cochlear implant," a multi-channel electrode surgically implanted into the inner ear, is connected to an external electronic speech processor that converts speech frequencies and other sounds into electrical impulses and feeds them to locations within the cochlea. These implants have led to improved functioning in several thousand adults and soon should be available for children. In addition to this successful clinical application, many individuals with cochlear implants serve as subjects in studies of the otherwise largely inaccessible inner ear. The resulting rapid increase of information on inner ear and central auditory function is an example of how rehabilitation research and basic physiological research can support and nourish each other.

National Cancer Institute (NCI) (\$9.6 million)

The goal of the National Cancer Institute's rehabilitation program is to conduct and support research necessary to restore or maintain the fullest physical, psychological, social, vocational, avocational, and educational potential for cancer patients. Much of this research is interdisciplinary and interlocked with the Institute's treatment and control research. Some rehabilitation research focuses on specific cancers. For example, research related to head and neck cancer includes activities to improve breathing, swallowing, and speaking following surgery and other treatment. Research related to bone cancer investigates limb-sparing techniques and the attachment of prostheses. While research related to breast cancer, prostate cancer, and melanoma has not specifically focused on rehabilitation, improved surgical techniques in these areas have led to reduced need for rehabilitation. Areas of rehabilitation research common to many cancers include quality of life, management of pain, self-care, childhood and adult cancer survivors, nutrition, and the adequacy of and needs for service of cancer patients and their families. NCI's information dissemination activities also address rehabilitation: About 10 percent of the calls to the Cancer Information Service are related to rehabilitation, and rehabilitation research is one of 66 topics covered in the Institute's monthly publication, *The Cancergram*. Because cancer mortality rates are decreasing in people under 65 years of age, the need for rehabilitation research and application is increasing, and activity in this area is expected to grow in the future.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) (\$3.6 million)

The National Institute of Diabetes and Digestive and Kidney Diseases supports research related to medical rehabilitation in two main areas. The first, behavioral or psychological research that involves intervention strategies, addresses problems arising from diabetes, obesity, or gastrointestinal disorders. An examination of the effects of conventional psychotropic agents on glucose regulation

in such patients and a longitudinal study of depression in newly diagnosed juvenile or insulin-dependent diabetics are under way. Other research is investigating the psychophysiology and psychological treatment of irritable bowel syndrome and is applying laboratory data on variables controlling food intake to the treatment of obesity in humans. The second area includes investigations of improved functional maintenance in patients with chronic disorders. Studies include refinements of peritoneal dialysis, total parenteral nutrition, and long-term insulin therapy. Research to develop a glucose substitute for use in peritoneal dialysis fluids may eliminate metabolic problems found in end-stage renal disease patients. In addition, a self-regulating osmotic insulin pump that may prevent many long-term complications of diabetes is being developed with NIDDK support. In addition, NIDDK is supporting a host of studies investigating the special dietary needs of patients undergoing total parenteral nutrition for a variety of disorders.

National Institute on Aging (NIA) (\$10.5 million)

Rehabilitation medicine research among older persons is a major focus of NIA in its epidemiologic, behavioral, clinical, and basic research programs. NIA support for rehabilitation-related research is \$10.5 million per year. Three ongoing initiatives of the NIA of special importance in geriatric rehabilitation are the following:

1. Reducing frailty as a result of injuries in older persons. This study is being carried out in collaboration with the National Center for Nursing Research. To support this research, NIA has allocated \$2 million per year beginning in FY 1990.
2. Rehabilitation and aging from biomedical and psychosocial perspectives.
3. Joint sponsorship with NIDRR of the University of Pennsylvania Rehabilitation Research and Training Center.

Division of Research Resources (DRR) (\$10.3 million)

The division provides an array of resources for multidisciplinary basic and clinical research that includes many projects falling under the category of medical rehabilitation research. In FY 1989, DRR-supported programs hosted 719 rehabilitation-related research projects at a cost of \$9.7 million. Almost two-thirds of this research was conducted under the General Clinical Research Centers (GCRC) program in a network of 78 centers across the country. It included research on joint or heart valve prosthesis, cochlear implants, chronic obstructive pulmonary disease, spinal cord injury, head injury, Alzheimer's disease, and other disorders. In addition, the DRR has a Biomedical Research Support (BRS) program, an Animal Resources Program (ARP), and a Biomedical Research Technology (BRT) program—all of which contribute to medical-related rehabilitation research projects within the various NIH institutes.

Department of Rehabilitation Medicine (DRM), Clinical Center

Several members of this department, representing a variety of disciplines, are principal investigators involved in intramural research projects reflecting the broad interests of staff and the patient populations treated here. Examples include the effect of exercise on patients with polymyositis, the development of normative ultrasound data bases of tongue configurations for use in comparison with disordered populations, and functional outcome of limb-spared patients. In addition, the department participates in a broad range of other research activities with investigators in other institutes on the NIH campus.

Testimony also was received from representatives of NIDRR and CDC regarding the nature and extent of their support for rehabilitation research. Major themes presented are summarized below. No information was presented regarding the rehabilitation research program of the Department of Veterans Affairs (VA) or of the voluntary health organizations which support such work.

Other Federal Agencies

National Institute on Disability and Rehabilitation Research (NIDRR)

Legislation authorizing NIDRR is exceptionally broad in scope. The President appoints its director, subject to Senate confirmation. The Institute is required to present to Congress, under the policy guidance of the Presidentially appointed National Council on Disability, a comprehensive rehabilitation research plan and a list of priorities every five years. It is required to set up an interagency committee to coordinate rehabilitation research throughout the Federal Government. (Some 33 agencies or units of the Federal Government have an identified rehabilitation component.)

Program content emphasizes both research and demonstrations, as well as diffusion of results of rehabilitation research and practice. Some centers funded by the NIDRR, including the Rehabilitation Institute of Chicago, have emphasized preventing disability, both primary and secondary. Some projects and centers also study the physical, social, psychological, and economic sequelae of disabling conditions. The only "basic" research conducted is incidental to or directly supportive of applied clinical or community demonstration research. Program content includes the study of the rehabilitation needs for persons having severe injuries, developmental disabilities, and chronic conditions, such as brain injury, spinal cord injury, congenital conditions, and adult onset of chronic diseases. Projects cover virtually the full spectrum of such disabilities. Most resources are committed to medical aspects of rehabilitation, with studies of applied technology a close second. Additional major efforts are in psychosocial and vocational aspects of rehabilitation. Also part of NIDRR is a strong program of research utilization and diffusion of rehabilitation practice and technology information

and a significant international component. The means for carrying out NIDRR's broad mission include large Rehabilitation Research and Training Centers (RRTC's), Model Spinal Cord Research and Demonstration Centers, Rehabilitation Engineering Centers (RECs), Research and Demonstration projects (priority-driven) research training grants, individual research fellowships, field-initiated research grants, and small (\$50,000) innovative grants.

The budget for this program authority has grown very slowly since its inception in 1979 and is now (FY 1989) \$65,525,000.

Centers for Disease Control (CDC)

The Centers for Disease Control provides \$2.9 million in support of rehabilitation research in the areas of injury control and disability prevention. CDC has emerged as the lead agency for coordinating injury control activities. It is supporting a year-long National Academy of Sciences study of the prevention of disabilities as a basis for further planning and program development. Rehabilitation projects in the injury control program include consequences of mild head injuries, cost of rehabilitation care, rehabilitation following spinal cord injury, and rehabilitation following lower extremity fractures.

Under the relatively new disability prevention program, three rehabilitation research projects are currently supported: prevention and management of urinary tract infections among spinal cord-injured persons; late onset of secondary disabilities among poliomyelitis patients; and frequency and costs of decubitus ulcers among spinal cord-injured patients.

The CDC program emphasizes applied research, not basic science, and coordinates its activities with other Federal agencies. Following the release of the Institute of Medicine (IOM) study on prevention of disabilities (expected early next spring), its programs may expand, and new linkages with state departments of health for surveillance data and local programs of prevention both of primary disabilities and secondary conditions may be initiated.

V. Scientific Relevance of Medical Rehabilitation Research

The testimony presented to the Panel by the research institutes of NIH, and by CDC and NIDRR, as well as speakers for organizations and programs devoted to rehabilitative medicine documented the scientific relevance and urgency of many areas of rehabilitation research. Indeed, scientific relevance is the basis for the substantial and continuing commitment of the institutes of NIH. The current scientific research programs related to rehabilitation medicine range from the development of devices and prostheses directly to relieve disability to fundamental cell biology aimed at understanding the basis for disability and allowing the informed design of corrective interventions.

Several speakers expressed the judgment that important and promising avenues of scientifically relevant research are not being pursued now for lack of commitment, funding, leadership, and a cadre of trained researchers. Specifically, in the words of one speaker, "much research related to rehabilitation" was described, but relatively little was being reported on the process of rehabilitation as distinguished from that of cellular healing or compensatory intervention. Thus, for example, there was spotty emphasis on research on psychosocial aspects of rehabilitation and little description of research on the process of rehabilitation itself. Some speakers cited disciplines and technologies that could be brought to bear in scientific research directed at rehabilitation, and they and others urged systematic development of training programs to produce scientists capable of focusing the full power of contemporary biological, clinical, and social sciences on scientifically relevant rehabilitation research. Finally, not all of the serious problems which some speakers cited as inhibiting effective clinical programs of rehabilitation are scientifically relevant or amenable to scientific solution.

In summary, the Panel heard convincing evidence of the scientific relevance of many specific problems and opportunities in rehabilitation research. It heard of the need for strengthened science-based research and research training on the general process of rehabilitation, and it heard of some deficiencies in rehabilitation capacity that are not scientifically relevant.

VI. *Principal Concerns of the Medical Rehabilitation Research Community*

The major concerns expressed in the presentations and discussions during the first day of the meeting are listed below.

1. No lead agency defines the scientific mission of rehabilitation research. As one result, no overall research plan or mechanism for setting priorities exists.
2. Scientists lack research training programs to prepare for rehabilitation research. In addition, the need to prepare physicians at all levels, including mid-career opportunities to acquire research skills, is acute.
3. Adequate mechanisms to ensure ongoing quality and scientific relevance of rehabilitation research are lacking. Additional review mechanisms, including study sections, need to be introduced.
4. Fragmentation of the rehabilitation research efforts among many agencies may lead to duplication of effort or failure to collaborate on related research questions. Improved coordination and strategies for implementation need to be emphasized.
5. Rehabilitation research needs to be more responsive to consumer needs. Greater consideration should be given to assessing how new knowledge, therapeutic interventions, and technologies affect consumers. The need for more research on outcomes and quality of life was underscored.
6. Lack of a continuum of research from the basic sciences through behavioral sciences resulting in compartmentalization may reflect a lack of recognition that the breadth and comprehensiveness of the rehabilitation process requires that research go beyond organ systems.
7. Consolidation of rehabilitation research into a single center may further fragment the research efforts by isolating them from other related research conducted in the various institutes.

8. Inadequate recognition of rehabilitation research expertise on existing NIH study sections may cause some research projects not to be fully appreciated or given priority because study sections may be unfamiliar with the relevance of the proposed research to the overall field.
9. Inadequate funding and bureaucratic barriers hamper the growth and development of rehabilitation research.

VII. *Issues and Considerations Presented During Public Testimony*

Individuals from 24 organizations representing disciplines and institutions engaged in rehabilitation research and/or direct service, facilities that train health professionals, and consumers of rehabilitation services presented oral and written testimony to the Panel at the November 20 session. Much of this testimony supported the need to enhance rehabilitation research. However, those organizations that discussed a specific mechanism for enhancing this research were divided about the approaches that should be adopted. One view supported the establishment of a freestanding center for rehabilitation research at the NIH. Others disagreed, saying that rehabilitation research efforts should be enhanced within the individual institutes.

The organizations advocating a freestanding center noted that, although research related to rehabilitation has been supported by a number of Federal and private agencies, society's growing need and demand for quality rehabilitative care necessitates an even stronger effort. Placing a center within the NIH may be the impetus for this enhanced effort. These organizations said that a freestanding center was necessary to develop a systematic approach for recruiting and training rehabilitation researchers as well as for developing innovative research strategies to investigate the complex questions of rehabilitation that cannot be addressed within existing biomedical models. These organizations also noted that the interdisciplinary nature of rehabilitation and rehabilitation research often creates difficulties in obtaining support for rehabilitation research. Funding programs are scattered among numerous granting sources whose priorities often do not match the needs of rehabilitation professionals or consumers. The funding of rehabilitation from multiple sources may also contribute to the duplication or fragmentation of research efforts and impede diffusion of new knowledge. Rigorous evaluation of rehabilitation research proposals by a consistent group of qualified peers is essential.

Organizations supporting the enhancement of medical rehabilitation research within individual institutes, rather than the establishment of a freestanding center, said that if rehabilitation research were concentrated in one entity at NIH, it would become isolated from related efforts in the individual institutes. Programs of rehabilitation research now active in a number of institutes could suffer. Establishment of a separate Federal entity, in addition to the National Institute on Disability and Rehabilitation Research, could dilute the impetus for rehabilitation research and result in further fragmentation and potential duplication of research efforts. Several of these organizations acknowledged the need for an administrative mechanism to promote and coordinate rehabilitation research efforts at the NIH and elsewhere.

Public testimony expressed general concern that establishing a new medical rehabilitation entity might hurt actual funding for rehabilitation research; both supporters and opponents of a freestanding entity voiced this concern. One view noted that a new entity could siphon off substantial funds to meet its administrative costs. Furthermore, some organizations said that a separate organization for rehabilitation research might reduce funding for rehabilitation research currently supported by many of the NIH institutes. The various options considered in the development of an administrative entity for rehabilitation research at NIH should be carefully analyzed regarding their potential impact on funding.

VIII. *Panel Recommendations*

Recommendation 1

That the Director, NIH, appoint a panel consisting of experts in rehabilitation research and persons with disabilities to define a research agenda with priorities, time lines to complete research, and dollars needed. Such a research agenda should include short- and long-term elements and a plan for developing a larger number of experts in rehabilitation research relative to the NIH mission.

[*Panel Vote: 18 yea; 0 nay; 0 abstain**]

Rationale for Recommendation 1

Panel members unanimously agreed that a good research program requires, first and foremost, a research agenda with priorities. Development and implementation of a research agenda and priorities should improve the status of rehabilitation research at the NIH, irrespective of whether an administrative entity for rehabilitation research is established.

In developing the agenda and priorities for rehabilitation research, Panel members agreed that the focus should be on research areas directly relevant to the NIH mission, not on all aspects of rehabilitation research or rehabilitation. The Panel discussed the possibility of an interagency mechanism to address broader issues related to rehabilitation, but it reached no conclusions about an appropriate site for this mechanism.

In concluding its discussion on this recommendation, the Panel emphasized the urgent need for identifying the research agenda and priorities for rehabilitation relevant to the NIH mission and stated that this step should be undertaken expeditiously.

* Table 2 on page 28 records the vote on all six recommendations by individual Panel member.

Recommendation 2

That the mission of any rehabilitation research administrative entity should be to foster research and research training in rehabilitation sciences and to promote all aspects of rehabilitation research within the mission of the NIH.

[Panel Vote: 18 yea; 0 nay; 0 abstain]

Rationale for Recommendation 2

The Panel unanimously agreed that any administrative entity to be established should consistently foster, encourage, and promote research and research training in the rehabilitation sciences and promote the availability of funds for this research. Panel members pointed out that critical to the progress of rehabilitation research is the perceived commitment to support this research, as evidenced by the number of proposals solicited and funded. Several Panel members also said that few quality proposals for rehabilitation research will be submitted if a perception exists that there is no great interest or investment in this area of research. One of the primary benefits of establishing any rehabilitation research entity is that the resulting centralized focus would assure consistent support for rehabilitation research and would be readily identified by potential researchers in the field as the source to turn to for research support or coordination.

Recommendation 3

That the Director, NIH, work through appropriate channels to create a high-level transgovernmental entity to monitor and coordinate rehabilitation research in all Federal agencies, to identify unserved rehabilitation research needs and opportunities, and to stimulate programs in appropriate agencies to address these needs and opportunities.

[Panel Vote: 18 yea; 0 nay; 0 abstain]

Rationale for Recommendation 3

The Panel viewed coordination and increased interaction of various agencies involved in rehabilitation research as necessary to make the best use of the finite resources available for research. Through such coordination, an attempt could be made to ensure that available funds are used appropriately to reduce duplication of effort and to maximize collaboration.

Some members felt it may be inappropriate to attempt to create a coordinating mechanism before an administrative entity for rehabilitation research is established within NIH. However, it was also argued that an entity is not necessary for coordination to occur, with the Biotechnology Science Coordinating Committee (BSCC) of the White House Office of Science and Technology Policy (OSTP) cited as an example. Although no single entity for support of biotechnology research exists, the BSCC addresses biotechnology research at multiple Federal

agencies: the Food and Drug Administration (FDA), the Environmental Protection Agency (EPA), the National Institutes of Health (NIH), the National Science Foundation (NSF), and the Department of Agriculture (DOA).

A number of approaches to enhancing coordination were discussed. One would be to work through existing groups with relevant functions, such as the Inter-agency Committee on Handicapped Research (ICHR) authorized by the legislation that established the NIDRR, or the National Council on Disabilities, a Presidentially appointed committee. Another approach would be to operate through OSTP. An entity could be established within OSTP to coordinate research across agencies. A third possibility would be to encourage one or more of the Cabinet to assume such a coordinating function.

Use of the ICHR was seen to have a number of drawbacks. Although the ICHR does have coordinating mechanisms in place, those mechanisms have never been used effectively. Furthermore, some of the agencies in which significant rehabilitation research takes place—for example, the Departments of Transportation, Commerce, Labor, and Defense—are not by law part of the ICHR. In addition, the focus of the ICHR is not restricted to rehabilitation research. The fact that an entity established by Cabinet Secretaries would have to report to several Members of the Cabinet was stated as another reason why this approach to coordination should not be used. The National Council on Disability, which has responsibility for all disability programs in the Federal Government, was mentioned as being effective in those disability-related initiatives on which it has chosen to focus, including the Americans with Disabilities Act and initiatives at the CDC and the Institute of Medicine (IOM). Panel members also view OSTP efforts as effective. However, the Panel did not reach any definite conclusions about the organizational locus for the recommended coordinating mechanism.

Recommendation 4

That the NIH establish a National Institute of Rehabilitation Sciences reporting to the Director, NIH, to accomplish the mission defined [to foster research and research training in rehabilitation sciences and to promote all aspects of rehabilitation research within the mission of the NIH].

[Panel Vote: 2 yea; 14 nay; 2 abstain]

Rationale for Recommendation 4

In deliberating on this recommendation, the Panel focused on the actual benefits and drawbacks to designating an institute-level entity for physical medicine and rehabilitation research. Several Panel members said that rehabilitation research efforts would be best served by using an incremental approach. They questioned whether discussing the establishment of an institute was appropriate before two other issues were resolved: the scope of the research agenda for any medical rehabilitation research entity to be established; and the best way to increase and

train professionals in this area of research to ensure that research conducted will be of the highest scientific merit. Furthermore, it was pointed out that the level of available knowledge in rehabilitation research within the NIH institutes and across other Federal agencies needed to be assessed before priorities for a new rehabilitation research entity could be established. The importance of well-developed plans for this research area was underscored by several Panel members who said that if the appropriate groundwork is not laid, funds appropriated for a new entity might not be allocated optimally to assure maximum scientific impact.

The impact on other institutes and research interests of establishing a new institute was viewed as potentially problematic by a number of Panel members. They felt that placing rehabilitation research in competition with other institutes at a time when the need for broad-based progress in rehabilitation research is increasingly recognized would be counterproductive. In this view, rehabilitation research at the NIH might become less coordinated within the continuum of specific sciences and less successful than if it continued as an important mission of every institute. It is well served by the current commitment to rehabilitation found in 13 NIH institutes. Some Panel members also argued that a new institute for medical rehabilitation research could dampen existing or potential commitment to rehabilitation research on the part of the institutes supporting such research.

Furthermore, it was noted that the creation of a new institute is not a guarantee of increased funding. The 1984 study of the NIH organizational structure by the Institute of Medicine found no cause and effect relationship between the creation of new institutes and funding patterns. The study found no evidence that establishing new institutes, in itself, led to an increased budget for NIH as a whole or that the new institutes tended to grow faster than the rest of the NIH.

The competitiveness of the funding process for NIH institutes also was noted. Rehabilitation research may not yet be mature enough to hold its own in this type of competition. Furthermore, no research area is receiving all of the funding that it needs. Current budgetary constraints allow funding of only 25 percent of approved grant applications at NIH. Given the limited funds available for research overall, it was argued that as much of available funds as possible should be applied directly to research rather than to administrative activities.

In contrast to some of these arguments, some Panel members believed that allying the forces of rehabilitation would result in heightened interest in rehabilitation and that renewed interest could lead to increased funding and increased commitment on the part of all interests involved. In general, however, deliberations indicated that it was not the desire of Panel members—even those who appeared to be most committed to the establishment of a distinct entity for rehabilitation research at the NIH—to recommend any action that could reduce commitment for rehabilitation research on the part of other institutes, increase competition among various interests within rehabilitation, or diminish the importance of the NIDRR. Recognition of the possibility that the establishment of an institute could lead to such outcomes prompted Panel members to consider other organizational options.

Recommendation 5

That a Center of Rehabilitation Sciences be created, either freestanding or integrated into an existing institute, to contain the following elements:

- training grant authority,
- gap-filling and cross-cutting award authority,
- a long-range plan for rehabilitation research that can be implemented,
- a central focus for rehabilitation,
- an advisory body (to include people with disabilities), and
- a way to coordinate and promote rehabilitation research throughout the NIH.

[Panel Vote: 12 yea; 6 nay; 0 abstain]

Rationale for Recommendation 5

After recognizing the potential problems associated with establishing an institute, the Panel reviewed nine organizational options, concentrating on center-level entities, including a center with relatively extensive, but not exclusive, grant-making authority (such as the Center for Nursing Research) and a center with only limited funding authority (such as the Fogarty International Center). Possibilities for establishing an entity within the Office of the Director, NIH, were also discussed.

Issues that received the most attention during the Panel's discussion of these options included

- whether extramural and intramural rehabilitation research components currently in other NIH entities would remain with these entities or be transferred into the newly established entity,
- whether the newly established entity would have grant-making authority, as well as coordinating authority or would have only coordination and information collection and reporting functions,
- what would be the relationship between type of organizational structure and budgetary issues, including control over allocation of funds and receipt of direct appropriations, and
- what would be the amount of actual authority invested in the entity.

Panel members appeared to hold two views of the type and function of any identified entity for rehabilitation research:

1. an entity within the Office of the Director, NIH, to serve coordinating and information-gathering functions related to rehabilitation research supported by other institutes and/or to implement the strategic plan for rehabilitation to be developed by a proposed panel (Recommendation 1), and

2. a more autonomous entity, such as a center, with authority for training grants and some rehabilitation-specific gap-filling and cross-cutting research awards.

Some of the arguments offered by Panel members to support an entity within the Office of the Director, NIH, rather than a freestanding center, were similar to those raised in the discussion about the potential problems associated with the establishment of an institute. Since many disciplines have a rehabilitation research component, some Panel members believed that a freestanding center might fragment rehabilitation research and remove it from the mainstream of research conducted at the NIH. Some also argued that rehabilitation research could be compromised in the short term if a center were to be established. For example, some Panel members believed that study sections might begin to discount grant applications for rehabilitation research when a separate center for rehabilitation research with grant-making authority is established. Some also noted that a significant period of time would be needed to establish any freestanding center with independent granting power; this delay could impede the momentum of the current movement.

Panel members who supported establishing an entity within the Office of the Director, NIH, suggested that this entity could implement a strategic plan. An emphasis of this plan could well be establishing training programs for rehabilitation research to develop a cadre of investigators. This approach was seen as establishing the kind of credibility needed to attract more people into rehabilitation research, as well as providing rehabilitation research with immediate visibility.

Panel members who supported a separate center argued that the time was ripe for an autonomous entity with more power and authority than would be possible if the entity were located in the Office of the Director, NIH. Grant-making authority was a major consideration in the discussion. Some members feared that if the entity were located in the Office of the Director, NIH, its grant-making authority would be curtailed. After an analysis of the nine organizational options presented to the Panel, members focused on the six elements to be included in any center for rehabilitation research proposed for the NIH.

Throughout the Panel's deliberations on this recommendation, the "element" dealing with the need for gap-filling and cross-cutting award authority received more attention than the other elements included in the proposed administrative entity. The potential value of establishing an environment in which basic sciences could be linked in collaborative efforts with more clinical disciplines to examine psychosocial, vocational, and quality of life issues was noted. However, it was argued that, at present, certain types of rehabilitation research, such as those cutting across a number of disciplines, have difficulty acquiring support through existing funding mechanisms. Consequently, the proposed center should have a nonexclusive grant-making authority. That is, the center should have the authority to support gap-filling and cross-cutting research that might not be supported by other NIH entities. At the same time, Panel members recognized the

need to maintain existing rehabilitation research programs in the institutes currently funding rehabilitation research efforts.

The Panel discussed the need for rigorous scientific review of rehabilitation research. Some members stated that such review of rehabilitation research applications would lead to more precision in rehabilitation research. Other Panel members pointed out that the limited number of reviewers with a recognized understanding of physical medicine and rehabilitation research reduced the probability of approval for rehabilitation research applications and that low approval rates reduced the willingness of investigators in the field to submit applications to the NIH.

The current lack of investigators to conduct rehabilitation research and the need to recruit and train scientists was stressed repeatedly throughout the Panel's deliberations. Furthermore, it was emphasized by a number of Panel members that the recruitment and training effort must be initiated as soon as possible. There was a strong consensus among Panel members that training in the area of medical rehabilitation research was paramount to assuring that the research agenda for medical rehabilitation is successfully implemented and that high-quality research is performed. It was also emphasized that training of both basic research scientists and physician scientists is needed.

Recommendation 6

That the Director, NIH, as an interim step, create an entity that includes the following elements:

- a long-range plan for rehabilitation research that can be implemented,
- a central focus for rehabilitation,
- an advisory body (to include people with disabilities), and
- a way to coordinate and promote rehabilitation research throughout the NIH.

[Panel Vote: 17 yea; 0 nay; 1 abstain]

Rationale for Recommendation 6

Panel members discussed what action could be recommended to give greater focus to rehabilitation research efforts at the NIH. As an interim step, the needs of this area of research could be met by developing a long-range plan for rehabilitation research, establishing a central point of contact for rehabilitation interests, coordinating and promoting rehabilitation research through the NIH, and establishing an advisory body for rehabilitation research. *Congressional authorization would not be required to implement these steps; consequently, such an approach could be implemented rapidly.*

Table 2
Individual Panel Member Vote
on the Six Recommendations

	Recommendations					
	1	2	3	4	5	6
Dr. Edward Brandt	Y	Y	Y	N	N	Y
Dr. Henry Betts	Y	Y	Y	Y	Y	Y
Dr. Stuart Bondurant	Y	Y	Y	N	N	Y
Dr. Cheryl Chanaud	Y	Y	Y	N	Y	Y
Dr. E. Y. S. Chao	Y	Y	Y	N	N	Y
Dr. John Ditunno	Y	Y	Y	AB	Y	AB
Dr. George Dohrmann	Y	Y	Y	Y	Y	Y
Dr. Douglas Fenderson	Y	Y	Y	N	Y	Y
Dr. Carmella Gonnella	Y	Y	Y	N	Y	Y
Dr. Dorothy Gordon	Y	Y	Y	N	Y	Y
Dr. Lauro Halstead	Y	Y	Y	N	Y	Y
Dr. Ruby Hearn	Y	Y	Y	N	N	Y
Dr. Frederick King	Y	Y	Y	N	Y	Y
Dr. Ronald Lamont-Havers	Y	Y	Y	N	N	Y
Ms. Abbey Meyers	Y	Y	Y	N	Y	Y
Dr. Oscar Reinmuth	Y	Y	Y	N	N	Y
Ms. Marilyn Spivack	Y	Y	Y	AB	Y	Y
Dr. Robert Waters	Y	Y	Y	N	Y	Y

Y = Yea

N = Nay

AB= Abstain

IX. *Summary and Conclusions*

During the two-day public meeting of the Panel on Physical Medicine and Rehabilitation Research, the Panel heard from an array of invited experts and received public testimony from 18 concerned organizations having an interest in medical rehabilitation research efforts. The presentations on the first day of the meeting, as well as the Panel discussions on the second day, focused on the importance of continued progress in this area of medical research. The Panel generally supported enhancing the growth, development, and scientific productivity of rehabilitation medicine. However, there was some debate about the best way to achieve progress in this area to benefit the disabled consumer, as well as to strengthen the discipline of medical rehabilitation research.

In presenting its recommendations, the Panel identified several areas that need further attention. It urged that the research agenda, priorities, and mission for a focused entity for rehabilitation medicine be identified soon and stated that such a clarification is an important step before developing any particular entity for this area of research. In discussing organizational options for a medical rehabilitation research entity at the NIH, the Panel identified several elements significant to the mission and authority of such an entity, including training grant authority; gap-filling and cross-cutting award authority; developing a long-range plan for rehabilitation research that can be implemented; making the entity readily identifiable by outside investigators as a focus for rehabilitation research efforts at the NIH; creating an advisory body consisting of scientists and people with disabilities; and assuming major responsibility for coordination and promotion of rehabilitation research throughout the NIH.

X. Individual Panel Member Statements

Statement by: Edward N. Brandt, Jr., M.D., Ph.D.
Executive Dean
University of Oklahoma
College of Medicine

Administrative structures should always be designed to achieve specified missions and objectives. Hence, specifications of our organizational structure without such is not appropriate. Such is the case with rehabilitation research. It is clear that the definition of a research agenda with priorities, time goals, and resource needs should be accomplished immediately. In addition, steps should be taken to effect coordination of NIH efforts.

No further action to establish an administrative structure should be taken until the above two steps are accomplished and there has been an evaluation of the effectiveness of the coordination efforts within NIH, across the HHS, and across the entire executive branch. If such steps are effective, no further changes will be required.

Statement by: Stuart Bondurant, M.D.
Dean, School of Medicine
University of North Carolina

I support all of the recommendations of the PPMRR except the recommendation that there be created a Center for Research on Medical Rehabilitation at this time.

In my judgment, the creation of such a Center is premature and would retard rather than accelerate research on rehabilitation. A more timely and effective course, in my judgment, would be the establishment of a position of Associate Director for Medical Rehabilitation Research in the Office of the Director of NIH, along with the creation of a Coordinating Unit in the Office of the Director, advised by an NIH Coordinating Committee of Institute Directors and reporting to the Associate Director for Medical Rehabilitation Research. Thus I recommend

both options five and three from the background material for the BID meeting of July 13, 1989.

In my judgment, a Center or other discrete organization should be established only after Rehabilitation Research is strengthened and coordinated in each of the Institutes of NIH. Creation of a Center at this time would, in my judgment, attenuate the commitment of some, if not all, of the Institutes to Rehabilitation Research in their areas of responsibility.

Statement by: Cheryl Chanaud, Ph.D.
Associate Director of Research
Medical and Research Affairs Department
Paralyzed Veterans of America

General Recommendation:

In order to establish an explicit commitment to PM&R research by NIH, and to create a means whereby PM&R research is supported through a variety of programs (research, training, educational and informational), I recommend the creation of a National Center of Rehabilitation Sciences.

Additional Recommendation for a Center or Other Organizational Entity:

Since rehabilitation is intended to benefit ill or disabled people directly, often for extended periods of time, and can critically affect the quality of life, it seems imperative that input or feedback from the disabled be given a high priority in this particular NIH entity, whether or not the presence of a relatively small number of disabled people (or their representatives) on an Advisory Committee is adequate to the needs of the patient population needs to be considered carefully. For example, it may be essential to include a fairly extensive cross-section of the disability community since each group may have unique medical and quality-of-life problems.

Additional Specific Recommendations for a Center:

In addition to the six primary purposes of an NIH Center of Rehabilitation Sciences (as listed under Recommendation 5), several other specific recommendations were mentioned during the Panel's discussions and are listed below:

1. An NIH Center must have a strong mission statement, including an explicit definition of "rehabilitation."
2. A Center of Rehabilitation Sciences should strongly support the functional assessment of new clinical treatments or newly developed services.
3. A Center should encourage longitudinal research studies and multicenter trials.
4. A Center should sponsor symposia and conferences on issues pertaining to physical medicine and rehabilitation.

5. A Center should also be committed to the dissemination of research information to patients/consumers.

Statement by: Edmund Y. S. Chao, Ph.D.
Professor of Bioengineering
Director, Orthopedic Biomechanics Laboratory
Mayo Clinic

Background:

Rehabilitation research is very broad and PMMR constitutes only one discipline but it is a key one.

NIH is engaged in rehabilitation research extensively even in the phase of delivery.

Rehabilitation service and delivery are different from rehabilitation research but the two are intimately related.

Research is essential to ensure rehabilitation devices and that methodology is safe and effective.

PMMR as a discipline is indeed relevant and scientifically justified.

There are rehabilitation-related problems that cannot be solved through research.

Problems:

1. No representatives at higher level of grant funding who determine priority of rehabilitation research.
2. NIDRR is not the right agency to initiate, support, or evaluate rehabilitation research.
3. Lack of funding to train PMMR researchers in research to be competitive within NIH arena.
4. Each Institute within NIH has not specifically emphasized the priority of rehabilitation-related research.

Recommendations:

1. Create a coordinating committee, office, or other visible organization under NIH Office of the Director to provide decisionmaking power to support rehabilitation research.
2. Mandate each related Institute, which has a component of functional rehabilitation, to allocate rehabilitation research funds and coordination among themselves and with NIDRR or other rehabilitation service delivery agencies.
3. Create special first award or career development award specifically related to research oriented PMMR physicians (but not limited to PMMR discipline).

4. Support workshop to identify the needs and review available resources in NIH existing programs that will benefit rehabilitation service and research.
5. Use NIDRR as a clearinghouse agency to digest, implement, and disseminate NIH research knowledge to rehabilitation service and delivery.

Statement by: **John F. Ditunno, Jr., M.D.**
Michie Professor and Chairman
Department of Rehabilitation Medicine
Jefferson Medical College of Thomas Jefferson University

The following comments and corrections of the draft report of November 30, 1989, by the Panel on Physical Medicine and Rehabilitation Research are appended.

- II. Introduction. Page 5, Paragraph 1. The budget estimate, based on current rehabilitation medicine research, goes far beyond what most people in the field would consider within the scope of the specialty. The inclusion of dental, eye, deafness, and mental retardation, as a few examples, results in an inflated estimate by more than double.
- VII. Issues and Considerations. Page 33, Last Paragraph. "...general concern...by the *majority* of organizations" is perhaps *overstated*. The divergence of opinion was fairly evenly divided, similar to the type of approach mentioned in Paragraph 1, Page 20. The possibility of increased funding due to the heightened interest by the American people in concern for the disabled, raised by Dr. Betts and others, is certainly *understated* here and throughout the report.
- VIII. Panel Recommendations. Page 42. The middle paragraph refers only to NIAMS. In reality, the Institute of Aging, Deafness and recently the Nursing Center have received significant increases in funding. The position as stated above *needs* to be balanced by the discussion and possibility of increased funding.
- IX. Summary and Conclusions. Page 53, 2nd Paragraph, Second Sentence. "It (Panel) urged..." is incorrect as phrased in reference "...an important step, prior to the development of...organizational entity." At most, a minority expressed this opinion as reflected in the vote of 9 to 7 in support of Recommendation 5. The establishment of an entity by Congressional action would result in the definition of the mission and research plan for rehabilitation medicine conducted by the National Institutes of Health.

Statement by: Douglas Fenderson, Ph.D.
Professor, Department of Family Practice
University of Minnesota Medical School

Existing legislation *requires* rehabilitation research at NIH.

It is now represented as (generally) various bits and pieces, with limited opportunities for RO1-type project grants.

Strategies for incorporating rehabilitation research in the NIDCD may serve as a model.

I support a paragraph in the letter by Abbey Meyers, NORD: "...should be a central office at NIH to coordinate rehabilitation research; keep track of funded projects; serve as ombudsmen between researchers, the public, and the Institutes; and most important, serve as a vehicle for translating the results of research into clinical applications and products."

Research training for rehabilitation physicians and other investigators is a compelling and immediate need.

I do not favor moving the medical rehabilitation research aspects from NIDRR or projects or funds from existing Institutes or programs.

Statement by: Carmella Gonnella, Ph.D.
Associate Professor and Director of Program Evaluation
Center for Rehabilitation Medicine
Emory University

Thank you for the opportunity to review and to respond to the report of our meeting.

I. Executive Summary

Personal comment:

Recommendations 1, 4, 5, and 6 are variations on strategies to achieve the intent of Recommendation 2. Some of these recommendations could well be subsets of another recommendation; e.g., Recommendations 1 and 6 could be initial phases of Recommendation 5. A vote by the panel to rank these strategies would be helpful.

II. Introduction

Page 3: I suggest a qualifier on the estimated amount spent in laboratory and clinical research. I recall discussion on some of the cited research as not being physical rehabilitation research; e.g., hearing impairments, MRIs, mental retardation. Thus, while the current efforts in NIH are commendable, the inflated amounts could be detrimental to adequate funding of rehabilitation research.

Personal comment:

Current activity in rehabilitation research at NIH is encouraging and I agree with the statement made at the meeting that rehabilitation should be everybody's business. That statement does not go far enough however. The recurring theme was the need for leadership and focus by rehabilitation specialists over and beyond the complementary and varying interests of non-rehabilitation specialists. Otherwise, as one panel member stated, much does fall between the cracks because of the primary interest of a specialty, limited time, limited funds, etc.

VII. Issues and Considerations

Page 21, first paragraph. Beginning with, "Those organizations...."

Personal comment:

While the sentiment in this paragraph is essentially as expressed, the opposing view balancing this concern appears not to be emphasized in this report to the same degree as I heard expressed at the meeting. Panel members reiterated the desirability of Institutes continuing their rehabilitation research as related to the major focus of their special mission...thus, the majority vote on Recommendation 5 and the negative vote on Recommendation 4.

Page 21. Personal comment:

The focus of NIDRR is much broader and diverse than that recommended for a Center for Medical Rehabilitation Research. The two should not be in conflict with each other. Each has its own legitimate reason for being.

Page 21, last paragraph. Personal comment:

The concern expressed in this section appears to be overstated. As I recall, from reading other materials, establishment of new entities in several instances has not had the predicted detrimental effect on actual funding for the designated research.

Similarly, the concern expressed over the siphoning off substantial funds to meet the administrative costs...appears also to be overstated. Whether the mission is achieved organizationally within an established Institute or in a separate entity, additional qualified staff will still be necessary. Can the considerably increased and focused workload be assumed realistically by current staffing? I support the cost comparisons that were recommended (last sentence, p. 22).

VIII. Panel Recommendations

Page 29, Rationale for Recommendation 4. Personal comment:

It is unfortunate that the reason one may have voted this recommendation down is not recorded. In reading the deliberations, a reader may think that all comments in the deliberations contributed equally to the negative vote. In fact the major and for some the only reason for not supporting the recommendation is the exclusive right of an Institute to conduct research

in its designated area. Thus the positive vote for a center, an entity which would provide for the focus needed and at the same time allow continuation of complementary efforts in other institutes.

Page 34, paragraph beginning with "Some of the arguments...."

Personal comment:

What is the evidence on "significant" negative impacts of a free standing center as suggested in the first paragraph. It would seem to me that rehabilitation may already be compromised within the Institutes if current budgets allowed funding of 25 percent of the applications approved. Because of the different focus in rehabilitation research between the Institutes and the proposed Center and the proposed gap filling and cross-cutting mission of the Center, the impact would have just the opposite effect. The contributions of rehabilitation research would be considerably enhanced.

IX. Summary and Conclusions

Page 38, second paragraph. Personal comment:

I differ on the suggestion that other activities mentioned in this paragraph proceed before the "development of any particular organizational entity...." Needs were identified; the importance of medical rehabilitation research acknowledged; essential mission elements tagged; and an administrative model in NIH identified, which comprises elements for significant and substantial response to these needs. In addition, if one looks at the various disciplines that comprise medical rehabilitation, beyond the physician component, there is collectively a body of qualified research scientists to draw upon in putting together the various components of a Center.

Statement by: Dorothy L. Gordon, D.N.Sc., R.N.
Director, Acute Care Program and Rehabilitation
The Johns Hopkins University

I believe the testimony and proceedings relevant to the Panel on Physical Medicine and Rehabilitation Research support the need for and the scientific relevance of a centralized approach to research in rehabilitation. I would advocate that current and forthcoming entities and reports adopt the nomenclature reflective of the multidisciplinary field, namely "rehabilitation medicine" or "medical rehabilitation." There is a distinction between "rehabilitation medicine" (interdisciplinary in nature, practiced by specialists from a variety of disciplines in a collaborative team effort) and Physical Medicine and Rehabilitation, which is the medical specialty practice of physiatrists. The multidisciplinary composition of the panel, the variety of organizations represented and speaking at the hearing, and the testimony itself reflected the purview to be "rehabilitation medicine research."

A focused center for medical rehabilitation research at NIH is timely. Although it may seem obvious and simplistic to say so, the eventual beneficiaries of this would be the persons in this country who are disabled, those who may become disabled, and their families. Their participation in any plan related to medical rehabilitation research should be amply provided for along with others.

Statement by: Lauro S. Halstead, M.D.
Director, Post Polio Program
National Rehabilitation Hospital

I am not including a specific new vote on each of the six recommendations voted on during the meeting. I want to keep my original votes the way they were made during the meeting of the Panel. Also, this action is not to be construed as abstaining.

On page 21 there is reference to the fact that if rehabilitation research were "concentrated" in one entity that research would become isolated. There is also reference to the fact that a "separate Federal entity" in addition to NIDRR could dilute the impetus of research and further fragment it. It was mentioned by some organizations and referred to on page 21 that a "new medical rehabilitation entity might have a detrimental effect on actual funding for rehabilitation research."

It should be noted that the organizations testifying for the creation of a new entity, and the background legislative material in the briefing book regarding S. 1392, both specify that the new entity was not intended as one in which funds would be concentrated. It is clear that S. 1392 is intended to strengthen efforts of existing institutes through planning and other activity. Second, the reference to the creation of a separate entity diluting research efforts seems misplaced since there are now some 11 separate entities in NIH supposedly devoting funds to rehabilitation research according to the background material supplied panelists and that has not, according to anyone, diluted the efforts of NIDRR. Finally, there are references to new entities at NIH and new initiatives through new entities having a detrimental effect on actual funding. The history of new entities at NIH in the last 20 years belies that proposition totally. While the Arthritis Institute has not had increased funding (this was cited by NIH staff to support the negative funding theory) the Aging Institute, the Nursing Center, and the Deafness Institute have all had significant funding increases after their creation and the rates of increase in funding for the Aging Institute and the Nursing Center over a number of years are greater than other entities generally except AIDS research. Also, the proposition that a new entity for rehabilitation medicine would result in existing rehabilitation funding decreasing was not supported by real examples. There are examples to the contrary however. The diabetes research initiative of the mid and late seventies involved the creation of a new entity in the form of a division within an Institute and a Directors Office planning and coordination entity. Research activity in diabetes was not concentrated in the Diabetes Division as a result and research regarding diabetes in the Eye Institute and the Heart Institute, among others, grew substantially. It also has

been mentioned that nursing-related research has not decreased because of the creation of the Nursing Center.

These same points are applicable to arguments cited on page 34 against the creation of a Center. There seems to be ample evidence that an entity can be created within NIH to undertake an initiative in an area of research in which other Institutes are involved that will result in increased and more efficient activity in all agencies and Institutes; the diabetes research initiative and the Nursing Center initiative support this concept.

Applications do not cease to be referred to other agencies because a new one is created so long as the applications specifically relate to those other agencies, e.g., diabetes.

In addition, two major points seem to have been missed entirely in the report that deal with the success of multi-agency activity when a new entity with grant-making authority, as well as planning and coordinating authority, is created. First, the research plan and planning process Panelists agreed upon enables the NIH and the research community to assure that there is budget and program growth in all the Institutes and agencies with programs in rehabilitation and with an interest in continuing and expanding them. Also, S. 1392 background material indicates that such comprehensive expansion of effort is likewise the goal of the research plan in S. 1392. Second, when it comes to budgetary allocations two organizations can effect them: NIH and Congress. Even if a new entity is created within NIH whose focus is rehabilitation, NIH can allocate funds to Institutes with rehabilitation programs, which wish to continue them. In addition, Congress retains the final word with respect to budgets for NIH and if a research plan calls for expansion of funding throughout NIH, or NIH so recommends, Congress can clearly budget funds according to such an approach. These two organizations, with the assistance of a research plan and the advocacy of interest groups, can assure that a new entity doesn't result in existing agencies of NIH losing programs in rehabilitation.

Statement by: Ronald W. Lamont-Havers, M.D.
Vice President for Research and Technology Affairs
Massachusetts General Hospital

It seemed clear from the discussions and the actions on the recommendations that the Panel felt that further in-depth study leading to an agenda for action was indicated. There seemed also to be a recognition that this activity could be a function of a coordinating center established either within one of the Institutes or in the Office of the Director. The discussion and vote on Recommendation 4 revolved in part around the present lack of definition of a research agenda and how training programs would be established. These concerns and others touched on in the discussion of Recommendation 4, which led to its defeat, clearly would be applicable to Recommendation 5, which would establish a Center of

Rehabilitation Science. The split vote on Recommendation 5 clearly reflects this relationship with the discussion on Recommendation 4.

Recommendation 2 related to the mission of any rehabilitation research administrative entity is relatively straight forward. One questions however, the emphasis in the Rationale section on "perceived commitment to support this research as evidenced by the number of research proposals solicited and funded." This emphasis on support is again emphasized in the last sentence of the Rationale section as a prime benefit from the establishment of an entity. It cannot be denied that the primary goal of the advocates of rehabilitation research is support. This is not inherent, however, in the subsequent discussions of the establishment of an entity as is shown by the discussion of Recommendation 4 and Recommendation 5.

Statement by: Ms. Abbey Meyers
Executive Director
NORD

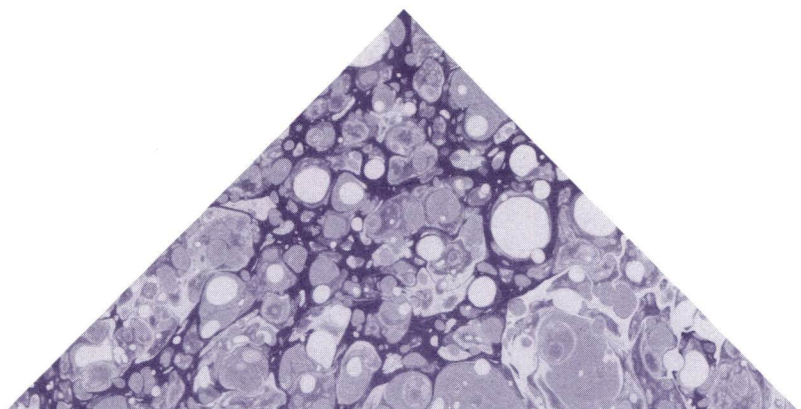
The central problem appears to be that rehabilitation research is the proverbial elephant being touched by blind scientists who each describe it as something else. I was moved by Marilyn Spivak's comments that psychosocial aspects do not receive proper focus, and that the discoveries of NIH scientists are not adequately and expeditiously translated into patient care. The transfer of technology is vitally important for all of NIH's discoveries. Too often research results do not filter down to patients in a clinical setting due to delays or misinterpretations in such transfers.

Thus there is a need to carefully plan the role and objectives of a rehabilitation research administration within NIH. The placement of the entity is not as crucial as defining its role. Once goals and an agenda are set in place, the location of the office can be changed if it is not satisfactory.

I firmly believe, however, that the office should be placed in a generic area of NIH so that the broad research interests of the entity will not be limited by the confines of its parent agency. This central office should advocate for rehabilitation research for *all* diseases and *all* ages. Moreover, the absence of rehabilitation experts on study sections is a valid concern that *must* be addressed. While NIH insists that study sections are fair to all applicants, and research is funded on the sole basis of scientific excellence, researchers believe this is not true when members of a study section are unfamiliar with the disease they are reviewing (see the 1989 report of the *National Commission on Orphan Diseases*). Ad hoc reviewers must be brought in, or a separate study section for rehabilitation research should be created, in order to avoid the perception that grant applications are given a low priority score because of the Review Committee's prejudice against rehabilitation research or their ignorance about the target disorder.

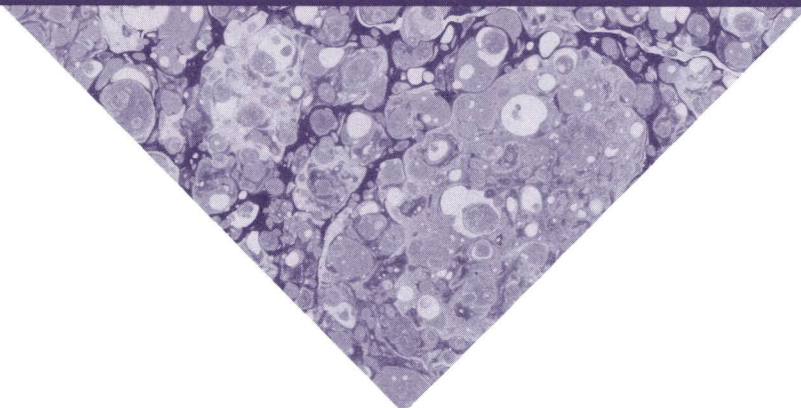
Statement by: Oscar M. Reinmuth, M.D.
Professor and Chairman, Department of Neurology
University of Pittsburgh

In addressing the change to the panel, strong emphasis needs to be given to distinguishing the concern for improved patient care continuing into psychosocial adjustment, for which all agree as to need, from the status of support for *research* in the broad concept of rehabilitation, without restriction to the narrower area of physical medicine and rehabilitation. This last distinction is particularly important in the decision as to the best mechanism to further investigation in rehabilitation. At present, some believe that establishment of a new Institute for Rehabilitation could not adequately provide the extensive scientific scope necessary and could risk diminishing present research support provided by multiple institutes. It is a time for new evaluation of the Federal role and further planning for better support of rehabilitation research.



APPENDIX A

■ Agenda



AGENDA

MEETING OF THE
PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

November 20-21, 1989

Building 31, Conference Room 10
National Institutes of Health
Bethesda, Maryland

Chairman Dr. Edward Brandt

First Day

MORNING SESSION

- 9:00-9:05 Opening Remarks and Introduction of the
Chairman and the Panel on Physical Medicine
and Rehabilitation Research. Dr. William Raub
- 9:05-9:10 Comments of the Chairman Dr. Edward Brandt
- 9:10-9:20 Overview: Purpose and Focus of the National
Institute for Disability and Rehabilitation
Research Dr. Paul Thomas
- 9:20-9:30 Overview: Evolution and Growth of Physical
Medicine and Rehabilitation
Research at the NIH. Dr. Murray Goldstein
- 9:30-10:20 Physical Medicine and Rehabilitation Research
Presently Supported by the NIH
- NCI. Dr. Edward Sondik
- NIDDK. Dr. Richard Farishian
- NIA. Dr. Evan Hadley
- NIAMS. Dr. Lawrence Shulman
- NICHHD. Dr. David Gray
- NIDCD. Dr. Ralph Naunton
- NINDS. Dr. Patricia Grady
- DRR. Dr. Judith Vaitukaitis
- Clinical Center/DRM. Dr. Lynn Gerber
- NHLBI. Dr. Peter Frommer

10:20-10:50 Selected Collaborative Rehabilitation
Research Initiatives

Electrodiagnosis Dr. Ernest Johnson

Neurobiology Dr. Wise Young

Biomechanics Dr. Barbara deLateur

10:50-11:05 COFFEE BREAK

11:05-11:20 GROUP DISCUSSION

Discussion Leader. Dr. Edward Brandt

11:20-11:30 Physical Medicine and Rehabilitation Research
Initiatives at the Centers for Disease
Control (CDC). Dr. John Finklea

11:30-12:00 Scientific Relevance of PM/R Research--Several
Perspectives

PM/R Research Community. Dr. Bruce Gans

NIH Research Community Dr. Robert Burke

General Research Community Dr. Jerome Tobis

12:00-12:30 GROUP DISCUSSION

Discussion Leader. Dr. Edward Brandt

12:30-1:30 LUNCH

AFTERNOON SESSION

1:30-2:30 Principal Concerns of the PM/R Research Community

Developing a Model Research Program for
PM/R Research. Dr. Theodore Cole

Support for Research Training. Dr. James Lieberman

Developing Scientific Leadership in PM/R
Research Dr. Leonard Diller

2:30-3:15 GROUP DISCUSSION

Discussion Leader. Dr. Edward Brandt

3:15-3:30 COFFEE BREAK

3:30-5:00 Public Testimony (concerned organizations)

Association of American
Medical Colleges Dr. Laurence Earley

Moss Rehabilitation Hospital Dr. John Whyte

National Multiple Sclerosis
Society. Dr. Labe Scheinberg

American Academy of Physical
Medicine and Rehabilitation. Dr. Barbara J. deLateur

American Congress of Rehabilitation
Medicine Dr. Marcus Fuhrer

Association of Academic
Physiatrists Dr. Randall Braddom

American Physical Therapy Association. Dr. Leopold G. Selker

American Geriatric Society Dr. Leo Cooney

American Academy of Otolaryngology--
Head and Neck Surgery. Dr. Aina Julianna Gulya

Association for Research in
Otolaryngology Dr. Murray B. Sachs

Friends of NIDCD Mrs. Geraldine Dietz Fox

American Speech-Language-Hearing
Association. Dr. Carol Frattali

American Spinal Injury
Association. Dr. Samuel L. Stover

Arthritis Foundation Dr. Rowland Chang

National Research Institute for
Neural Injury. Mrs. Louise McKnew

American Academy of Neurology. Dr. Fletcher McDowell

Association of Rehabilitation
Nurses Dr. Shirley Hoeman

Lasker Foundation Ms. Marguerite Donoghue

5:00

ADJOURN

Second Day

MORNING SESSION

8:00-10:30 GROUP DISCUSSION

Discussion Leader. Dr. Edward Brandt

10:30-10:45 COFFEE BREAK

10:45-12:00 GROUP DISCUSSION

Discussion Leader. Dr. Edward Brandt

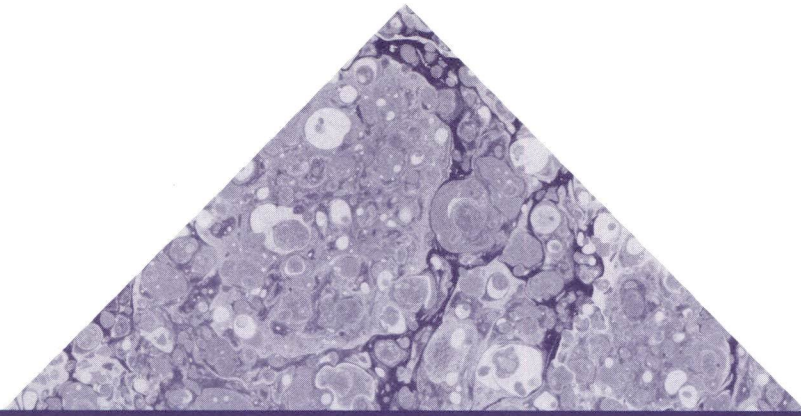
12:00-1:00 LUNCH

AFTERNOON SESSION

1:00-3:50 REPORT DRAFTING

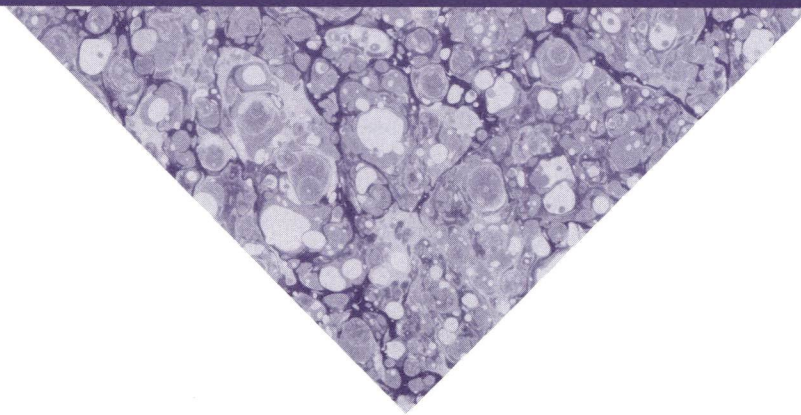
3:50-4:00 Closing Remarks. Dr. Edward Brandt

4:00 ADJOURN



APPENDIX B

- List of Invited Speakers
 - Speaker Statements
-



MEETING OF THE
PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

November 20-21, 1989

Presenters

Robert E. Burke, M.D.
Chief, Laboratory Neural Control
BND, DIR, NINDS, NIH
National Institute of Neurological
Disorders and Stroke/NIH
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Bethesda, MD 20892

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Professor, University of Washington
School of Medicine
Physiatrist-in-Chief
Harbor View Medical Center, ZA57
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Seattle, WA 98104

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Rusk Institute of Rehabilitation
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Deputy Director, OPPE
National Institute of Diabetes,
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Bethesda, MD 20892

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Extramural Grants Program of the
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and Injury Control
Centers for Disease Control
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Atlanta, GA 30341

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Deputy Director
National Heart, Lung, and Blood
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Bethesda, MD 20892

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Chief, Department of Rehabilitation
Medicine, Clinical Center
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National Institutes of Health
Bethesda, MD 20892

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National Institute of Neurological
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Chief, Geriatrics Branch
National Institute on Aging
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Professor and Chairman
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Bethesda, MD 20892

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Director, Medical Sciences Program
National Institute on Disability and
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Wise Young, M.D., Ph.D.
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A COMPREHENSIVE PROGRAM FOR DISABILITY AND
REHABILITATION RESEARCH

J. Paul Thomas, Ph.D.
Director, Medical Sciences Program
National Institute on Disability and Rehabilitation Research

The National Institute on Disability and Rehabilitation Research (NIDRR) (formerly known as the National Institute of Handicapped Research) provides leadership and support for a national and international program of comprehensive and coordinated research on the rehabilitation of disabled individuals. The Institute's mission also encompasses the dissemination of information concerning developments in rehabilitation procedures, methods, and devices that can improve the lives of people of all ages with physical and mental handicaps, especially those who are severely disabled. One of the most important aspects of research supported by the Institute is that it helps to assure the integration of disabled persons into independent and semi-independent community life.

The results to be achieved through the exercise of this mission include

- Identifying the causes and consequences of disability
- Maximizing the healthy physical and emotional status of disabled persons, their functional ability, self-sufficiency, self-development, and personal autonomy
- Preventing or minimizing the personal and family physical, mental, social, educational, vocational, and economic effects of disability.
- Reducing physical, social, educational, vocational, and environmental barriers to permit access to services and assistance, and to allow disabled persons greater use of their abilities in daily life
- Promoting the coordination of rehabilitation research conducted by the Federal agencies

BACKGROUND

The National Institute of Handicapped Research was created in 1978 by P.L. 95-602, the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments to the 1973 Rehabilitation Act and modified by subsequent amendments. The Rehabilitation Act Amendments of 1986 changed the Institute's

name to the National Institute on Disability and Rehabilitation Research.

In June 1979 personnel from the research component of the Rehabilitation Services Administration of the Department of Health, Education, and Welfare were transferred into the new Institute. Today, the NIDRR is a part of the Department of Education and, organizationally, is in the Office of Special Education and Rehabilitative Services.

PROGRAM AND ACTIVITIES

Rehabilitation Research and Demonstration Projects

One of the activities through which the Institute carries out its mission is through the Research and Demonstration Program. By awarding grants and contracts, the Institute investigates unsolved problems relating to vocational rehabilitation and other services and the specific needs of disabled persons. These efforts generate new knowledge, fill gaps in research, and create and validate innovative approaches to rehabilitation.

Projects under this program may include scientific, technical, and methodological areas of interest in rehabilitation. Investigations may involve identifying the causes and consequences of disability, devising methods of analyzing them, and discovering means to provide restorative techniques. Areas of investigation might include studies and analyses of industrial, vocational, social, physical, psychiatric, psychological, economic, and other factors affecting the rehabilitation of handicapped individuals, including the special problems of homebound and institutionalized individuals.

Specialized research activities under this program include such areas as international research and training; joint projects with other Federal agencies and with private industry; research related to disabled children and the elderly; projects designed to develop and demonstrate methods to provide information to persons in rural areas; and other topics of interest in rehabilitation.

Rehabilitation Research and Training Centers (RRTC's)

Some of the research discussed above is carried out on a long-term basis at the Institute's Rehabilitation Research and Training Centers. The specific mission of each RRTC is to conduct research in priority core areas; to transpose research knowledge into tangible products useful to rehabilitation practitioners; and to disseminate the information through training for incorporation into existing service delivery.

programs. This work is carried on in settings where patient/client services, research, and training are viewed as interdependent activities essential to accomplishing maximum rehabilitation results.

Medical RRTC's deal with a full range of disability problems such as spinal cord injury, neuromusculoskeletal, and cardiovascular diseases, and psychosocial adjustments. Other centers conduct research in such areas as blindness, deafness, aging, mental retardation, and vocational rehabilitation. Most centers also offer vocational rehabilitation services to ensure that a continuity of rehabilitation care is maintained after the clients are discharged.

Core research areas emerge both from particular needs of disabled persons in the area serviced by the center and from priority areas perceived by NIDRR through its planning process to be crucial to the rehabilitation of handicapped persons. Individual research projects within core areas are based on a demonstrated need for the research, the availability of proper resources, and the probability that such research can be successful.

Rehabilitation Engineering Centers (REC's)

NIDRR supports Rehabilitation Engineering Centers in the United States and abroad to develop methods of applying advances in medical technology, scientific achievement, and psychological and social knowledge to the problems of disabled persons and their environment. Each center is encouraged to establish official working relationships with institutions of higher learning in medicine, engineering, and related sciences. Each assists in the development of manpower and training programs through which the techniques, hardware, and systems developed can be introduced safely into the service delivery system.

Duplication of effort is avoided through effective inter-center coordination. Each center has an approved core area of research emphasis, and each reflects the needs of major patient populations of the center.

The International Research Program

The Institute's international research, demonstration, and training program cuts across almost all NIDRR activities. Information about advances in rehabilitation in the United States is disseminated abroad, and information found to be useful there is brought to the U.S. rehabilitation community. This is done through, among other methods, the exchange of expert professionals in the field of rehabilitation. The international program of the NIDRR also includes efforts to encourage the

expansion of bilateral cooperative agreements for research. In addition, NIDRR has sponsored seminars, special studies, and workshops at home and abroad under this program. Technical assistance is provided as well to the overseas projects and to foreign government departments.

Coordination and Cooperation

One of the most important mandates of the 1978 legislative amendments was the establishment of an Interagency Committee on Handicapped Research (ICHR), which is responsible for promoting coordination and cooperation among Federal agencies conducting rehabilitation research. The Director of NIDRR is the chairman of the ICHR, which holds formal quarterly meetings but functions more regularly through its subcommittees. The ICHR enhances the exchange of information and promotes joint research activity among the participating agencies.

Active subcommittees are working in such areas as medical rehabilitation, rehabilitation engineering and technology, deafness and hearing impairment, demographics, and low vision and partially sighted. The Committee also has established an information retrieval system to provide information on the various ongoing research activities of the member agencies of the ICHR.

NIDRR also cooperates with and receives policy guidance from the National Council on the Handicapped. A presidentially appointed body, the Council includes noted rehabilitation professional and consumer members.

Research Utilization

The utilization of research knowledge is stressed throughout the legislation authorizing NIDRR. A significant part of the Institute's work is to transform its utilization activities into a comprehensive system that will inform disabled persons and the public about innovative research findings. The goals of the NIDRR utilization program are (1) to conduct research and demonstration projects to ensure that useable results will be produced, (2) to encourage grantees to prepare and submit final reports on the results of their research, (3) to disseminate these reports and other information directly, (4) to link foreign and domestic research information and rehabilitation personnel, and (5) to generate a body of knowledge about effective research utilization.

The National Rehabilitation Information Center (NARIC) offers information services to the rehabilitation community through computer-assisted and manual databases. Publications, produced

by NIDRR grantees or by contract, also are used as a means of disseminating research knowledge.

Fellowships and Other Programs

The Institute sponsors the Mary E. Switzer Fellowship Program, which provides fellowships to highly qualified persons to engage in scientific research related to the solution of the rehabilitation problems of disabled persons.

In order to expand the flexibility of its program, NIDRR also awards grants for Field Initiated Research projects. It also makes available small Innovation Grants for unique projects, the purchase of prototype devices for evaluation, developing unique rehabilitation training curricula, and to respond to special initiatives of the Secretary.

Areas of Special Interest

The Institute is charged with conducting a program for spinal cord injury research and demonstrations, incorporating a system of model centers devoted to interdisciplinary and comprehensive research about the treatment and rehabilitation of those with spinal cord injuries and the dissemination of information about advances in this area.

The rehabilitation needs of specific populations such as ethnic or racial minorities; those living in isolated, rural areas; and those who are very old or very young also are addressed in NIDRR-funded projects.

Additional information about the Institute can be obtained from

National Institute on Disability and
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U.S. Department of Education
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Washington, DC 20202

AN OVERVIEW OF THE NIH REHABILITATION RESEARCH PROGRAMS

Murray Goldstein, D.O., M.P.H.
Director, National Institute of
Neurological Disorders and Stroke

Thank you for the opportunity to discuss the NIH research endeavor focused on rehabilitation and restitution of function. I plan to provide you with an NIH research Institute Director's perspective; I could hardly hope to describe in detail all the programs and all the attitudes of the NIH. Institute representatives will provide you with these details later today.

The size and scope of the NIH investment in rehabilitation research is larger than that of any government agency. I bring to your attention that, measured in dollar terms, the present NIH investment is somewhere between \$100 million and \$130 million a year. It involves every one of the 13 research and research granting units of the NIH. The NIH rehabilitation research programs are integral parts of the specific research responsibilities of its respective institutes and divisions. These dollar figures are based principally on an analysis utilizing the definition of the American Academy of Physical Medicine and Rehabilitation.

In this brief presentation, I plan to address three issues:

- (1) The scientific direction of the present programs of NIH biomedical, biobehavioral, and psychosocial research aimed at rehabilitation and restitution of function;
- (2) The organizational structure of NIH and its science administrative strategies for accomplishing its research objectives; and if time permits,
- (3) An area of research in rehabilitation, specifically physical medicine, which in my opinion needs additional emphasis: controlled clinical trials.

First, an overview of the presently active NIH biomedical, biobehavioral, and psychosocial research programs on restitution of function.

As with all biomedical research, rehabilitation research can be looked at from the perspective of basic research, clinical research, and applied or technology research. Basic biomedical research is a particularly strong point of the total NIH program, including its rehabilitation research program. How does the dysfunction of a cell, a tissue, a body part affect the homeostasis? Why do renal calculi form in the paraplegic? How does muscle atrophy? Why does the cartilage of a joint

degenerate? What are the brain's mechanisms for compensating for loss of sensory input--visual, auditory, tactile? How is complex behavior patterned in the infant? Why does coordinated activity falter in the aged? What are the mechanisms for repair of damaged cells? tissues? organs? performance?

The importance of this basic knowledge doesn't need elaboration to this sophisticated panel. Suffice to say, basic biomedical and behavioral research is a principal instrument of the NIH. I say "instrument" because basic research per se is not an isolated goal of the NIH; research on disease prevention, treatment, and restitution of function is the legislated responsibility of the NIH; basic research is an integral part of the NIH strategy to meet this responsibility.

Clinical research is also a key part of the NIH activity. How to intervene to lessen disability, restore lost function, and prevent secondary dysfunction is a critical part of its research agenda. The NIH perspective of restitution of function is of a broader scope than the usual clinical perspective associated with rehabilitation. For example: the reconstruction of a mandible destroyed by neoplasia; an auditory prosthesis to restore hearing; the elements of a sheltered workshop to assist in the restoration of the activities of daily living for the cardiac patient; the repair and reconstruction of joints immobilized by arthritis; the depression and withdrawal of the elderly because of multiple disabilities. All of these are included in the menu of NIH rehabilitation clinical research. All are given identity and priority as illustrated by the announcements published each year by the research programs of the NIH soliciting increased research attention to these matters by the scientific community.

One additional comment on psychosocial research resulting from disability. Three units of the NIH have given particularly high priority to this matter: the NICHD, the NIA, and the NCNR. The impact of disability on behavior and the impact of social situations on the prolongation of disability are of major emphasis in these programs geared to the problems of two highly vulnerable segments of our population, children and the aged.

Applied research and technical development is also a part of the NIH research agenda on restitution of function. It concerns itself with both basic research (e.g., materials and electronic development) and clinical research (e.g., prosthesis development and evaluation) to provide assistance strategies and devices for the physically impaired. Examples are micro implantable electrodes which are one-tenth the size of a human hair; implantable computers the size of a pin; also the development and evaluation of artificial hips, cardiac assistance pumps, auditory prosthesis, functional muscle stimulators, transcutaneous spinal cord stimulators, etc.

Later this morning, Institute and Division representatives will provide you with the details of each of these NIH-supported intramural and extramural rehabilitation research programs. Unfortunately, because of ever-increasing restrictions on resources, these research programs--like all the others--face serious constraints.

Now to the matter of the NIH organizational structure. The NIH is organized principally by disorder problem area: cancer, heart, arthritis, diabetes, brain, etc. Some Institutes and Divisions are cross-cutting: child health, aging, general medical sciences, research resources. However, the NIH is not organized by research discipline: chemistry, cell biology, surgery, pharmacology, or rehabilitation. These disciplines are all integral parts of the research portfolios of every research Institute and Division. In addition, Institutes and Divisions work very hard at encouraging multidisciplinary, coordinated research approaches to disease area problems; the scope of these problems demand multidisciplinary attention. Fostering multidisciplinary activity is not easy because the disciplinary organization of medical institutions too often protects provincial disciplinary isolation.

The organizational structure of the NIH reflects the differences in the problems of the patient with a specific disability. Restrictions in the activity of daily living of the cardiac patient are quite different from those of the paraplegic; the problems of ambulation of the child with cerebral palsy are different from those of the aged with degenerative joint disease. These research problems of rehabilitation research are being addressed in the research environment of heart disease, spinal cord injury, cerebral palsy, and arthritis. To isolate specific research endeavors such as rehabilitation or drug development from the intellectually rich research environments of their disease orientation would threaten collaboration and foster isolation--perhaps supporting even additional administrative barriers to multidisciplinary interaction. The strength of the NIH-supported research environment is the integration of research disciplines to solve a problem--not the administrative separation of scientific specialists.

Would research on head injury, the post-polio syndrome, paraplegia, Tourette's syndrome (all of interest to specific members of this panel) be better served by having an NIH Institute of Prevention? an NIH Institute of Experimental Pathology? an NIH Institute of Surgery? an NIH Institute of Rehabilitation? Would important clinical problems receive the research attention they demand in Institutes organized by disciplines rather than disorders? I look forward to hearing your discussion and learning from you about this.

Another issue is that of duplication of effort. What would be the relationship of a "nondisease," "cross-cutting" NIH rehabilitation research program to the already legislatively mandated and funded noncategorical rehabilitation research program of the National Institute on Disability and Rehabilitation research? Are these to be two Federal programs with identical objectives? If not, what are the differences?

Finally, an area of research need of great importance to rehabilitation: clinical trials. As I review the literature on improvement in rehabilitation methodologies, I am surprised by the absolute dearth of clinical trials.

I suspect there is a serious lack of the use of the research methodology of the controlled clinical trial to evaluate the efficacy and applicability of rehabilitation methodologies presently being used or being developed. How do we know we are helping the patient? What are the characteristics of the patient who is being helped? Of certainly equal importance, how do we know we are not harming the patient? There are too many examples in the scientific literature in pharmacology and surgery in which well-intentioned physicians using clinical judgment based on case observations were, in fact, doing harm. Active programs of evaluation and outcome research in these disciplines are now in place. Rehabilitation methodologies must be put to similar tests. To avoid doing this is medically unethical and socially unacceptable in all clinical disciplines, internal medicine, surgery, and rehabilitation.

Outcome research is becoming important in every other area of clinical medicine; it also needs priority emphasis in rehabilitation research. Working together, NIH and rehabilitation scientists must aggressively address this issue.

In conclusion, NIH has a rich and active program of research on restitution of function. Like prevention research, the scope of rehabilitation research is buried in the organizational terminology of the NIH. However, it is there and it is active. It clearly needs better identity and additional emphasis. Is administrative reorganization the most efficient way of accomplishing this? Will separating rehabilitation research from daily contact with the core of knowledge of the disorder problem enrich the substance of rehabilitation research? Would such separation injure the opportunity for progress for the patient populations we are dedicated to serve? Should we focus on administrative ways to solve a research problem or get on with meeting its scientific needs? We need to consider what a former Surgeon General put so well: "Administrative reorganization usually trades one set of problems for another set of problems without solving either." This may be an overstatement, but it does pose a critical question this panel needs to consider.

PHYSICAL MEDICINE AND REHABILITATION RESEARCH
SUPPORTED BY
THE NATIONAL CANCER INSTITUTE

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National Cancer Institute

INTRODUCTION

The goal of the National Cancer Institute's (NCI) rehabilitation program is to conduct and support the research necessary to restore or maintain to the cancer patient the fullest physical, psychological, social, vocational, avocational, and educational potential. The program is aimed at developing interventions designed to compensate for, prevent, or minimize long-term or permanent adverse effects of cancer or cancer therapy. Rehabilitation also includes continuing care, which emphasizes the importance of cancer care across the entire course of the disease, including periods when recovery is unlikely.

Congress has recognized the need for this activity in Public Law 100-607, the Health Omnibus Extension Act of 1988:

Section 410. Purpose

The general purpose of the National Cancer Institute (hereafter in this subpart referred to as the "Institute") is the conduct and support of research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

Section 412. Cancer Control Programs

The Director of the Institute shall establish and support demonstration, education, and other programs for the detection, diagnosis, prevention and treatment of cancer and for rehabilitation and counseling respecting cancer. Programs established and supported under this section shall include... (1) (B) The continuing care of cancer patients and the families of cancer patients, and (c) rehabilitation and counseling respecting cancer, to physicians and other health professionals who provide care to individuals who have cancer.

Because cancer is a complex constellation of diseases affecting various parts of the body and its functions, cancer research must address the full course of cancer care, the spectrum of rehabilitation approaches and specialists is broad. This is

reflected in the composition of research teams addressing specific cancer rehabilitation problems and the integration of cancer rehabilitation into the Institute's multiple information dissemination programs.

Rehabilitation research falls into two categories. Programs and projects may:

- Target many specific tumor types, and focus on understanding long-term sequelae, or
- Address common problems encountered by patients with different tumor types or treatments.

The effect of cancer treatment on multiple organ systems and the impact of those effects on the individual's life are critical issues in rehabilitation research. The ultimate goal is the design of cancer therapies with minimum adverse effects and maximum rehabilitation potential. The broad range of problems being studied is reflective of the complexity of cancer rehabilitation.

FOCUS ON SPECIFIC TUMORS

Table 1 shows the number of cases and deaths for 1989 associated with the following cancers which are the principal foci of rehabilitation research at NCI: head and neck cancers, bone cancers (both primary and as metastases from other sites), breast cancer, melanoma and other skin cancers, and prostate cancer. These cancers constitute an appreciable portion of all cancers which for 1989 amount to an estimated 1,010,000 new cancers and 505,000 deaths, not including non-melanoma skin cancer.

Table 1:

National Cancer Institute

Principal Cancers Estimated Annual Cases and Deaths United States, 1989

Site	Cases	Deaths
Head and Neck	54,200	13,375
Prostate	103,000	28,500
Bone (Primary site)	2,000	1,300
Bone (Metastases)	100,000+	N/A
Breast (Female)	142,000	43,000
Melanoma	27,000	8,200
Other skin	500,000+	N/A

N/A indicates that data are not available.

Head and Neck Cancer

Because of the small confines of this anatomical region, both the cancer and its therapy can have a major impact on swallowing and subsequent nutrition, breathing, and speaking. Numerous projects focus on the constellation of problems, including the evaluation of the effect of a surgical procedure (cricopharyngeal myotomy) on postoperative swallowing problems; assessment of the impact of a preoperative nutrition program on surgical morbidity; the examination of taste and smell changes; and physical therapy interventions to maintain maximum mobility of the region.

Bone Cancer

The structural and functional losses associated with primary or metastatic bone cancers are major challenges in rehabilitation research. Improved therapies have resulted in the ability to save affected limbs and demand meticulous research to develop appropriate prosthetic systems. These studies encompass examining the metal composition of prosthetic implants, and testing different methods of attachment to soft tissues and disease-free bone. The potential for fractures at sites of metastatic cancer is a difficult clinical situation. Studies are underway to improve methods of evaluating the fracture risk and to determine the need for and timing of prophylactic bone stabilization procedures.

Melanoma and Other Skin Cancers

Substantial portions of the skin can be affected by melanoma, and associated problems include skin grafting, cosmetic procedures, and attendant psychological problems.

Breast

A variety of physical and psychological problems are associated with breast cancer. Such problems as a tight chest wall, difficulty in lifting, and arm weakness and numbness all have been reported. Psychological problems include anxiety and worry about recurrence, depression, worries about family and self. Recent advances in treatment have shown that less extensive surgery--lumpectomy versus radical mastectomy--has the same survival characteristics as the more extensive and debilitating procedures. This has been a considerable advance in that less rehabilitation is required and that with less invasive treatment shorter delay in seeking diagnosis and treatment should be the result.

Prostate Cancer

Loss of potency is a major issue in treatment of prostate cancer. Recent advances have included the nerve-sparing radical

prostatectomy (preserving potency in 52 to 72 percent of patients) and radiation therapy (preservation of potency in 73 to 82 percent of patients). Radical prostatectomy preserves potency in less than 10 percent of patients.

FOCUS ON COMMON PROBLEMS

Needs and Services

Living through cancer and its therapy has the potential to impose substantial burdens on both patients and families. In order to document the extent of the needs and the adequacy of services, several projects are underway. Studies have been supported that examine home care needs for the State of Rhode Island, New York City, and western Pennsylvania. Another team is examining the issues throughout the State of Montana, which should provide valuable information on rural cancer care. In addition, two research teams are testing interventions to improve the ability of patients to get concrete services, such as assistance with the administrative problems of insurance claims.

Problems Associated with Survival

As therapy for childhood cancer has improved, so has the number of childhood cancer survivors. Interventions to assist the adult who has survived childhood cancer to reach optimal employment and obtain adequate insurance are being tested. Another team is using behavioral management protocols to foster optimal school attendance among newly diagnosed childhood cancer patients. These investigators believe that school is a normalizing experience and that regular school attendance preempts future academic and psychosocial difficulties. Repeated neuropsychological assessments of children with cancer are being conducted by one of the national clinical trials groups as well as an independent investigative team. These data will document the full effects of cancer therapy on functions such as memory and learning, and guide the development of goals for school achievement and optimal functioning.

More recently, clinicians and researchers have been challenged by adults who are surviving cancer. Information from studies of childhood cancer survivors is forming a useful basis from which to explore ways of assisting adults. As part of the clinical trials network, investigators are testing interventions to assist breast cancer patients to return to work. It is anticipated that additional studies in this area will be forthcoming.

Another issue associated with surviving cancer is the long-term sequelae of therapy. Studies are being conducted both in the clinical trials networks and by independent investigators to

examine the effects of various therapies on reproductive function. An unfortunate consequence of cancer therapy may, in fact, be the induction of another cancer. While the incidence is low, investigators are evaluating the benefits of seemingly comparably effective therapies against the risk of developing a second malignancy. Lymphocyte assays are being explored for their potential to provide human genetic monitoring for cumulative damage from exposure to either radiation therapy or chemotherapy. Also, long-term follow-up of children treated for cancer is part of the clinical trials program.

Quality of Life

The full impact of cancer and its treatment must be measured in terms of the individual's quality of life. In order to better understand these relationships, to evaluate therapies in a holistic manner, and to ensure that the rehabilitation goals of cancer care are met, quality of life measures are being incorporated into clinical trials. The Institute has supported the development of the Cancer Inventory of Problem Situations (CIPS), a self-report measure which has been demonstrated to be sensitive in identifying rehabilitation needs. A Global Function Scale (GFS) has been designed to evaluate rehabilitation outcomes and is now being tested in a randomized trial for the delivery of information about rehabilitation to breast and colorectal patients. In addition, a longitudinal study of 1,500 Italian breast cancer patients to identify problems associated with adjuvant therapy and recurrent disease is being supported. Data from these projects will guide the Institute in developing and supporting rehabilitation interventions to improve issues of quality of life as documented by patients.

Nutrition

Adequate nutrition is a cornerstone of rehabilitation, and thus numerous studies have sought improved methods of achieving it. As noted above, the head and neck cancer patient has been the focus of much nutrition-oriented research, but researchers are also focusing on nutrition problems among other cancer patients, such as food aversions learned in association with selected treatment regimens. Techniques to block the development of such aversions are being tested. The influence of reduced gastric emptying is being examined among metastatic tumor patients with primary non-small cell lung cancer, esophageal, and prostate cancer. Within the clinical trials network, dietary counseling interventions are being evaluated to assess their effectiveness on excessive weight gain among patients receiving adjuvant therapy for breast cancer.

Self-Care

Helping patients and families to care for themselves both during and after treatment allows them maximum independence and control which are issues central to rehabilitation. Six ongoing studies are testing nursing interventions to promote self-care associated with symptoms occurring during radiation and chemotherapy. Investigators are seeking data about what conditions and circumstances patients can and cannot manage. Protocols designed to enhance the patients' ability to adhere to treatment regimens are also being studied. Assisting childhood cancer patients and parents to better manage the highly stressful and common event of bone marrow aspiration is being examined with a combination of behavioral and pharmacologic approaches.

Pain

Among the symptoms associated with many types and stages of cancer is pain. Research in both the clinical trials network and a program project are examining the prevalence and severity of pain in children. Major problems are related to clinical application of pain management principles. Refinement of clinical judgment of cancer pain severity and development of behavioral techniques to enhance drug management is the goal of one major project. Small businesses also are contributing to the dissemination of cancer pain management knowledge through the development of computer-based systems using innovative artificial intelligence, expert learning systems, and other state-of-the-art techniques.

INFORMATION DISSEMINATION

An integral part of achieving the goals of rehabilitation is sharing rehabilitation information with patients, families, and health care professionals. A variety of strategies are used to ensure that as many people as possible receive relevant rehabilitation information.

The Cancer Information Service

The Cancer Information Service (CIS) is a national toll-free telephone network to answer questions from both professionals and the general public. Approximately 10 percent of these calls relate to cancer rehabilitation. In addition, the phone counselors often follow up by mailing relevant Institute literature to the caller.

Publications

The Institute publishes a great deal of information about all aspects of cancer. Interwoven throughout materials for both the

general public and health care professionals is specific rehabilitation information. In addition, the Institute is developing specific literature aimed at cancer survivors and expanding the rehabilitation-oriented content of existing materials to address issues of cancer survivorship.

Cancergrams

Cancergrams are monthly current awareness bulletins covering 66 cancer-related topics. One bulletin is devoted entirely to rehabilitation and supportive care and contains 30 to 100 abstracts which provide readers with a comprehensive and authoritative look at the issues. Topics typically covered include pain, physical rehabilitation, psychosocial aspects, nutrition, reconstructive surgery, prosthesis, speech, and occupational therapy.

FUNDING

NCI funding for rehabilitation research amounts to over \$9 million dollars for Fiscal Year 1989. (Table 2) Similar amounts are estimated for Fiscal Years 1990 and 1991. These figures do not include research on treatment with rehabilitative aspects including research on less invasive breast cancer treatments, research on prostate cancer treatment, and limb-sparing treatments regarding bone cancer.

Table 2:

National Cancer Institute Funding (dollars in thousands)

	1989 Estimate	1990 Estimate	1991 Estimate
Intramural			
Grants	\$ 1,793	\$ 1,818	\$ 1,829
Contracts	6,984	6,984	6,984
	242	242	242
TOTAL, NCI	\$ 9,019	\$ 9,019	\$ 9,109

SUMMARY

Cancer rehabilitation is integral to the overall care of the cancer patient, involving a complex matrix of various tumors and treatment approaches which have both common and unique characteristics. Depending upon the patient situation, the composition of the clinical and research teams may vary dramatically. Numerous specialists may work together in order to

be part of these cancer rehabilitation efforts: medical and surgical oncologists, therapeutic and diagnostic radiologists, nutritionists, physical and speech therapists, psychologists, nurses, immunologists, and metallurgists. Successful cancer rehabilitation and practice requires this diverse cadre of specialists.

In addition, it is important that information about all aspects of rehabilitation reaches both cancer patients as well as health care professionals. The Institute accomplishes this goal through the efforts of telephone counselors, computer experts, and publishing groups.

It is clear that both varied resources and diverse groupings of experts from throughout the Institute and the cancer care community are essential to achieve the overall goal of cancer rehabilitation.

PHYSICAL MEDICINE AND REHABILITATION RESEARCH SUPPORTED BY
NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

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The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) supports approximately 20 research projects related to physical medicine and rehabilitation. This research, which is supported by all three of the Institute's categorical extramural divisions, falls into two general areas. The first involves behavioral or psychological research that includes an intervention strategy. Most of these studies address problems arising from diabetes, obesity, or gastrointestinal disorders.

The second area involves investigations of improved functional maintenance in patients with chronic disorders, including studies of patients undergoing hemo- or peritoneal dialysis, total parenteral nutrition, or insulin therapy.

All of these projects, while related to physical medicine and rehabilitation, primarily focus on chronic disorders and general research that is within the mission of the NIDDK. These projects are, without exception, integrated tightly into the research programs that support them. They cross-cut and complement a number of programmatic research areas in ways that provide a better understanding of the full scope and impact of these diseases and related clinical problems and, most importantly, provide the basis for the development of appropriate and effective therapeutic interventions.

In the area of behavioral and psychological research, the NIDDK's Diabetes Program is supporting a number of projects examining psychological problems associated with diabetes, and means of treating those problems. Affective and anxiety disorders are three to four times more common among adults than they are in the general population. These psychiatric disorders are associated with poor blood glucose regulation; a number of serious complications result from poor glucose regulation. To address this problem, an NIDDK grantee is conducting a clinical study to examine the effects of conventional psychotropic agents on glucose regulation in patients with poorly controlled noninsulin-dependent diabetes and with actively symptomatic affective or anxiety disorders. The study will determine if the treatment of the psychiatric disorder will have a beneficial impact on glucose regulation and patient health.

Depressive disorders are the most prevalent psychiatric outcomes of diabetes. An NIDDK grantee is conducting a longitudinal study

of depression in newly diagnosed juvenile, or insulin-dependent, diabetics. It is anticipated that this investigation will provide guidelines as to the longitudinal characteristics and process of coping with diabetes among children, adolescents and their parents, and young adults. To facilitate early intervention, the investigators will identify risk rates and correlates of depression and other psychiatric illness. This study may clarify unresolved issues in the field and provide data for clinical management, psychosocial intervention, and patient education.

A similar NIDDK-supported study is examining the influences of family and individual psychosocial forces on clinically relevant diabetes outcomes in order to, again, identify risk factors that may be amenable to early psychosocial interventions.

Another NIDDK grantee is investigating the effects of psychological and hormone stressors on blood glucose levels, while still another is exploring the efficacy and mechanism of progressive relaxation training and drug therapy in improving glucose metabolism in noninsulin-dependent diabetes.

Along these same lines, our Gastrointestinal Disorders Program is supporting two projects studying the psychophysiology and psychological treatment of irritable bowel syndrome (IBS). One of the studies is aimed at identifying the physiological and psychological mechanisms for the symptoms of IBS, while the other will evaluate a multicomponent psychological treatment program for patients with IBS.

In addition, the NIDDK's Nutritional Sciences Program is supporting a project that is applying information gained from laboratory studies of the variables that control food intake to the treatment of obesity in humans.

In the area of improved functional maintenance in patients with chronic disorders, the Nutritional Sciences Program is also supporting a host of projects investigating the special dietary needs of patients undergoing total parenteral nutrition for a variety of disorders.

The NIDDK's Kidney Program is funding a small business grant to develop a substitute for glucose for use in peritoneal dialysis fluids. The high glucose content of the dialysate has been identified as a source of several metabolic problems in end-stage renal disease patients undergoing peritoneal dialysis, especially those who are also diabetic. An effective glucose substitute will likely eliminate such problems, two of which are hypertriglyceridemia and excess weight gain.

The severe anemia associated with end-stage kidney disease is due primarily to erythropoietin (EPO) deficiency. Anemic

complications result in debilitation, deterioration in quality of life, and economic loss for the patient and the patient's family. Two grantees of the NIDDK's Hematology Program have made major contributions to understanding the anemia of chronic renal failure (CRF). Included in their findings is that recombinant human EPO replacement is effective in treating patients with CRF who are not on hemodialysis. This means that the many complications caused by anemia may be prevented by treating these patients with EPO before dialysis becomes necessary, thus maintaining their rehabilitation.

Finally, an NIDDK Diabetes Program grantee is developing and testing the feasibility of a self-regulating osmotic insulin pump. This type of device would provide closed-loop control of glycemia, and would mimic the endocrine action of the normal, nondiabetic pancreas. Such a device might prevent many of the long-term complications of diabetes.

REHABILITATION RESEARCH PROGRAMS
OF THE NATIONAL INSTITUTE ON AGING

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Literally millions of older persons suffer from physical and other disabilities which could be lessened by rehabilitation techniques. The interface between geriatrics and rehabilitation is so necessary that the modest development of geriatric rehabilitation to date is surprising. To promote progress in this much-needed field, the National Institute on Aging (NIA) places a major emphasis on rehabilitation-related research. NIA's current support for research in this area is approximately \$10.8 million per year.

Needs and potential for rehabilitation among older persons are major foci of NIA's epidemiologic, behavioral, clinical, and basic research programs. NIA's epidemiologic studies are revealing the extent of specific disabilities in community-dwelling populations, and identifying preventable risk factors for them. NIA's behavioral research programs are identifying behavioral and social factors which crucially affect older persons' responses to rehabilitation.

NIA supports clinical research on such topics as rehabilitation of disabling physical performance deficits in frail older persons and improved techniques of functional assessment for geriatric patients. Such studies have shown that even very frail older persons can show significant functional improvement in response to rehabilitation programs. NIA also supports research on cognitive rehabilitation techniques to counter age-associated memory problems. Basic studies on the causes of chronic degenerative conditions of later life, which may provide the basis for fundamental advances in rehabilitation strategies, are also an important NIA focus.

Three ongoing NIA initiatives of particular note in geriatric rehabilitation are

Reducing Frailty and Injuries in Older Persons. NIA, in collaboration with the National Center for Nursing Research, has allocated \$2 million per year, beginning in FY 1990, for clinical trials of improved interventions to reduce physical frailty and injuries in older persons. These trials will test rehabilitation programs to restore functional deficits related to cardiovascular, musculoskeletal, and other dysfunctions, as well as behavioral and environmental rehabilitation approaches to reduce dependency and risk of falls and injuries. This solicitation has attracted strong interest from the

rehabilitation research community. NIA has received 42 applications, two-thirds of which include major research participation by individuals with expertise in physical medicine and rehabilitation, physical therapy, and related fields.

Rehabilitation and Aging: Biomedical and Psychosocial Perspectives. This was issued in the May 5, 1989, issue of the NIH Guide to Grants and Contracts. It encourages research grant proposals on rehabilitation for older persons with physical, sensory, and cognitive disabilities resulting from disuse, disorders, or injuries of the musculoskeletal, cardiovascular, or other physiological systems. Research is encouraged on biomedical, social, and behavioral aspects of rehabilitation and the combined application of medical and psychosocial strategies. This announcement covers rehabilitation of both newly developed and long-established disabilities in older persons, and has generated considerable interest from the rehabilitation research community.

Joint Sponsorship with NIDRR of the University of Pennsylvania Rehabilitation Research and Training Center. Beginning in 1988, NIA has provided equal support with the National Institute on Disability and Rehabilitation Research (NIDRR) for this Center, which is focused on rehabilitation issues related to aging. The Center supports studies on the feasibility and effectiveness of a combined geriatric rehabilitations service, the role of nurses' aides in geriatric assessment, and the role of cardiac problems in rehabilitation of older persons, and the effect of aging changes in muscle function on rehabilitation potential.

PHYSICAL MEDICINE AND REHABILITATION RESEARCH PRESENTLY
SUPPORTED BY THE NATIONAL INSTITUTE OF ARTHRITIS AND
MUSCULOSKELETAL AND SKIN DISEASES

Lawrence E. Shulman, M.D., Ph.D.
Director

National Institute of Arthritis and Musculoskeletal
and Skin Diseases

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) has primary responsibility at the National Institutes of Health for research, research training, and research career manpower development for numerous diverse disorders that include the many types of arthritis; muscle disorders; diseases of bone and other skeletal support structures; and skin diseases. The mission of the Institute also includes research on the normal structure and function of joints, muscles, bones, tendons, ligaments, and the skin. The Institute carries out its mandate through both extramural and intramural programs of grants and contracts which includes a broad range of basic and clinical research. Research of direct concern and interest to the fields of rehabilitation is supported in these various programs. The Institute is the leading focus at the NIH for combating and preventing musculoskeletal disability and promoting musculoskeletal fitness.

The Arthritis Program concerns the more than 100 forms of rheumatic diseases. These include inflammatory diseases such as rheumatoid arthritis; arthritis in children; osteoarthritis in the elderly; spinal arthritis; serious connective tissue diseases, both acquired (e.g., lupus) and inherited (e.g., Marfan's syndrome); tendonitis, and bursitis.

The Muscle Biology Program is concerned with muscle strength and weakness, basic mechanisms of muscle contraction and force production, the regeneration of muscle, use and control of energy, metabolic response of muscle to exercise and disease, muscle injuries and repair, and exercise pathophysiology.

The Institute's Musculoskeletal Diseases Program supports a great deal of research of special interest to the field of rehabilitation. Among the research areas are the structure growth and mineralization of bone; major bones diseases such as osteoporosis, the leading cause of bone fractures; inherited bones diseases, such as the tragic osteogenesis imperfecta; reconstructive surgery by joint replacements (hips, knees, others) and bone grafts; back disease (the leading cause of disability in those 17 to 44 years of age); sports medicine; and physical fitness.

Much interesting rehabilitation research is being conducted in the Institute's Multipurpose Arthritis and Musculoskeletal Diseases Centers. These research centers are comprehensive, and each has a translation component with a number of projects in the field of health services research. Such research includes the assessment of function, the assessment of outcomes, and the efficacy of interventions. The Institute also has a multifaceted Skin Diseases Program, and an office with expertise in clinical trials.

The Intramural Research Program of NIAMS, in its Arthritis and Rheumatism Branch, has a very close relationship with the Department of Rehabilitation Medicine, directed by Dr. Gerber, at the NIH's Clinical Center; and is helping to support its research program in biomechanics.

NIAMS organized and chairs the Arthritis and Musculoskeletal Diseases Interagency Coordinating Committee. Over the years, the Committee has had excellent representation from the RSA, the NIHR, and the NIDRR. Arthritis and musculoskeletal diseases have become "new" priority areas for these agencies. NIAMS staff have served as consultants to both the research programs and the leadership of the agency. Collaborative research workshops have been generated with the leadership of the fields of physical medicine and rehabilitation.

The following research projects are selected and presented as examples (a representative sample) of rehabilitation research supported by NIAMS:

Joint Function

- Clinical biomechanics of the knee
- Force and stability analysis of human elbow
- Functional forces in normal and abnormal fingers

Musculoskeletal Function

- Locomotion: idling metabolism and gait dynamics
- Computer modeling system for dynamic analysis
- Control of timing precision of human movement

Reconstructive Surgery

- Total hip replacement: cementless
- Mechanisms of loosening
- Bone remodeling around porous implants
- Biomechanics of total knee replacement

Factors of survival of bone grafts
Cartilage allografts
Controlled cartilage repair
Exercise-induced adaptations of muscle grafts

Nonpharmacologic Treatment

Ultrasound on knee mobility
Radiation synovectomy in arthritis
Continuous passive motion after knee surgery

Bone Research

Bone physiologic response to applied stress
Fracture healing by electric fields
Strength training on bone density

Spine Research

Growth and remodeling in scoliosis
Recovery of disc after enzyme treatment
Low back injuries in postal workers

Muscle Research

Molecular basis of muscle fatigue
Electrical stimulation in muscle rehabilitation
Exercise-induced growth of muscle
Mechanisms of disuse atrophy in muscle

Ligaments and Tendons

Ligament insertions
Tendon cell attachment to synthetic fibers
Tendon cells: responses to stress
Anterior cruciate ligament--functional biomechanics

Assess Function

Dynamic modeling of prosthetic gait
Arthritis Impact Measurement Scales (AIMS)
Health Assessment Questionnaire (HAQ)
Role limitations in rheumatoid arthritis
Vocational evaluation in rheumatoid arthritis

Assess Outcomes

Psychosocial outcomes in juvenile arthritis
Disability in the elderly
Long-term outcome in rheumatoid arthritis

Occupational Rheumatology

Modify carpal-tunnel syndrome; grocery clerks

Psychosocial Research

Psychological variables in juvenile arthritis

Role of depression in outcomes in rheumatoid arthritis

Arthritis self-management course

MEDICAL REHABILITATION RESEARCH ACTIVITIES AT THE
NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

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The National Institute of Child Health and Human Development (NICHD) has primary responsibility for basic and clinical research associated with maternal and child health and human development. These studies examine the biological and behavioral factors important to normal and abnormal growth, maturation, and development from gametogenesis through maturity. The mission of NICHD includes those health, family, education, vocational, and social problems associated with disordered development consequent to biological or environmental influences acting singly or in concert.

Early detection, diagnosis, and treatment of abnormalities of development are studied by NICHD-supported scientists. Institute-supported research has provided new or improved methods for early detection of a variety of conditions which, if left untreated, result in serious loss of functional abilities. PKU and hypothyroidism are but two of the many abnormalities which are detected early and treated effectively as a result of NICHD-supported research. Early detection of chromosomal anomalies has allowed parents and physicians time to prepare for special care which is needed during the life of the infant with a disability. Amniocentesis and chorionic villus sampling techniques were developed through the NICHD to allow physicians to detect and diagnose numerous genetic abnormalities very early in pregnancy. Automated and easily used tests for detecting hearing loss are being developed to allow early intervention to prevent deficient or delayed language development. New methods for analyzing infant cry are being developed to detect and predict later abnormalities in behavioral and physical development. Taken as a whole, these studies illustrate that early diagnosis and treatment of physical or behavioral impairment may result in an improved functional outcome for the individual with the disability.

The NICHD funds 12 Mental Retardation Research Centers to study the etiology and treatment of mental retardation and other developmental disabilities. These multidisciplinary centers examine, over a long period of time, the individual with mental retardation in the context of his or her family, school, and vocation. For the past 25 years these centers have provided a research base for the continuing national discussion on the benefits of mainstreaming individuals with disabilities into integrated community health, social, and vocational support systems. One cluster of currently funded research is

investigating the influences of a child with physical, behavioral, or both physical and behavioral disabilities on the family. The effects of poor economic and social environments are being addressed by a study which provides children from these conditions with improved opportunities for physical and behavioral development. Behavioral and pharmacological treatments of destructive behaviors exhibited by individuals with developmental disabilities is the subject of several NICHD-supported investigators.

As a result of the recently published "Learning Disabilities: A Report to Congress," the NICHD has increased efforts to detect, diagnose, and treat individuals with learning disabilities. In 1989, two new multidisciplinary research centers were funded for the purpose of examining biological and behavioral factors involved in learning disabilities. The centers research program includes studies of genetic, neurological, and environmental contributions to etiology as well as remediation through the development of special educational programs and devices, family intervention, and vocational adjustments.

The NICHD funds research on the treatment of infants at risk for abnormal development as a result of poor nutrition, genetic abnormalities, very low birth weight, and exposure to environmental toxins. One example is the work on the development of leg braces for children with osteogenesis imperfecta which was performed by Dr. Gerber of the Clinical Center in coordination with the NICHD genetics intramural program. Other areas of investigation include the effects of intraventricular hemorrhaging on subsequent physical and behavioral functioning. Kinematic analysis of pediatric movement disorders, tardive dyskinesia, CNS sequelae of CMV infection, behavioral effects of AIDS on infant and child development, cognitive and physical consequences of Rett syndrome, and numerous other conditions originating early in development through early adulthood are being carried out by Institute-supported investigators.

Recently, the NICHD has begun to expand funding in the area of medical rehabilitation through the use of funds from the Small Business Innovation Research mechanism. Over \$2 million are spent annually to develop mechanical equipment and educational materials to assist in restoring or replacing function for individuals with disabilities. These projects include "talking" computer screens for teaching dyslexics to read, visual control systems for "environmental" control by individuals with head injury, paralysis, or cognitive deficits, new measurement tests for predicting preschool-age children at risk for low academic performance, and neural network development to improve motor performance of individuals with cerebral palsy. Another SBIR project is examining the efficacy of teaching mathematics to disadvantaged adolescents through the use of a new software program which emphasizes entrepreneurial skills. Measurement

systems for assessing listening comprehension, effectiveness measures of vocabulary knowledge, computer-animated sign synthesis for teaching ASL, computer-assisted writing instructions for teaching individuals who are deaf, and the development of bar code technology for providing visual and auditory instructions and feedback on student performance are being adapted for use by individuals with disabilities.

An exciting new direction for the NICHD is the development of a coordinated effort to study the efficacy of the treatments given to infants, children, and young adults who are treated in intensive care units as a result of disease, genetic anomaly, surgery, or accident. The collaboration of a large number of intensive care units (ICU) will provide data for research scientists to analyze and to provide feedback on "best" practice to the physicians and allied health professionals who staff the ICUs. In the tradition of other research supported by the NICHD, these studies will follow the effects of treatment for both acute and chronic conditions, study the treatment effects over a long period of time, and take measures in many functional domains. Formalizing treatment protocols will both improve the treatment rendered and provide a solid data base for the statistical analyses needed to examine effectiveness. Because individuals with disabilities utilize the health system disproportionately when compared to nondisabled individuals, this new approach should impact the quality of care provided by ICUs and improve the quality of life of individuals with disabilities.

Early detection and intervention, restoration and replacement of function, and the development of treatments to minimize subsequent functional loss characterize many of the longitudinal and multidisciplinary studies funded by the NICHD. The results of this research have been well utilized by individuals with disabilities and their families to improve their quality of life in the mainstream of activities in American culture.

PHYSICAL MEDICINE AND REHABILITATION RESEARCH
SUPPORTED BY THE NATIONAL INSTITUTE ON DEAFNESS AND
OTHER COMMUNICATION DISORDERS

Ralph F. Naunton, M.D.

Acting Director, Extramural Activities

National Institute on Deafness and Other Communication Disorders

There are at least two possible strategies I might adopt in putting together a 4- or 5-minute account of the support the National Institute on Deafness and Other Communications Disorders (otherwise known as the Deafness Institute or NIDCD) is providing for physical medicine and rehabilitation research: I could list the many scientific areas and items receiving support--thus precipitating mass narcosis and qualifying you all for emergency rehabilitation--or I could pick out an item I think might interest you most and that will at the same time best illustrate the Institute's involvement in rehabilitation research and physical medicine.

I will adopt the latter strategy and talk to you about only one item, but only after telling you that the Institute is involved to a major extent in supporting rehabilitation research into many varieties and degrees of hearing impairment, speech, voice and language disorders, and disorders of balance.

One of the topics of greatest popular and scientific interest at the moment is that of electronic inner ear or cochlear implantation for individuals who are profoundly deaf. The so-called "cochlear implant" in its present stage of development is a multichannel electrode, sometimes carrying as many as 22 channels, which is implanted surgically into the inner ear or cochlea; this electrode is connected to an external electronic speech processor--a device that converts the various frequencies of speech and other sounds into electrical impulses and feeds them to various locations within the coiled cochlea. The presumption is that, even if the hair cells within the cochlea that normally convert sound into electrical energy have been destroyed by disease, there will still be functional neuronal connections between the cochlea and the auditory areas in the central nervous system and that a sensation of hearing can result from electrical stimulation.

Several thousand adults worldwide have now received these implants and the results have, in many respects, been spectacular. As I learned and practiced middle ear surgery, it was the accepted wisdom that to enter the inner ear led certainly to inner ear destruction. Cochlear implantation has shown us that this is not necessarily the case; some individuals have now carried electrodes in their inner ears for a considerable number of years and the ear does not suffer further damage; on the

contrary, there is even a possibility that electrical stimulation protects the inner ear and central auditory nervous system against disuse atrophy. Some individuals, previously profoundly deaf, are now functioning spectacularly well with cochlear implants even to the point of being able to converse over the telephone. And even those at the other end of the "success" continuum are, with very, very few exceptions, functioning more efficiently than was possible before implantation using even the most powerful conventional hearing aid. The use of these implants in children is still investigational, but it seems likely that implants will be generally available for use in children in the near future.

My brief focus on electronic cochlear implants has more implications for us than hearing habilitation or rehabilitation alone; cochlear implants have provided and continue to provide a valuable window into the otherwise largely inaccessible inner ear; many implant users have consented to serve as guinea pigs in studies of inner ear function and, as a direct result, information on inner ear and central auditory function has burgeoned in recent years at a rate never experienced before. The lesson for us all is clear: rehabilitation medicine and research are not in competition; they support and nourish each other and are of equal importance in the full spectrum of the biomedical sciences.

PHYSICAL MEDICINE AND REHABILITATION RESEARCH PRESENTLY
SUPPORTED BY THE NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS
AND STROKE

Patricia A. Grady, Ph.D.
Health Scientist Administrator
National Institute of Neurological Disorders and Stroke

The National Institute of Neurological Disorders and Stroke (NINDS) appreciates the opportunity to discuss the topic of rehabilitation and rehabilitation-related research. Such research is an integral part of the Institute's activities. The topic is not new to us. As many of you will recall, in 1985, the congressional Committee on Appropriations, through House Report 99-289, requested that the National Institutes of Health submit a report on rehabilitation-related research in the National Institutes. This task was delegated to the then National Institute of Neurological and Communicative Disorders and Stroke because of the inherent scientific and medical association of that subject with our Institute's mandated responsibilities. In addition, the Director of the Institute was, and is, the representative of the Director of the NIH to the Interagency Committee on Handicapped Research (now known as the Interagency Committee on Disability Research). In that report, we used the working definition of rehabilitation of the Interagency Committee, which reiterates that "research related to rehabilitation of handicapped individuals generally includes all studies directed toward acquiring...knowledge on functional restoration, improvement or stabilization of performance and independence." All aspects of that working definition can be subsumed under the term "restitution of function." This is the ultimate goal of much of our Institute's basic and clinical research on head injury, spinal-cord injury, stroke, and a number of demyelinating and neuromuscular disorders, the sequelae of which are often devastating and life-long. In fulfilling its mission, the NINDS supports the rehabilitation research efforts of individual investigators, the business community, and groups working in large specialized centers. Today I would like to provide an overview of this ongoing work.

In February 1988, the Division of Stroke and Trauma issued a program announcement entitled, "Restitution of Function and Rehabilitation After Injury to the Nervous System." The overall goal of the announcement was to encourage applications for research that could improve the functional capacities of victims of injury to the central nervous system. We received 14 applications in response to that announcement--and we continue to seek more.

Since the Institute's philosophy and practice places rehabilitation on a continuum with disease or injury states, a

segment of our research activity, ranging from basic science through clinical trials, is directed toward salvaging damaged neurons. We have supported many promising biochemical and physiological advances that may make it possible to decrease the amount of brain tissue that is lost as a result of stroke or injury. These advances have provided the basis for studying the plasticity of the central nervous system--the possibility that alternate pathways and groups of neurons in the brain and spinal cord may be used to replace functions lost as a result of injury or disease processes.

Several investigators are addressing the return of function after injury to the spinal cord. In animal models, studies of the movements of the limbs, as well as posture, have shown that some types of therapy may actually be detrimental to regaining of locomotor function. Investigators have suggested that recovery may be "trained out" under certain conditions, perhaps due to changes in the neuronal circuitry within the spinal cord.

The NINDS supports over 20 specialized centers dedicated exclusively to the study of spinal cord injury, head injury, and stroke. These centers are primarily studying recovery from injury and the stimuli for regeneration of injured tissue with the overall goal to decrease long-term disability. Several additional centers are using positron emission tomography (PET) and other imaging modalities to study disorders of the central nervous system.

The advent of new technology holds yet additional promise for advances in the field of rehabilitation. These methods provide a mechanism to assess damage in the human brain and spinal cord. An example of this is the use of magnetic resonance imaging (MRI) in the head-injured population. Compared to conventional methods, a better correlation was found with neurobehavioral sequelae of less-than-severe head trauma patients. Using MRI, additional brain lesions were detected. Thus, the need for rehabilitation was identified in patients who would otherwise not have been placed in these programs. Positron emission tomography (PET) technology provides a powerful means to look inside the nervous system at both structure and metabolism. Studies of language and aphasia are being carried out using PET to identify active areas of the brain in an effort to guide rehabilitation strategies; PET studies of hypotonic and hypertonic phases of paralysis have been used to develop new approaches for clinical management. The information gained from such studies can be used to design specifically tailored rehabilitation programs that will maximize remaining functional capability.

Pioneering efforts and accomplishments are emerging from the field of neural prostheses, as was demonstrated recently in the Twentieth Annual Neural Prosthesis Workshop sponsored by the NIH. Examples include studies in magnetic stimulation of the human

central and peripheral nervous systems, and the use of implantable microstimulators for muscle groups. Tactile sensors and motor prostheses are being developed to deal with problems of paralysis. Spinal and bulbar control of micturition are being studied to deal with the problems of urinary incontinence.

Studies of higher cortical function and mental processes continue to provide valuable information for rehabilitation. Studies of long-term effects of and recovery after stroke and injury reveal that the brain is functionally more dynamic than was previously believed. Neurons may be recruited from active areas of the brain to perform alternate functions. An example of this is the use of cognitive methods to control motor movement.

A major problem of the head-injured who have overcome motor deficits is confusion and the loss of memory. Several projects are ongoing to determine the mechanisms of this memory loss and to develop ways to deal with this debilitating problem. One study in particular, "Rehabilitative software for head trauma victims," began as a Phase I small business grant, and progressed to a marketable product. Personalized software was created that teaches head trauma patients the math, reading, and writing skills basic to independent living and has made a major contribution to rehabilitating this large population.

Major advances have been made in understanding mechanisms and treatment of the depression that frequently occurs after stroke or injury, and often delays active rehabilitation. The results of this work may be helpful to other chronically disabled populations.

The NINDS has a mandated mission and a strong commitment to rehabilitation and rehabilitation-related research as a part of its overall responsibility related to neurological disorders and stroke. The position of our Institute on this issue is that rehabilitation is on a continuum with disease or injury states. Rehabilitation must not be restricted to physiotherapy, which utilizes primarily technical approaches. The appropriate goal of rehabilitation, we believe, is restitution of function.

In summary, thank you for your attention. We, at the National Institute of Neurological Disorders and Stroke, are pleased with this interest and enthusiasm from the physical medicine and rehabilitation community in support of a field in which we have a long history of research commitment, a strong current interest, and, using this as a base, aspire to an even stronger future involvement. We invite your support in this effort and we welcome your suggestions and comments as we progress forward in this important endeavor.

PHYSICAL MEDICINE REHABILITATION RESEARCH PRESENTLY
SUPPORTED BY THE DIVISION OF RESEARCH RESOURCES

Judith L. Vaitukaitis, M.D.
Director, General Clinical Research Center Program
Division of Research Resources

The Division of Research Resources (DRR), through its several programs, provides an array of multi-user resources for multidisciplinary basic and clinical research, including Medical Rehabilitation Research. Investigators accessing those resources usually obtain their primary research funding from the other components of the National Institutes of Health. Consequently, the array of research across the DRR Programs will reflect the research missions of the several categorical institutes at the National Institutes of Health. In addition, investigators may obtain primary research funding from other Federal, State, and local agencies as well as from the private sector. In FY 89 the several DRR programs hosted 719 rehabilitation-related research projects at a cost of \$9.7 million.

The General Clinical Research Centers (GCRC) Program accounted for almost two-thirds of the rehabilitation-related research hosted by DRR. The GCRC Program currently supports a national network of 78 Centers to interface multicategorical basic and clinical research. The Centers provide facilities for inpatient and outpatient research, specialized research nursing and dietary staffs, computerized data management and analysis systems, and specialized laboratories for sophisticated testing. In FY 89, 65 of the 78 Centers hosted 235 research projects at a cost of \$6.1 million. The rehabilitation-related research hosted across those Centers includes development of joint or heart valve prostheses, cochlear implants and other hearing devices, as well as intraocular implants. Other studies focus on rehabilitation of individuals with chronic obstructive pulmonary or cardiovascular disease. Other ongoing studies concentrate on the effect of either exercise or nutrition on reversing the adverse consequences of marked bone loss (osteoporosis), cardiovascular disease, diabetes mellitus, and abnormal lipid metabolism. Neurologic studies include therapeutic approaches to overcome or minimize memory deficits, spinal cord injury, head trauma, and stroke, as well as chronic progressive disorders such as amyotrophic lateral sclerosis (ALS) and Alzheimer's Disease. Pediatric studies include those for defining and treating developmental disabilities and hearing loss associated with viral infections. Finally, other rehabilitation-related studies include drug delivery systems and chronic pain rehabilitation.

The Biomedical Research Support (BRS) Program of DRR complements existing NIH-supported research. That Program provides funds through its Biomedical Research Support Grant Program for pilot

studies to explore new ideas or novel approaches to basic and clinical research problems; through its Shared Instrumentation Grant (SIG) Program, it provides access to expensive, state-of-the-art research equipment for shared usage by funded investigators. In FY 89, the BRS Program provided \$1.4 million for 379 pilot research projects and another \$1.1 million for 50 shared instrumentation grants to undergird rehabilitation-related research. The array of studies supported in part by that Program reflect many of those described previously for the General Clinical Research Centers Program. In addition, studies focus on development and design of restorative materials and computer-based methods of communication by handicapped persons.

The Animal Resources Program of DRR provides research scientists with access to nonhuman primates and other animals to serve as models of human diseases. Through its seven Regional Primate Centers, the ARP provided \$0.7 million to host 20 research projects at the Primate Centers. Investigators supported through the ARP conduct rehabilitation-related research that includes prosthetics, intracorneal and dental implants, vascular graft materials, and osteoporosis research.

The Biomedical Research Technology (BRT) Program of DRR translates the latest advances in the physical, mathematical, engineering, and computer sciences into equipment that enhances biomedical research. Rehabilitation-related research supported by this Program includes imaging techniques for damaged joints, nerves, and muscle, optimizing surface materials for grafts and prostheses, as well as designing and evaluating speech processors for auditory prostheses. In FY 89, the BRT Program provided \$0.3 million to support 34 research projects.

In summary, the several Programs within the Division of Research Resources undergird a wide array of multicategorical basic and clinical rehabilitation-related research studies across disciplines. That support will continue for the foreseeable future.

PHYSICAL MEDICINE AND REHABILITATION RESEARCH
SUPPORTED BY THE DEPARTMENT OF REHABILITATION MEDICINE

Lynn H. Gerber, M.D.
Chief, Department of Rehabilitation Medicine
Clinical Center, NIH

The Department of Rehabilitation Medicine is a clinical department providing PM&R consultation to all NIH physicians. The Department is located in the Clinical Center, a 500-bed hospital and outpatient facility on the Bethesda, MD, campus.

The mission of our Department is to provide comprehensive rehabilitative services to NIH patients. In addition, we have a secondary mission, which is to support and collaborate with or initiate research in the area of rehabilitation as it pertains to NIH patients and the problems that they confront while patients at NIH.

In addition to that, our third mission is to provide education for students and co-professionals. Staff is active in training occupational therapy, physical therapy, and psychiatric residents and rheumatology fellows. Most recently, in conjunction with NIAMS, we will be training our first biomechanist in the Biomechanics Laboratory.

The NIH has been very supportive and quite generous in the applications of its resources to this department. We were granted a division of biomechanics in 1983 to join the remaining typical sections within our own department: namely, the Speech Pathology Section, the Physical Therapy Section, the Occupational Therapy Section, our Physical Medicine Section, and most recently our Biomechanics Laboratory.

With respect to the clinical responsibilities, over the past five years we've seen an average of 7,200 patients per year for approximately 27,000 visits to the department. It's approximately 50 percent inpatient and 50 percent outpatient visits.

We offer an array of services. From these services have sprung a number of research questions. One of our major efforts, a spinoff of work done at our sister institution in Carville, Louisiana, was the management of the hypersensitive and insensitive foot, and the development of a variety of biomechanical aides to walking, such as the hindfoot orthotic, and other insoles and shoe modifications. This has significant application to the NIAMS intramural program.

We support the Cancer Institute in a major way in their efforts in limb-sparing surgeries using a variety of prosthetic interventions as well as rehabilitative techniques for managing patients with limb-spared procedures.

We are using biofeedback techniques as a way to achieve relaxation and training for temperature-sensitive patients such as those with Raynaud's Phenomenon.

We have committed substantial departmental resources in conjunction with the Child Health Institute to assist in the support of the normal, or as near normal as possible, development of children with osteogenesis imperfecta. In conjunction with Children's Hospital National Medical Center, we have devised an early intervention program beginning with custom-molded seating, exercise and positioning, and the fabrication of long leg braces. We are able to study time 3D gait in our biomechanics laboratory.

Our speech pathologists have been actually leading the way in a series of studies looking at the evaluation of swallow and tongue motion using ultrasound, an example of which is ultrasound image of the oral pharynx that one can see by placing a transducer at the base of the pharynx. We have used this technique in the medical section to examine relaxation and contraction of the quadriceps muscle, demonstrating configurational change during a concentric contraction.

Departmental activity proceeds by protocols. We have a number of active protocols, some of which have been initiated by our department, others in conjunction with other investigators at the NIH. One example is that of the work of Doctor Jeanne Hicks, who demonstrated that we are able to strengthen patients with an active myositis, polymyositis, without a significant increase in CPK. One of the concerns, of course, in exercising patients with an inflammatory disease is that we exacerbate the process and send the enzymes up, hence do more harm than good. This small study demonstrates that we are effective in strengthening muscle without undue harm. This does have functional consequences with respect to ability to carry out normal daily activities.

We have some data from the results of the studies that we have done in conjunction with our biomechanist in the biomechanics laboratory looking at children with osteogenesis imperfecta. In our study, trying to understand the mechanism of action of those long leg braces, we have discovered that the major impact that these braces have on movement in these children has been in controlling pelvic rotation. Hence, if we're concerned about femoral fracture, or problems that children may confront with respect to femoral torque and usual physical activity, this brace does offer them a significant benefit without significant impact on knee flexion, hip flexion, and extension, and that we do feel that we are able to control the rotation at the hip.

In short, we are a support department to the Clinical Center patients and have had the opportunity to do a number of research projects in collaboration with our NIH Institute physicians.

PHYSICAL MEDICINE AND REHABILITATION RESEARCH
SUPPORTED BY NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

Peter L. Frommer, M.D.
Deputy Director
National Heart, Lung, and Blood Institute

Rehabilitation in its broadest sense--and consistent with the American Academy of Physical Medicine and Rehabilitation definition¹--is ameliorating the impairment of those with chronic illness or other condition, and preventing acute illness from resulting in chronic impairment.

A major fraction of the Institute's research, demonstration, and education programs in the management of heart, lung, and blood diseases is directed at these goals.

It may be useful to consider more narrow definitions of rehabilitation.

The narrowest definition of rehabilitation--physical medicine with the goal of rehabilitation--would narrow the scope markedly and, for the National Heart, Lung, and Blood Institute (NHLBI), would include such activities as:

- Exercise and respiratory muscle training and other techniques of reconditioning patients with chronic obstructive pulmonary disease and cystic fibrosis.
- Exercise alone or as part of comprehensive cardiac rehabilitation programs following myocardial infarction, coronary bypass surgery or other open heart

¹The American Academy of Physical Medicine and Rehabilitation has defined rehabilitation as:

Rehabilitation is the study of physical disability in a group of diseases, including neurological, musculoskeletal, cardiovascular, and system disorders in which impairment, disability, and handicap is defined by quantified physiologic, physical, behavioral, and functional parameters. It is also the study of the reduction of residual disability, prevention and reduction of secondary complications, the restoration of physical function, communicative ability, and psychological, social, and vocational adaptation by interventions which include, but are not limited to, physical agents and exercises, bioengineering applications and their mode of delivery. Finally, it is the study of maintenance of function in chronic disorders during the course of the disorder.

procedures, using angiocardiographic, echocardiographic, and quantitative physiological endpoints during exercise.

- Exercise physiology and return-to-work evaluation.

The addition of bioengineering with rehabilitation goals--without quantification--would be misleading, as it would include not only the development of portable oxygen sources (conducted under small business innovation research awards), but also cardiac pacemakers and implanted defibrillators, prosthetic heart valves and vascular conduits, and implanted artificial heart and related devices. The latter are certainly designed to rehabilitate disabled individuals, but they are no more (and no less) rehabilitation than a surgical procedure that does not involve bioengineering.

Another definition might be considered--treatment that (1) has functional, physiological, and/or psychological goals of decreasing or compensating for impairment and (2) requires the continued involvement of the patient over a period of time in activities or behaviors more complex than taking medications. This would include

- Activities cited under the narrowest definition of physical medicine,
- Long-term therapy in which the patient must take an active role to bring about the results, e.g.:
 - adjustment to and coping with the disease state following heart surgery or myocardial infarction
 - self-management to ameliorate symptoms and decrease relapse for such conditions as asthma (both childhood and adult) and cystic fibrosis
 - smoking cessation interventions targeted on cardiovascular disease and the avoidance of relapse
 - biofeedback in control of hypertension
 - coping response strategies to stress
 - dietary modification for such problems as:
 - respiratory muscle impairment in chronic obstructive pulmonary disease
 - hypertension
 - hypercholesterolemia (though it is definitional whether this is a direct "impairment")
 - educational programs to the public and the medical profession for many of the above activities
 - descriptive biobehavioral studies built into long-term clinical trials.

Almost all of these activities are part of a continuum that ranges from amelioration of impairment (i.e., rehabilitation) to secondary prevention and primary prevention; the fundamental science is generally the same whether the focus is rehabilitation, secondary prevention, or primary prevention. Also, these rehabilitation activities are only a part of each patient's therapy and generally a closely interlinked part of his or her overall therapeutic regimen.

ELECTRODIAGNOSIS

Ernest W. Johnson, M.D.
Professor
Physical Medicine
The Ohio State University

My comments are based on 33 years of clinical practice in EDX with added dimensions of developing and teaching four to eight continuing medical education courses in electromyography (average number in attendance 60--one-half physiatrists and one-half neurologists).

I have trained 154 residents in the program at The Ohio State University.

I am on the American Board of Electrodiagnostic Medicine and on the PM&R Residency Review Committee.

My publications exceed 120, a plurality related to electrodiagnosis; recently completed editing the second edition of Practical Electromyography; serve as Editor of the American Journal of PM&R and on the Editorial Boards of Muscle & Nerve, Reviews in PM&R, and VA Practitioner.

While "electromyography" as a name has historical validity, some would say "clinical neurophysiology" is more apt, while other suggest electrodiagnosis, neuromyography, electrodiagnostic medicine.

I. Central Evoked Potentials

- A. Somatosensory EP are required by PM&R Residency Review Committee
- B. Some physiatrists do Brainstem Evoked Potentials, Visual Evoked Potentials (few PM&R specialists do EEG)

II. Peripheral Evoked Potentials

- A. Motor Conduction Validity with compound muscle AP (CMAP)
- B. Sensory Conduction Velocity with sensory nerve AP (SNAP)
- C. Repetitive Nerve Stimulation to evaluate myoneural junctions
- D. Mixed Nerve Action Potentials

III. Conventional Electromyography

- A. Spontaneous Activity
Fasciculations and Fibrillations
- B. Motor Unit Analysis
- C. Recruitment Patterns

IV. Late Responses

- A. F waves
- B. H waves
- C. Axon waves

V. Special Techniques

- A. Single fiber EMG--Blocking, Jitter, and Fiber Density
- B. Macro EMG--Size of MU
- C. Scanning EMG--Territory of MU

VI. Special Stimulation Techniques

- A. Spinal Nerve Stimulation
- B. Cortical Stimulation (Magnetic)

COLLABORATIVE RESEARCH

Basic Science--Physiology, Anatomy, Biochemistry, Pharmacology,
Toxicology, Pathology

Imaging--With increasingly advanced technology structure, will
need to be correlated with function, e.g., Disk vs. Nerve

Clinical Disciplines--All

Examples:

Fibrillation Potentials --

Cause in other than denervation
(Membrane Physiology)

Toxicology/Pharmacology/--
Pathology

Axonopathic effects (Methyl Butyl
Ketone) evaluating diabetic
neuropathy

Immunology	--	Guillain-Barre/Polymyositis/Aids Myasthenia Gravis Paraneoplastic Syndromes
Occupational Medicine	--	Diagnosis and Prognosis: Repetitive Movement Disorders
Anesthesiology/Surgery	--	Spinal Cord Monitoring

In Areas of Diagnosis

In Prognosis

Guillain-Barre Syndrome
Radiculopathy (in first week)
Entrapment Syndromes

In Management

Peripheral Neuropathies
Other Motor Unit Diseases
Trauma

MOST COMMON CLINICAL CONDITIONS FOR EDX*

1. Radiculopathy--Lumbar
2. Carpal Tunnel Syndrome
3. Cervical Radiculopathy
4. Diabetic Neuropathy
5. Other Entrapment Syndromes
6. Myopathy
7. Motor Neuron Disease
8. Generalized Peripheral Neuropathies (e.g., G-B Syndrome)
9. Neuro-muscular Junction Conditions
Lambert-Eaton; Myasthenia Gravis, etc.
10. Spinal Cord monitoring during surgery

In summary, the areas for collaborative investigations in electrodiagnosis are manifold and opportunities, many original, are limited only by the ingenuity of the researchers.

* Based on a survey of the CME course attendees

NEUROBIOLOGY

Wise Young, M.D., Ph.D.
Director, Neurosurgery Research Laboratories
New York University Medical Center

Physical medicine and rehabilitation (PM/R) research is a much neglected but crucial component of the NIH mandate to improve U.S. health care. PM/R research addresses critical questions of functional recovery and mechanisms of nonpharmacological therapies aimed at restoring and maximizing function. These questions have been largely ignored by mainstream medical research. The current paucity of basic scientists in PM/R research is a serious obstacle to solving our most urgent medical problems, particularly neurological disorders. To reverse this trend, a consistent, well-planned, and long-term program is required to attract scientists to PM/R research. It is important to increase the number of PM/R research centers, to increase and stabilize research funding of existing research centers, and to maintain training programs within these centers. These centers will serve as nurseries for young scientists interested in PM/R research. This is clearly a long-term investment in the future of PM/R and medical research.

PM/R research is grossly underfunded by NIH given the magnitude of the scientific problems that need to be addressed in the field. Rehabilitation focuses on restoring and maximizing function. Physical medicine encompasses a wide range of therapeutic tools, ranging from electrical, mechanical, thermal, and other therapies of tissues, as well as orthotic and prosthetic devices. Little is known about the mechanisms by which these treatments affect recovery of function. PM/R researchers are inadequately represented on NIH peer review groups. As a consequence, PM/R research interests do not receive appropriate attention or support from peer review groups. PM/R grant applications cannot compete successfully for funds. This situation is unlikely to change unless PM/R researchers are adequately represented in NIH study sections, formal programs are established to encourage PM/R priorities within individual NIH institutes, and funding is increased to support PM/R research.

PM/R research has been and is becoming more isolated from mainstream medical research. Medical researchers seldom read PM/R journals or attend PM/R symposia, and vice versa. This isolation can have serious consequences for both PM/R and medical research. For example, in my particular specialty of spinal cord injury research, PM/R research is key to understanding the nature and mechanisms of functional recovery but communication between clinical researchers studying acute and chronic spinal cord injury has been limited. This problem has been aggravated by the existence of separate funding sources for studies of the same

disease process and often the same patients. For example, clinical trials of acute spinal cord injury supported by NINDS (National Institute for Neurological Disorders and Stroke) are not well-coordinated with PM/R Regional Spinal Cord Injury Centers supported by the National Institute for Disability and Rehabilitation Research (NIDRR). Although we often study and care for the same patients, our outcome measures are different and data are not effectively shared. There is unnecessary duplication of effort and bureaucracy. While efforts are being made on many levels to improve communications between PM/R and other researchers, these efforts need to be strongly encouraged and funded on a wider scale. A formal program is required to establish mechanisms for cross-fertilization between PM/R research and medical research. This includes funding interdisciplinary symposia addressing PM/R research and emphasis on funding medical centers that have shown evidence of close collaboration between PM/R and other medical fields. In my opinion, establishing a separate national institute to fund PM/R research would be inimical to the goal of integrating PM/R research with mainstream medical research. Such segregation would only further segregate PM/R research and aggravate current deficiencies in both PM/R and medical research.

BIOMECHANICS
SELECTED EXAMPLES OF COLLABORATION

Barbara J. de Lateur, M.D., M.S.
Professor
University of Washington School of Medicine

I have chosen examples of which I have first-hand knowledge. The time available for preparation did not permit a survey of other institutions; thus, omission of a more widespread sampling does not imply a lack of collaboration elsewhere.

Members of the Department of Rehabilitation Medicine at the University of Washington collaborate with persons of other medical specialties, different disciplines within the department, other schools within the University, other universities, and with members of independent research organizations.

The collaborative efforts vary not only with respect to discipline and school but also with respect to approach, which includes development and exploratory technology and engineering applications in addition to experimental, case control, and outcome-oriented research.

Engineering students, graduate and undergraduate, have carried out their projects in our department for more than 20 years. Supervision is provided by engineering faculty as well as physical medicine and rehabilitation (PM&R) faculty. A series of undergraduate students worked on the problem of reducing shear forces in power-reclining wheelchairs to permit high-level quadriplegic persons to stay in their chairs for a full day without developing pressure or shear-related lesions. Such low-shear chairs are now commercially available. A doctoral engineering student (Kirkpatrick) developed a new force-plate in response to gait laboratory needs and this development also served as partial fulfillment of doctoral thesis requirements. The engineering applications program is an ongoing clinical program in the PM&R department. It is run by an occupational therapist and an engineering technician. Its function is to customize off-the-shelf devices so that severely disabled persons can gain greater independence or actually return to work. The most remarkable example of this program occurred when a device costing less than 10 dollars was used to interface a high-level quadriplegic with a hands-free communication system that enabled him to return to work running a store. The PM&R department (Lehmann) collaborates with the Seattle-based Prosthetic Research Group (Ernest Burgess, M.D., orthopedist) to study the relative energy costs of walking and running with some of the newly developed prosthetic feet, such as the Flex foot or the Seattle foot, compared with more conventional feet such as the SACH (Solid-Ankle-Cushion-Heel) foot. Both groups comprise one or

more physicians, engineers, and technicians. The role of one group is to develop the devices; the role of the other (PM&R) group is to design and conduct experiments to analyze the relative effects of the devices. Physiatrists Joe Czerniecki and Andrew Gitter (Dr. Gitter is an engineer in addition to being a physiatrist) are collaborating with Orthopaedic Bioengineering to study the effects of tissue loading on transcutaneous oxygen measurements. They are also collaborating with Dr. Bruce Sangeorzan to study the effects upon gait parameters of ankle fusion in Charcot-Marie-Tooth (CMT) patients. Within the department, resident physiatrist/engineer Dr. Tim Dillingham is studying the origin of forces on the trunk in normal gait. His thesis committee includes two physiatrists (Lehmann & de Lateur), as well as two engineers, one from within the department (Price) and one from the school of engineering (Colin Daly, Professor of Mechanical Engineering). Dr. de Lateur was principal investigator on a 3-year collaborative study of the rehabilitative outcome of major burns. This study involved surgeons (Heimbach), nurses, social workers, clinical psychologists, physical and occupational therapists, and an exercise physiologist in addition to the physiatrist principal investigator. A biomechanical component of this comprehensive outcome study was a test of the "armor theory," i.e., the extent to which extensive, heavy burn scar would increase the oxygen requirements of standard tasks by increasing the resistance to motion. Dr. de Lateur and Dr. Jurkovich (trauma surgeon at Harborview Medical Center, a King County-owned Level I trauma center managed by the University of Washington) are cooperating in a recently funded, multicenter fracture outcome study (principal investigator is Ellen MacKenzie at Johns Hopkins). Dr. de Lateur's main contribution to this study is development of a low-cost convenient method of functional mobility assessment. Dr. Linda Michaud, a physical therapist, pediatrician, and physiatrist, is doing her 2-year research fellowship training in the CDC-funded injury prevention study (Fred Rivara, professor of pediatrics, principal investigator) at Harborview Medical Center and Children's Hospital and Medical Center. This highly rated program project was particularly praised for its rehabilitative component (Kenneth Jaffe, pediatric physiatrist, provides the main input in this area). A practical outcome has been met. A manufacturer of high quality helmets is making them available at approximately 40 percent discount. Within the PM&R department, there is collaboration among physiatrists, engineers, therapists, and exercise physiologists to quantitatively study gait, balance spasticity, and various interventions in various disorders; in drug intervention studies, neuropsychologists are involved as well. Extensive collaboration is present with the geriatrics program project grant (Itamar Abrass, principal investigator) that studies the effects of exercise and other interventions on gait, balance, bone density, and other health parameters of older individuals. On the study of persons who fall and the falls intervention study, there is cooperation among the PM&R

department, the geriatrics group, the School of Public Health and Community Medicine, and the Group Health Cooperative, the first health maintenance cooperative in the area.

This list is by no means exhaustive, but is meant to provide a sample that suggests the extensive collaboration and cooperation occurring in medical rehabilitation (including health maintenance) research.

REHABILITATION-RELATED RESEARCH
SUPPORTED BY THE CENTER FOR ENVIRONMENTAL
HEALTH AND INJURY CONTROL OF THE
CENTERS FOR DISEASE CONTROL

John F. Finklea, M.D.
Extramural Grants Program of the
Center for Environmental Health and Injury Control
Centers for Disease Control

OVERVIEW

- The Centers for Disease Control (CDC) support rehabilitation-related research through the disability prevention and injury control programs of the Center for Environmental Health and Injury Control (CEHIC).
- During fiscal year 1989, CEHIC provided \$2.9 million in funding for one center grant and 12 research project grants having rehabilitation as their focus.
- CEHIC generally supports applied research, not basic biomedical research.
- CEHIC is interested in the coordination of research dealing with all aspects of injury control, including prevention, acute care, and rehabilitation.
- The CEHIC disability control program has as one of its major interests the prevention of secondary disabilities among persons with chronic conditions that interfere with normal activities.

THE INJURY CONTROL PROGRAM

- Was legislatively mandated and established following the 1985 National Research Council report entitled Injury in America;
- Was proposed as the lead agency for coordinating Federal injury control activities; (CDC served as the lead agency in developing the Nation's Year 2000 Objectives dealing with the control of intentional and unintentional injuries);
- Currently provides \$9.8 million for the support of seven injury prevention research centers and 31 research project grants, including \$2.2 million for rehabilitation research;

- Funds nine rehabilitation research projects dealing with
 - the consequences of mild head injury,
 - rehabilitation costs,
 - rehabilitation following spinal cord injury,
 - rehabilitation following lower extremity fractures.

THE DISABILITY PREVENTION PROGRAM

- Is working with the Institute of Medicine to develop a national agenda for disability prevention;
- Supports four applied rehabilitation-related research projects dealing with
 - the epidemiology, costs, prevention, and management of urinary tract infections among spinal cord-injured persons,
 - the descriptive epidemiology of late onset secondary disabilities among poliomyelitis patients, and
 - the frequency and costs of decubitus ulcers among spinal cord-injured patients.

Table 1:

Rehabilitation Research Grants Supported By the Centers for Disease Control (\$ in Millions)

CDC Program	FY 1987	FY 1988 (actual)	FY 1989 (actual)	FY 1990 (estimate)
Injury Control	0.7	0.8	2.2	1.6
Disability Prevention	--	0.7	0.7	0.7
Total	0.7	1.5	2.9	2.3

MEDICAL REHABILITATION RESEARCH

Bruce M. Gans, M.D.
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Detroit Medical Center

This paper describes characteristics of medical rehabilitation research in order to clarify the differences inherent in the needs of this discipline from the extant research programs of the National Institutes of Health. It will also describe the clinical characteristics of medical rehabilitation as background to the rationale for concentrating a research program on medical rehabilitation needs.

Medical rehabilitation research in its fullest sense is the process by which methods of treatment and management of patients with impairments and disabilities are created, understood, systematically evaluated, and improved. To understand and describe the full scope of these research needs, a review of the scope of the clinical practice of medical rehabilitation is first necessary.

CLINICAL MEDICAL REHABILITATION

Medical rehabilitation is a process of care that is applied to a patient with a permanent loss of physical function. Most commonly, this loss is due to illness, injury, or congenital defect. The typical diagnostic categories of patients for whom medical rehabilitation is needed include children with cerebral palsy or muscular dystrophy, young adults with head or spinal cord injury, adults with arthritis or multiple sclerosis, individuals with amputations, and older persons with stroke or complicated hip fracture. Many other conditions are also managed using medical rehabilitation services (Delisa, 1988).

The problems that all these patients share are their physical losses of motor function, and their resultant inability to perform normal functional activities such as walking, dressing, self-feeding, and so forth. Many of these individuals also experience associated problems such as loss of sensation, intellectual impairment, and speech disorders.

The hierarchical distinction between impairment, disability, and handicap is a useful paradigm for considering the needs for research in medical rehabilitation (Bury, 1987). As a consequence of the physical impairments and disabilities of body systems, individuals are handicapped, and unable to engage in normal human activities such as traveling in the home and community, working, participating in normal family life, and enjoying leisure time activities.

The process of medical rehabilitation recognizes the complex interrelationships between disorders of physiologic systems and the resultant functional and social disruption. More importantly, it applies in a systematic manner the services of multiple health professionals and medical technologies to not only resolve the medical disorders but also to address the patient's inability to achieve function.

In the management of disability, programs of care are orchestrated with functional objectives in mind. The child with cerebral palsy is braced and taught to walk with crutches. The adult with spinal cord injury-induced quadriplegia is educated to manage his own paralyzed bowel and bladder independently. The older person with a stroke is given new technologies to communicate when speech has become impaired.

These improvements are achieved by the coordinated and integrated application of the therapeutic knowledge and skills of a variety of health providers working as members of a multidisciplinary team. The team includes physiatrists and other physicians, nurses, physical therapists, occupational therapists, psychologists, speech and language pathologists, orthotists, prosthetists, rehabilitation engineers, and many others. Services are delivered to inpatients in comprehensive hospital programs and to outpatients in a variety of home, school, and clinic settings.

ADVANCES IN MEDICAL REHABILITATION

Since its inception, the technology of medical rehabilitation has evolved and become more sophisticated. Improved medical knowledge has allowed treatment and prevention of major medical disorders, such as infection, bed sores, bladder dysfunction, respiratory paralysis, and others. For example, improvements in technology have allowed quadriplegic individuals to become independent and live at home while remaining ventilator-dependent.

The process of rehabilitation has likewise been improved and made much more efficient. The average length of stay in a rehabilitation hospital has dropped from more than 60, to fewer than 25 days over the past 10 years. Despite this dramatic reduction, evidence suggests that the quality of outcomes has at least remained constant (Granger and Gresham, 1984).

What has produced these improvements and is needed to continue them is research. Research has led to a better understanding of the concept of functional limitations and the mechanisms of impairment, disability, and handicap. Research has brought better measures of function, interventions, and outcomes. Research has developed new and improved methods for treating and rehabilitating disabled patients. Finally, research has helped

to improve the societal and economic benefit-to-cost ratio of rehabilitation interventions.

MEDICAL REHABILITATION RESEARCH SCOPE

Rehabilitation research is the application of scientific principles and methods to solve the problems of disabled persons. It is necessary to improve the health, ability to function, and opportunity to live more normally for disabled individuals. It involves the study of assessment methods, treatment techniques, and management strategies. It focuses on persons of all ages who have physically disabling impairments that result in long-term losses of motor, sensory, cognitive, and/or communicative functions.

Rehabilitation research differs from conventional medical research in some ways, but also shares some common characteristics. To the extent that research needs are focused upon the illness and disorders of a patient, rehabilitation research will be quite similar to other organ- and disease-oriented research activities. The study of the functional consequences of that illness, however, and methods to improve performance despite residual organ dysfunction are unique to rehabilitation research.

As an example, research to further improve the control and treatment of urinary tract infections in patients with spinal cord injuries would appear to be consistent with both disease-oriented research and rehabilitation research. Expansion of the problem to include how the management of bladder dysfunction impacts on an individual's ability to return to work, however, is exclusively in the domain of rehabilitation research.

SPECTRUM OF MEDICAL REHABILITATION RESEARCH

The broad nature of the field of medical rehabilitation requires diverse research activities. Following are a selected few examples that demonstrate the scope of research needs and opportunities.

Basic research needs in medical rehabilitation exist in the areas of measurement. There is a major need to develop better clinometric abilities to measure disability and handicap. Because of the complexities of the nature of these phenomena, measurement tools that are valid and reliable (as well as sensitive enough to be useful) are still not generally available (Gans et al., 1988).

There are also needs to clarify the mechanisms of dysfunction that prevent return to independence for disabled individuals. Studies of the quantitative relationships between health status, functional limitations, intervention programs, and functional

outcomes must be pursued to allow the clarification of the best management strategies for improving function (Berninger and Gans, 1986).

Many severely disabled individuals are able to reestablish functions with the use of advanced technologies. For example, spinal cord-injured individuals can now exercise their paralyzed limbs with computer controlled electrical stimulation. Adults with severe degenerative neurologic diseases such as amyotrophic lateral sclerosis can continue to communicate and be mobile while dependent upon a respirator with the use of computers and powered wheelchair systems. The development and evaluation of these and other technologies for the functional enhancement of disabled persons falls within the scope of rehabilitation research (Gans, 1987; Gans et al., 1987; Gans and Hallenborg, 1987).

The understanding and elimination of economic, social, and health policy-related barriers to achieving independence for disabled persons is also within the scope of rehabilitation research. These types of studies include analysis of the impact of workers compensation programs on return to work, and quantifying the presence of inadvertent disincentives in public support programs for disabled individuals (Batavia, 1989; Snook and Webster, 1987).

UNIQUE ASPECTS OF MEDICAL REHABILITATION RESEARCH

While the traditional research activities of existing sponsored programs within the NIH have been of high quality, they have largely been targeted toward highly refined and narrowly defined problems. While this approach is certainly reasonable for the study of the specific questions that have been raised, it is insufficient to deal with the broader issues that medical rehabilitation addresses (Fuhrer, 1985).

Medical rehabilitation research is unique in that it cuts across almost all traditional boundaries of medical research: organ systems, diagnoses, age groups, and levels of research (basic mechanisms through social implications). It is precisely this different point of view that mandates the need for a distinct research focus on medical rehabilitation (Findley, 1987; Kirby, 1989).

There is an additional reality associated with medical rehabilitation research--it is more difficult to conduct than other more traditional medical research programs. The types of research that have been engaged in by traditional research programs are easier to achieve than the types of research needs identified for medical rehabilitation. This is due to the inherent complexity of rehabilitation problems, and the inability to easily control variables or create large comparable groups for study, among other factors (Aitken, 1987).

CONCLUSIONS

In conclusion, medical rehabilitation is a unique clinical discipline that deals with disabled individuals. Rehabilitation research is necessary to enhance our understanding of the basic mechanisms of disability and handicap, to improve existing treatment and management efforts, and to create newer and more effective solutions to the problems of disabled persons. Because of the unique focus and scope of medical rehabilitation, and its difficulty, the necessary focus of resources upon the problems of medical rehabilitation will only be achieved through the creation of a specific research agency whose sole mission is the solution of medical rehabilitation problems.

REFERENCES

- Aitken, C. A medical view of research methodology in rehabilitation. Int J Rehabil Res 10(4 Suppl 5):50-54, 1987.
- Batavia, A.I. Representation and role separation in the disability movement: should researchers be advocates? Arch Phys Med Rehabil 70:345-348, 1989.
- Berninger, V.W., Gans, B.M. Language profiles in nonspeaking individuals of normal intelligence with severe cerebral palsy. Augment Alternat Commun 2:45-50, 1986.
- Bury, M.R. The ICIDH: a review of research and prospects. Int Disabil Studies 9:118-128, 1987.
- Delisa, J.A., Currie, D., Gans, B.M., Gatens, P., McPhee, M. (eds.). Principles and Practice of Rehabilitation Medicine. J.P. Lippincott, Philadelphia, PA, 1988.
- Findley, T.W., Findley, S.E. Rehabilitation needs in the 1990s: effects of an aging population. Medical Care 25:753-763, 1987.
- Fuhrer, M.J. Issues in the federal funding of rehabilitation research. Arch Phys Med Rehabil 66:661-669, 1985.
- Gans, B.M. Rehabilitation engineering technology and the arthritis patient. J Rheumatol (Suppl 15) 14:68-71, 1987.
- Gans, B.M., Haley, S.M., Hallenborg, S.C., Mann, N., Inacio, C.A., Faas, R.M. Description and interobserver reliability of the Tufts assessment of motor performance. Am J Phys Med Rehabil 67:202-210, 1988.

- Gans, B.M., Hallenborg, S.C. Advances in wheelchair design.
Phys Med Rehabil: State of the Art Reviews 1:95-109, 1987.
- Gans, B.M., Wilson, A.B., Massey, P.R. Summary. J Rheumatol
(Suppl 15) 14:72-73, 1987.
- Granger, C.V., Gresham, G.E. Functional Assessment in
Rehabilitation Medicine. Williams and Wilkins, Baltimore,
MD, 1984.
- Kirby, R.L. Excellence in rehabilitation through research:
commentary. Am J. Phys Med Rehabil 68:43-44, 1989.
- Snook, S.H., Webster, B.S. The cost of disability. Clin Orthop
Rel Res 221:89-98, 1987.

COMMENTS ON THE SCIENTIFIC RELEVANCE OF PM/R RESEARCH

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I have been asked to comment on the "scientific relevance of PM/R research" from the perspective of someone who works within the NIH Intramural Program. I realized when I began to formulate my remarks that I did not understand the question. My first problem was that if "PM/R research" asks valid questions and returns solid, replicable results, then it is science, not something separate from it. I view "science" as a seamless whole. Its various disciplines may differ in approaches and perspectives but the body of information that we refer to as science is one entity. An investigator ideally makes use of information associated with many disciplines in order to advance understanding of a given research problem.

I have been involved in research on the neural control of movement for over 25 years but I must admit to some confusion about how to identify "PM/R research" as a distinct corpus. The current definition used by NIDRR of "Physical Medicine and Rehabilitation Research" says that it "...includes all studies directed toward acquiring new, or improved knowledge, or modifying existing knowledge applicable to or impacting on the functional restoration, improvement or stabilization of physical, emotional, social, academic, and/or vocational performance and independence of physically and/or mentally disabled individuals." To my mind, this would encompass at least 50 percent of what we now call neuroscience, plus a good deal of work in many other identifiable scientific and clinical disciplines. Again, all of that is certainly "science." Therefore, I have to conclude that the question is improperly formulated. It would certainly be too narrow a viewpoint to consider only work originating in departments identified specifically as "physical medicine" and/or "rehabilitation" or published in journals identified as such. I also think it too restrictive to include only "applied research" directed specifically at rehabilitation problems.

I am the current chief of an intramural laboratory that was founded by Dr. Karl Frank over 20 years ago, with the express intent to explore ways in which newly emerging knowledge about the central nervous system can be amalgamated with bioengineering and materials science to foster the development of neural prostheses to aid handicapped individuals. Although the focus of the laboratory has evolved more toward "fundamental" research on CNS motor systems, we have nevertheless contributed, directly and indirectly, to advances in neural prostheses through our involvement in functional neuromuscular stimulation, cochlear implants, and the still embryonic visual prosthesis. Our staff

scientists and engineers continue to be actively involved in these areas, mostly through collaborative work with other groups inside and outside NIH.

In addition, our fundamental work on the function of the spinal cord and on the neurobiology of motor units, including changes produced by reinnervation, spinal cord lesions, immobilization, and functional overusage, has been well received by PM/R groups. I believe that such "basic science" contributes to the understanding of abnormal spinal cord function, and thus to better appreciation of the situation of neurologically disabled people. Should this work be regarded as falling under the rubric of "PM/R research"? I should like to think so but it is really a semantic question for others to answer.

Our case is, of course, not unique. As I suggested earlier, virtually all neuroscientists who work on central nervous system function in vertebrates gather information that is relevant, directly or indirectly, to understanding the situation of neurologically handicapped people. It is from such understanding that ideas emerge as to how best to ameliorate their handicaps. There are any number of other research groups in this country and abroad who combine "fundamental research" on CNS function with work specifically designed--read "applied"--to ameliorate neurological handicaps. The same investigators switch back and forth from "basic" to "applied" research with such ease that I think it irrelevant to make the distinction.

In summary, I think that solid and reliable PM/R research, however one wants to define it, is not merely relevant to "science" but is, in fact, science. I continue to learn a good deal of importance to my own thinking about spinal motor systems from clinical and "applied" work, as well as from discussions with physiatrists, physiotherapists, and even athletic coaches. People whose goal is to maximize the performance of normal or impaired subjects have a wealth of observations that are important to a full understanding of CNS function. What they have to say cannot be ignored by anyone interested in a full picture of the current state of the art. Empirical knowledge and its application to the human condition is a seamless whole and it seems to me rather artificial to insist that one or another aspect be considered in isolation, except perhaps for descriptive convenience.

I hope that you find these views sufficiently clear as to be of some use in your deliberations.

SCIENTIFIC RELEVANCE OF PM/R RESEARCH
GENERAL RESEARCH COMMUNITY PERSPECTIVE

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University of California, Irvine
Medical Center

I. My background

- A. An academic physiatrist who has been funded on four occasions by the National Institutes of Health. At the present time I am the principal investigator on a 5-year program project grant of \$3.2 million from the NIA and a 3-year ROI for \$1.2 million. Both grants are in the field of aging.
- B. In my long career I have never been a member of an established study section. I have served on an ad hoc study section and also as an outside reviewer--even though I have received recognition from the NIH with a Geriatric Medicine Academic Award and a Fogarty Senior Fellowship.

II. My experience

- A. On a few occasions I have felt that some of my proposals that were not approved, or approved and not funded, were not understood because no physiatrist was included in the study section.
- B. Finally, as a physiatrist I have always felt that my field of Physical Medicine and Rehabilitation was not represented at NIH. It has only been with the establishment of the Institute on Aging that I have felt a sympathetic environment toward rehabilitation.

III. Logistical considerations

- A. Having an Institute for Rehabilitation Medicine Research will guarantee a review by peers. Every discipline has its own jargon which leads to difficulty of communication and perhaps prejudicial reviews of scientific proposals.
- B. Establishment of such an institute will provide a more favorable climate for funding of rehabilitation research.

- C. Finally, much of rehabilitation medicine has a broad psychobiological approach or view to research problems. This interdisciplinary approach has been described by George Engel, the noted psychiatrist of the University of Rochester. I'd like to conclude with an anecdote which George Engel described. It is from a 1986 lecture to an AOA Society. It is entitled "Where you think you stand determines what you think you see." To explore that theme he tells the following story.

I'll tell a little story about my twin, Frank, and myself from when we were not quite 4 years old. It was the summer of 1917, and the family was vacationing at the old Catskill Mountain House. What I remember so vividly about the Catskill Mountain House was a hill where everyone went to see "the view." I remember scrambling up this hill with my brother--often we had to be lifted because the boulders were as big as we were--but finally we would get up there, and people would wander to the edge and they would "ohh" and they would "ahh" and they would say, "What a beautiful view." Then they would turn to us and say, "Do you see the view?" "Isn't it beautiful?" Sometimes someone would pick one of us up in his arms and say, "Isn't that a beautiful view?" And we would nod in agreement and say yes. What else could a little boy say? But then, one memorable day, after one of these excursions, as we were scrambling down the hill hand-in-hand, Frank said to me, "What's a 'vu'?" (I remember so clearly, "vu," not "view.") "I don't know," said I, shrugging my shoulders. "Neither do I," said he. I don't know how long it was before I learned what a "vu" really was.

What one sees in terms of questions to be asked depends on one's experiences and training.

The scientific interests and expertise of Physical Medicine and Rehabilitation are, like any other professional discipline, unique. The field has special contributions to make to an unexplored body of knowledge in the study of the disabled person.

RESEARCH ACTIVITIES

PATIENT (organ systems)

MUSCULOSKELETAL

PERIPHERAL VASCULAR

NEURAL

ENDOCRINE

CARDIOPULMONARY

UROLOGIC

FUNCTION

RANGE OF MOTION

STRENGTH

ENDURANCE

SKILL

ENERGY COST

COMMUNICATION

THERAPEUTIC PROGRAM

PHYSICAL THERAPY

OCCUPATIONAL THERAPY

GROUP TREATMENT

SPEECH & HEARING THERAPY

VOCATIONAL COUNSELING

SHELTERED WORKSHOP

THERAPEUTIC COMMUNITY

COMMUNITY

HOME CARE

OUT PATIENT DEPARTMENT

DAY HOSPITAL

COMMUNITY CENTER

JOB

NURSING HOME

DEVELOPMENT OF A MODEL RESEARCH PROGRAM IN
MEDICAL REHABILITATION

Theodore M. Cole, M.D.
Professor and Chairman
Department of Physical Medicine and Rehabilitation
University of Michigan

Panel members and guests, I am Chairman of the Department of Physical Medicine and Rehabilitation at the University of Michigan. I welcome this opportunity to present to you an example of how a successful research program in medical rehabilitation has been established at my institution. I will reference the specific steps which were undertaken at the University of Michigan Medical Center. It should be understood that the specifics relative to my institution generalize to a similar development in any academic medical center even though specific arrangements will be unique to a given location. In the process of developing our research program, I addressed six areas of need:

1. Faculty
2. Resources
3. Environment
4. Incentives
5. Credibility
6. Leadership

These six areas are not only common to the development of a research program in rehabilitation medicine but would also be important in the development of a research program in any clinical discipline. In this brief presentation I will describe our experiences, and what we consider most important to fostering development of a physical medicine and rehabilitation research program. I will also tell you about the organization that I chose to develop and the basic philosophies which I pursued. I will describe how my university generally addresses research development, and what goals the University of Michigan is seeking to achieve.

As an organizational approach I chose the Chairman-led model rather than the model in which a research director leads the effort. I prefer this approach because the Chairman controls the resources and rewards. However, a Research Director-led approach can be effective if the Director has sufficient authority and accountability. The research director may be a physician or a nonphysician, but should be an accomplished investigator in a basic or clinical science.

The research philosophy that I have pursued gives rise to four directions for rehabilitation research:

1. Investigations into the fundamental mechanisms of human function and response to physical impairment.
2. New interventions to remove or ameliorate the disabilities which are produced by physical impairments.
3. Technological advances which may help restore human function or assist people in adapting to its loss.
4. Individual and societal strategies to strengthen and protect a person's sense of self-worth, dignity, and love for life.

My university is addressing research in a vigorous manner. Research potential and demonstrated research accomplishments undergird all faculty recruitment. Although not all faculty is expected to produce a like amount of research, no one is recruited without a clear understanding of how he/she will do scholarly work and relate to our research mission. Departmental resources are allocated to protect sufficient resources for our selective research projects. Attention is paid to the scientific integrity of each faculty member and this flows directly from the University's expressed expectation. The University and the Medical Center have largely completed an ambitious facilities construction program. It provides our faculty with state-of-the-art laboratories and clinical research settings, a clear message from the University to its faculty. Fund-raising and endowment activity is ongoing and each academic unit is expected to participate where it can and seek endowments where appropriate. Scholarship is recognized through a recurring program of lectureships, merit awards, sabbaticals, visiting professorships, and interaction with outside academic communities.

What is the University of Michigan seeking to achieve? I believe it wishes to be counted as one of the major research universities in the United States. In addition, coming from the rust belt, we feel a keen sense to innovate and attract industry through scholarship and opportunity. We work vigorously to attract students to fulfill our mission of diversity, and we recruit and retain faculty with the same mission in mind. Toward this end, all of the academic units are aware that they must attract extramural support to further departmental and institutional research objectives. This is an excellent environment for the growth and development of rehabilitation research.

Rehabilitation has not always been able to contribute its share to the university environments or to the pool of medical research. Indeed the credibility of rehabilitation as an area in which to invest research resources has not been recognized until recent years. In some settings this recognition has not yet occurred and some institutions do not allow rehabilitation to compete with other medical disciplines for scarce resources.

SIX AREAS OF NEED

Area One: Faculty

Faculty are a minority of personnel in departments of physical medicine and rehabilitation. We employ approximately 300 full-time employees but only 25 are faculty. Moreover, diverse skills are needed for rehabilitation: physicians, engineers, clinical and counseling psychologists, educators, and basic scientists are a minimal necessity. Because of the recent emergence of rehabilitation medicine as an academic field, there are not many senior investigators to be recruited. This is especially true of physicians specializing in physiatry. Only in the last 6 to 8 years have PM&R training programs attracted an ample supply of highly qualified residents and fellows for specialty training. As a result, most academic programs have a plethora of junior and paucity of senior investigators. Most of our faculty have been "grown in recent years" and in many cases the academic department must "grow its own." This imposes great difficulty upon academic rehabilitation departments. When a faculty member leaves there is not a large pool from which to draw in order to replace the lost resource. Indeed, vacant faculty positions may exist for many years, thus hampering a line of research development that may have started to be fruitful. At the University of Michigan, we have grown our own cadre of faculty. Of our 15 faculty, only 6 are graduates of other training programs. There are many advantages to growing our own. An in-house resident training program gives us annual access to outstanding recruitment candidates, and also gives us early insight into the research potential of a potential new faculty member. It allows us to facilitate residents to begin a research career while still in training. It also allows us to knowledgeably match our needs as a department with demonstrated skills and interests of potential faculty candidates. The net effect is that we no longer have difficulty attracting top level candidates to our institution. However, this was not always the case. When I arrived at the University of Michigan 12 years ago, I was the only full-time member of the faculty, the only tenured person in my department, and the only person with a track record of research. Fortunately those days are gone and now 20 percent of our physician faculty are tenured and 50 percent are senior faculty.

Area Two: Resources

American medical schools are facing shaky financial times and sufficient resources are not available to allow parallel development of all promising research possibilities. Institutions set research priorities which are, in part, based upon available funding. Since there is not a robust base of funding for rehabilitation medicine, academic departments often languish for lack of institutional support. In addition, the shortage of trained research faculty is severe and works additional handicaps upon already stressed academic departments. Construction of new clinical facilities is limited by the

certificate-of-need process and incremental research space is restricted by lack of funds. This makes it difficult for small departments with low institutional priority rankings to effectively compete for research resources.

The strategy I employed was to develop symbiotic research relationships with other departments in the Medical Center and in the University at large. I found these in both the basic and clinical sciences, and they have led to extremely productive research programs and accomplishments. In addition, I have encouraged faculty to develop relationships outside of the University with the larger community of rehabilitation investigators. Thus, two faculty spend 3 months each year at the Woods Hole Marine Biological Laboratory working side-by-side with other scientists studying fundamental processes in neurobiology and muscular physiology. In addition, we have gained from our working with colleagues in multicenter studies and interdepartmental projects. Because of scarce external resources, we have turned inside and outside our university for research support. UM's Biomedical Research Council has provided seed funding for promising projects. Local and statewide foundations have also been occasional sources for start-up funds. We have received support for research training and this has influenced our decisions in utilization of departmental resources. Our parent institution has provided experimental equipment, space, and computational hardware/software. Perhaps, most importantly, I have invested our own department's resources, monies earned by the faculty practice plan, to motivate and channel our own research ideas. However, the bulk of our support has resulted from our success with national funding sources, such as the NIH, NIDRR, NSF, CDC, and the Robert Wood Johnson Foundation. The net effect is that we are considered healthy among fellow departments of rehabilitation medicine across the country.

Area Three: Environment

Environments create expectations, and expectations affect performance. The environment at the University of Michigan is one that expects research commitment and productivity. The philosophy of the University, mission of the Medical School, and role of each individual department all mandate that research is one of the primary reasons for our existence. I cannot overemphasize the importance of this expectation. As one department succeeds, it serves as a role model to others. Each department is reminded of the success of fellow departments by circulation of departmental research reports and by the visibility of educational programs in our medical center. Collaborating across departmental lines is highly encouraged and frequently rewarded. Rehabilitation research, by its nature, is often the product of interdisciplinary efforts, thus diversity and depth of a major medical center is a boon to research in rehabilitation. All of these forces play upon my department and have had a powerful influence upon choices I made.

Area Four: Incentives

Twelve years ago, the University of Michigan Medical Center established a system of practice plans for physicians from all departments. Each department was responsible for its own practice plan and gained or lost as a result of physicians' clinical and research efforts. The Medical School provided unifying principles and central guidance for each practice plan individually and all plans collectively. Some practice plan dollars are returned to the Medical School for academic activities and others to the Hospital for space and services contracts. This arrangement creates an enormous financial boost to the Medical Center and produces real benefits to support research programs in all departments.

Physical Medicine and Rehabilitation has shared fully in this plan. We offer a system of financial incentives for faculty incomes in medical and nonmedical disciplines. We also offer incentives for individual faculty who wish to gain further support for their research programs. Details of these incentives are not appropriate to this brief discussion, but are available to this panel if desired.

Incentives have played a major role in guiding our success. Incentives influence the Department's leadership as well as the tenure track and clinical faculty. In the hands of a focused department incentives have gone far to channel faculty toward academic objectives. They have been effective offsets to the well-known disincentives which inhibit interdisciplinary activities.

Area Five: Credibility

Nothing breeds success like success. As each research project gains visibility, our reputation as a competitive department is improved. As we gain exposure at regional and national meetings, we grow in the eyes of our peers and colleagues. In house we hold seminars showcasing departmental research projects and faculty. Outside of the University we have found productive relationships with other institutions, thus increasing our potential for research achievement. We have enhanced our ability to attract support because of individual faculty reputations as well as departmental credibility. However, a continuing lack of understanding of rehabilitation research makes it necessary for us to "advertise" faculty interests to colleagues even within our own setting.

Area Six: Leadership

Leadership both sets the tone and carries the responsibility for maintaining an environment conducive to rehabilitation research. I welcome internal and external criticism if it is couched in constructive terms. Toward this end, I have established a system of department review by external, respected academicians in

rehabilitation medicine. At periodic intervals we report our clinical, research, educational, and administrative activities. A visiting review committee then meets with Department faculty, clinical leaders in other departments, and the leadership from the Hospital and Medical School. A report and recommendations are then sent to the department for planning purposes. This mechanism provides us with insights for improvement which we might not otherwise appreciate. It also sets the expectation at my institution that my department is serious in its efforts to succeed in a major research university.

I have strongly supported fellowship training beyond residency years. Toward this end, we have supported clinical and research fellows in neuromuscular diseases, spinal cord injury, pediatrics, and brain injury. In addition, I encourage the establishment of post-doctoral fellowships in the nonmedical disciplines. Thus we have advanced training in rehabilitation medicine, electrodiagnosis, engineering, clinical psychology, and health education.

The separated offices of the Chairman and of the Research Director must work in close unison with each other. Frequent meetings are necessary to plan departmental priorities and resource allocations, as well as to brainstorm innovative approaches to institutional and extramural resources. We consciously seize as well as avoid opportunities in order to keep focused upon those areas of research which we have chosen for our department.

SUMMARY

Responsibility for rehabilitation research should be distributed widely throughout a rehabilitation department. Although the Chairman is ultimately responsible for all departmental activities, I choose to delegate large amounts of responsibility and authority to the faculty in support of research. I look for qualities of leadership among faculty which I believe are central to success in the academic environment. In rehabilitation medicine, our leaders must be able to understand the fragility and strengths of our discipline since we have both. We must remain balanced and at the same time focused. We must seek recognition through persistence at providing proud and high-quality programs within a proud and traditional institution. Toward these ends, I look for qualities of trust, humor, and intelligence as I distribute responsibilities toward research in the Department of Physical Medicine and Rehabilitation at the University of Michigan.

SUPPORT FOR RESEARCH TRAINING

James S. Lieberman, M.D.
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Department of Physical Medicine and Rehabilitation
Professor of Neurology
University of California, Davis, School of Medicine

The multidisciplinary field of rehabilitation medicine has, in general, been well accepted in the clinical community. However, the same cannot be said for its acceptance in the academic and research communities.

Professionals in the field of rehabilitation medicine acknowledge problems in both the quantity and quality of medical rehabilitation research. In addition, medical rehabilitation research has not been entirely successful in providing a basic foundation of knowledge for the practice of rehabilitation. A number of publications in recent years have addressed the problems in medical rehabilitation research, and these should be consulted for a detailed description of the problems.^{1,4-12} The perceived reasons for the inadequate research productivity have also been described in several of the publications.^{1,7,11,12}

Many perceived barriers to adequate research productivity in medical rehabilitation are cited. However, the most significant reason for inadequate research productivity is, either directly or indirectly, the lack of adequately trained researchers in the field of rehabilitation medicine.

This problem is compounded by the fact that there is no tradition or long-standing practice of specific research training or fellowships prior to the assumption of an academic position in, at least, the medical discipline of physical medicine and rehabilitation. Thus, there are a large number of current physical medicine and rehabilitation junior and even senior faculty without adequate research training. Many physical medicine and rehabilitation departments have attempted "on-the-job" research training, but this has not been very successful. In addition to a backlog of current faculty, there is now a constant supply of newly trained clinicians who need adequate research training if they are to have successful academic careers and if rehabilitation medicine is to flourish academically.

It seems reasonable to assume that many of the problems with rehabilitation research could be corrected by a major focused attempt to increase the number of properly trained rehabilitation investigators in a short period of time.

Stolov has estimated¹² that the desired increase in research productivity among physiatrists could be accomplished by training

20 physiatrists per year for the next 10 years. Similar estimates are not available for nonphysician rehabilitation researchers. However, the needs are probably of a similar magnitude.

Until 1986, there was no source of focused research training support in medical rehabilitation. In 1986 NIDRR instituted some funding for career development (research training). The NIDRR program utilizes institutionally approved programs and has no provisions for individual awards. At the present time, it is my understanding that 12 programs are funded but that this will drop shortly, and only 3 programs per year will be able to start or finish trainees. Therefore, few trainees can or will be produced from this program. It also seems unlikely that NIDRR will be able to commit further funds in this area due to their many other priorities. Thus, a training program of the magnitude described would best be accomplished through NIH because of its vast experience in designing, overseeing, evaluating, and funding training programs for biomedical investigators.

Rehabilitation medicine has traditionally been very clinically oriented. Therefore, it is not unreasonable to assume that a majority of investigator trainees would select programs that would train them to be clinical investigators. Thus, any program developed to increase the numbers and quality of rehabilitation investigators would have to support the training of clinical investigators.

Despite the probable emphasis on clinical investigator training, investigator training in the basic sciences and in basic research should also be available through appropriate programs for those trainees who desire such a career pathway. In fact, it is my opinion that the demand for more basic research training will increase over time as better prepared individuals enter the various rehabilitation medicine disciplines. Such a shift to better qualified applicants for physical medicine and rehabilitation residencies has already been identified.

The American Academy of Physical Medicine and Rehabilitation/ Association of Academic Physiatrists Joint Research Committee^{2,3} and the American Congress of Rehabilitation Medicine Research Committee² have proposed the purpose and objectives of research training programs in medical rehabilitation.

The objectives are to

1. Provide research training opportunities for individuals interested in careers that include substantial involvement in rehabilitation research.
2. Train rehabilitation clinicians in a manner that will improve their ability to identify worthwhile research

pursuits and to objectively assess the significance of the outcome.

3. Broaden the trainee's background so as to facilitate the integration of basic and applied rehabilitation research.
4. Increase the overall research capability within the field of rehabilitation medicine.

Obviously, at the end of the training period, the trainee should be prepared to be an independent investigator capable of writing well-formulated problem statements, well-designed methodology, carefully executed analysis, and tightly drawn conclusions.¹²

Further, the Committees recommended that the major initial emphasis of a concentrated rehabilitation research training program be on initial training rather than on mid- or senior-level career development. At the appropriate time, more mid- and senior-level training can be provided.

Finally, the AAPM&R/AAP Joint Research Committee has thoroughly discussed guidelines for programs for training physician investigators in physical medicine and rehabilitation.³ This Committee report discusses several types of training, i.e., modular, formal, and apprenticeship. It is the consensus of the field that the apprenticeship type that is common via NIH programs is the most likely type to produce productive investigators.

The NIDRR currently utilizes an institution-based format for funding rehabilitation research training. The NIH appears to have both institutional and individual programs available. Such a mix is probably best. In addition, it should be emphasized that trainees should be able to receive training in other than physical medicine and rehabilitation departments.

In reviewing material from recent issues of NIH grant and contract guides, it appears that the NIH has several programs that are appropriate for mounting a concentrated effort to increase the number of well-trained rehabilitation investigators. They include the K08, K11, K12, F32, T32, and even T35 programs. Certainly, for training physician investigators, the K08, K11, and K12 programs are ideal.

It should be noted that the research training methodology in rehabilitation medicine should be no different than for any other discipline. The rehabilitation medicine research community subscribes to the basic principles of research training as espoused by the NIH in their various program descriptions. The need to develop a critical mass of properly trained rehabilitation investigators is certainly present. In addition, there is a need to train a large number of them quickly. The NIH

would appear to be an appropriate source for assistance in meeting this need.

It is also the consensus in the field that the NIH and the rehabilitation research community could best realize the goal of a substantial increase in training investigators in rehabilitation medicine by developing a center for rehabilitation medicine at the NIH.

REFERENCES

1. Fowler, W.M., Jr. Viability of Physical Medicine and Rehabilitation in the 1980s. Archives of Physical Medicine and Rehabilitation 63:105, 1982.
2. Fowler, W.M., Jr. Report #1, Medical Rehabilitation Research Fellowships: Recommendations for Level, Type, and Criteria. American Academy of Physical Medicine and Rehabilitation/Association of Academic Physiatrists Joint Research Committee, American Congress of Rehabilitation Medicine Research Committee.
3. Fowler, W.M., Jr., Bach-y-rita, P., and Stolov, W.C. Report #1-B, Guidelines for Programs for Training Physician Investigators in Physical Medicine and Rehabilitation. American Academy of Physical Medicine and Rehabilitation/Association of Academic Physiatrists Joint Research Committee, January 22, 1986.
4. Fuhrer, M.J. Medical Rehabilitation Research: Distortions, Deflections and Detractions. Archives of Physical Medicine and Rehabilitation 63:49-54, 1982.
5. Fuhrer, M.J. Rehabilitation Research in the 1980s, Advances in Clinical Rehabilitation. M.G. Eisenberg (editor-in-chief), vol. 2, pp. 232-256. New York: Springer, 1988.
6. Grabois, M., and Fuhrer, M.J. Physiatrists, Update on Current Professional Practices. Current Concepts in Rehabilitation Medicine 2:1-2, 1985.
7. Grabois, M., and Fuhrer, M.J. Physiatrists' Views on Research. American Journal of Physical Medicine and Rehabilitation 67:171-174, 1988.
8. Kirby, R.L. Excellence in Rehabilitation Through Research: Commentary. American Journal of Physical Medicine and Rehabilitation 68:43-44, 1989.

9. Kumar, V.N., Redford, J.B., and Hassanein, K.M. Physiatrists: Career Development and Professional Interests. Archives of Physical Medicine and Rehabilitation 62:28-31, 1981.
10. Ozel, A.T., and Kottke, F.J. Research Trends in Physical Medicine and Rehabilitation. Archives of Physical Medicine and Rehabilitation 59:166-170, 1978.
11. Stolov, W.C. Rehabilitation Research: Habit Analysis and Recommendations. Archives of Physical Medicine and Rehabilitation 64:1-5, 1983.
12. Stolov, W.C. Rehabilitation Research Training. Archives of Physical Medicine and Rehabilitation 65:54-56, 1984.

DEVELOPING SCIENTIFIC LEADERSHIP IN RESEARCH
IN REHABILITATION MEDICINE

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New York University Medical Center

Sometimes the obvious is worth restating. There is clearly a growing population of individuals who are or will be on their way to experiencing disability/handicap. This population creates a need for the expansion and/or improvement of the services encompassed by rehabilitation medicine. The services which are delivered or are to be delivered in the future deserve the support of a sound knowledge base. The development and testing of a sound knowledge base requires a body of scientific work which is relevant and in touch with the issues in the field.

One would have thought, therefore, that the growth of the practice of rehabilitation medicine would be associated with the growth of research productivity. And this growth would be driven by governmental funds for research. Yet, this does not appear to be the case. Consider the following. During the years 1976 to 1988, the Archives of Physical Medicine & Rehabilitation, which might be considered the lead journal in the field, found an actual decline in papers reporting support from the major governmental agencies in this field--the Department of Education (DOE) and National Institutes of Health (NIH)--from 31 percent in 1976 to 14 percent in 1988. Indeed papers supported by the DOE declined from 24 to 10 percent and by the NIH the decline was from 8 percent to 4 percent. More than 70 percent of the articles were not funded by any supporting agency.

Table 1:

Articles and Funding Source in Arch. Phys. Med. Rehab.
1976-1988

	<u>DOE</u>	<u>NIH</u>	<u>Other Agencies</u>	<u>No Support Cited</u>	<u>Total</u>
1976	24	8	7	63	102
1988	17	8	27	126	178

Granted that investigators supported by the DOE and the NIH for research in rehabilitation medicine most certainly publish in other journals, and that the sampling in a single journal is too narrow a data base to use as a basis for definitive judgment or many other caveats which may be cast at this observation, nonetheless, one would be concerned about the impact of Federally funded research on the science and practice of rehabilitation medicine. One would suspect that the lead journals of other

medical specialties have a much higher percentage of their articles supported by major governmental agencies.

The practice of rehabilitation medicine is concerned at a minimum level with reducing the burdens of functional limitations. This perspective on practice provides an integrative context for the operations of rehabilitation medicine. It requires not only the application of specific procedures developed from a knowledge base of a single discipline, physiatry, but also the integration of procedures developed from interdisciplinary knowledge bases around physiatry. There is recognition that an individual with a severe physical impairment is usually placed in a situation with a wide range of problems that touch on psychological, economical, and social factors. To be effective, rehabilitation requires solutions to practical problems which work. Compliance with therapeutic procedures may require more active participation by the patient. The problems of translating data from clinical and laboratory findings to facilitate optimal adaptation is a source of continuous query and problem solving. Stover (1989) has pointed out that training programs for individuals with higher levels of paraplegia have been modified to accommodate to the fact that they will not ambulate upon return to the community. The focus on functional solutions which have to fit idiosyncratic naturalistic contents is sufficiently absorbing on a clinical level, so that even clinicians who are concerned about issues of evidence and efficacy of interventions may be overwhelmed by practical circumstances and not invest in the problem of trying to make science out of dirty situations.

While this picture might suggest that rehabilitation medicine research can, therefore, be subsumed under health services research, such a categorization would be too simple. For the context of rehabilitation medicine practice involves not only ways of developing or testing the efficacy of service delivery but also drawing on individual knowledge bases which themselves have to be probed both in their own right as well as in relation to the delivery of service. Questions under study, therefore, might draw on a single modality or a combination of interventions or an attempt to link discrete levels of knowledge on a single domain driven by a functional question. Examples abound. I'll cite one close to my experience.

Teaching a person with traumatic brain injury to learn a skill and to generalize that learning to everyday life may require a study not only to demonstrate efficacy of the procedure in that this individual applies what he/she has learned--a problem in service delivery but a chain of substudies involving different aspects of learning or instruction--a problem in neuropsychology or neurophysiology which might draw on animal as well as human models. Our interventions need empirical justification, but, as Bach-y-Rita (1989) has noted, interventions also need a theory or a rationale based on more fundamental principles. Experience is

fine when it works. But a theory is needed to guide us in knowing where to look when things don't work out.

The community of medical psychiatrists appears eager to support the development of a research base in rehabilitation medicine. This is seen in the responses to a questionnaire by Fuhrer and Grabois (1988). Furthermore the majority of psychiatrists expressed interest in participating or conducting research and cited lack of funding and support as the major obstacles. These observations should be noted in light of the comments in a report of a recent conference sponsored by NIDRR, edited by Bach-y-Rita (1989), where it was noted that Federal agency representatives had strong words of advice for the participants. While these words need not be repeated here, just a few points may be mentioned. There are no short cuts to validating therapies, developing measurement instruments, developing nomenclatures to permit adequate communication, good models,, and above all, controlled prospective randomized trials. Dr. Michael Walker of NIH saw a major issue in our becoming paralyzed by the magnitude of the problems. Research issues must not only be prioritized, but they must be sequenced with defined intermediate and end points. He indicated that the brightest ideas often come from the community rather than from central research agendas.

Research leadership in rehabilitation medicine requires a mastery and integration of at least two of three specific domains. These include (1) knowledge of the state of a particular field of inquiry with regard to critical issues in the field or techniques which require further testing on a given population or a given situation, (2) knowledge of the philosophy and operations of rehabilitation with an intimate grasp of what is feasible and what is not feasible, and (3) knowledge of scientific methodology including the constraints in framing an hypothesis, operationalizing a question so as to yield data which are as unambiguous as possible, research design, measurement, and statistical inference. Each of these domains requires both study and experience in order to work in a comfortable way. Study and apprenticeship in each of these areas separately or combined requires time and effort from a well-intentioned student and support from the environment. Such support includes not only fiscal aid, but an academic atmosphere which fosters learning and an immediate environment which does not get in the way of long-term goals.

The notion of leadership in research in rehabilitation medicine is not exactly a well-defined or precise expression. While leadership in scientific research might be judged by several indicators such as amount/size of research grants or awards for distinguished scientific contributions, it might be more fruitful to turn to citation analyses as an indicator of influence on one's scientific peers. In citation analysis the frequency with

which one's writings are referenced in the literature is a marker of intellectual property by information scientists.

In reviewing authors who have been most cited in "Current Contents," a weekly review listing articles in current scientific panels, several points may be noted. While citations accumulate over time, the typical author of a frequently cited scientific article states that the original idea or the actual work on the article or book took place in the early years of a professional career, upon completion of post-doctoral training. The work was cited because it created or articulated a paradigm for other investigators. The work was performed in a strong academic atmosphere which nurtured scholarliness as well as an opportunity to explore and follow through on personal observations and experiences. Often the support came from a respected mentor or a like-minded colleague. Another common characteristic is that the original work is later modified, developed, and pursued as the author's career unfolds.

While the notion that the most creative achievement in medicine and other scientific fields comes during the third decade of life, there is ample evidence that scientific productivity confirms past the fourth decade (Lehman, 1953) and that older scientists have a profound influence on younger ones, serving as role models.

Scientific leaders in short pay great respect to support, intellectual as much as physical. NIH is in a good position to provide a framework for such support.

Levy et al. (1988) state that for faculty members in academic departments of medicine with an M.D. degree, being an active researcher and principal investigator for peer-reviewed research grants was directly related to length of research training. The findings based on a survey of 5,064 faculty indicated that there is a formula to be a successful researcher in academic medicine: 2 or more years of post-doctoral training; 2 to 3 years of full research support from the academic institution until the first extramural grant is obtained and commitment of at least 33 percent time to research activities. Recommendations for improving training programs suggested less time should be allocated to clinical work and greater emphasis be given to formal instruction in statistics, research techniques, and the basic sciences. With regard to the development of leadership in rehabilitation medicine research, I would, therefore, recommend:

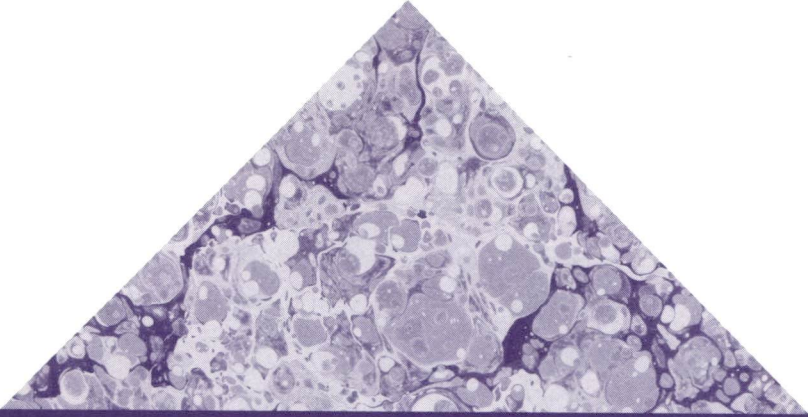
1. The development of an administrative structure with a mission statement focused on rehabilitation medicine and a plan developed by the scientific community.
2. A training program to develop scientists in rehabilitation medicine. There is a framework for providing research

training at different stages of a career, including graduate training, post-doctoral training, first independent research support, research development awards, academic teacher awards, and senior fellowships.

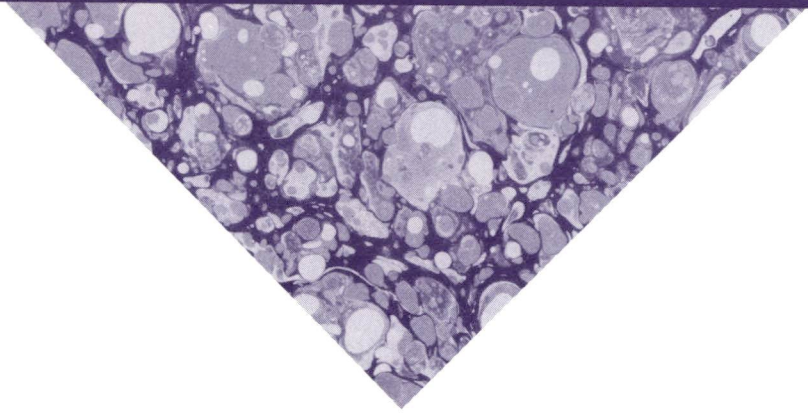
3. A program of field-initiated support in rehabilitation medicine to be peer reviewed.
4. Program research to integrate basic scientists and clinical scientists.

REFERENCES

- Bach-y-Rita, P. 1989. Traumatic Brain Injury. New York: Demos Press.
- Fuhrer, M. J., and Grabois, M. 1988. Information sources that influence physiatrists' adoption of new clinical practices. Arch. Phys. Med. Rehab., 69, 167-169.
- Lehman, H. C. 1953. Age and Achievement. London: American Philosophical Library.
- Levey, G. S., Shuman, C. R., Gentile, N. O., Hough, L. J., Dial, T. H., and Jolly, P. 1988. Post-doctoral research training of full-time faculty in academic departments of medicine. Ann. Int. Med., 109, 414-419.



APPENDIX C

- List of Concerned Organizations Invited to Testify
 - Testifier Statements
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MEETING OF THE
PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

November 20-21, 1989

Concerned Organizations, Professional Associations, and
Other Interested Parties Presenting Testimony

American Academy of Neurology

Fletcher H. McDowell, M.D.
Executive Medical Director
The Burke Rehabilitation Center

American Academy of Otolaryngology

Aina Julianna Gulya, M.D.
Associate Professor of Surgery
George Washington University
Division of Otolaryngology--Head and
Neck Surgery

American Academy of Physical
Medicine & Rehabilitation

Barbara J. deLateur, M.D.
Past President
American Academy of Physical
Medicine & Rehabilitation

American Congress of Rehabilitation
Medicine

Marcus Fuhrer, Ph.D.
Past President
American Congress of Rehabilitation
Medicine

American Geriatrics Society

Leo Cooney, M.D.
President-Elect
American Geriatric Society
Yale New Haven Hospital

American Physical Therapy Association

Leopold G. Selker, Ph.D., P.T.
Illinois Geriatric Education Center
University of Illinois at Chicago

American Speech-Language-Hearing
Association

Carol Frattali, Ph.D.
Director, Health Services Division
Professional Services Department
American Speech-Language-Hearing
Association

American Spinal Injury Association

Samuel L. Stover, M.D.
Director of Rehabilitation Medicine
Spain Rehabilitation Center
University of Alabama at Birmingham

Arthritis Foundation

Rowland Chang, M.D., M.P.A.
Arthritis Section
Department of Medicine
Northwestern University Medical School

Association for Academic Physiatrists

Dr. Randall Braddom
Association for Academic Physiatrists

Association for Research in Otolaryngology

Murray B. Sachs, Ph.D.
Association for Research in Otolaryngology
The Johns Hopkins University
Center for Hearing Sciences

Association of American Medical Colleges

Laurence E. Earley, M.D.
Chairman, Department of Medicine
School of Medicine
University of Pennsylvania

Association of Rehabilitation Nurses

Shirley P. Hoeman, Ph.D., M.P.H., C.R.R.N.
Rehabilitation Nurses Foundation
Association of Rehabilitation Nurses

Friends of NIDCD

Mrs. Geraldine Dietz Fox
Executive Director
Friends of NIDCD

Lasker Foundation

Marguerite Donoghue, R.N., M.N.
Legislative Director
Capitol Associates

Moss Rehabilitation Hospital

John Whyte, M.D., Ph.D.
Director of Brain Injury Research
at The Drucker Brain Injury Center
Philadelphia, Pennsylvania

National Multiple Sclerosis Society

Labe Scheinberg, M.D.
Member, Medical Advisory Board
National Multiple Sclerosis Society
Albert Einstein College of Medicine

National Research Institute for Neural Injury

Mrs. Louise B. McKnew

Founder and Director

National Research Institute
for Neural Injury

AMERICAN ACADEMY OF NEUROLOGY

I am Dr. Fletcher McDowell, here to represent the American Academy of Neurology and give you a statement about its position on your questions. I am also a neurologist and Director of the Burke Rehabilitation Center. For the past 15 years I have had a major interest in rehabilitation and research.

The American Academy of Neurology believes that:

1. The most promising future for research lies in the support of studies to better understand the possible usefulness in rehabilitation of neurobiology and neuro-regeneration.
2. Mechanisms for funding research in a number of areas, including clinical psychologic engineering and social aspects of rehabilitation in diseases of heart, lung, bone, joint and brain, already exist through current institutes in the NIH.
3. Creation of another mechanism in addition to those that already exist in the NIH and NIDRR would be expensive and probably not more productive.
4. The difficulties encountered in research in rehabilitation are mainly due to the problem of finding solvable questions that produce meaningful answers, not lack of support.

The members of the American Academy of Neurology, especially its practicing physician group, also have a strong interest in research in rehabilitation. At any given time they are faced with many patients who have serious physical disability caused by neurological illness. Most of the disability is lifelong, and correction or reduction of handicap by any means is extremely desirable. Neurologists are increasingly aware of their responsibility to be concerned with patient management from diagnosis through acute care and rehabilitation and to engage in research in this continuum. The most common problem they encounter is the

physical disability resulting from cerebrovascular disease, head trauma, spinal cord injury, multiple sclerosis, Guillain-Barre syndrome, Parkinson's disease, Lou Gehrig's disease and brain tumor.

Many of the research centers in the United States are investigating the causes of these conditions and the programs include research related to rehabilitation. Rehabilitation research programs are currently sponsored by several institutes of the National Institutes of Health. Cardiac rehabilitation programs obtain research support from the Heart and Lung Institute, and orthopedic and rheumatological rehabilitation research is supported by the National Institution of Arthritis and Metabolic Diseases. It has also been possible for any investigator with a good program for rehabilitation research to submit requests to the National Institute of Neurological Diseases and Stroke for research support. If the proposals are deemed worthwhile by peer review, the research requests have been funded. This mechanism has worked well, and there is a broadening interest among neurologists to become more active in rehabilitation research. The problems considered in the realm of research in rehabilitation vary from basic research on neuroregeneration and neurobiology to research in the management of specific clinical, mechanical, psychologic and social problems encountered by victims of stroke, spinal cord injury or head injury.

There is currently an enormous interest in research in the basic science of neurobiology and neuroregeneration and its possible human application. Advances in these fields have not yet been addressed to humans with disability, but the future for doing this over the next decade or two looks extremely promising. Application of knowledge of basic neurobiology to the young science of neuro-restoration offers the

best hope that meaningful advances will be made in rehabilitation and that the true meaning of the word rehabilitation - "restoration to a previous condition" - will be realized.

The American Academy of Neurology believes that the present system of applying for and using funds from the National Institute of Neurological Diseases and Stroke has worked well. There has been no restriction of rehabilitation research funds to any particular discipline, although most of the research requests and programs for funding have come from the neurological or neurosurgical community. There is also a considerable amount of money available for rehabilitation research from the Department of Education which has been allocated to a large number of Rehabilitation Research and Training Centers around the country, Model Systems for spinal cord and brain injury management and research, as well as to a sizeable number of smaller research and innovation grants.

Slowness of progress in the development of rehabilitation research has not been from lack of willingness to support appropriate research programs, but rather the extreme difficulty in putting together a program of research which is likely to produce useful information.

The notion that research in rehabilitation might be fostered by having a separate institute within the National Institutes of Health deserves some comment. This potential change would have several disadvantages. First, it would be the only occasion in which an institute of the National Institutes of Health is based on technology rather than an organ system. Second, it would create an additional bureaucracy, which is always expensive and would subtract money from the funds available to the NIH for research. Third, it is unlikely that

Congress would at this time or in the near future vote additional money for rehabilitation research. It is much more likely would be that monies currently being spent for rehabilitation in the various institutes would be subtracted from their respective budgets and handed to a new institute if it were created. These changes would actually reduce the overall money for rehabilitation research. Fourth, there is no reason to believe that a new institute would add much in the way of new ideas or new information that could not be gained through existing Institutes. Fifth, money would be siphoned away from those scientists now supported by other Institutes, the ones best trained to perform such research.

The American Academy of Neurology believes that adequate mechanisms for funding of research in rehabilitation are available, that the problem is not lack of availability of funds or willingness to spend funds on rehabilitation; rather, it is the difficulty of the conceiving programs based on ideas that are solvable. In the long run basic science and neuroregeneration research offer more promise for true rehabilitation.



THE AMERICAN ACADEMY OF OTOLARYNGOLOGY—HEAD AND NECK SURGERY, INC.

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TESTIMONY OF
AINA JULIANNA GULYA, MD, FACS
REPRESENTING
THE
AMERICAN ACADEMY OF OTOLARYNGOLOGY-HEAD AND NECK SURGERY, INC.

BEFORE THE
PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

CONFERENCE ROOM 10
BUILDING 31, NIH
3:30 PM, MONDAY, NOVEMBER 20, 1989

Mr. Chairman and members of the Panel, I am Aina Julianna Gulya, MD, FACS, a practicing otolaryngologist here in the Washington, DC area, and I also serve on the faculty of the George Washington University. I am here today as a representative of the American Academy of Otolaryngology--Head and Neck Surgery, Inc., the largest organization of otolaryngologists--head and neck surgeons in the world with more than 8,000 members, including 96% of all board certified otolaryngologists.

The specialty of otolaryngology--head and neck surgery encompasses surgeons whose expertise involves the management of disorders of hearing, balance, the facial nerve, the nose, facial bones, as well as benign and malignant disorders of the mouth, trachea, larynx, thyroid, and esophagus.

On a regular basis, our members care for patients whose management, in part, depends heavily upon integrated cooperation with our colleagues in the fields of physical medicine and rehabilitation. The \$20 million allocated by the NIDCD for research related to the rehabilitation of communication disorders is in recognition of this fact.

I would like to present a few vignettes in order to illustrate how this cooperation works.

The rehabilitation of the hearing impaired is a major concern of the otolaryngologist--head and neck surgeon; we do what we can medically and surgically for these patients, but we also rely upon our audiology, speech pathology, and speech therapy colleagues to help in maximizing the communication abilities of such individuals. Patients with hearing aids, and

even more significantly, patients with the cochlear implant, need extensive counselling and ongoing rehabilitation in order to maximize their benefit from their devices, and their speech intelligibility. Clinical trials of the cochlear implant, funded by the NIDCD, incorporate as an integral part the rehabilitation procedures that are utilized.

Our member physicians also care for patients with dizziness or balance disorders, particularly common complaints among our aged population. In many such cases, medical and surgical remedies are either of no benefit or not tolerable, and again, we turn to our physical medicine and therapy colleagues for assistance. Particularly in the past few years, we have seen an increasing utilization of, as well as therapist interest and participation in, the physical rehabilitation of such patients. Such rehabilitation appears to be showing some promise as an efficacious mode of therapy.

Patients with head and neck cancer represent a significant proportion of the patient population cared for by the otolaryngologist--head and neck surgeon. Surgical procedures such as radical neck dissections are often necessary in such patients, and may result in painful and stiff shoulders. Referral to physical medicine and rehabilitation is routinely carried out in order to minimize such undesired difficulties.

Similarly, patients who have undergone major head and neck ablative procedures, and in whom graft reconstruction is not feasible, can seek prosthetic device reconstruction as an alternative.

The patient with congenital or traumatically induced maxillofacial disorders also is cared for by the otolaryngologist--head and neck surgeon, and the rehabilitation of such patients is an ongoing concern to our membership.

As a final example, I would like to consider the patient with either a post-operative or age-related swallowing disorder. Again, if surgical techniques are not effective or not indicated, our member physicians involve the therapist in the long-term management and rehabilitation of such a patient.

The Academy appears before the Panel on Physical Medicine and Rehabilitation Research to present our concerns, as an interested group, with respect to the proposal to establish a freestanding center for rehabilitation research at the NIH.

We believe that the establishment of another government institution, in addition to the National Institute on Disability and Rehabilitation Research (NIDRR), would not only further dilute the impetus for research in physical medicine and rehabilitation, but also would result in further fragmentation and potential reduplication of research efforts.

In keeping with the spirit of collaborating with members of the physical medicine and rehabilitation disciplines, the Academy has been working with the NIDRR to promote joint research efforts, particularly in the field of maxillofacial injury in the setting of brain and spinal cord injury.

In addition, as mentioned previously, the NIDCD has allocated \$20 million to research efforts in the area of rehabilitation.

The growth, development, and scientific productivity of physical medicine and rehabilitation research can be best served by emphasizing collaboration with the other institutes of the NIH, such as the the NIDCD, the NIA, the NINDS, the NCI, and the NIDR. The mandate of the NIDRR should be expanded so that it is to act as a "clearing house" for information regarding rehabilitation-related research at the NIH and elsewhere, thus providing the information base to encourage such collaboration.

Thank you for giving us the opportunity to appear before the panel, and I will be pleased to answer any questions you may have.

**TESTIMONY ON BEHALF OF THE
AMERICAN ACADEMY OF PHYSICAL MEDICINE & REHABILITATION
BY BARBARA J. DE LATEUR, M.D., IMMEDIATE PAST PRESIDENT**

This testimony is based in large part upon the November 8, 1989 meeting of the American Academy of Physical Medicine & Rehabilitation/American Congress of Rehabilitation Medicine (AAPM&R/ACRM) task force on medical rehabilitation research, which took place at the annual meetings of these two professional groups in San Antonio, Texas. I have appended a consensus mission-statement for medical rehabilitation research on a draft of white paper, by Dr. Bruce Gans, on the nature, scope, advances and uniqueness of medical rehabilitation research. I have also appended a copy of my Presidential address and an extended quotation, by Goethe, on the topic of commitment to a goal.

The Academy submits that citizens of the United States with a disabling condition deserve a clearly defined research presence at the National Institutes of health which effectively ameliorates the disabling consequences of illness, injury and birth defects.

The justification for a center at NIH for medical rehabilitation research was posed by three questions:

1. Does Rehabilitation Medicine provide an important health-care delivery system?
2. Does it have a knowledge base?
3. Should its research be peer-reviewed?

The needs of the Rehabilitation Medicine scientific community were stated:

1. A center for Medical Rehabilitation Research at the NIH with a clearly articulated mission statement and plan developed by the scientific community.
2. A training program to develop a cadre of scientists in Rehabilitation Medicine.
3. A peer reviewed (by RM investigators) program of unsolicited research.
4. Programmatic research to integrate basic scientists and clinical scientists in Rehabilitation Medicine (RM).

The NIDRR structure, due in large part to the restrictions of the EDGAR rules, does not provide:

1. A formal advisory group which modifies and monitors the research plan.
2. Permanent study section which provide consistent, quality peer review.
3. Criteria for grant awards which are appropriately weighted toward rigorous research design and methodology.
4. Adequate support of the training of scientists and unsolicited grants.
5. Adequate support of basic science research in Rehabilitation Medicine.
6. Adequate support or mechanisms for multicenter trials.

Clearly the above six items are also to be viewed as needs of the RM research community.

RECOMMENDATIONS:

The Rehabilitation Medicine scientific community strongly urges the NIH to establish a structure that mandates:

1. RESEARCH TRAINING: Adequate support to post-doctoral and career development awards in Rehabilitation Medicine to establish a cadre of scientists.
2. RESEARCH FUNDING: A chartered study section in RM to assure consistent and quality peer review by RM scientists; to develop additional research programs based on a plan and input from the field.
3. RESEARCH PLANNING: Development and implementation of a long range plan of RM research with a mechanism for the monitoring of the plan by the scientific and consumer communities.

MISSION STATEMENT FOR MEDICAL REHABILITATION RESEARCH

Medical Rehabilitation Research is the study of physical disability in a group of diseases including neurological, musculoskeletal, and cardiovascular system disorders in which the impairment, disability and handicap is defined by quantified physiologic, physical, behavioral and functional parameters. It is also the study of reduction of residual disability, prevention and reduction of secondary complications, the restoration of physical function, communication ability and psychological, social and vocational adaptation by interventions which include, but are not limited to, physical agents and exercises, bioengineering applications, behavioral adaptations and their mode of delivery. Finally, it is the study of maintenance of function in chronic disorders during the course of the disorder.

Testimony for the American Congress of Rehabilitation Medicine
before the
Panel on Physical Medicine and Rehabilitation Research
National Institutes of Health
November 20, 1989

This testimony is presented on behalf of the American Congress of Rehabilitation Medicine, the multidisciplinary organization that represents all of the disciplines and professions that are engaged in medical rehabilitation services, educational efforts, and research. We value this opportunity to present our views because an expressed mission of ACRM is to foster rehabilitation research.

I shall devote the allocated five minutes to specific recommendations that we hope the panel will embrace as its own. Our principal recommendation concerns development and implementation of an overarching plan by NIH to increase this country's research capacity and productivity relevant to improving medical rehabilitation practices and to understanding disablement.* Other recommendations deal specifically with the NIH role in increasing the necessary research manpower and investigative activity.

Before presenting those recommendations, I want to address a semantic consideration. Your group has been designated as the "Panel on Physical Medicine and Rehabilitation." That title connotes a group of physicians whose specialty is indeed central to the panel's concerns. We believe, however, that your focus transcends the concerns of any one group of physicians, or for that matter, any one of the professions or disciplines that, working interdependently, comprise our field. That field is appropriately designated as "medical rehabilitation" or "rehabilitation medicine." We hope the panel will adopt that terminology in order to promote better understanding of its intended purview.

I shall proceed now to our four recommendations.

1. We recommend that NIH develop and implement a comprehensive plan for enlarging research capacity and productivity that are needed to improve the effectiveness of medical rehabilitation services and to promote understanding of disablement. At a minimum, this plan should include the following:

- An explicit mission statement expressing the nature and degree of the NIH commitment to fostering research in these fields;
- Ample provision in developing the plan for the participation of persons with with disabilities, as well as rehabilitation service providers and researchers;

*By an emerging convention, the latter term applies collectively to the intertwined concepts of impairment, disability, and handicap. Its synonym in common parlance is "disability."

- Concrete objectives and timelines for their realization dealing with research manpower development and as well as increased research support and productivity;
- Specific mechanisms for facilitating the coordination of relevant activities in NIH, other federal agencies, and the private sector;
- Means of maintaining oversight regarding the plan's execution and needs for its revision;

Our second and third recommendations highlight two particularly important components of this plan.

2. We recommend that NIH develop and implement a systematic strategy for manpower recruitment and development relevant to research on medical rehabilitation and disablement. That strategy should mobilize all available NIH funding mechanisms for supporting the research training and subsequent career development of investigators.

3. We recommend that NIH develop and implement a systematic strategy for generating significantly more research activity relevant to improving rehabilitation practices and to understanding the biological, psychological, social, and environmental causes and implications of disablement. That strategy should include: a) creation of a chartered study section for reviewing investigator-initiated (ROI) proposals that pertain to medical rehabilitation or disablement; b) development and implementation of a substantive research planning process to designate research issues of particularly high priority that, in turn, becomes bases for soliciting proposed research.

4. Our last recommendation is that NIH lend its support to current legislative initiatives to establish a National Center for Medical Rehabilitation Research within NIH as the surest means of attaining the above stated objectives. The center is intended to be a focal point within NIH for planning, coordinating, and supporting research on medical rehabilitation and disablement. We believe that anything less than that organizational accommodation will result in grievous underachievement of the stated objectives.

In closing, we acknowledge being concerned about probable resistance to these recommendations, even if the Panel endorses them. Knowledgeable observers have pointed out that some of the very characteristics of NIH that have made it the premier institution worldwide for supporting biomedical research are the very characteristics that make it resistant to change. Chief among those characteristics is the vigor with which it pursues its current program commitments in the face of hotly contested priorities and limited resources. Additionally, these recommendations are likely to reactivate long-standing debates within NIH regarding the relative value of basic versus clinical research and of achieving research impacts other than cure or the reduction of mortality. We believe, therefore, that ultimate adoption of these recommendations will require persistent advocacy by persons within NIH as well as by representatives of rehabilitation practitioners and researchers, disabled persons who are the

intended beneficiaries of these proposals, and of the general public which bears the aggregate costs of disablement that result from an inadequate knowledge base to support effective rehabilitation services.

Presented by: Marcus J. Fuhrer, Ph.D.
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STATEMENT

before the

PHYSICAL MEDICINE AND REHABILITATION RESEARCH PANEL

of the

NATIONAL INSTITUTES OF HEALTH

Presented by

Leo M. Cooney, Jr., M.D.

President-Elect

November 20, 1989

I am Dr. Leo Cooney, professor of medicine at the Yale University School of Medicine, and I am pleased to appear before this panel on behalf of the American Geriatrics Society. The focus of your efforts--the need to assure continued progress in the area of rehabilitation research--is of special importance to the Society. Older persons often experience a gradual decline in their ability to function independently. Rehabilitation services are often needed to help these individuals resume independent living. The Society believes that a strong rehabilitation research effort is essential to improve these services and to determine under what circumstances they can be effective.

The American Geriatrics Society, an organization of almost 6,000 members, is comprised primarily of physicians but includes nurses and other allied health professionals. The Society was formed for the purpose of focussing the attention of physicians and health professionals from a variety of fields on the special problems of the elderly. The objectives of the Society are to ensure access to geriatric medical care and to expand the number of health professionals trained in geriatrics. In addition, our annual meeting and journal provide opportunities for the presentation of research on aging.

Background on Geriatrics and Rehabilitation Medicine

As NIA Director Franklin Williams has stated, "The real goal of geriatrics is fundamentally rehabilitative: to restore and/or maintain the maximum degree of independence possible for each older

person...We have clear examples of what can be accomplished through a marriage of geriatric and rehabilitative efforts." New treatments and technologies in the fields of geriatrics and rehabilitation medicine are being used together to benefit older persons with disabling conditions. This important relationship has been a focus for those seeking to improve training in geriatric medicine:

- In a 1987 report to Congress, the NIA recommended that the medical curriculum in geriatrics give special attention to rehabilitative medicine.
- Our Society has developed guidelines for fellowship training in geriatric medicine which state that programs must provide training experience in geriatric rehabilitation including those measures available to orthopedic, arthritic, cardiac and neurologic rehabilitation.
- The American Academy of Physical Medicine and Rehabilitation has developed guidelines for training geriatric fellows in rehabilitation.

Rehabilitation is a process which has great relevance for the elderly. While only 1.2 to 3.8% of those aged 18 to 64 are disabled, disabilities affect 12 to 17% of those 65 and older. The major disabling events of adulthood--stroke, fractured hips, and amputations--occur predominantly in those 65 and older. The rehabilitation of the older patient is often compounded by problems of altered mental status, co-existing medical problems, pre-morbid dysfunction, and psychosocial problems quite different from the younger disabled individual.

The strong connection between geriatric care and rehabilitation medicine is also reflected in the research agenda for these fields. Currently, the NIA is allocating about \$10 million of its budget to rehabilitation research projects including efforts to develop techniques to counter memory loss in the elderly, to assess interventions that may reduce frailty and injuries among older persons, and to study how altered muscle function in older adults affects the potential for rehabilitation. It is important to recognize that scientific studies directed at the rehabilitative problems of the elderly require a substantially different approach than research focussed on the rehabilitation needs of younger patients. The success of the rehabilitation of an elderly patient with a fractured hip, for example, depends more on the patient's mental condition, pre-fracture function, and co-existing medical conditions than the type of fracture, operative approach taken, and physical therapy provided. Efforts to rehabilitate such patients will be improved only through a coordinated approach, involving all disciplines necessary for the care of the frail elderly.

Drawbacks of Consolidating NIH Rehabilitation Research Efforts

The American Geriatrics Society believes that it is extremely important for the National Institute on Aging to continue to pursue its rehabilitation research objectives. Consequently, we have been extremely concerned about legislative proposals that would consolidate the NIH rehabilitation research effort into a single center within the agency. We recognize that those advocating this

arrangement do so in the hope of strengthening the NIH-sponsored rehabilitation research program. However, the centralization of this research effort has some major drawbacks:

- It would isolate rehabilitation research from related efforts within the NIA, such as those described previously.
- It would isolate rehabilitation research from the related efforts of other institutes. Rehabilitation techniques are being studied and refined with respect to a number of diseases including arthritis, stroke, Parkinson's disease, osteoporosis, ischemic heart disease, and chronic lung disease. Rehabilitation research programs of the various institutes focused on the study of these and other disorders should remain intact to allow maximum opportunity for cross-fertilization.
- The additional costs of a separate NIH component are not apt to be offset by increased appropriations, thereby necessitating the diversion of funds from the support of research.

Recommendations for Continued Progress

The American Geriatrics Society believes that NIH rehabilitation research efforts are hindered by the same factor that is compromising so many NIH programs at present: inadequate funding. We recognize that this panel was charged to assess the current administration of rehabilitation research at NIH. In our view, the administration of such efforts should not be centralized but should remain at the discretion of the various institutes,

thereby preserving their flexibility to pursue specific rehabilitation research opportunities. Continued progress in rehabilitation research will require increased funding, not additional bureaucracy. We urge you to:

- work with the leadership of the individual institutes to identify areas that have been underfunded, to develop recommendations on how their existing rehabilitation research programs might be expanded, and to determine whether training efforts are adequate, and
- provide information to the Director's Advisory Committee as to the additional funding needed to strengthen or expand the institute's existing efforts.

The Society believes that NIH rehabilitation research programs will benefit far more from an assessment of budgetary needs than an examination of how the agency administers an inadequately-funded effort. We urge you to focus your agenda accordingly.

Thank you for this opportunity to express the views of the American Geriatrics Society. I would be happy to respond to any questions.



WRITTEN TESTIMONY
on
REHABILITATION RESEARCH NEEDS

Submitted to: The Advisory Committee to the Director, Physical Medicine and Rehabilitation Panel
From: The American Physical Therapy Association
November 13, 1989

The past forty years have seen rapid advancement in biomedicine and health care. The coming decades are likely to encompass continuing growth of knowledge and technology. For example, advances in biomedicine will lead to control and/or cures of many acute and infectious diseases; continuing to probe the frontiers of human genetics will lead to prevention and control of some of the major inherited diseases. Refinements in surgical techniques will permit removal of diseased tissue, major organ repairs and improvements in organ transplantation. Thus, we are a society that is increasingly effective at saving and prolonging life. However, as we grow better at keeping people alive we also must be committed to offer quality to the lives we prolong. Included in quality of life is maintaining and improving physical functioning and skills in healthy states, following disease and injury and as a result of aging. This can be viewed as the essence of rehabilitation.

Virtually every major category of disease (including cardiovascular, pulmonary, neurological, metabolic diseases, cancer, and AIDS), disability, disorder and injury, as well as the aging process is associated with some degree of functional loss. Debilitation also may result from treatment procedures. In some cases, return to normal functional capacity is accomplished with little or no intervention. For many, however, approaching a return to normal is not possible without rehabilitation.

Recognition of the importance of rehabilitation was a stimulus to the evolution and growth of several rehabilitation-focused health professions. These professions have continued to play an important role in the health care delivery phase of the biomedical spectrum. Today, however, researchers in these professions and in related disciplines are seeking responses to many unanswered questions and knowledge that will help advance the quality of health care delivery. Thus, like other areas of biomedicine, rehabilitation has entered the time when research is needed across the biomedical spectrum, from basic and applied research, through clinical trials, health services research, and demonstration/outreach activities.

As in any field of biomedicine, basic studies of underlying physiologic and pathological processes are important to advancing the general area of rehabilitation. However, due to the nature of the field there is a compelling need for applied and clinical research and for studies relevant to health services. Among the general areas of research need and opportunity are the following:

Studies of the effectiveness of rehabilitation. Such research is likely to investigate the outcomes of rehabilitation relative to specific diseases and/or conditions (e.g., stroke, heart attack, various neurological diseases, cancer, traumas, developmental disorders, etc.) Further, there is a need to approach outcomes from the perspective of specific types of rehabilitation interventions.



- Investigation of the relationship between rehabilitation, functional capacity and physiological status. This may need to encompass investigation of physiological status before and after rehabilitation.
- Studies of the timing of initiating rehabilitation (i.e., early versus late intervention) and the functional and physiological outcomes.
- Investigations of the optimum length of rehabilitation as related to functional and physiological outcomes.
- Research on the relationship between the setting of care and outcomes of rehabilitation.
- Studies on the speed of recovery and degree of recovery relative to age.
- Research on maintenance of functional capacities as a result of the aging process.
- Investigation of the relationship between rehabilitation and the psychological well being of the patient.
- Studies of the role of rehabilitation in preserving functional independence in patients with AIDS.
- Efforts to develop a database of conditions/disease and rehabilitation outcomes.

The above are merely examples of areas in which results from well designed research studies can stimulate advances in the quality of care offered to the American population.

Concurrent with efforts to foster new research efforts related to rehabilitation, there will be a need to provide research training opportunities to rehabilitation professionals. Much of the needed rehabilitation research falls within the domain of clinical studies and therefore will require involvement of the health professionals that provide patient care. As in other areas of biomedical research, these health care professionals are not adequately trained in the design, conduct and management of such research studies; special efforts, such as those designed to attract and train physician researchers, will be needed for these other professions. Since the area of rehabilitation encompasses several professions, these training efforts must be offered to all appropriately educated providers.

Over the last decade, the profession of physical therapy has mounted diligent efforts to stimulate research to strengthen the scientific base of the profession and to improve the quality of clinical care. A more intense focus on rehabilitation research and associated training needs will certainly help advance this thrust. In addition, it may also have important secondary consequences related to alleviating the shortage of physical therapists by providing resources and opportunities for increasing faculty research funding and productivity and advanced research training for physical therapists interested in pursuing academic careers. A similar secondary effect also may occur in other rehabilitation professions.

The American Physical Therapy Association (APTA) strongly believes that there is a pressing need to enhance the breadth and quality of research related to rehabilitation. Although research related to rehabilitation has been supported by a number of Federal and private funding agencies, the societal need and demand for quality rehabilitative care may necessitate an even stronger research effort. The proposal to establish a National Center for Medical Rehabilitation Research within the structure of the National Institutes of Health may be an impetus to this enhanced effort. Placing this Center within the NIH facilitates linking this area with the ongoing and highly relevant basic, applied and clinical work supported by the NIH and will enable this emerging research area to benefit from the well established and respected peer review systems of the NIH.

Although rehabilitation related research currently is supported by several of the Bureaus/Institutes/Divisions at the National Institutes of Health, this current work tends to be oriented toward basic research investigations and/or disease specific. Such studies are critical and must be continued. However, much of the clinical studies and health services research that are and will be needed may cut across NIH structural boundaries. Thus, a mechanism to facilitate this collaborative and coordinated approach to stimulating and supporting rehabilitation research is likely to have a beneficial effect.

Beyond the support of research by the NIH, the establishment of a National Center for Medical Rehabilitation can be expected to have a positive impact beyond the NIH. The establishment of mechanisms for collaboration among Federal agencies involved in rehabilitation may offer one avenue for effectively identifying research needs and directions and for monitoring progress. Further, based on experience with other areas of research focus within the NIH structure, the establishment of the Center may provide an impetus for private funding agencies to more clearly define their interest and role in support of rehabilitation research.

Thus, the APTA believes that the establishment of a National Center for Medical Rehabilitation will strengthen the interest in and quality of much needed rehabilitation research provided that adequate funding is available specifically for this area. These funds are likely to well exceed the current level of funding for rehabilitation related projects at the NIH.

Although the APTA also supports the establishment of a formal Center within the NIH, we believe that various organizational approaches should be thoroughly examined. Of primary concern is the creation of an administrative structure that may lessen funds available for direct support of research.

Finally, the APTA expresses its hope that a National Center for Medical Rehabilitation, irrespective of its organizational and administrative structure, will actively and formally seek input and involvement from the range of communities of interest, including professionals and associations representing the rehabilitation professions, voluntary health associations, and patient and consumer groups. The APTA is pleased to have the opportunity to present its views to the Advisory Committee to the Director of the Physical Medicine and Rehabilitation Research Panel and expresses its interest in continuing to participate in this effort.

The American Physical Therapy Association (APTA) is a national professional organization representing more than 50,000 physical therapists, physical therapist assistants and physical therapy students in the United States. Its goals are to serve its members and the public by increasing understanding of the physical therapist's role in the biomedical and health care spectrum and by fostering improvements in physical therapy education, research and practice.



American Physical Therapy Association

BACKGROUNDER

AMERICAN PHYSICAL THERAPY ASSOCIATION

The American Physical Therapy Association (APTA) is a national professional organization representing more than 47,000 physical therapists, physical therapist assistants and students throughout the United States. Organized in 1921 in the wake of World War I, APTA offers opportunities for physical therapists in the United States to exchange information and improve skills, and assists them in maintaining the quality and integrity of their profession.

The Association's efforts are directed towards serving its members and the public by increasing the understanding of the physical therapist's role in the health care system and by fostering improvements in physical therapy education, practice and research.

Some of the activities that foster APTA's goals include:

Accreditation. APTA is recognized as the sole accrediting agency for entry-level physical therapist and physical therapist assistant education programs in the United States.

Professional Development. Conferences, seminars, workshops and other kinds of professional development activities are sponsored by the Association and its components on a regular continuing basis.

Quality Assurance. The quality assurance program of APTA assists members in evaluating the quality and effectiveness of physical therapy treatments, in developing the skills needed to conduct their own evaluations, and in other ways assuring the highest quality of physical therapy care possible.

Research. APTA promotes clinical and basic research in physical therapy through graduate education programs, presentation and publication of research reports, special research awards, and close collaboration with the Foundation for Physical Therapy. Methods for increasing and improving research are part of the Association's efforts to see that the most effective physical therapy care is made available to the public.

Information Dissemination. Communication is the backbone of the Association, ensuring a proper understanding of the physical therapist's role in the health care system. APTA provides accurate information to the public, the media, federal, state, and local governments, other health care professionals, and to APTA members.

An information brief prepared and distributed by the APTA. For more information contact the APTA Public Relations Department, 1111 North Fairfax Street, Alexandria, Virginia 22314, 703/684-2782.





AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Panel on Physical Medicine and Rehabilitation

National Institutes of Health

Testimony

Presented by

**The American Speech-Language-Hearing Association
Rockville, Maryland**

November 20, 1989

10801 Rockville Pike, Rockville, Maryland 20852 (301) 897-5700

On behalf of the American Speech-Language-Hearing Association (ASHA), I would like to thank you for the opportunity to respond to the Panel on Physical Medicine and Rehabilitation. ASHA is pleased to have the opportunity to present its views on this area of research.

BACKGROUND

The American Speech-Language-Hearing Association is the scientific and professional association representing over 60,000 speech-language pathologists and audiologists. Speech-language pathologists and audiologists are professionals who hold either the master's or doctoral degree and are qualified to identify, assess, and provide treatment for individuals with speech, language, cognition, hearing, swallowing, and related disorders. Speech-language pathologists are specialists in the understanding and expression of human communication, its normal development, its disorders, and the prevention of its disorders. Audiologists are specialists in the prevention, identification, and assessment of hearing impairment and related disorders, and in the rehabilitation of persons with hearing impairments, including the fitting and dispensing of hearing aids. These professionals are engaged in research, teaching, and clinical activities, all of which benefit the infant to geriatric population with communication and related disorders.

Many research issues that are of interest to physical medicine and rehabilitation are also of interest to speech-language pathologists, audiologists, and speech, language, hearing scientists as our knowledge bases, research domains, and clinical activities overlap. Speech-language pathologists and audiologists work in a wide variety of professional settings. These settings include both residential and non-residential health care facilities, which are the work facilities for almost 40% (38.7%) of ASHA affiliates. Hospitals, in fact, are the second largest employment setting for our members. The most frequent primary activity of ASHA members is the provision of clinical services. ASHA members often are integral members of physical medicine and rehabilitation teams.

RESEARCH NEEDS

The testimony presented today focuses on research needs in physical medicine and rehabilitation. While physical medicine and rehabilitation is faced with significant issues other than research, issues surrounding research was indicated as the focus of this panel.

General Research Needs

General research needs, for the purposes of this testimony, refer to issues common to the various disciplines involved in physical medicine and rehabilitation or to issues that cut across several disorders or diseases requiring rehabilitation services.

1. Collaborative Efforts

To produce high caliber research results in physical medicine and

Research in prosthetics, for example, may require input from biomedical engineering, psychology, neurophysiology, dentistry, speech-language pathology, and physical therapy. Given the need for collaboration, the structure under which research is conducted must foster interdisciplinary teamwork. The process of conducting research must foster the same goal.

2. Interdisciplinary Approaches to Rehabilitation

A prominent goal of physical medicine and rehabilitation is to restore disturbed or impaired functions, which follow serious disease, injury, congenital disorders, or illness. This goal is shared by communication sciences and disorders, since these professionals serve persons with communication disorders as a result of illness, injury, genetic defects, developmental disabilities, etc. An interdisciplinary approach is currently advocated and practiced in the diagnosis and rehabilitation of these individuals, since they experience impairment to one or more senses or systems of the body, which, in turn, affects physical functioning, mobility, communication, swallowing, and cognition.

3. Assessment Tools

Of particular interest to policy makers, practitioners and researchers alike is the functional outcome of rehabilitative services. As the field of rehabilitation has shifted its focus from disorder-oriented to function-oriented care, the tools to measure function have received growing attention. Functional assessment measures are described as powerful research tools which can be used to set prospectively-determined payment rates for rehabilitation, to determine candidacy for rehabilitation and level of health care need, and to improve the quality of care. Yet today, there is still confusion about the definition of functional assessment, little agreement on what core elements should constitute a measure, potential clashes in federal and state laws on user stipulations, and less than rigorous efforts made to establish these measures' reliability and validity. Nevertheless, federally-funded studies are underway, whose goal is to set public policy in the rehabilitation field, using various functional assessment measures -- measures which may not address the critical areas of function as identified by these rehabilitation professionals.

Speech-language pathologists and audiologists have expressed concern that several of these tools do not sufficiently address communication and cognitive abilities. Some functional assessment measures are limited to assessment of physical function and address only the basic activities of daily living (bathing, dressing, feeding, toileting, continence, and transfer). If communication abilities are addressed, the sensitivity of the measures may not be sufficient to capture change in communicative function. Other measures rely on self-report of speech, language, and hearing problems; these self-assessment measures are believed to yield data that often underrepresent the prevalence of communication impairments.

To this end, physical medicine and rehabilitation research efforts should be directed toward refining functional assessment tools and coming to agreement on what core elements should constitute a measure before these tools are used to set public policy. In 1988, a coalition of organizations (including ASHA) sponsored a landmark symposium on "Access to Quality Care in Rehabilitation". The symposium provided a forum for health policy leaders to discuss critical issues affecting the provision of quality rehabilitation services. Among several

collective recommendations were the following:

- A uniform instrument, which considers a multiplicity of functional abilities and needs, be developed to measure outcomes of rehabilitation; and
- Development and implementation of a uniform industry standard for data collection to be used by every rehabilitation facility to measure outcomes and functional status and to evaluate programs related to treatment.

4. Consistent Research Data

The heterogeneity of populations included in physical medicine and rehabilitation research raises issues of consistency of research design to permit comparison of findings across studies, sufficient detail reported to allow replicability of research studies, and reporting subject information across studies. Of course, these problems are not unique to physical medicine and rehabilitation. To address them, the National Joint Committee on Learning Disabilities (NJCLD) recommended that research include subject descriptors. While many of the specific descriptors are not applicable to physical medicine and rehabilitation, consideration of developing a list is recommended here. The NJCLD statement is appended for information purposes (See Appendix A.).

5. Models of Best Service Delivery

Disorders relevant to physical medicine and rehabilitation are seen throughout the life span, although they concentrate in the young and elderly populations. Individuals with problems are increasing in numbers as scientific and technological advances have increased life expectancy and reduced mortality rates, but increased morbidity rates. Although more people survive, these clients are often left with complex, multiple disorders, which require more extensive health care services, among them rehabilitation services. With decreased infant mortality, rehabilitation professionals are faced with caring for infants with multiple and severe problems. Among the young are youngsters with cerebral palsy, children with peripheral hearing impairment, and adolescents with traumatic brain injuries.. The elderly end of the continuum includes those with central auditory processing deficits, degenerative neurological disorders, strokes, arthritis, hip fractures, pulmonary and cardiac diseases, vascular diseases, and musculoskeletal diseases. Because many disorders and diseases are not curable, research is needed to prevent them in future generations and to provide the best treatments in the current generation.

6. Efficacy Research

Among the research priorities noted by ASHA's Committee on Scientific Affairs (Ashe, 1989) is the need for research on the efficacy of intervention services for persons with speech, language, and hearing disorders. There is a need for clinical trials research regarding which treatments improve functioning above and beyond that achieved with no treatment, which treatments result in the greatest improvements, and which treatments are effective in improving or maintaining function. These research studies are needed in other rehabilitation fields as well, such as in physical therapy and occupational therapy. Efficacy studies are needed in several diagnostic categories of language, hearing, speech, cognitive, and swallowing disorders, as well as across the life span, from infancy through old age. For example, we do not know the long term effects of

amplification for hearing impairment on infant speech and language development.

In addition to the efficacy of treatment within any one discipline, we need to determine the relative merits of different models of interdisciplinary team approaches to rehabilitation service delivery as well as the influence of inpatient versus outpatient paradigms. That efficacy studies may rely on functional assessment instruments to demonstrate progress across disorders and treatment types underscores the need for reliable and valid measurement tools.

7. Prognostic Studies

Prognostic studies that will maximize rehabilitative efforts are needed. Examples include the early identification both of those with hearing and language disorders and of those who are at risk of developing disorders, as well as studies to assign individuals differentially to appropriate treatments.

8. Epidemiological Research

While statistics are available on the incidence and prevalence of communication disorders, the data are frequently out of date and those available often have been obtained by self-report rather than from actual patient testing. When viewing disability, additional demographic information is also needed on relevant variables, such as age, sex, geographic distribution, income, and racial/ethnic background.

9. Research Knowledge Transfer

Mechanisms need to be in place that ensure the transmission, translation, and application of advances in basic science to clinical service delivery. Not only are both basic and applied research needed, but also the vehicles to ensure that this research is widely disseminated are needed. Practitioners can provide the best service only if they are current in what the best practice is, which means that they must both be aware of the latest research advances and apply them to their clinical practice.

10. Cost-Benefits Studies

The cost-benefits and value of rehabilitation need to be clearly demonstrated. This necessitates that research be conducted on rehabilitation outcomes. Such research This will be facilitated by developing and using standards for data collection. Studies are not limited to but should include cost-benefits analyses, and comparisons of costs of rehabilitation, rehospitalization, and no rehabilitation (Access to Quality Care in Rehabilitation Symposium Draft Proceedings, 1988).

Specific Research Needs

Specific research needs, for the purposes of this testimony, include the research needs of specific patient populations, specific disorders, or particular rehabilitation technology.

1. Elderly Population

Especially with the increased elderly population (20% of the population will be 85 years or older by the year 2010) and with the increased incidence of related problems in this age group, research must be conducted to meet the needs of this expanding group. Not only must research attempt to improve functioning when that is a realistic goal, but also research must demonstrate the efficacy of providing treatment to maintain function that will improve the quality of life.

2. Noise Pollution

An industrial society suffers the consequences of exposure to environmental pollutants, among them noise. The systematic effects of noise need research in several areas--its effects on the individual himself/herself, its effects on intracellular functioning, and its effects on job performance, for example.

3. Research in Assistive Technology

Persons with speech, language, and hearing disorders can benefit from assistive and/or augmentative devices. Research in this area needs to target the development of better devices, better access to these devices, and better use of them. These devices may take the form of assistive devices to provide augmentative communication for a broad range of persons with neurological impairments; sensory aids for all types of hearing impaired persons, including digital hearing aids, vibrotactile aids, and cochlear implants; and assistive devices to increase the intelligibility of persons with neurological impairments.

3. Balance Disorders

An estimated 90 million Americans have experienced a dizziness or balance disorder. These problems may accompany hearing problems, such as Meniere's disease, or neurological problems, such as ataxia. Just as research is needed to better understand the structure and functioning of the auditory system, parallel research is needed to understand the vestibular mechanism. As with other disorders, research should emphasize the development of better diagnostic methods and testing procedures, an increase in demographic information, and the study of treatment efficacy (National Institute on Deafness and Other Communication Disorders, 1989).

4. Children with Hearing Impairment

A client population with particular research needs is hearing impaired children. For 30% of children with hearing impairment, the sensory deficit does not exist in isolation, but in concert with other disorders. When multiple impairments are present, interdisciplinary management teams are especially appropriate. Two examples of research needed in this population are highlighted:

- investigation of the prevalence of motor speech, fine and gross motor, and visual processing disorders among the hearing-impaired, school-aged population and their effects on receptive and expressive sign language, speech and speechreading abilities; and

- longitudinal studies of children with severe to profound sensorineural hearing impairment regarding the effects of different communication methodologies

on English and American Sign Language knowledge acquisition, reading abilities, and academic achievement.

5. Swallowing Disorders

For an estimated 6 to 10 million Americans, swallowing may present as an isolated problem or may accompany neurological dysfunction resulting from disease or injury. Because of their knowledge and training, many speech-language pathologists take a leading role in establishing rehabilitative programs to evaluate and treat individuals with a swallowing disorder. This role has been recognized by the Office of Health Technology Assessment (National Center for Health Services Research and Health Care Technology Assessment, 1989) and the Health Insurance Association of America. While other professional groups could potentially provide a similar service, the speech-language pathologist has often had both the most interest in and the greatest experience with swallowing rehabilitation.

Physical medicine and rehabilitation research teams led by speech-language pathologists must develop programs to identify, evaluate, and treat persons with dysphagia and document the efficacy of such intervention.

6. Cognitive-Communicative Disorders

The development of cognition and communication are inextricably interrelated. Individuals who have cognitively-based communication impairments include those with either congenital or acquired disorders and span the life cycle from birth to old age. There is a need for physical medicine and rehabilitation research teams to draw from the contribution of speech-language pathologists in the management of these individuals as well as for these teams to evaluate the effectiveness of various models of intervention.

STRATEGIES FOR ACHIEVING CONTINUED RESEARCH PROGRESS

1. Collaborative Research

The days when a single discipline could study a disorder or a treatment regime have passed. With today's knowledge in biomedical spheres and in technology, to achieve notable advances frequently requires the efforts of a variety of disciplines. Collaborative research that employs truly interdisciplinary efforts is needed.

Facilitating the collaboration between researchers and the clinical community could also result in innovative research programs that would answer research questions particularly relevant to clinical issues.

2. Interprofessional Awareness

In studying complex problems that occur as the sequelae of stroke or traumatic brain injury, each discipline approaches the problems from a different perspective. Professionals contribute expertise from their own discipline. In addition, however, through discussion and mutual respect, their collective expertise may supercede the sum of their individual expertise. "The whole is greater than the sum of its parts" phenomenon can work to the advantage of more

creative research and, consequently, better service delivery to patients in need.

3. Clinical Research Training

In communication sciences and disorders, there is an urgent need for more researchers. Efforts need to be made to make research a viable career option for students to select, to encourage new investigators to pursue research careers, and to support current researchers to maintain their research careers. Only 1% of ASHA affiliates report research as their primary professional activity. If the advances needed are to be made, a larger cadre of researchers is clearly necessary. Mechanisms must be developed to attract more individuals to select research career tracks in our academic training programs. This message was clearly and strongly delivered at a recent Research Training Workshop held by the National Institute on Deafness and Other Communication Disorders (NIDCD) in July 1989 and at the Access to Quality Care in Rehabilitation meeting in October 1988. Models of education to meet these needs must be explored.

4. Coordination and Dissemination of Research Priorities and Results

If specific areas are targeted as priorities for research activities, publishing these priorities and soliciting comments from research, clinical, and consumer communities could have an important impact in shaping the priorities to address the most urgent needs in the most efficient manner.

If not already formally established, mechanisms should be developed or refined so that announcements of available grants and proposals and research results are disseminated to appropriate target groups. The community needs to be aware that research opportunities exist for which they might be eligible. If research advances are not applied in everyday clinical practice, an important reason for doing the research is missed. The research results need to be applied to practitioner needs and to be disseminated to them. Because research is being done by various groups and in various locations, coordination of the dissemination efforts is needed.

To increase the awareness of the public and professional sectors of the importance and benefits of rehabilitation, clearinghouse and networking functions could be undertaken within NIH. While the specific functions of such an information clearinghouse would necessarily be defined by the populations it was designed to serve, such a clearinghouse would serve to collect, categorize, store, and disseminate information that is currently not easily accessible to the target groups.

5. Equitable Distribution of Disciplines in the Review Process

In the peer review process, when funding decisions are being made, it is extremely important to have representation from all groups germane to the topic under review. More frequently than is desirable, review teams make decisions about communication disorders projects without representation of the discipline on the review panel.

6. Financial Support

Critical to the development and implementation of a research agenda in physical medicine and rehabilitation is a sound financial foundation. As in

other areas of medical research, support for individual and program grants is essential if scientific advances are to be realized. ASHA has consistently lobbied Congress to support a level of appropriations that will allow research in biomedical science to advance.

REFERENCES

Access to Quality Care in Rehabilitation Symposium Draft Proceedings. (October, 1988). Washington, D.C.

Committee on Scientific Affairs. (1989). Activity Report. Asha, 31(3), 68.

National Center for Health Services Research and Health Care Technology Assessment. (1989). The role of speech-language pathologists in the management of dysphagia. Health Technology Assessment Reports. Number 1. Rockville, MD: Department of Health and Human Services.

National Institute on Deafness and Other Communication Disorders. (1989). A report of the task force on the National Strategic Research Plan. Bethesda, MD: National Institutes of Health.

APPENDIX A

THE NEED FOR SUBJECT DESCRIPTORS IN LEARNING DISABILITIES RESEARCH: PRESCHOOL THROUGH HIGH SCHOOL YEARS

A Statement of the National Joint Committee on Learning Disabilities
September 30, 1989

Research activities in the area of learning disabilities are extensive. The findings from these studies have influenced funding, program development, education, and treatment for individuals with learning disabilities. Research is based on the use of single subject, within subject, and group comparison models. Across studies there is inconsistency in the description of subjects. There is also inadequate information regarding subject selection and study methodology. These inconsistencies and omissions are of concern to the National Joint Committee on Learning Disabilities (NJCLD). Limited subject description makes it difficult to interpret and generalize research findings and interferes with replication studies.

The purpose of this paper is to provide a set of descriptors the NJCLD believes are necessary to describe subjects in studies of learning disabilities. Documentation of these descriptors will facilitate replication of research and application of findings by practitioners. This paper will provide guidance to funding agencies, investigators, university programs and other agencies that conduct or supervise research as well as to authors, editors, and publishers who disseminate research findings.

The need for specific subject descriptors in learning disabilities research is based on recognition of the following factors:

- the heterogeneity of learning disabilities necessitates a description of subjects included in a research study;

- many research studies include individuals classified as learning disabled on the basis of state or local service agency criteria, which vary among agencies;
- various procedures are used to determine ability, aptitude, and achievement.

The NJCLD recognizes that there may be problems collecting subject information as a result of factors such as study setting, e.g., school, clinic, and hospital. These difficulties can limit the kinds and amount of subject information available. Therefore, the NJCLD recommends that investigators report all relevant facts related to the collection of subject information.

The NJCLD urges all investigators to document the criteria for subject inclusion as well as provide a description of all tests and experimental measures used in the study. To facilitate replication, consistency in research design, and reporting of subject information across studies, the following subject descriptors are recommended:

I. Demographic Data

Sample size	Chronological age
Gender	Race
Socioeconomic status	Maternal education
Cultural/ethnic background	Locale: urban, suburban, rural
Dominant language dialect	Geographic region

II. Health and Medical History

Medical, including neurological/developmental, history
Sensory System problems

III. Education Data

- Grade placement
- Educational history
- Related services provided
- Curricular and instructional histories

IV. Characteristics at the Time of Study

- Sensory and medical status at the time of the study
- Intellectual level
- Behavioral and emotional status
- Receptive and expressive language abilities
- Achievement levels



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November 20, 1989

TESTIMONY

FOR THE ADVISORY COMMITTEE TO THE DIRECTOR

PHYSICAL MEDICINE AND REHABILITATION RESEARCH PANEL

Samuel L. Stover, M.D.

My name is Samuel L. Stover, M.D. I am representing the American Spinal Injury Association (ASIA). Thank you for this opportunity to provide written testimony to the Advisory Committee.

The American Spinal Injury Association is an organization of almost 400 physicians in various medical specialties who are concerned about the care of victims with spinal cord injury. In the early 1970's, the American Spinal Injury Association was organized by the first directors of the Model Spinal Cord Injury Care Systems. These Systems were funded by the Rehabilitation Services Administration to organize coordinated Systems of Care for this devastating and often permanent condition which most commonly affects young men. It was recognized that fragmentary care was inadequate in providing needed services for persons with these severe impairments, and yet was very expensive. The model systems included emergency medical management, acute care, rehabilitation, community integration, long-term follow-up, and efforts at prevention. This required a team of medical specialists as well as many other professionals in the health related disciplines. The American Spinal Injury Association was organized to provide a vehicle for communication among those interested in the management of spinal cord injury. In addition, the organization developed educational programs to help train professionals in the care of spinal cord injury and promoted and encouraged research.

I am Professor and Chairman of Rehabilitation Medicine at the University of Alabama at Birmingham, and a past President of the American Spinal Injury

Association. I am the Project Director of one of these Spinal Cord Injury Care Systems at the University of Alabama at Birmingham and the Director of the National Spinal Cord Injury Statistical Center.

After funding was provided to develop these Model Systems, it was recognized that the Model Systems needed to collaborate to document their activities and collect data about spinal cord injury in a uniform way which would be useful for clinical and research purposes. In 1975, the National Spinal Cord Injury Data Research Center was established to organize and collect a uniform database. This activity has continued with some revision of the variables collected, and is now known as the National Spinal Cord Injury Statistical Center. As of October 1989, 12,954 new patient entries and 52,867 entries for annual follow-ups spanning up to 14 years have been entered into this spinal cord injury database. This database has provided important demographic information as well as a natural history of the methods of management, secondary complications and rehabilitation outcome. As an example, the proportion of incomplete injuries documented at hospital discharge has gradually increased over the 14 years of database collection from 40.8% to 56.4%. This increase is in part a reflection of improved emergency medical services and acute management, allowing preservation of neurologic function (please see Appendix 1). In many ways, spinal cord injury has now become a model for management and long term follow-up of other medical conditions, such as severe head injury, which often cause permanent impairment. The spinal cord injury database has now identified many important research questions which require both clinical and basic science research to find solutions which will improve the rehabilitation outcome of patients with spinal cord injury.

The Model Spinal Cord Injury Care Systems are currently funded and administered by the National Institute on Disability and Rehabilitation Research (NIDRR) in the Department of Education. We have had very productive years in NIDRR, however, there are certain limitations imposed by the Education Department General Administrative Regulations (EDGAR) which do not allow us to proceed with needed

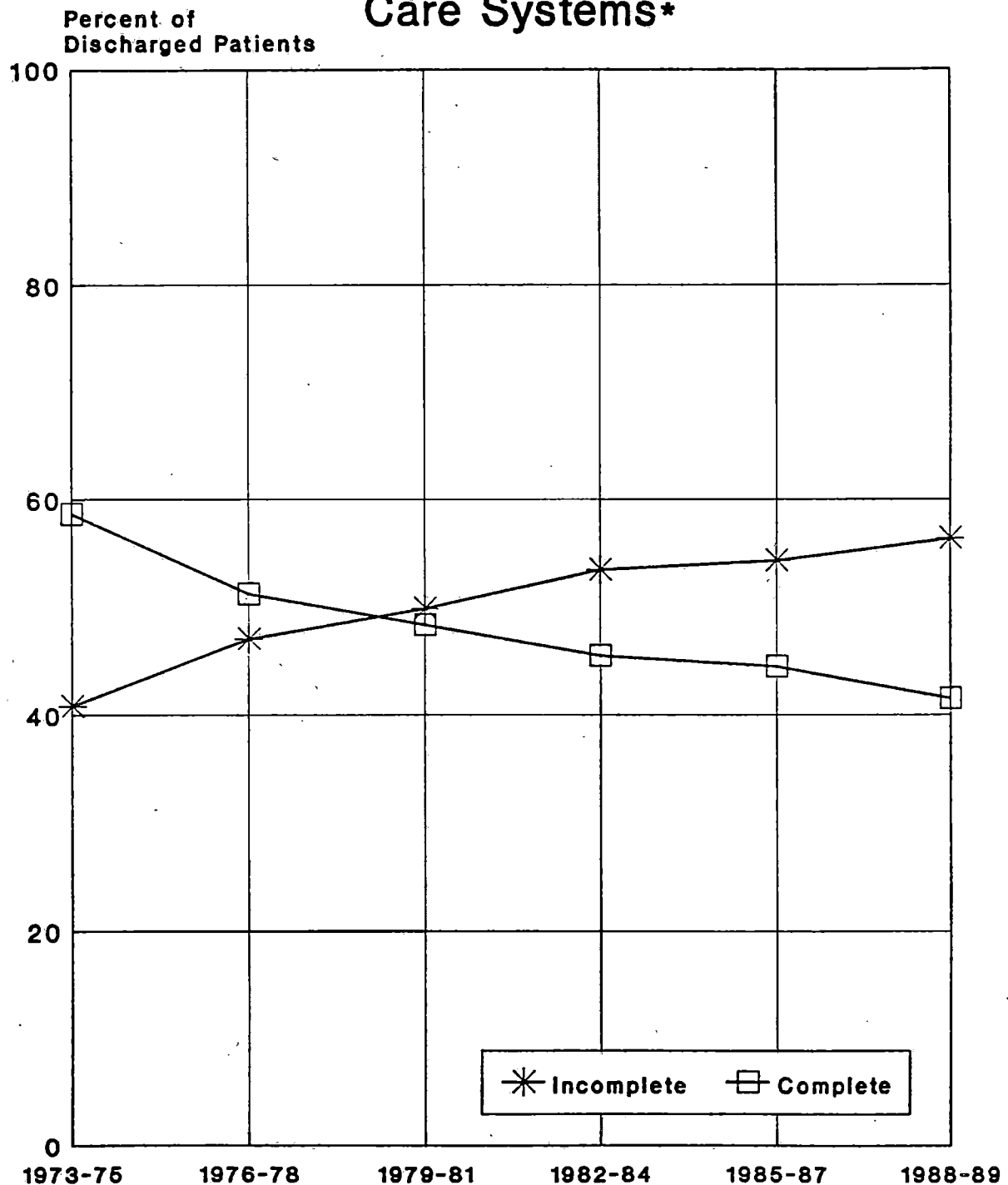
medical research. Clinical research often requires basic science research as a next step in answering research questions. The Department of Education is not oriented or interested in conducting basic science research in medical areas.

In a condition such as spinal cord injury, which has a relatively low incidence rate and extremely high associated costs, multi-center studies are needed to answer many research questions. There is a need for a more independent structure attuned to both clinical and basic science research which can help in organizing, funding and directing the activities of such multi-center studies, as already demonstrated by many of the Institutes in The National Institutes of Health. This requires a different approach than is currently available through the NIDRR which uses only a peer review system for competing applications. Appropriate advisory groups and study sections are required to organize, review and administrate such research, and often, long-term commitments are required to achieve meaningful results from either clinical research or basic science research which can influence and lead to changes in clinical management. All of these efforts require adequately trained researchers in the clinical and basic science disciplines. It is not surprising that the Department of Education is not interested in training such researchers.

In summary, the American Spinal Injury Association feels there is critical need to have a framework in the National Institutes of Health which will allow us to conduct both clinical and basic science research relating to spinal cord injury and permit oversight of this research by an advisory group and study section. The administrative structure to conduct multi-center studies and train researchers is also important.

APPENDIX 1

Spinal Cord Injury Care Systems*



The Spinal Cord Injury Care Systems and the National Spinal Cord Injury Statistical Center are funded by the National Institute on Disability and Rehabilitation Research



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ARTHRITIS FOUNDATION

TESTIMONY

Presented by

ROWLAND CHANG, M.D., M.P.H.

of

Northwestern University Medical School

and the

Rehabilitation Institute of Chicago

for the

ARTHRITIS FOUNDATION

BEFORE THE

NATIONAL INSTITUTES OF HEALTH

ADVISORY COMMITTEE TO THE DIRECTOR

PHYSICAL MEDICINE AND REHABILITATION RESEARCH PANEL

Bethesda, Maryland

November 20, 1989

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TESTIMONY FOR THE ADVISORY COMMITTEE TO THE DIRECTOR;
PHYSICAL MEDICINE AND REHABILITATION RESEARCH PANEL
BY ROWLAND CHANG, M.D., REHABILITATION INSTITUTE OF CHICAGO
REPRESENTING THE ARTHRITIS FOUNDATION - NOVEMBER 20, 21, 1989.

I WOULD LIKE TO THANK THIS PANEL FOR ALLOWING THE ARTHRITIS FOUNDATION WHICH REPRESENTS AN ESTIMATED 37 MILLION AMERICANS IN THE COUNTRY, THE OPPORTUNITY TO PRESENT TESTIMONY IN SUPPORT OF CREATING A NATIONAL CENTER FOR MEDICAL REHABILITATION RESEARCH (NCMRR) AT THE NATIONAL INSTITUTES OF HEALTH (NIH).

MY NAME IS ROWLAND CHANG. I AM CURRENTLY A PHYSICIAN AND RESEARCHER AT THE REHABILITATION INSTITUTE OF CHICAGO AND SERVE AS A VOLUNTEER WITH THE ARTHRITIS FOUNDATION.

BACKGROUND ON THE ARTHRITIS FOUNDATION AND ARTHRITIS:

"THE MISSION OF THE ARTHRITIS FOUNDATION IS TO SUPPORT RESEARCH TO FIND THE CURE FOR AND PREVENTION OF ARTHRITIS AND TO IMPROVE THE QUALITY OF LIFE FOR THOSE AFFECTED BY ARTHRITIS.

"THE MISSION WILL BE ACCOMPLISHED BY:

- * FUNDING RESEARCH THAT ADDS TO THE SCIENTIFIC KNOWLEDGE ABOUT ARTHRITIS, IT CAUSES AND METHODS OF TREATMENT
- * CONDUCTING EDUCATION PROGRAMS FOR HEALTH PROFESSIONALS TO BETTER UNDERSTAND ARTHRITIS AND EFFECTIVE METHODS OF TREATMENT

- * PROVIDING COMMUNITY EDUCATION AND SUPPORT SERVICES FOR PEOPLE WITH ARTHRITIS AND THEIR FAMILIES
- * INFORMING THE PUBLIC ABOUT ARTHRITIS AND ABOUT THE IMPORTANCE OF EARLY DIAGNOSIS AND TREATMENT
- * ADVOCATING THE INTERESTS OF PEOPLE AFFECTED BY ARTHRITIS
- * SEEKING FUNDS FROM THE PUBLIC TO SUPPORT PROGRAMS AND SERVICES."

THE ARTHRITIS FOUNDATION STRONGLY SUPPORTS BASIC BIOMEDICAL RESEARCH THAT IS CURRENTLY BEING DONE AT THE NATIONAL INSTITUTES OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES. THE FOUNDATION BELIEVES THAT A CURE FOR ARTHRITIS MUST BE FOUND.

HOWEVER, UNTIL A CURE CAN BE FOUND FOR ALL OF THE DIFFERENT KINDS OF ARTHRITIS, THE FOUNDATION STRONGLY BELIEVES THAT REHABILITATION AND DELIVERY OF SERVICES FOR ITS CONSTITUENTS ARE ESSENTIAL SO THAT THE PEOPLE CAN LIVE WITH AS MUCH QUALITY IN THEIR LIVES AS POSSIBLE. TO DATE, REHABILITATION EFFORTS FOR PEOPLE WITH ARTHRITIS HAVE HELPED TO MAKE A DIFFERENCE IN THEIR FUNCTIONAL STATUS AND THEIR QUALITY OF LIFE. BUT, MORE NEEDS TO BE DONE.

HERE ARE THE SOBERING FACTS. OVER 37 MILLION PEOPLE IN THIS COUNTRY SUFFER FROM SOME FORM OF ARTHRITIS WHICH COSTS SOCIETY ABOUT \$35 BILLION PER YEAR. ARTHRITIS CONDITIONS ARE CHRONIC AND OFTEN CAUSE FUNCTIONAL DEFICITS. MANY INDIVIDUALS WITH ARTHRITIS STRUGGLE WITH JOINT IMPAIRMENTS THAT RESTRICT THEIR ABILITY TO

MAINTAIN INDEPENDENT LIVING. IT IS ESTIMATED THAT 70% OF IMPAIRED ELDERLY PEOPLE HAVE ONGOING PROBLEMS WITH ARTHRITIS. WHILE APPROXIMATELY 21% OF THE DISABLED ELDERLY RESIDE IN A NURSING HOME, ALMOST 80% LIVE ON THEIR OWN OR WITH FAMILY AND FRIENDS IN THE COMMUNITY. THE MAJORITY OF CARE IN THE LATTER SITUATION IS UNPAID, NONSKILLED, AND PROVIDED AT HOME PRIMARILY BY WOMEN. THOSE LIVING ALONE WITHOUT INFORMAL CAREGIVERS ARE MORE LIKELY TO BE INSTITUTIONALIZED AS A RESULT OF INADEQUATE OR EXPENSIVE OUTSIDE ASSISTANCE.

IN ADDITION, CHILDREN AND ADULTS UNDER THE AGE OF 65 WITH FUNCTIONAL DEFICITS ACCOUNT FOR 51% OF LONG-TERM CARE PATIENTS. THIS DISABLED YOUNGER POPULATION ALSO LIVES PRIMARILY AT HOME AND RELIES ON CARE FROM OTHERS. THE DISABLED YOUNG AND ELDERLY WITH ARTHRITIS HAVE SIMILAR "LONG-TERM" CARE NEEDS. BOTH GROUPS ARE MORE LIKELY TO REQUIRE NONSKILLED ASSISTANCE IN DAILY ACTIVITIES SUCH AS MEAL PREPARATION, HOUSEWORK, GETTING AROUND IN THE COMMUNITY AND PERSONAL HYGIENE. THEY ARE ALSO LIKELY TO RECEIVE REHABILITATION SERVICES SUCH AS PHYSICAL THERAPY TO INCREASE MOBILITY AND STRENGTH AND OCCUPATIONAL THERAPY TO LEARN ADAPTIVE TECHNIQUES TO COMPENSATE FOR THE ARTHRITIS DEFORMITIES.

WE SUPPORT THE MOVEMENT TO CREATE A NATIONAL CENTER FOR MEDICAL REHABILITATION RESEARCH BECAUSE WE BELIEVE THAT SUCH RESEARCH WILL EVENTUALLY LEAD TO IMPROVE QUALITY OF LIFE OF THOSE AFFECTED BY ARTHRITIS AS WELL AS REDUCE THE ABOUT MENTIONED BURDEN TO SOCIETY.

OVERVIEW:

FEDERAL LEGISLATION HAS BEEN INTRODUCED THAT WOULD AMEND TITLE IV OF THE PUBLIC HEALTH SERVICE ACT, ADDING THE "NATIONAL CENTER OR MEDICAL REHABILITATION RESEARCH" (NCMRR) WITHIN THE NATIONAL INSTITUTES OF HEALTH (NIH). IN THE HOUSE OF REPRESENTATIVES, REP. WALGREN (D-PA) INTRODUCED H.R. 4013 AND IN THE SENATE, SENATOR KENNEDY (D-MA), CHAIRMAN OF THE SENATE LABOR AND HUMAN RESOURCES COMMITTEE, INCLUDED IN HIS BILL, S. 2222, A PROVISION TO CREATE A NCMRR WITHIN THE NIH. RECENTLY, THE SENATE COMMITTEE FAVORABLY REPORTED OUT ITS BILL FOR FULL SENATE CONSIDERATION. THE ARTHRITIS FOUNDATION WHOLEHEARTEDLY SUPPORTS THESE INITIATIVES.

IF MANDATED, NCMRR WOULD:

- * ENHANCE THE SCIENTIFIC PROGRAM OF REHABILITATION MEDICINE BY HAVING THE MEDICAL RESEARCH LED BY THE NATIONAL INSTITUTES OF HEALTH
- * CONSOLIDATE RESEARCH IN MEDICAL REHABILITATION INTO ONE FACILITY AND ENCOURAGE THE INTERACTION OF BASIC AND CLINICAL SCIENCE IN THIS AREA
- * PROVIDE A LEVEL OF VISIBILITY TO MEDICAL REHABILITATION WHICH COULD ENHANCE ITS DEVELOPMENT IN THE MEDICAL COMMUNITY AND AT THE FEDERAL LEVEL
- * LEAD THE WAY IN PREVENTING AND MINIMIZING THE EFFECTS OF DISABILITY AND IN REMOVING BARRIERS TO FULL SOCIAL AND ECONOMIC PARTICIPATION BY AMERICANS WITH DISABILITIES.

BEFORE DISCUSSING MEDICAL REHABILITATION RESEARCH, LET ME FIRST DESCRIBE TO YOU A MODEL WHICH HAS PROVIDED A USEFUL CONTEXT FOR MY OWN UNDERSTANDING OF HOW REHABILITATION FITS INTO THE HEALTH CARE AND HEALTH SCIENCE UNIVERSE. IT INCLUDES THE CONCEPTS OF IMPAIRMENT, DISABILITY, AND HANDICAP DEFINED BY A WORLD HEALTH ORGANIZATION COMMITTEE DURING THEIR DELIBERATIONS ON HEALTH.

IMPAIRMENT. IMPAIRMENT IS DEFINED AS ANY LOSS OR ABNORMALITY OF PSYCHOLOGIC, PHYSIOLOGY, OR ANATOMICAL STRUCTURE OR FUNCTION. IMPAIRMENT SIGNIFIES THAT A PATHOLOGICAL STATE IS EXTERIORIZED TO CAUSE DISTURBANCE AT THE ORGAN LEVEL. THE SUBCLASSES OF IMPAIRMENT INCLUDE INTELLECTUAL, PSYCHOLOGICAL, LANGUAGE, AURAL, VISCERAL, SKELETAL, DISFIGUREMENT AND SENSORY.

DISABILITY. THIS INCLUDES ANY RESTRICTION OR LACK OF ABILITY TO PERFORM AN ACTIVITY IN THE MANNER CONSIDERED NORMAL. DISABILITIES REPRESENT DISTURBANCES AT THE LEVEL OF THE PERSON AND THE PRINCIPAL SUBCLASSES ARE CONCERNED WITH BEHAVIOR, COMMUNICATION, PERSONAL CARE, LOCOMOTION, BODY DISPOSITION, DEXTERITY, AND PARTICULAR SKILLS.

HANDICAP. A HANDICAP IS A DISADVANTAGE FOR ANY INDIVIDUAL, RESULTING FROM AN IMPAIRMENT OR DISABILITY, THAT LIMITS OR PREVENTS THE FULFILLMENT OF A ROLE THAT IS NORMAL (DEPENDING ON AGE, SEX, AND SOCIAL AND CULTURAL FACTORS) FOR THAT INDIVIDUAL. HANDICAPS ARE CONCERNED WITH INTERACTION AND WITH ADAPTATION TO SURROUNDINGS. THEY REPRESENT SOCIALIZATION OF ILLNESS EXPERIENCE

AND OCCUR, THEREFORE, WHEN THERE IS INTERFERENCE WITH THE ABILITY TO SUSTAIN WHAT MIGHT BE DESIGNATED AS SURVIVOR ROLES, INCLUDING ORIENTATION, PHYSICAL INDEPENDENCE, MOBILITY, OCCUPATION, SOCIAL INTEGRATION, AND ECONOMIC SELF-SUFFICIENCY. A MODEL WHICH SYNTHESIZES THE ABOVE ELEMENTS AND EXPLICITLY INCLUDES DISEASE ACTIVITY WAS PROPOSED BY MATTHEW LIANG AT AN ARTHRITIS REHABILITATION RESEARCH CONFERENCE CO-SPONSORED BY THE ARTHRITIS FOUNDATION IN 1987.

DISEASE ACTIVITY X TIME - DISABILITY - HANDICAP - DEATH

FIGURE. A CONCEPTUAL MODEL OF THE CONSEQUENCES OF DISEASE (FROM LIANG, 1987)

LET US CONSIDER RHEUMATOID ARTHRITIS IN THE MODEL. SINCE RHEUMATOID ARTHRITIS PRESENTLY HAS NO CURE, THE MANAGEMENT OF RA IS DIRECTED AT TREATING OR PREVENTING THE ADVERSE CONSEQUENCES OF DISEASE. TREATMENT CAN BE APPROACHED BY ATTEMPTING TO ALTER DISEASE ACTIVITY, OR THE RESULTING JOINT IMPAIRMENT, FUNCTIONAL DISABILITY, AND/OR HANDICAPS. THUS ONE WAY OF CONSIDERING THE WIDE VARIETY OF ASSESSMENT AND TREATMENT OPTIONS FOR RA IS TO CONCEPTUALLY CLASSIFY EACH PARAMETER WITHIN THE ABOVE PRESENTED CONCEPTUAL MODEL.

THE ADVANTAGES OF THIS PERSPECTIVE IN RA ARE ESPECIALLY RELEVANT TO INTERDISCIPLINARY TEAM CARE WHICH THE ARTHRITIS FOUNDATION AND REHABILITATION PROFESSIONALS VIGOROUSLY SUPPORT. FIRST, THE MODEL DEFINES THE BREADTH OF KNOWLEDGE AND PERSPECTIVE OF THE

COLLECTIVE GROUP. SECOND, ALTHOUGH NO SINGLE HEALTH PROFESSIONAL IS CAPABLE OF BEING EXPERT IN ALL ASPECTS OF ARTHRITIS ASSESSMENT AND CARE, EACH HAS A PARTICULAR LEADERSHIP ROLE TO PLAY IN THE MANAGEMENT DEPENDING ON WHERE THE PATIENT PROBLEMS FALL WITHIN THE MODEL. THUS THE RHEUMATOLOGIST IS PARTICULARLY WELL SUITED TO ASSES AND TREAT DISEASE ACTIVITY. THE ORTHOPEDIC SURGEON CAN NOW PROFOUNDLY AFFECT A CONSEQUENCE OF DISEASE ACTIVITY, JOINT IMPAIRMENT, I.E. A DESTROYED HIP OR KNEE JOINT. REHABILITATION PROFESSIONALS SUCH AS PHYSIATRIST, PHYSICAL THERAPISTS, OCCUPATIONAL THERAPIST, SOCIAL WORKERS, CLINICAL PSYCHOLOGISTS, SPEECH PATHOLOGISTS, ORTHOTIST, AND VOCATIONAL COUNSELORS EXPERIENCED IN ARTHRITIS CARE ARE EXPERT IN ASSESSING AND TREATING THE DISABLING AND HANDICAPPING CONSEQUENCES OF JOINT IMPAIRMENT. THIRD, THE MODEL EXPLICITLY ACKNOWLEDGES THE INTERRELATIONS BETWEEN PROFESSIONALS IN THE MANAGEMENT OF RA. THE WAY A PHYSICAL THERAPIST ASSESSES AND TREATS A PATIENT WITH RA SHOULD BE INFLUENCED BY AN UNDERSTANDING OF THE UNIQUE NATURE OF THE DISEASE PROCESS AND ITS CONSEQUENT AFFECT ON JOINT IMPAIRMENT AND FUNCTIONAL DISABILITY. SIMILARLY, A RHEUMATOLOGIST'S UNDERSTANDING OF RA'S CONSEQUENCES BEYOND THE DISEASE ACTIVITY LEVEL WILL LEAD TO A PERSPECTIVE THAT WILL MAXIMIZE HIS OR HER ABILITY TO HELP RA PATIENTS MANAGE THEIR LIVES.

HOW DOES ONE THINK ABOUT RESEARCH IN THIS MODEL'S CONTEXT? I WOULD CONSIDER ONGOING RESEARCH IN IMMUNOLOGY, BIOCHEMISTRY, AND MOLECULAR BIOLOGY RELEVANT TO THE RHEUMATIC DISEASES AND

SUPPORTED TO A LARGE DEGREE BY THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES AS RESEARCH IN THE DISEASE PROCESS. BIOMECHANICS RESEARCH COULD BE AIMED AT THE DISEASE PROCESS, FOR INSTANCE IN WORK WHICH INVESTIGATES THE RELATIONSHIP BETWEEN ABNORMAL BIOMECHANICAL STRESS ON ARTICULAR CARTILAGE AND OSTEOARTHRITIS. OR IT COULD BE AIMED AT THE IMPAIRMENT IN THIS CASE A DESTROYED JOINT, FOR INSTANCE RESEARCH LEADING TO IMPROVED DESIGNS OF TOTAL JOINT REPLACEMENTS. REHABILITATION RESEARCH CAN BE AIMED AT THE IMPAIRMENT, FOR INSTANCE IN A STUDY OF THE EFFECT OF ULTRASOUND ON KNEE CONTRACTURES. IT OFTEN DEALS WITH DISABILITY, AN EXAMPLE BEING A STUDY DEMONSTRATING THE BENEFICIAL EFFECT OF AEROBIC CONDITIONING ON THE FUNCTIONAL STATUS OF RHEUMATOID ARTHRITIS PATIENTS. ARTHRITIS HEALTH SERVICES RESEARCH OVERLAPS WITH REHABILITATION RESEARCH AND HAS PRIMARILY CONCENTRATED ON INVESTIGATIONS INTO THE DISABILITY AND HANDICAPS (ESPECIALLY ECONOMIC) WHICH RESULT FROM RHEUMATIC DISEASE. ANOTHER WAY OF LOOKING AT THE TOTALITY OF RESEARCH IS THAT BASIC BIOMEDICAL RESEARCHERS DEVELOP AND TEST HYPOTHESES REGARDING DISEASE, REHABILITATION AND HEALTH SERVICES RESEARCHERS DEVELOP AND TEST HYPOTHESES REGARDING IMPAIRMENT, DISABILITY, AND HANDICAP.

WHILE MEDICAL REHABILITATION ULTIMATELY FOCUSES ON THE CLINICAL OR APPLIED SCIENCE, IT DOES INCLUDE THE USE OF AND KNOWLEDGE FROM THE BASIC MEDICAL SCIENCES. FOR EXAMPLE, RESEARCH IN ARTHRITIS REHABILITATION REQUIRES AN UNDERSTANDING OF THE NERVOUS, MUSCULOSKELETAL, BONE, SKIN AND VARIOUS OTHER ORGAN SYSTEMS.

REHABILITATION MEDICINE FOCUSES ON THE DISABLING EFFECTS OF DEGENERATIVE CONDITIONS LIKE ARTHRITIS. REHABILITATION PROFESSIONS ARE CONCERNED ABOUT THE CAUSE AND PROGRESSION OF THE DISABILITY IN ARTHRITIS PATIENTS AND TRY TO FOCUS THEIR EFFORTS ON BOTH ITS PREVENTION AND TREATMENT.

THE NIAMS HAS SUPPORTED AND CONTINUES TO SUPPORT BIOMEDICAL, ORTHOPEDIC, REHABILITATION, AND HEALTH SERVICES RESEARCH THROUGH ITS MANY PROGRAMS INCLUDING INVESTIGATOR INITIATED RESEARCH (R01) AND RESEARCH CENTERS (P30 AND P60), THE MULTIPURPOSE ARTHRITIS CENTER PROGRAM BEING A MAJOR EXAMPLE OF THE BROAD NATURE OF THE RESEARCH THE INSTITUTE SUPPORTS. IN FACT IT IS ESTIMATED THAT ABOUT \$93 MILLION IS BEING SPENT ON MEDICAL REHABILITATION RESEARCH WITHIN ALL OF THE NIH INSTITUTES AND ENTITIES. WHY THEN DO WE NEED A NATIONAL CENTER FOR MEDICAL REHABILITATION RESEARCH AT THE NIH?

ONE REASON RELATES TO THE NATURE OF REHABILITATION.

REHABILITATION IS CONCERNED WITH UNDERSTANDING, PREVENTING, AND TREATING DISABILITY. REHABILITATION PROFESSIONS' GOALS ARE TO RESTORE PHYSICAL AS WELL AS PSYCHOLOGICAL, SOCIAL AND VOCATIONAL FUNCTION. THIS FIELD OF REHABILITATION MEDICINE IS UNIQUE IN THAT IT INVOLVES MORE THAN ANY OTHER DISCIPLINE, A TRUE TEAM APPROACH. TYPICALLY, THE REHABILITATION TEAM INVOLVES PHYSICIANS--PHYSIATRIST, ORTHOPEDIC SURGEONS, INTERNISTS, NEUROLOGISTS, --NURSES, PHYSICAL THERAPISTS, OCCUPATIONAL THERAPISTS, SOCIAL WORKERS, PSYCHOLOGISTS, SPEECH PATHOLOGISTS,

VOCATIONAL COUNSELORS, PROSTHETIST, ORTHOTIST, AND REHABILITATION ENGINEERS. THERE IS MUCH LEARNED BY A REHABILITATION TEAM FORM GROUPS OF PATIENTS WITH NEUROLOGIC IMPAIRMENT FROM STROKE THAT COULD BE QUITE RELEVANT TO THE CARE OF A PATIENT WHO HAS JOINT IMPAIRMENT FORM AN ARTHRITIS CONDITION. FOR INSTANCE, WORK IN MOTOR CONTROL PRIMARILY DONE WITH STROKE PATIENTS MAY GIVE US INSIGHTS INTO BETTER EXERCISE TRAINING REGIMENTS FOR PATIENTS WITH ARTHRITIS.

WHILE THERE IS GOOD REHABILITATION RESEARCH BEING SUPPORTED BY THE NIH, THERE IS NO COORDINATING BODY WHICH COULD FACILITATE THIS KIND OF INTERDISCIPLINARY AND CROSS IMPAIRMENT THINKING THAT COULD LEAD TO GREAT ADVANCES IN DISABILITY TREATMENT STRATEGIES. A CENTER FOR MEDICAL REHABILITATION RESEARCH AT THE NIH COULD FILL THIS VOID.

A SECOND REASON FOR THE CENTER CONCERNS THE RIPENESS OF THE FIELD FOR A GREAT LEAP FORWARD IN ITS SCIENTIFIC UNDERPINNINGS. MEDICAL REHABILITATION IS A FIELD THAT HAS ONLY BEEN IN EXISTENCE FOR 42 YEARS. IT IS GROWING IN IMPORTANCE AND ONE THAT YIELDS GREAT PROMISE TO HEALTH CARE IN THIS COUNTRY.

AS OPPOSED TO 10 YEARS AGO, MANY GOOD YOUNG PHYSICIANS AND PH.D.S ARE BEING RECRUITED INTO THE FIELD. FOR REHABILITATION TO BE RECOGNIZED AS A "CREDIBLE" SCIENCE WITH STANDING AT OUR COUNTRY'S MOST VISIBLE SCIENTIFIC ENTITY, THE NIH, WOULD CREATE THE RIGHT SIGNAL FOR YOUNG AND BRIGHT INVESTIGATORS CONTEMPLATING A

REHABILITATION RESEARCH CAREER.

ADVANCES IN REHABILITATION RESEARCH ARE CRITICAL TO IMPROVING THE QUALITY OF LIFE FOR PEOPLE WHO HAVE ARTHRITIS. THE PROPOSED NCMRR LOCATED WITHIN THE PRESTIGIOUS BIOMEDICAL RESEARCH ENVIRONMENT OF NIH WOULD GREATLY FACILITATE ACHIEVEMENTS IN THE REHABILITATION FIELD.

CURRENTLY, THE ENTITY PROVIDING THE FOCAL POINT FOR MEDICAL REHABILITATION RESEARCH IS HOUSED WITHIN THE DEPARTMENT OF EDUCATION AND IS CALLED THE NATIONAL INSTITUTE OF DISABILITY AND REHABILITATION RESEARCH (NIDRR). BECAUSE THIS INSTITUTE IS HOUSED AT THE DEPARTMENT OF EDUCATION (DOED), ITS MISSION TENDS TO HAVE EDUCATIONAL AND VOCATIONAL EMPHASIS. VERY LITTLE OF ITS FUNDING WHICH RUNS ABOUT \$50-55 MILLION PER YEAR-- IS DEVOTED TO THE BASIC OR CLINICAL MEDICAL REHABILITATION RESEARCH. THE FUNDING PRIORITIES IN THIS AGENCY HAVE BEEN (INCONSISTENT) AND FLUXUATE GREATLY FROM YEAR TO YEAR. THIS IS NOT A GOOD AMEN FOR THE BUDDING SCIENCE OF REHABILITATION MEDICINE.

MEDICAL REHABILITATION RESEARCH TRULY NEEDS THE LEADERSHIP AND RESOURCES FOR SCIENTIFIC MANAGEMENT.

- * SCIENTIFIC AND CONSUMER ADVISORY COUNCILS
- * WELL ESTABLISHED PEER REVIEW SYSTEMS FOR THE MANAGEMENT OF GRANT AWARDS
- * THE USE OF EXPERIENCED MEDICAL RESEARCH PERSONNEL AT THE NIH TO ASSIST IN THE DEVELOPMENT OF RESEARCH PROGRAMS AND PROJECTS, AND
- * THE USE OF NIH PLANNING TECHNIQUES, INVOLVING THE SCIENTIFIC COMMUNITY TO FOCUS ON THE USE OF FUNDS IN PRIORITY AREAS.

WITH THESE ITEMS IN PLACE, THE POTENTIAL FOR MEDICAL REHABILITATION RESEARCH IS PHENOMENAL. THIS POTENTIAL IS CRITICAL TO OUR ABILITY TO DELIVER EFFECTIVE AND EVER-IMPROVING MEDICAL CARE TO THOSE WITH CHRONIC DISEASES AND DISABILITY-LIKE ARTHRITIS.



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TESTIMONY ON BEHALF OF THE ASSOCIATION OF ACADEMIC PHYSIATRISTS

TO: Physical Medicine and Rehabilitation Research Panel,
Advisory Committee to the Director of NIH

DATE: November 20, 1989

BY: Randall L. Braddom, M.D. President, AAP

VP of Medical Affairs, Moss Rehabilitation Hospital
Chairman of PM&R Dept., Albert Einstein Medical Center
Assoc. Prof. and Deputy Chairman, Dept. of PM&R,
Temple University, Philadelphia, Pennsylvania.

I appreciate very much the opportunity to testify before you today. I represent the 600+ members of the Association of Academic Physiatrists (AAP). A Physiatrist is a medical specialist in the field of Physical Medicine and Rehabilitation (PM&R). Time does not permit a full explanation of the field of PM&R, but I believe it is explained in other presentations today.

The AAP was founded in 1967 to serve as the national organization of those physiatrists who are affiliated with medical schools. The AAP is a member organization of the Association of American Medical Colleges (AAMC). The objectives of the AAP are to promote the advancement of teaching and research in PM&R in the academic environment. The organization acts as a sounding board and forum for the exchange of ideas and information in all phases of the art and science of PM&R. It promotes the distribution of information to young physicians who will be practicing this art and science for the benefit of the public health and welfare. The organization also assists in the exchange of information from other areas of medicine, both in basic science and in clinical areas of teaching and research.

Members of the AAP are required to be physicians qualified to practice medicine in a country of the North American continent. They must also be a diplomate of the American Board of Physical Medicine and Rehabilitation (or of the equivalent group in their country). A member must also hold an academic appointment as a physiatrist in a North American Medical School. Residents and Fellows in PM&R can be Associate members.

The AAP is a very active and growing organization that holds two meetings of its members each year. One is held in the Fall in conjunction with the annual sessions of the American Academy of PM&R, and one in the Spring that focuses on an issue of current interest in physiatric research, education or academic medical practice. The AAP also publishes an official journal, the American Journal of Physical Medicine.

The whole field of PM&R and academic physiatrists are growing rapidly. From humble beginnings some 50 years ago, PM&R has shown steady growth, due mainly to the ever increasing need for physiatric services. Our society will continue to have increasing numbers of individuals with handicapping conditions. This is due not only to the "graying" of America that will continue until at least the year 2020, but also due to improved medical technology that saves lives that previously would have been lost. The elderly and those of all ages who make up this growing list of "survivors" need and are beginning to demand rehabilitative services.

There are three great branches of medicine; preventive, curative-management and rehabilitative. Each is a critical component of any formula for American medicine that offers "quality of life." Merely saving life and creating survivors cannot be the whole purpose of medicine in an advanced and ethical nation. Our medical system cannot be designed just to save lives. It must also have programs in place to reduce the impact of residual impairments on the quality of life. We have a duty to disabled Americans who ask for an improved quality of life; a life of independence, and a chance to live out their own personal American dream. They are seeking the kinds of rehabilitative help that restore freedom of choice and action. They ask for a chance to regain the freedom that was taken away from them not by political tyranny, but by congenital and acquired physical impairments.

It is the belief of the AAP that the NIH needs to play a critical role in the future rehabilitative efforts of this nation. The NIH can do this by developing a Rehabilitation Medicine Center that has a clear Mission Statement, as well as a plan developed jointly with the rehabilitation medicine scientific community.

One of the initial goals of such a center should be to foster the development of a group of rehabilitation scientists. Clearly we cannot meet the demands of the disabled community in the future unless we have a much larger group of qualified rehabilitation scientists. Other goals of the center should include helping to integrate the work of basic scientists and clinical scientists in rehabilitation; and the development of a program for peer review of rehabilitation grant applications.

While the AAP greatly appreciates the work and dedication of the NIDRR and pledges its continued support for NIDRR programs, it feels that a center within the NIH is essential to the future needs of our nation for adequate rehabilitation research. The NIH should establish a structure that fosters research training, research funding and a long range blueprint for action in the form of research planning. Such a center could also be a focus for rehab-related work that is already going on in the NIH. Rehab research in the NIH at this time lacks an overall plan and is splintered over many institutes.

The academic portion of the PM&R community appreciates very much the opportunity to present its viewpoint to the panel today, and also to endorse the comments by representatives of the American Academy of Physical Medicine and the American Congress of Rehabilitation Medicine.

Thank you, and I would be happy to respond to questions.

R Braddom MD

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President
Association of Academic Physiatrists

Association For Research In Otolaryngology

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Statement to

Panel On Physical Medicine and Rehabilitation Research

Murray B. Sachs

November 20, 1989

AAO-ARO Research Forum

September 25-26, 1989
New Orleans, Louisiana

ARO Midwinter Meeting

February 4-8, 1990
St. Petersburg Beach, Florida

Thank you for the opportunity to appear here today. I am representing the Association for Research in Otolaryngology, a 1000 member organization devoted to the advancement of basic, clinical and applied research in the areas of hearing, balance, speech, language, taste and smell. The members of the Association include basic scientists, clinical scientists, physicians and other clinicians, educators and experts in the rehabilitation of persons handicapped by disorders in all of these areas. I myself am a basic hearing scientist, who has served on a number of NIH review and planning panels and have recently been a member of a committee studying the role of rehabilitation medicine at the Johns Hopkins School of Medicine. I shall not comment on the role of the proposed new Center, but only on the crucial importance of maintaining a high level of rehabilitation research within the newly created National Institute of Deafness and other Communication Disorders.

Public Law 100-553, Oct. 28, 1988, which established the NIDCD, repeatedly charges the Institute with responsibilities in the area of rehabilitation research. The reason for the emphasis on rehabilitation in the Institute's charter should be obvious: our constituency represents one of the largest, if not the largest, group of handicapped Americans. There are more than 20 million hearing impaired persons alone and that number is growing with the increasing age of our population. The joy of our task is that very significant rehabilitation of a vast majority of these impaired persons is either currently possible or is clearly within the realm of the feasible in the foreseeable future.

However, even the application of currently available techniques of rehabilitation require a sophisticated knowledge of the principles of function of the special sensory and cognitive systems responsible for

hearing, balance, speech, language, taste and smell and of the handicapping disorders of these systems. Let me give you a brief example of the importance of maintaining rehabilitation research in an environment of the highest sophistication with regard to the processes of the special senses. It would probably not surprise you to know that one of the greatest unmet challenges facing us today is the development of a hearing aid that can allow effective communication in the kinds of noisy environments in which we all live. At first blush this problem seems like a simple technological one. Integrated circuits, more efficient power sources, amplification of signals. Not quite so simple say those of you somewhat more familiar with the problem-- what is needed are some frequency-selective filters to boost the sound in frequency bands where the hearing impaired person has suffered most loss. Simple enough in the new age of digital devices, you say. All sorts of digital hearing aids have been tried and still the problem is little closer to solution than it was ten years ago. The problem lies in the complexity of the mechanisms responsible for converting sound waves into perception. Specifically, there are nonlinear mechanisms in the inner ear which allow us to discriminate sounds in noisy backgrounds. These mechanisms appear to be very susceptible to insult and thus are absent in many if not all forms of inner ear deafness. The solution to many problems of the hearing aid may be building systems which can emulate these inner ear nonlinearities. Thus, we have a clear case where where the solution to the rehabilitation problem can only be adequately addressed by a team which includes real experts in the underlying basic sciences as well as in the state-of-the-art technology. Such a team needs, I believe, an environment of intense communications sciences research such as that provided by the programs of the NIDCD.

A closely related problem is the rehabilitation of the profoundly deaf person

following implantation with an inner ear electrical stimulation device. Such a device stimulates what neural elements remain in the deafened ear directly with electrical currents. The currently available implant devices provide only a very rough simulation of the signals produced by the normal ear, and yet results with some subjects are enormously impressive, so that considerable attention is being paid to developing strategies for both optimizing the implant signal processing for the individual subject and to developing the methods of training subjects to use the information provided by the implant in an optimum manor. Progress in this promising area requires the work of highly skilled audiologists who can fully understand operation and limitations of both subject and device. I believe strongly that such skill and understanding are achieved best in the context of a research and clinical environment dedicated to a broad attack on problems of communications disorders.

Similar examples can be found in rehabilitation from disorders of balance, speech, language and the chemo-senses. We in the ARO would urge, therefore, that nothing be done to diminish the charge of 100-553 to the NIDCD to continue and expand its efforts in the area of rehabilitation.

STATEMENT

OF THE

ASSOCIATION OF AMERICAN MEDICAL COLLEGES

PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

NOVEMBER 20, 1989

Statement by: Laurence E. Early
Chairman, Department of Medicine
School of Medicine
University of Pennsylvania



Association of American Medical Colleges / One Dupont Circle, N.W. / Washington, D.C. 20036 / (202) 828-0525

My name is Laurence E. Earley. I presently serve as Chairman of the Department of Medicine at the University of Pennsylvania School of Medicine. Today, I appear as a representative of the Association of American Medical Colleges. Since its founding in 1876, the Association has steadily expanded its horizons so that today it represents the whole complex of individual organizations and institutions charged with undergraduate and graduate education of physicians. It serves as a national voice for the 126 accredited medical schools and their students; the 420 major teaching hospitals in the United States; and 92 academic and professional societies whose members are engaged in medical school teaching, patient care and biomedical research.

My views on the matters before this panel have been shaped by recent personal experience. During my tenure as Chairman of the American Board of Internal Medicine (ABIM) in 1987, I was involved in initiating an effort to establish standards and criteria for a combined training and certification in Physical Medicine and Rehabilitation (PM&R) and Internal Medicine. This dual pathway for graduate medical education has now been approved by both certifying boards. More recently, I have served for more than two years as interim Chairman of the Department of Physical Medicine and Rehabilitation at the University of Pennsylvania. These roles have increased my awareness of the

importance of rehabilitation to the delivery of complete medical care and of the potential breath for applying rehabilitation in many disciplines of medicine.

The Association applauds the decision by the NIH to hold this conference at this time on this set of issues. As this audience is well aware, rehabilitation is a pervasive dimension of the treatment of a vast number and variety of diseases and disabilities. Until relatively recently, physicians failed to perceive the enormous differences in patient outcome that rehabilitation can make. In fact, the founder of modern rehabilitative medicine, Dr. Howard Rusk, died only last month. But as the value of PM&R became increasingly apparent, so also physicians began to recognize that limitations on available knowledge precluded more effective therapy in many areas; those pioneers who had become aware of the extent to which recovery from illness or injury was incomplete have taught us to recognize the magnitude of the problem, the inadequacy of the existing knowledge base, the limited armamentarium to attack the problems and the urgent need for research to illuminate more clearly the nature of the problems and to create appropriate solutions.

This morning's historical recapitulation of the evolution of the engagement of the NIH with research in PM&R has been most informative. Clearly a substantial and growing commitment has been made, and important progress has ensued. But, as in so many

other fields of biomedicine, we continue to confront new challenges as well as rich opportunities. There should be no question that research efforts in the broad area of rehabilitation should be intensified.

The question of how best to represent this effort in the organizational structure of the NIH is one on which my expertise certainly is limited. However, the major organizing principle at the NIH has clearly been disease or category of disease--cancer, heart disease, arthritis, infectious disease, neurological disease, blindness--while research in rehabilitative medicine is orthogonal to this principle; rehabilitation, like etiology, pathogenesis and diagnosis, is one aspect of almost every disease or category of disease. Therefore, sophisticated research in this area is, almost of necessity, multidisciplinary and reliant on specialized and subspecialized expertise in both preclinical and clinical sciences as well as in disciplines entirely outside of medicine, such as engineering. As our horizons in this arena extend beyond the current conceptual framework, for example, to "turning on" long dormant regenerative processes, recruitment from additional scientific disciplines will be essential. Frequently, at least in my experience, the composition and talents of the team that tackles a rehabilitation problem in one specific category of disease will be quite different than that for another category. Thus, I personally, and the AAMC institutionally, believe that research in rehabilitation should

be initiated, stimulated, nurtured, supported, overseen and managed as part and parcel of the mainstream research programs in each of the several categorical institutes.

Despite this very diverse nature of rehabilitation there is the common goal of achieving the highest possible level of function following acute illness or trauma. Thus, a focused effort to bring as much coordination and coherence as possible to this inherent diversity would be highly desirable. This might best be accomplished through an appropriately staffed coordinating office charged with:

- compiling and periodically publishing an overview, such as presented today, of the current research activities of the NIH, of other Federal agencies such as Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), National Institute of Disability and Rehabilitation Research (NIDRR), and the Veterans Administration, and of the private sector.
- compiling and publishing, in collaboration with the National Library of Medicine, recurrent bibliographies of research in rehabilitation, categorized by specific medical disciplines.

- consolidating and reporting data on the research training programs of the various federal and non-federal sponsors of rehabilitation research.
- commissioning timely critical reviews in areas of intense activity, interest or productivity.
- sponsoring meetings, such as this one, that facilitate dialogue between the rehabilitation research community and its major sponsors.

The discharge of these functions, valuable in their own right, might also facilitate the convergence of related areas of research and maximize cohesion amid diversity. It could be of help to each of the national institutes and other sponsors of research in identifying areas of research need and would certainly be a stimulus as well as an important source of information to the research community.

Some such function for coordination could perhaps be constituted under the aegis of the National Institutes of General Medical Sciences (NIGMS) whose charter authorizes it to function in areas "which have significance for two or more other national research institutes or are outside the general area of responsibility of any other national research institute."

Alternatively, a focus for coordination might be created within the Office of the Director, NIH.

The AAMC also applauds the decision of the NIH to convene this conference because it believes the process underway to be precisely the best way to examine research priorities and to probe the effectiveness of the agency in dealing with a set of problems that, at least in the opinion of a large segment of the biomedical research community, deserves attention. In 1983, the Institute of Medicine's Committee for a Study of the Organization Structure of the NIH requested comments on its assignment from, among others, the Association I represent today. The AAMC's response, developed at the September 15, 1983 meeting of its Executive Council strongly recommended the use of a procedure such as that in which we are now engaged, for a variety of cogent reasons. I have appended an extract of the Association's comments to my statement. The Ebert Committee's recommendation that "the Director of NIH should establish an NIH-wide mechanism to (1) keep abreast of the views, concerns and proposals of the NIH scientific and public constituencies' (2) assess their potential implications for NIH and its functioning; and (3) plan responses" seemed entirely consonant with the AAMC recommendation to it that "the NIH extend and formalize their current procedures to receive, evaluate and appropriately publicize proposals by advocacy groups for modification in program content, emphasis or priority." Today's meeting fits both recommendations.

I'd be pleased to respond to any question the Committee might wish to ask.

Thank you.

The Organization of the National Institutes of Health
Comments by the Association of American Medical Colleges

Pressure for the establishment of new national institutes at the National Institutes of Health (NIH) have increased significantly in recent years. Uncertainty as to what criteria should be met to justify a new organizational unit and dis-ease to the consequences of a rapid proliferation of new institutes brought a request to the National Academy of Sciences (NAS) and its Institute of Medicine (IOM) for advice. The latter, in turn, has invited comments from interested organizations, including the Association of American Medical Colleges (AAMC).

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Constraint on Proliferation

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Over short periods, the annual cycles of budget development provide a reasonable basis for accommodating scientific progress. However, to improve the fidelity with which program content tracks scientific progress, the AAMC suggests that:

the NIH extend and formalize their current procedures to receive, evaluate and appropriately publicize proposals by advocacy groups for modifications in program content, emphasis or priority.

and

.....

First, the forum. It is established policy at the NIH to be open to suggestions from all quarters. But interactions between special interest advocates and NIH officials have not been systematically documented, nor have the context and outcomes of the discussions been made generally available. Some special interest groups are well organized, funded and staffed, their areas of concern are concordant with major NIH program emphasis; they share a large set of common interests as well as a very common information base with NIH officials; the magnitude and

urgency of the problems to which they are committed, as well as the size of the NIH commitment to these problems, are matters of which the NIH, the scientific community and the public are widely aware. Clearly, these groups have no major problems, and require no special processes, to have their day in court. The proposal for some kind of a forum, however, would encourage less powerful groups to interact officially and publicly with the NIH. Thus, the NIH could reap the benefit of the information and insights of organizations focused intensely on problems of diseases that, while perhaps less frequently encountered, account for significant mortality and morbidity and profound human tragedy. Interaction with these groups would also provide the NIH the opportunity to examine and display the extent of its engagement with the problem under discussion, a mutually useful exercise. The records of such meetings, with the views of both parties on the state of research in the field, would be useful to others besides the participants: the scientific community at large should find the information valuable in assessing the validity of NIH program priorities; the higher levels in the Executive Branch should welcome the inclusion of material from these interactions in budget justifications; and the Congress should find enlightening the discussion between the NIH and the special interest advocates on the scientific issues at stake.

The absence of a formal and visible public forum for presenting claims on the NIH budget increases the credibility of claims that access to a fair, impartial, objective hearing is not possible; and, thereby, it invites political intervention. The creation of a process of the type suggested would not only enhance the public trust in the integrity and fairness with which the national research enterprise is managed, but also increase the sensitivity with which the annual budget process adjusts program priorities.

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TESTIMONY TO THE PANEL

PHYSICAL MEDICINE AND REHABILITATION RESEARCH

NATIONAL INSTITUTES OF HEALTH, BETHESDA, MARYLAND

November 20, 1989

Testimony of the Association of Rehabilitation Nurses

Shirley P. Hoeman, Ph.D., M.P.H., RN, CNA, CRRN
Chairman, RNF Research Committee

The Association of Rehabilitation Nurses (ARN) is an international organization of more than 6,500 professional nurses. ARN's mission is to promote and advance professional rehabilitation nursing practice through education, advocacy, and research; and to enhance the quality of life of those affected by disability. The Rehabilitation Nursing Foundation (RNF) is the research and development foundation of rehabilitation nursing. Each year RNF awards grants for rehabilitation nursing research using a competitive peer review process.

One of the hallmarks of scientific research evaluation is a review of the merits and design of research proposals by a group of peers, including content experts. Peer review includes both the research design and the significance of the content or merit of the idea. Because rehabilitation research has unique aims it should be reviewed by peers knowledgeable in the principles and concepts of rehabilitation, as well as in the construct of research design.

The goals are to improve outcomes of care and quality of life for clients, prevent further disabilities or complications, promote health protection and maintenance, and develop cost-effective assistive devices or technology. Theoretically, peer review in rehabilitation would direct rehabilitation research funding toward rehabilitation concerns and consumer/client benefits.

Rehabilitation research includes both basic and applied investigations of phenomena that cross disciplines. Research leads to usable knowledge about factors that make a difference in how well clients actually live out their lives with chronic or disabling conditions. Rehabilitation research seeks to explain and predict barriers whether physical, psychosocial, or societal, that prevent individuals from realizing their optimal potential for independent living and quality of life.

Rehabilitation research improves the scientific base and expands the scope and depth of knowledge about rehabilitation. It has unique foci that address the scope of consequences following disabilities. These include: interactions and multiple variables in response to physical and biopsychosocial phenomena, the readjustment process of clients and their families following

disability, technology and assistive devices or techniques, self-directed care, and lifelong management.

Medical rehabilitation depends upon interdisciplinary collaboration in research and practice. Collaboration among various disciplines is a unique characteristic of rehabilitation research projects. Because of this, a principal investigator, whether nurse, physician, or other member of the interdisciplinary team, may encounter difficulties locating sources or obtaining funding when opportunities are scattered among numerous granting sources. For example, requests for proposals may be incorporated under age or disease listings rather than under headings specific to rehabilitation.

In some instances, potential funds for rehabilitation research may be administered by agencies whose priorities do not address or accomplish the distinct needs of rehabilitation professionals and consumers. Funding priorities are often set in response to the larger goals derived from the agency's special interest. Changes of funding priorities are also dictated by overall strategic goals of an agency. The result may jeopardize organized approaches for rehabilitation research. Funding of rehabilitation research from multiple sources contributes to duplication or fragmentation of research efforts.

Moreover, fragmentation may impede the diffusion of new knowledge among the community of rehabilitation scholars. It is our belief that individual and collaborative research data from multiple disciplines must contribute to a unified scientific body of knowledge about rehabilitation practices. Researchers need opportunities in their areas of expertise as well as in meeting overall program priorities, provided the research contributes to the body of knowledge. It is critical to achieve balance between both individual and program research and basic or applied research.

There is a need for new measures of cost effectiveness that extend beyond traditional measures of length of stay and basic functional abilities; beyond tabulations of the actual dollars expended. This means that funding must be available for longitudinal research studies that investigate outcomes of therapeutic interventions over time. Chronic and disabling disorders are lifelong; clients are changing and developing individuals.

Client participation in setting priorities is to be encouraged so research findings can eliminate physical, societal, and psychological barriers. Findings can be used to improve the physical and socioeconomic access of disabled persons, as well as to promote the societal value of disabled persons as individuals, rather than labeled as diagnostic categories. Additionally, funds designated for rehabilitation research may mistakenly compete with funds for services to the same clients. Rehabilitation research priorities must be client-centered, not system-driven.

Recommendations:

- A panel of rehabilitation experts that represent the multiple disciplines, including consumer representation, to set short-term and long-term priorities and propose a strategic plan for research agenda, including peer review;

- program and research evaluations for funding based on medical rehabilitation principles and concepts, related to medical rehabilitation priorities. These may expand upon or differ from traditional applied or experimental criteria. For example, long-term outcomes with relative values assigned to quality of life ratings would augment productivity or cost measures.

- centralized data regarding research funds available for medical rehabilitation research; including provisions for collaborative interdisciplinary or multiple discipline research and for individual researchers.

- provisions for dissemination of findings of medical research in a readily retrievable manner. Research data must be retrievable in order to replicate studies and validate findings. Results must be disseminated throughout the rehabilitation research and practice community and to consumers so that research evidence from various disciplines can be incorporated into a unified body of knowledge.

- allocation and awarding of funds for research and education/training of the multiple disciplines which comprise medical rehabilitation.

- seek alternative sources and new pathways for funding of research and education/training for all rehabilitation disciplines.

Thank you for the opportunity to present this testimony.

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PANEL ON

PHYSICAL MEDICINE AND REHABILITATION RESEARCH

November 20, 1989

Statement by:
Geraldine Dietz Fox
Executive Director
Friends of NIDCD

C-87

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Dept. of Otology & Laryngology
Harvard Medical School

ROBERT J. RUBEN, M.D.
Professor and Chairman
of Otolaryngology
Albert Einstein Coll. of Medicine
Yeshiva University

JAMES B. SNOW, M.D.
Professor and Chairman
Dept. of Otolaryngology and
Human Communication
Univ. of PA Medical School

PAUL H. WARD, M.D., F.A.C.S.
Professor and Chief
of H/N Surgery-Otolaryngology
UCLA School of Medicine

Thank you for the opportunity to provide testimony as a representative of Friends of NIDCD--The National Institute on Deafness and Other Communication Disorders of the NIH. Our position is to support the current location of physical medicine and rehabilitation within each of the Institutes of the NIH, and **NOT** to encourage the creation of a "freestanding center" for rehabilitation research at the NIH.

To substantiate the evidence that rehabilitation research is being conducted within the research portfolio of the NIDCD, we can identify almost \$20 million that support studies related to habilitation or rehabilitation of the 33 million Americans suffering from a type of communication disorder. This represents a major commitment of our total research projects, emphasizing the importance our Institute places on this area of research.

When Congress wrote the authorizing legislation for NIDCD, they mandated that the Institute should be responsible for: "research into the evaluation of techniques and devices used in diagnosis, treatment, rehabilitation, and prevention of disorders of hearing and other communication processes." Techniques were further defined by Congress to include "surgical, medical and behavioral approaches." Devices were to include "hearing aids, implanted auditory and nonauditory prosthetic devices, and other communication aids."

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Friends of the National Institute on Deafness and Other Communication Disorders

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We have focused our intelligence, energies, and expertise on this complex, technical, scientific field which requires the management by physicians and researchers who specialize in these disorders.

I would now like to describe one example of this rehabilitation research conducted by NIDCD which only could have succeeded within the context of an "organ or disease" institute. It is the cochlear implant.

This device for electrically stimulating the inner ear of a deaf person, was developed over the past 10 years in our prosthesis research and development program. Research supported by NIDCD developed diagnostic procedures for determining who would benefit from such a device. Clinical trials are ongoing to determine the efficacy of different implant designs.

Built into clinical trials of this type are numerous rehabilitation procedures: (1) to evaluate how much information a patient is receiving through his cochlear implant, and (2) to develop means for improving both the speech reception ability, and the speech production ability, of the patient.

This is only one example of many in deafness and communication disorders to justify the need to keep rehabilitation studies within the respective Institutes. If rehabilitation were separated out, the close collaboration of clinicians and rehabilitation specialists would most likely be fragmented, or possibly lost. It is doubtful that multidisciplinary projects such as I have described with the cochlear implant would even be conceived, let alone supported.

The Friends of NIDCD, whose only goal is to make life better for our communicatively impaired citizens, are strongly in favor of keeping physical medicine and rehabilitation within each respective Institute.

Thank you.

MRS. ALBERT D. LASKER
870 UNITED NATIONS PLAZA
NEW YORK, NEW YORK 10017
TELEPHONE 758-1242

November 6, 1989

Dr. William Raub
Acting Director
National Institutes of Health
Shannon Building
900 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Raub:

I understand that an Advisory Committee will be meeting at the NIH to review the importance and place in the NIH for rehabilitation research.

This is an issue I have been involved with for over 30 years. As a result, I would certainly appreciate it if you would be so kind as to read my statement of support for the record and let the committee members and Chairman Brandt know of my strong feelings about the importance of having a Rehabilitation Research Institute or Center at the NIH.

Thank you very much for your help and support, and warm good wishes to you.

Sincerely,



Mary W. Lasker

Enclosure

The testimony for the Mary Lasker Foundation

is being read for Mrs. Mary Lasker by

Ms. Marguerite Donoghue, Capitol Associates.

Mr. Chairman and members of the advisory panel, I would like to take this opportunity to urge your favorable consideration for the creation of a National Center, or Institute, of Medical Rehabilitation Research at the National Institutes of Health.

I have been a long time supporter of basic medical research at the National Institutes of Health. I have also been a long time supporter and advocate for the disabled and for rehabilitation research.

In the early 1970's I helped to bring together some key individuals interested in doing more in terms of research for the disabled. At the time, rehabilitation activities were housed at the former Department of Health, Education and Welfare, and it was widely believed that more needed to be done in the area of rehabilitation research. It was then that I proposed during those discussions that an Institute for Rehabilitation Research should be housed within the National Institutes of Health. Unfortunately, I was in the minority at the time. The majority felt that it would be far better to house rehabilitation research within the Department of Education so that all of the rehabilitation and handicapped activities could be consolidated under one umbrella.

I firmly believe that my initial reaction was the correct one -- that rehabilitation research and medical research belong together. Not only have we learned that science complements science in all fields, but that the tremendous progress we have made in

neurological, human development, and other molecular and genetic bases of disease benefits those in need of rehabilitation. Cancer, heart disease, blindness, arthritis and many other tragic diseases often require rehabilitation. Rehabilitation is merely an extension, or the result, of our medical research programs.

For those scientists in this up and coming field, the NIH would lend the prestige, visibility, experience and collaboration of efforts between the science disciplines that is needed.

As a result, I urge you to complete what was begun nearly 25 years ago and give to the NIH a Center or Institute for Rehabilitation Research.

Mary Lasker

**Moss Rehabilitation
Medicine, Inc.**

*A professional corporation
providing comprehensive
medical rehabilitation services*

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TO: PHYSICAL MEDICINE AND REHABILITATION RESEARCH PANEL
ADVISORY COMMITTEE TO THE DIRECTOR, NIH

DATE: November 20, 1989

BY: John Whyte, M.D., Ph.D.
Director of Brain Injury Research
Moss Rehabilitation Hospital

C-95

Herbert Avart DO
Randall Braddock MD
M. Evans Brown MD
Jane Dorval MD
Brian Ernstoff MD
Albert Esquenazi MD
Robyn Gansner MD
Gary Goldberg MD
Usha Gulati MD
Anne Idiculla MD
Leonard Kamen DO
Judy Kleppel MD

Raymond Lafontant MD
Nathaniel Mayer MD
Diego Morales MD
Jeanne Pelensky MD
Jeffrey Perkins MD
Harry Schwartz MD
Mary Smith MD
Margarita Torres MD
John Whyte MD PhD
Edward Wikoff MD
Susan Zimmerman MD

My name is John Whyte. I was trained through the federally supported Medical Scientist Training Program (MSTP) at the University of Pennsylvania to be a physician-researcher. My Ph.D. is in experimental psychology. I have long had an interest in recovery of function following central nervous system insults. I chose physiatry for my clinical specialization because of my fascination with the process of recovery (as opposed to any specific disease), a topic that I will return to shortly. For the last 5 years I have worked both clinically and in research in the area of traumatic brain injury, with a particular interest in attentional disorders and psychopharmacology. Today I represent Moss Rehabilitation Hospital, a specialty rehabilitation hospital in Philadelphia that has a strong commitment to rehabilitation research.

We suport the development, within the National Institutes of Health, of a center for rehabilitation research. Such a center is needed for a number of reasons that may be familiar to you. Chronic diseases and disabilities are taking on

increasing importance in the American health care system. There is a significant shortage of trained researchers in rehabilitation, particularly physicians. Furthermore, funding in rehabilitation up until now has focused to a large degree on program development and education and training rather than more scientifically oriented projects.

In order for such a center in NIH to have the desired effects on progress in the field, however, it is important to understand how rehabilitation research differs (and indeed must differ) from the more familiar biomedical model of research. In rehabilitation, our concern is with patient function rather than organ pathology or diagnosis. The process of regaining function may differ markedly among patients suffering from the same disease, or may be quite similar among patients suffering from different diseases. Thus, as I alluded to previously, recovery to a functional state is a topic of research potentially quite separate from the study of individual diseases and their treatments.

Impairments (that is, organ dysfunctions) are the subject of traditional biomedical research, whereas disability and handicap (that is, the effects of disease on the performance of skills and the fulfillment of social roles) are the subjects of rehabilitation research. The connections between impairments (or pathology) and disabilities (or function) are highly complex.

These facts have profound implications for the organization of research in rehabilitation. Global functional outcomes

following hospitalization, such as discharge placement, ability to perform activities of daily living, or employment status are typically the product of multiple interacting factors. For example, a patient with a brain injury may have difficulty obtaining work because of a combination of language impairment, motor weakness, a short temper, loss of a driver's license, and the lack of a good premorbid work history. It is unlikely that a treatment directed at any one of these problems will have a very dramatic effect on employment. Thus, controlled research trials of such treatments will be found "ineffective." In clinical practice we are likely to address all of these problems in combination through an interdisciplinary treatment model. This may be quite effective in improving employment status. Unfortunately, from a research perspective, we are unlikely to find many other patients who suffer from the exact same combination of deficits, so it will be difficult for us to test the efficacy of this particular combination treatment prescription in a controlled fashion, on a group of patients.

The state of rehabilitation research is relatively primitive not only because of lack of resources and training, but because of the inherent complexity of the questions at hand. The important questions in rehabilitation emerge from a functional perspective, spanning a continuum from molecular biology to sociology and, hence, will always be "messier" than questions addressed by the biomedical model.

An NIH center for rehabilitation research can have a profound impact on the field. In order to do so, however, it must not seek to fit the questions of rehabilitation into existing biomedical models. Rather, it must make use of the interdisciplinary clinical expertise in the field to seek new and innovative research strategies. We hope that such a center within NIH can be developed and that it can be a source of stimulation for scientists to begin to grapple with the very real clinical complexities that we and our patients face.



NATIONAL MULTIPLE SCLEROSIS SOCIETY

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Testimony for the November 20, 1989 Meeting of the NIH Panel on Physical Medicine and Rehabilitation Research

Labe Scheinberg, MD
representing the
National Multiple Sclerosis Society

About 90 years ago, S. Freud, a former neurologist, wrote, "People who want to make a living from the treatment of nervous patients must clearly be able to do something to help them".

I come to you as a representative of the National Multiple Sclerosis Society as an outside expert to speak on the issues surrounding physical medicine and rehabilitation research.

The National Multiple Sclerosis Society, founded in 1946, is the only non-profit health organization in the United States supporting programs of national and international research into the cause, prevention, cure and treatment of MS.

The Society has approximately 400,000 members nationwide in 140 chapters and branches. Policies and goals are established by a National Board of Directors consisting of outstanding leaders in the business and professional world, as well as individuals with a personal interest in multiple sclerosis. Society programs and activities are organized in four major areas:

- research to find the cause of the disease and to explore methods of preventing its onset, alleviating its symptoms and halting its

C-101

progression;

- programs and services at the community level for people with multiple sclerosis and their families;
- dissemination of information to people with MS, their families, professionals and the public;
- mobilization of private and public resources in support of these goals.

My credentials are that I am a neurologist who has been dealing with multiple sclerosis patients for almost forty years. Not unlike the character in the Moliere play, "Le Bourgeois Gentilhomme" who learned that he had been speaking prose, said "Good heavens, for forty years I have been speaking prose without knowing it." I feel the same way about my practice of neurology. For forty years I have been practicing rehabilitation without knowing it. It is the only way that I can help most of the conditions that I deal with, in particular multiple sclerosis which is a chronic unpredictable disease of the central nervous system which is usually progressive and results in severe difficulty walking along with a host of other physical and emotional problems. At the present time we have no cure and one does not seem to be imminent despite millions of dollars invested in the effort by the government and voluntary health agencies. I will speak more of this later.

I have been a member of the American Academy of Neurology almost since its founding and am Chairman of its Committee on Disability and Rehabilitation. I helped establish and became the first president of the Section of Neurorehabilitation, of the American Academy of Neurology which is the largest and fastest growing section with over 500 members. We do not intend to make rehabilitation specialists of neurologists but to indoctrinate them with the principles of rehabilitation, or what Rusk called the third phase of medicine after diagnosis and acute care; in other words what one does for the patient

after he has recovered from stroke or injury and before he has returned to work. Personally speaking, I had long been disappointed at my efforts to help people with most disorders of the nervous system. Once a patient has a stroke, serious injury, disease, or defect of the nervous system, such as polio, multiple sclerosis, spinal cord injury, or traumatic brain injury, the cure may stop or slow the progression of the condition but it will not restore the individual to normal activities. For example, with research we have prevented and eliminated polio as a summer fear among individuals, but we are still left with thousands of individuals who have residual paralysis and disabilities. I did not want to transfer my patients to another physician's care and have discontinuous therapy. I wanted to learn the techniques of rehabilitation and continue the care of my patients with whom I had spent years in building a doctor/patient relationship.

The continuum of practice in neurology is (1) diagnose, (2) attempt a cure (usually unsuccessful), and (3) refer for rehabilitation or a nursing home. This has been stated in the vernacular as "diagnose and adios". It is not good medicine. It is not done in psychiatry, pediatrics, cardiology, or most specialties. It can be prevalent in orthopedics and neurologic surgery where the physicians are engaged full time in the episodic care of major catastrophies. We may prevent spinal cord injury and traumatic brain injury with seat belts, laws against driving while intoxicated, etc. but we will be left with the residual population who have already suffered injury and will not recover. The central nervous system does not regenerate and the adult brain does not readily transfer functions from one part to the other.

For disease such as multiple sclerosis, muscular dystrophy, and amyotrophic lateral sclerosis we do not have the means of prevention or cure. And as Dr. George Kraft noted in a recent address to the Consortium of MS Centers, even if we had the cure, considering only the 656 MS patients in the Puget Sound area, we would still require six million patient-years of treatment for this population even if no new cases occurred. Translate this into the more common conditions,

for example neurotrauma, developmental disorders of the nervous system, stroke, and degenerative disorders of the nervous system such as Alzheimer's disease and amyotrophic lateral sclerosis, you will get some idea of the magnitude of the problem. It could not be handled even if every other man, woman and child in the country was a trained rehabilitation professional.

What is to be done? I think that the research must be focused on finding cures so that we do not have new cases and so we might stop the progression of early cases. We have to evaluate the present rehabilitation interventions to determine which are effective and which are labor intensive placebos; we must have more research in technology, rehabilitation and engineering to get better assistive devices; we must have more research in the psychosocial aspects of rehabilitation to motivate patients to help themselves more, to educate families to involve themselves in the restorative efforts, and most important, to provide more basic research in restorative neurology for regeneration and retraining of the nervous system.

11-20-89

TO: PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

FROM: Louise B. McKnew
Director, National Research Institute for Neural Injury
President, Independent Living Assistance, Inc.
Consumer Advocate

With deep appreciation for the opportunity to share my views with you, I will condense them to the five minutes you have allocated. My concerns are as follows:

- The needs of the community which is supposed to benefit from rehabilitation research do not seem to be your priority here. The structure of the committee, the published agenda, and the list of experts you have called to testify manifest scant concern for people whose physical conditions require some form of rehabilitation.

Where are the physically compromised people? There is not one among you, not one among those of us who are here to testify. You have one consumer representative on the panel, and two on the list of "concerned organizations." All others represent the research community, or those who will receive research funds. I worry that you will create a self-serving fiefdom, a new Center dedicated to the interests of rehabilitation specialists, one that perhaps will enhance intellectual credibility, professional status, or financial power. But not one whose priority includes the disabled population.

- The establishment of a new Center appears to place, erroneously, the focus on technique. Rehabilitation is not one discipline. Rather, the term serves to identify those efforts designed to preserve and extend the capabilities of people whose bodies have been severely damaged. The rehabilitation requirements are dictated by the specific problem, and whatever research is mounted should be determined by the problem, not on the technique. What common denominators are involved in heart rehabilitation research, cancer rehabilitation research, spinal cord injury research? What demands of the investigators, other than the self serving ones, call for consolidation into a rehabilitation research center?

- The limited funds now allocated for neurological rehabilitation research will be funnelled off into the sexier cancer or heart research. Further, researchers go where the money is, and those now investigating central nervous system problems will be syphoned off into the more lucrative fields.

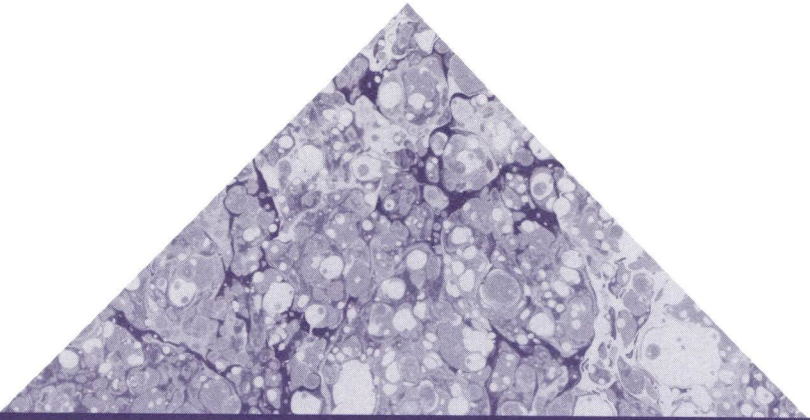
- For people with central nervous system impairments, the fine

line between restoration of function and rehabilitation is rapidly disappearing, and the researchers in both areas need more collaboration, not less. Rehabilitation and restoration research are not tidy little pockets into which you can plug problems, each totally independent from the results of the other. An independent Center dedicated to funding rehabilitation research discourages interdisciplinary research in this area, at a time when it is critically promising.

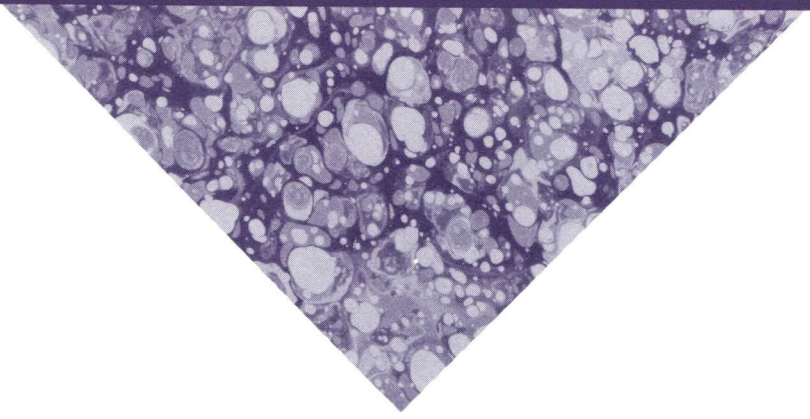
The current practice of NIDRR funding of rehabilitation research is unacceptable. Millions of dollars are wasted, opportunities are ignored, and the allocation of funds are often made on the basis of other than scientific merit. For over a decade, I have met with every new director appointed by the President, and each has encountered the same internal problem. There is a bureaucracy at NIDRR that remains insensitive to innovative research, preferring to award grants on the basis of "old-boy network" status, and on the basis of who knows whom, and who helps whom. If for no other reason, I would support the creation of a new rehabilitation research Center because it offers a chance to clear out the personnel mess at NIDRR.

With the above concerns in mind, I support the creation of a new Center. But know that those of us in the consuming public will be ever watchful. Establish a new Center, fund new programs, hire new people, but do so aware that we are paying for this enterprise, that we are supposed to benefit from these efforts, and that the programs ultimately must serve people and patients, not just a profession.

Many thanks -



APPENDIX D

- **Statements from Concerned Organizations Submitted for the Record**
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MEETING OF THE
PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

November 20-21, 1989

Organizations Presenting Written Testimony
for the Record

American Academy of Orthopaedic Surgeons
Newton C. McCollough, III, M.D.
President

American College of Rheumatology
Ms. Amanda L. Spitler
Government Affairs Representative

American Hospital Association
Bruce McPherson
Group Vice President

National Stroke Association
Thelma Edwards, R.N.
Director of Program Development

Rehabilitation International
Monroe Berkowitz, Ph.D.
Director of Research

TESTIMONY
OF THE
AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS
BEFORE THE
PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

Newton C. McCollough, III, M.D.

November 20-21, 1989

American Academy of Orthopaedic Surgeons

Mr. Chairman and members of the panel, I am Newton C. McCollough, III, M.D., President of the American Academy of Orthopaedic Surgeons and Medical Director of the Shriners Hospitals.

The Academy has over 14,000 Fellows, all of whom are Board certified orthopaedic surgeons. Our mission is to foster and assure the highest quality musculoskeletal health care through: education of orthopaedists, other providers of health care and the public; promotion and support of research; and communication with other professionals concerned with the diagnosis and treatment of musculoskeletal diseases and disorders.

We appreciate this opportunity to present testimony on the important subject of physical medicine and rehabilitation research at the NIH. The number of individuals, from children to senior citizens, requiring rehabilitation services is substantial and increases with age. For example:

- * There are 20,000 persons crippled because of spinal cord injury and the number increases by several thousands each year.

American Academy of Orthopaedic Surgeons

- * Over one million persons are amputees and several million more must use an orthotic device of some type.
- * Over 10 million people are afflicted with neuromuscular disorders.
- * Eight percent of our citizens suffer some significant musculoskeletal impairment.

The cost of these conditions to the nation are enormous in terms of medical care, disability and lost productivity. Thus, the need for expanded research at the NIH in the field of physical medicine and rehabilitation is, in our mind, appropriate and necessary.

While rehabilitation, provided by orthopaedists and other professionals, has resulted in returning many of these otherwise dependent individuals to active participation in society, there is a tremendous need for new knowledge based on basic research. Some areas that we believe require attention and have the potential for producing results are:

- * developmental problems of children;
- * geriatric injury: prevention and rehabilitation;

American Academy of Orthopaedic Surgeons

- * improved function of prostheses and orthoses (e.g. sensory feedback and manipulative ability for upper extremity prostheses; improved energy efficiency of lower extremity prostheses);
- * spinal cord injury: function restoration and néural tissue healing and/or by-pass;
- * scientific investigation of effects of rehabilitative and preventive exercise;
- * application of sports medicine principles to the rehabilitation of the severely disabled;
- * defining, quantifying and validating the outcome of functional restoration for various disabilities
- * motorizing the paralyzed patient, including patients with SCI, head injury, stroke, and cerebral palsy; and
- * investigating methods of sensory feedback for patients with paralysis and limb deficiencies.

American Academy of Orthopaedic Surgeons

We recognize that various NIH institutes currently support some research in the field of physical medicine and rehabilitation, and moreover, we recognize that other agencies such as the Veterans Administration, the Department of Defense, the National Institute on Disability and Rehabilitation Research are supporting research in this field; however, we believe that the overall federal effort needs additional funding and coordination.

As such, it is hoped that some administrative mechanism could be established to provide for the immediate coordination of current federal rehabilitation research efforts, the identification of priority areas of research, and the identification of the overall research dollars needed to address this costly societal problem. An administrative focus is needed in order for the government to plan and design research programs and to maximize its current and future investment.

The orthopaedic community appreciates this opportunity to present testimony and we stand ready to assist you and others in the field in advancing rehabilitation research efforts.

American Academy of Orthopaedic Surgeons



AMERICAN COLLEGE OF RHEUMATOLOGY

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TESTIMONY OF

THE AMERICAN COLLEGE OF RHEUMATOLOGY

to the

Physical Medicine and Rehabilitation Research Panel

November 20, 1989

National Institutes of Health
Office of Science Policy and Legislation
Shannon Building #218
9000 Rockville Pike
Bethesda, MD 20892
Attn: Dr. Suzanne S. Medgyesi-Mitschang

The American College of Rheumatology (ACR) is the world's largest organization of physicians and scientists dedicated to providing leadership in arthritis research, education and patient care. As you know, several of the forms of arthritis and related diseases can result in chronic disability. As specialists who treat and care for people with these diseases, we are therefore integrally involved in the development of appropriate steps which can literally "open the door" to increased mobility and productivity, and to improved quality of life for our patients.

The College is pleased to have the opportunity to provide input as this panel assesses the current administration of rehabilitation research at the NIH, and works to develop suggestions for approaches to assure continued progress in this area of research. We are pleased to report that there now exist many rehabilitation activities which are integral components of the care we provide to people who have diseases of the joints, muscles and bones. In addition, there are some exciting research opportunities which should be explored in the future. The ACR stands ready to assist this advisory body in efforts aimed at increasing national focus on rehabilitation research and patient care activities.

Congress has taken an increasing interest in rehabilitation and related issues over the past several years, most recently shown by the Senate passage and expected enactment of the Americans with Disabilities Act. In its report on FY 90 Appropriations for the Departments of Labor, Health and Human Services and Education (S. Rept. 101-127) the Senate Committee also emphasized its strong support for medical rehabilitation research within the NIH, citing recommendations for expanded rehabilitation research efforts contained in recent reports of the Institute of Medicine and the National Academy of Sciences. The Committee asked the NIH to report on its plans for expanding research in medical rehabilitation throughout NIH. We are pleased to assist this panel in making recommendations in connection with this endeavor. We offer the following suggestions concerning the conduct and federal support of rehabilitation research generally, and more specifically, concerning research on rehabilitation from the effects of arthritis and related rheumatic diseases.

I Importance of Arthritis Rehabilitation Research and Suggested Areas for Increased Emphasis:

Much arthritis rehabilitation research is conducted at the Multipurpose Arthritis and Musculoskeletal Diseases Centers supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). For example, a machine has been developed which produces continuous passive motion for joint mobilization after surgery. This is now being evaluated in clinical settings. Focusing on intervention, another group of researchers has been working with different occupational groups and teaching them ways to approach job tasks that will minimize the occurrence of carpal tunnel syndrome. At Boston University, many NIAMS investigators are working on improving arthritis health status measures. Patients report problems in specific areas including mobility, physical activity and activities of daily living. The ACR has taken the lead in establishing functional classifications for rheumatologic diseases, and sees efforts such as this as critical to achieving advances in both research and patient management.

Given the importance of the research being conducted through the NIAMS centers program, it is particularly ironic that funding constraints will necessitate reductions estimated at 18% in the funding levels of these centers in the next fiscal year. With increasing Congressional interest in medical rehabilitation, however, we believe that it

would be very fitting to remind legislators of the importance of providing more appropriate funding levels, so that existing rehabilitation-oriented activities can be conducted as they were originally envisioned. Toward this end, the ACR will be involved in highlighting examples of advances in arthritis rehabilitation research in its communications to the Appropriations committees.

The ACR also believes that an expanded research effort would be desirable for several key areas in arthritis rehabilitation. We confidently predict that the results of such research ultimately will contribute to on-going efforts to improve patient care. The NIAMS currently devotes a significant (11%) portion of its budget to rehabilitation-oriented research; it will spend more in this area in the upcoming fiscal year than any past year. However, there is a great deal more high-quality rehabilitation research which is now available to be done, if sufficient funding is provided to the institute: Research on primary rehabilitation, including the role of exercise, the control of inflammation and the entire area of pain control during rehabilitation, should be expanded. In the area of secondary rehabilitation (or maintenance) we need to improve our understanding related to preserving joint and muscle function, and more must be done to improve intervention strategies aimed at preventing the decline of function.

II Coordination and Expansion of Rehabilitation Research at the NIH:

In the 100th and 101st Congresses, Senator Edward Kennedy (D-MA) introduced bills which included a proposal for the creation of a freestanding center for rehabilitation research within the NIH. At that time, the ACR provided testimony to the Senate Committee on Labor and Human Resources stating our support of an increased emphasis on medical rehabilitation research, and stressing that we believe that enhancing the rehabilitation activities of existing NIH institutes will best contribute toward an increased focus on rehabilitation and to improved patient care. We continue to have some concerns about the proposal for the creation of a separate entity for rehabilitation research within the NIH, for the following reasons:

- Rehabilitation research activities for different diseases and conditions are uniquely diverse.

Although the individual areas of rehabilitation research do share certain underlying principles, each area is also very different in the details of its focus. For example, rehabilitation research on traumatic head and spinal cord injuries differs substantially from the research on rehabilitation from the effects of diseases of the joints and muscles. In light of the specialized expertise and focus of researchers within existing institutes, we believe that each institute is ideally suited to support rehabilitation research within its own field.

- A separate entity might work to isolate researchers from other research activities within their disciplines.

Research in rehabilitation medicine is primarily clinical, but often includes, and inter-relates with, basic biomedical science involving the nerves, muscles, bones, or other organ systems. The coordination of such rehabilitation research with related basic research efforts within a particular field is therefore very important. For example, investigators in arthritis rehabilitation would continue to benefit from their interactions with other members of the arthritis research community—ideally under an expanded program within the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). We believe that the conduct of

rehabilitation research within the existing institutes will increase cohesiveness among members of the research team, as well as the cohesiveness of the discipline, itself. As professionals with different research orientations work cooperatively within a particular area of medicine, a higher level of effectiveness is possible than if clinical and basic science efforts were to be fragmented.

- The creation of a separate administrative entity within the NIH structure might actually dilute funding which could be otherwise be available for the conduct of research.

Especially in light of our other concerns about the functioning of such a center, we are convinced that the administrative costs involved in establishing a separate center for medical rehabilitation research are not justified in order to achieve an increased focus and coordination of medical rehabilitation research efforts. As you know, the budget deficit has necessitated constraints on all discretionary spending. Although the FY 90 budget reconciliation process is not yet finalized, it is obvious that NIH research funds will be severely restricted this year. ACR strongly feels that available funds should be expended by existing institutes so that they may be more fully directed at additional research. We believe that whatever benefits exist from the creation of a new center do not justify the "start-up" and continuing administrative costs which would be incurred. Strengthening the rehabilitation mandates of exiting institutes would be far more cost-effective.

III Conclusion

- The ACR believes that medical rehabilitation research activities should be enhanced in order to better help Americans who have been disabled through a variety of causes lead more productive lives.
- Although rehabilitation research is also conducted through other federal agencies—such as the National Institute on Disability and Rehabilitation Research—we believe that because of its existing strong rehabilitation mandate, the NIH is the ideal entity to serve as a focus for all scientific and medical aspects of rehabilitation research.
- We continue to believe that the goal of enhancing medical rehabilitation research activities is best served by increasing the rehabilitation activities of the existing institutes rather than through the creation of a separate administrative entity. The coordination of rehabilitation research NIH-wide could be provided through a permanent advisory group.
- The ACR strongly believes that efforts should be made to urge Congress to provide a specific, substantial funding increase for research relating to the diagnosis and treatment of disabling physical conditions within its yearly appropriations to each of the institutes which have rehabilitation interests and activities. ACR will take a leadership role in this effort.
- We hope that the report of this panel to the Advisory Committee to the Director, NIH, will serve as a focal point for interested organizations to begin to address the need for increased emphasis, and for the coordination of federally-supported medical rehabilitation research. We appreciate the opportunity to contribute to it.



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November 13, 1989

Dr. Suzanne S. Medgyesi-Mitschang
National Institutes of Health
Office of Science Policy and Legislation
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Mitschang

We are pleased to have the opportunity to make recommendations for setting rehabilitation research objectives for the 1990's to the Physical Medicine and Rehabilitation Research Panel of the Advisory Committee to the Director of the National Institutes of Health. The American Hospital Association represents nearly 5,500 member institutions and more than 45,000 personal members. Among those are approximately 800 members of the Section for Rehabilitation Hospitals and Programs, a special constituency section within the AHA representing the special concerns and interests of medical rehabilitation providers.

The ongoing diversification of the U.S. health care delivery and payment system requires systematic research, training and development activities to ensure the needs of the disabled are recognized, services are available and coordinated, and that funding sources are adaptive. The continuum of care required in the rehabilitation process encompasses an array of medical, vocational and community-based delivery sites. Too frequently, a disabled individual is not efficiently and effectively matriculated through this vast and confusing array.

As representatives of the hospital-based component of the continuum, the Section for Rehabilitation Hospitals and Programs would like to recommend that the research training and development activities be encouraged and/or directed to facilitate accessible, coordinated, and quantifiable medical quality care to disabled individuals. The following are specific areas of interest and concern:

- The cost-effectiveness of multi-level rehabilitation – whether some rehab settings are more effective for treating certain categories of patients
- The effect of the declining length of stay on the quality of care provided
- Economic and financial disincentives to incorporating rehabilitation in the medical process, or long-term research on cost-benefits of rehabilitation specifically geared to the needs of payors of rehabilitation care
- The development of management information systems for rehabilitation to help managers make better decisions
- Productivity measures for rehabilitation
- Clinical and management developments in rehabilitation to improve the quality and efficiency of rehabilitation services.

Dr. Mitschang/2

These efforts also need dissemination to the payor and consuming community at large and the NIH might consider disseminating policy research information through instructional conferences interagency federal agency collaboration, written materials addressing medical care for the disabled for insurance companies, health maintenance organizations, etc, and development of an evaluation methodology for community services to the disabled; video training programs for professionals who work with the disabled; development of a networking system for consumers, providers, and payors of rehabilitation, etc. The AHA Section for Rehabilitation Hospitals and Programs would be pleased to assist in the evaluation of these concepts and in the appropriate implementation of subsequent action plans.

Thank you for your attention to these important issues. It is a pleasure to have an opportunity to provide recommendations on this very important and all too often frequently misunderstood component of the health care continuum.

Sincerely

A handwritten signature in dark ink, appearing to read "Bruce McPherson". The signature is fluid and cursive, with the first name "Bruce" being more prominent and the last name "McPherson" following in a similar style.

Bruce McPherson
Group Vice President



National Stroke Association

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November 13, 1989

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National Institutes of Health
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Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitchang:

As we enter the Decade of the Brain in 1990, National Stroke Association (NSA) will continue to address the need for education, prevention and research of cerebrovascular disease in this country.

We applaud the objectives of the National Institutes of Health Public Meeting on November 20 & 21, 1989.

In 1984, NSA was founded to not only address the lack of resources and education of stroke but also the limited funding being directed towards research in the prevention, treatment and rehabilitation of cerebrovascular disease.

Recommendations of NSA:

- I. Expand the emphasis and funding of physical medicine and rehabilitation research on stroke.

Stroke is the third leading cause of death in this country and the leading cause of adult disability. Ninety percent of those surviving stroke will require some degree of rehabilitation services.

Statistics and reports indicate that even though there is a decrease in stroke mortality, incidence may be increasing. This is attributed to improved diagnostic procedures, patients surviving coronary heart disease, better treatment of other risk factors such as hypertension and diabetes and a rapidly aging populous.

1989 federal government research budgets confirms that stroke is not receiving sufficient funding in respect to the impact it has on society.

Dr. Suzanne S. Madgyesi-Mitschang
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Consider the following comparison:

\$1.3 Billion to Aids

\$1.4 Billion to Cancer

\$1 Billion to Heart Disease

\$50 Million to Stroke

II. To establish the efficacy of rehabilitation of the stroke survivor

- This will need to be presented to clinicians
- Candidates for rehabilitation are not routinely being referred.

We receive numerous requests and inquiries from families through our Stroke Information and Referral Center for therapy resources or continuation of therapy programs.

III. National Stroke Association will actively support and promote research in the neuroscience diseases, primarily stroke.

Through the guidance and participation of many noted professionals on our Scientific Advisory Committee and Board of Directors, we will continue our mission to address the needs and concerns of the stroke survivor, the family caregivers and the community. With matching grant monies from Allied-Signal, Inc., NSA established the Career Development Fellowship Awards. Four young investigators were awarded fellowships in October, 1989, and will focus their research interests and efforts on the causes, mechanisms and treatment of cerebrovascular disease.

Information on their field of research and clinical affiliation is attached.

Dr. Suzanne S. Madgyesi-Mitschang
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National Stroke Association is eager to continue our ongoing relationship with National Institutes of Health to assist in establishing national standards for stroke rehabilitation.

Sincerely,

NATIONAL STROKE ASSOCIATION

A handwritten signature in cursive script, reading "Thelma Edwards".

Thelma Edwards, R.N.
Director of Program Development

TE:saa

Enclosures

David Warren Newell received a B.A. degree in Biology at Boston University, and an M.D. degree at Case Western Reserve University in 1982. He trained in Neurosurgery at the University of Washington in Seattle, where he completed his chief resident year in 1988. He is currently an Acting Instructor in Neurosurgery at the same institution.

Dr. Newell plans to study ischemia, which is the deficiency of blood supply, in the brain. His proposal includes developing a model using neuronal cultures derived from rat hippocampus, (this is the part of the brain most vulnerable to damage for ischemia) then demonstrating and studying a mechanism for providing protection against the death of neurons following ischemia. He will be blocking NMDA receptors using MK-801 to attempt this protection. This project will take 3 years.

Michael Diringer is a graduate of the University of Kentucky where he received his M.D. degree in 1982. His previous activities have been in neuropsychopharmacology and he has received a B.A. degree in Psychology from the State University of New York at Stony Brook. He has been Chief Resident in Neurology until 1986 at Stony Brook, and he was a Neuroscience Critical Care Fellow in the Department of Neurology at the Johns Hopkins Hospital until 1988. He is now an Instructor at the same institution.

Hyponatremia and cerebral edema are frequent consequences of many diseases of the brain, including stroke. The mechanisms causing them are poorly understood, and current treatment is inadequate for these potentially fatal problems. Dr. Diringer proposes to help explain the mechanisms behind these complications by studying the role of atriopeptin and its regulation of water and sodium in patients who have experienced subarachnoid hemorrhage, as well as in mongrel dogs. This is a two year project

Betsy B. Love received her B.A. degree from Augustana College in Illinois. She received an M.D. degree in 1985 from the University of Iowa College of Medicine. She just completed her residency in Neurology in June of '89 at the University of Iowa. Currently she is a fellow in the Division of Cerebrovascular Disease at the same institution.

Dr. Love plans to investigate the prevalence and severity of coronary artery disease in patients with asymptomatic carotid bruits, asymptomatic carotid stenosis, and transient ischemic attacks. This study could provide useful guidelines for the optimal method of identifying the presence of coronary artery disease in patients with cerebrovascular disease. This is a one year project.

Kenneth P. Madden is a graduate of the University of Texas in San Antonio where he received his M.D. degree in 1985. His previous degrees include a B.A. in Biology from the University of Texas in Austin, and a Ph.D. in Physiology from the University of Texas in Galveston. He just completed a chief resident year in Neurology at the University of California at San Diego in June of 1989. His current position is as a fellow in cerebrovascular disease at the same institution.

Dr. Madden plans to study ischemia, which is deficiency of blood supply, in the spinal cord of rabbits. He proposes to attempt to prevent the death of neurons following ischemia by administering a calcium channel blocker, omega-conotoxin GVIA. We will fund him for one year.



Rehabilitation International

Date: November 16, 1989

Facsimile Transmission

To: Dr. Suzanne S. Medgyesi-Mitschang

Organization: National Institutes of Health

Fax No.: 301-402-0280

Ref. No.:

Subject: Public Meeting to Discuss Rehabilitation Research

From: Monroe Berkowitz, Ph.D, Director of Research

Total number of pages transmitted (including this page): 2

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Fax Message: Thank you for the opportunity to respond regarding the November 20 and 21 Public Meeting of the National Institutes of Health to Discuss Physical Medicine and Rehabilitation Research. Unfortunately we did not receive the notification until November 10 but are conveying our response in the hope that it may be useful even at this late date.

As Director of Research for the oldest and largest non-governmental worldwide organization in the disability and rehabilitation field, I would like to submit the following points of information for your consideration:

Strengthening of the U.S. role in international rehabilitation research exchange mechanisms would be immensely useful. There are many major initiatives, some on-going, some time limited, to assess rehabilitation research developments on an international level. Some are undertaken by United Nations bodies, such as the International Labor Organization and the World Health Organization while others are developed by non-governmental organizations, such as Rehabilitation International. The U.S. role and participation has not been as visible as is warranted by its leadership position in this field.

In an era of ever shrinking resources for research, it would be especially cost-beneficial to the U.S. rehabilitation research community to take advantage of the multitude of cross-national and international research channels which are, in our opinion,

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currently utilized in a more substantial manner by other countries' research establishments.

If this suggestion is of interest to the group, Rehabilitation International and its close research collaborator, the World Institute on Disability, would be glad to develop some practical recommendations on how this increased participation of the U.S. rehabilitation research establishment could be effected.

