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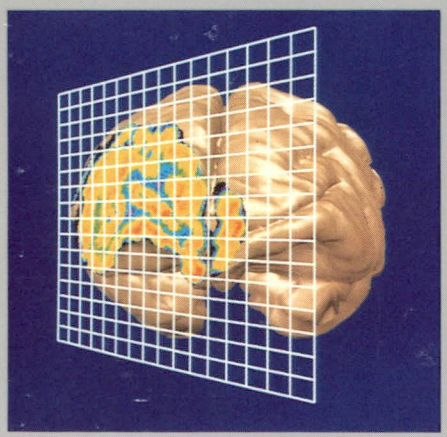
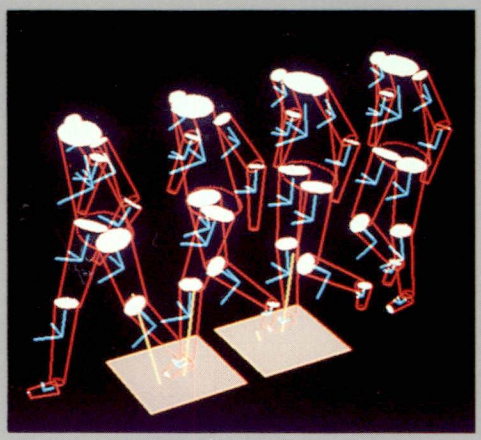
Report of the Task Force on

MEDICAL REHABILITATION RESEARCH





June 28–29, 1990
Hunt Valley Inn
Hunt Valley, Maryland

Cover Illustrations

Top: left to right
Levels of metabolism (2-deoxyglucose uptake) illustrated with a grid overlay providing a technique orientation.
A computer-generated figure demonstrating gait.

Bottom: left to right
Research scientist at the National Institutes of Health.
Disabled child confined to a wheelchair using the resources of a library.

Report of the Task Force on

MEDICAL REHABILITATION RESEARCH

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Acknowledgment

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Preface

Although rehabilitation medicine is more than 50 years old, it is just now coming of age as a scientific discipline. This stage of development comes none too soon for the field of biomedicine that most directly addresses the consequences of chronic illness, impairment, and disability, which are, arguably, the Nation's leading health problems. Continued growth of the population of older adults—the age segment at highest risk for disability—and the survival of people with once-fatal, but still-incurable diseases are among several trends that portend a growing need for effective rehabilitative interventions and disability-prevention strategies.

This report represents the combined contributions of more than 100 clinicians and researchers with expertise in a wide range of medical, biological, allied health, and social sciences. As members of a Task Force convened by the National Institutes of Health, these experts conducted a sweeping survey of research needs, challenges, and opportunities in rehabilitation medicine. The aim of this large and difficult endeavor was not only to identify priorities for study, but also to begin building the foundation for what truly must be an interdisciplinary research undertaking.

The Task Force's work is an essential and long-overdue first step toward meeting this Nation's changing health needs. We believe that this report is both seminal and nascent. It provides the most comprehensive perspective on the diverse field of rehabilitation medicine research that has ever been undertaken. It is hoped that this perspective will help to open many doors for the work that must follow. It is also hoped that the report will demonstrate the urgency, need, and wisdom of aggressively pursuing the priorities and goals it outlines. Foremost among these goals are the establishment of (1) a solid program of basic research in a broad range of scientific disciplines, and (2) a comprehensive effort to evaluate the outcomes of existing and emerging treatments used in rehabilitation medicine.

Because rehabilitation medicine's ultimate focus is on improving the quality of lives of people with impairments and disabilities, the breadth of the field's supporting research efforts is necessarily large. While the conditions of some patients may have relatively simple physiological solutions, complexity tends to be the rule rather than the exception. In many people with impairments and disabilities, two or more body systems are affected, and the combined effects of multiple dysfunctions can diminish functioning in many domains of human activity—physical, social, behavioral, psychological, and cognitive. Therefore, rehabilitation medicine not only addresses the underlying pathophysiology of impairment and disability, but also endeavors to integrate affected people back into their physical and social environments. And unlike acute care medicine and its

episodic nature, rehabilitation medicine must address changing needs and issues that arise over the lifespans of individuals with impairments and disabilities.

Thus, it is no wonder that this report recommends that rehabilitation medicine research be led by the biological, behavioral, and social sciences—all at the same time. The Task Force stresses the need for collaboration among public and private agencies and organizations, among academic departments and institutions, and among individual researchers. For this complex and diverse field to grow and accomplish the tasks outlined here, effective collaboration is essential. There must be more intensive participation by the community of scientists whose work can provide the bases for developing the new concepts, tools, and techniques necessary for continuing improvement of clinical practice in rehabilitation medicine. Strong, new linkages must be forged among the basic sciences, clinical sciences, and bioengineering. This report is intended to catalyze the formation of these interdisciplinary linkages.

The Task Force has developed the beginnings of a plan to propel rehabilitation medicine into the 21st century as a leading clinical science and as a branch of medicine focused on optimizing the quality of life for people with chronic impairments and disabilities. The goals presented in this report are achievable, and the American people should expect the scientific community to be aggressive in the pursuit of these goals.

On November 16, the President signed into law P.L. 101-613, establishing a National Center for Medical Rehabilitation Research within the National Institute of Child Health and Human Development. The mandate of the Center includes the conduct and support of research and research training, the dissemination of health information, and other programs for rehabilitation of individuals with physical disabilities stemming from diseases or disorders. It is indeed a timely event that this legislation was signed into law as the Task Force report was being completed. Thus, the law and the opportunities, challenges, and recommendations presented in this report meet at a unique point in history to benefit children and adults with impairments, disabilities, and handicaps. We concur with Lister Hill's exhortation: "We must develop a communications system so that miraculous triumphs of modern science can be taken from the laboratory and transmitted to all in need."

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Executive Summary

Overview

Between 35 million and 43 million Americans have a disability, a total roughly equivalent to the combined populations of California and Florida, two of the Nation's most populous States. Almost 4 percent of the U.S. population have disabilities so severe that they are unable to carry out the major activity of their age group (playing, attending school, working, or attending to self-care). An additional 6 percent of the population are restricted in their major activity, and another 4 percent are limited in other types of activity.

Besides the penalty on human functioning, disability imposes enormous economic costs, estimated at 6.5 percent of the gross national product. Thus, in terms of prevalence and cost, disability ranks as this Nation's largest health problem.

Aggregate numbers and cost estimates, however, do not convey the personal consequences of disability, or of the chronic impairments that can lead to it.

Virtually every American will experience these consequences directly or through family members or close friends who develop disabling conditions. In fact, the average American spends nearly 12 years in a state of limited functioning because of acute and chronic conditions.

This Nation has long judged the success of its efforts to improve the health of its citizens on the basis of mortality statistics. Since 1900, average life expectancy at birth has increased from 47.3 years to nearly 75 years, and people who reach 65 can expect to live an average of 16.4 more years. Though significant, these gains in human longevity have given rise to an important and difficult question: How well do people live during these additional years?

The answer to this question is important not only to older adults, but to the entire population with impairments and disabilities. For example, many infants born with congenital impairments—an increasing number of whom owe their survival to the life-saving interventions of modern medicine—face long lives with functional limitations that pose special challenges at each stage of development from birth through old age.

At this tumultuous stage in the evolution of the Nation's health care system, emphasis has begun to shift from quantity of life to quality of life, but survival for tens of millions of Americans has meant learning to tolerate chronic impairments or disabilities. The time has come to devote more attention and resources to developing the interventions and services that will help the one in seven Americans with disabilities lead fully productive lives.

This report by the Task Force on Medical Rehabilitation Research addresses an important component of efforts to accomplish

this goal. It presents the outlines and many of the details of a national plan for carrying out the research needed to build the scientific foundation on which to develop efficacious and effective rehabilitative interventions.

Task Force Focus and Rationale

Rehabilitation medicine research is the study of impairments, disabilities, and handicaps resulting from illnesses, injuries, and developmental processes that begin before birth and continue until the last stages of life. It focuses on health-related improvement in human functioning—physical, cognitive, behavioral, and social. Rehabilitation medicine research explicitly includes the application of new knowledge to the development of medical, behavioral, psychological, social, and technological interventions designed to optimize functioning after impairment, disability, or handicap.

As defined here, the field encompasses research in a broad range of disciplines in the biological, social, behavioral, psychological, and allied health sciences. Unfortunately, while there is much ongoing research relevant to the interests and aims of rehabilitation medicine, the overall effort has no coherence. In fact, those who identify themselves as rehabilitation medicine researchers are few, and many scientists whose work is clearly related to the needs and interests of rehabilitation medicine fail to recognize the relevance of their efforts to the field's primary goal of improving human functioning.

Because of the severe shortage of rehabilitation medicine investigators and the paucity of resources available to support needed research, progress toward improving the effectiveness of rehabilitative interventions will likely continue to be slow. This is not to say that relevant advances will not be made, but they will probably be piecemeal, and important facets of issues and problems will be neglected.

Thus this Task Force was convened by the National Institutes of Health (NIH) during the summer of 1990 to begin the long-overdue process of comprehensively building the scientific foundation on which the practice of rehabilitation medicine must stand. For too long, rehabilitation medicine and the basic sciences have operated in separate spheres. Much can be gained by integrating the aims of the branch of medicine that most directly addresses the consequences of chronic diseases, impairments, and disabilities with investigative efforts to unravel the underlying complexity of human functioning and behavior.

Task Force Organization

The Task Force was composed of nine panels. Four focused on major areas of scientific concentration: neurophysiological dysfunction, musculoskeletal disorders, cancer rehabilitation, and geriatric rehabilitation. Five panels addressed issues that transcend the entire field of rehabilitation medicine: developmental issues (i.e., needs and opportunities for addressing problems and challenges that arise over the life span and development of people with disabilities); basic and clinical research training; biomechanics, ergonomics, and engineering design; assessment and epidemiology; and information resources.

Collectively, the panels examined the adequacy of current efforts to understand the spectrum from impairment to disability and handicap. They also evaluated ongoing efforts to develop and apply the knowledge necessary to devise health care interventions, social services, and personal health practices to maximize the chances for people with disabilities to live autonomously and to pursue their personal, social, and vocational interests.

The Task Force review covered most of the major areas of physical disability, but

time did not permit the examination of the current state of research for all causes of disability. The omission of cardiovascular disorders, acquired immunodeficiency syndrome, diabetes, and other important causes of disability does not suggest that these conditions are of lesser importance than those directly addressed by the Task Force. Rather, omission reflects the fact that disability is a potential consequence of hundreds of pathologies or impairments and all of them could not be adequately reviewed within the time available.

It should be recognized, however, that disability is an entity distinct from disease. Disabilities are limitations in function that result from disease and injury. The same type of disability can have many causes. Limited mobility, for example, can be caused by a congenital birth defect, an injury, a stroke, or an amputation because of peripheral vascular disease or the complications of diabetes. Moreover, the limitation can result from the interaction between co-occurring conditions, neither one of which by itself is sufficient to cause disability.

Because it can arise from multiple causes, disability is not a discretely defined topic of basic biological research, at least not within the current organization of the Nation's research efforts. For example, the institutes of NIH, the Nation's largest funder of biological research, are largely organized according to disease entities (such as cancer and diabetes) or organ systems (such as the heart and the eye). Thus, the research needs of rehabilitation medicine and the emphases of the major sponsors of biological and other health-related research are often obliquely aligned, but they are not incompatible.

The Task Force recommendations, particularly those made in the chapters on the four major scientific areas, suggest how many of the needs of rehabilitation medicine research can be incorporated into the current organization of funding for biological research. But the recommendations also draw attention to important research needs that will likely be unaddressed if research sponsors do not fully embrace rehabilitation medicine as a scientific discipline.

General Needs

The research interests of rehabilitation medicine extend from the molecular level to the functioning of people in their physical and social environment. So although the topics awaiting greater investigative effort are many, diverse, and complex, the Task Force concluded that three overriding needs are critically important to the field's progress:

- Develop meaningful quantitative measures of impairments, disabilities, and handicaps, and of the outcome of rehabilitative interventions. These measures are needed to guide the collection of epidemiological data, to assess the effects of functional limitations on normal human activity and on the quality of life, and to guide the development of therapeutic strategies that best address the needs and problems of people with impairments, disabilities, and handicaps.
- Develop standards and guidelines for the design and application of evaluative tools. Related to the first need, this step is necessary to achieve consistency and uniformity of effort. Currently, the field has no "common language," a fact that limits the comparison and applicability of research findings and stands as a major obstacle to greater interdisciplinary collaboration, especially between basic and clinical researchers.
- Evaluate the effectiveness of existing and emerging rehabilitation procedures.

The following sections present the major recommendations in each of the areas addressed by the Task Force. Specific chapters

in this report list the priorities identified by the Task Force in full.

Neurophysiological Dysfunction

The human nervous system regulates and controls the functions of the body and in a broader sense integrates the individual into the environment. Because of these regulatory and integrative functions, humans are capable of skilled voluntary movements and are apprised of their environment by the various sensory systems. Each system is composed of a hierarchy of subsystems, and damage to any of them can result in extensive neurophysiological impairments, many of which require long-term rehabilitation.

Major causes of neurophysiological dysfunction include stroke, traumatic brain injury, spinal cord injury, and demyelinating disorders such as multiple sclerosis. These injuries and disorders affect millions of Americans. For example, each year about 500,000 Americans suffer strokes. About 30 percent die, making stroke the third leading cause of death. The great majority of stroke victims survive, however, and it is estimated that 2.1 million stroke victims are alive today. A significant proportion require rehabilitation services. Indeed, about one-third of all survivors are left with permanent disabilities.

In the past, the impacts of neurophysiological dysfunction were rarely studied. It was taken on faith that improving organ function would decrease levels of disability or handicap. Experience has shown that the relationship between pathology and disability or handicap is much more complex. Moreover, consumers and health care insurers are now demanding that providers of rehabilitation services document the effectiveness of interventions. Such proof requires measuring the level of impairment, functional limitation, or disability and the quality of life—before and after rehabilitation. A pressing need, then, is to develop and standardize physiologically based measurements that incorporate current scientific knowledge and methods.

Characteristic of the research needs in this area is the continuing controversy over the effectiveness of the various techniques used in the cognitive retraining of people who sustain disabling traumatic brain injuries. Many of these people have cognitive deficits that result in diminished decision-making abilities, problem-solving capabilities, and capacity for adapting to the uncertainties of everyday life.

There is little evidence, however, that cognitive retraining has any direct benefit on the cognition of patients with traumatic brain injuries. In contrast, considerable evidence exists that some aspects of cognitive retraining—such as memory training—have no effect at all. Furthermore, studies have shown that people who undergo training cannot generalize learned behaviors to novel tasks.

Nonetheless, cognitive science—a new discipline that merges psychology, neurophysiology, computer modeling, artificial intelligence, and linguistics—should provide powerful new tools with which to address cognitive deficits. Major advances in neuropharmacology and neuroimaging techniques are also likely to yield important contributions.

Recommendations

- Investigate pharmacological agents and therapeutic mechanisms that might reduce the extent of neuronal damage or death caused by disease or injury. A description of the sequence of the physiological and biological events that can lead to cell death or to survival in the nervous system would provide key basic information.
- Define the molecular, cellular, and systemic mechanisms influencing neuronal

reorganization and other elements of functional plasticity, and then determine whether chronic administration of pharmacological agents or other interventions can induce functional plasticity.

- Define the mechanisms of motor-skill acquisition and learning.
- Investigate and define the potential of electrical stimulation as a strategy to treat sensory and motor impairments.
- Develop discriminating, quantitative tests for assessing the capacity for and the ability to perform voluntary muscular activities.

Musculoskeletal Disorders

About 23 million people, or 10 percent of the U.S. population, have one or more chronic disorders of the musculoskeletal system that affect the structure and function of the joints, muscles, bones and cartilage, ligaments, and tendons. Within this diverse category of disorders are such chronic diseases as osteoporosis and the more than 100 forms of rheumatic disease, including the various types of arthritis; congenital malformations and defects (such as spina bifida and clubfoot); inherited diseases (such as Duchenne muscular dystrophy and osteogenesis imperfecta); and fractures, sprains, dislocations, and other mechanical defects caused by injury. Collectively, these disorders affect all age groups, with consequences ranging from pain to severe disability and handicap.

Musculoskeletal disorders are the main cause of disability among the working-age population, and they are among the leading causes of disability for other age groups. For the entire population, orthopedic impairments and arthritis rank as the top two causes of activity limitation, affecting 9.2 million people. Osteoporosis is one of the most prevalent disorders of the bones and other skeletal support structures. The leading cause of fractures among women aged 75 and older is osteoporosis. Each year, about 200,000 older adults incur hip fracture injuries that often precipitate serious health deterioration.

Research questions relevant to the rehabilitation of the millions of Americans with musculoskeletal disabilities are many. Major categories include the following: control of movement, joint mechanics and pathophysiology, musculoskeletal physiology and plasticity, orthotics and prosthetics, the interaction of musculoskeletal impairments, and the biology of pain.

In the short term, intensified efforts in three major categories of activity are necessary to build a foundation for future research and to foster synergy among studies already under way. In two of these categories—functional assessment and outcomes research—basic and clinical researchers are addressing these needs, although the level of effort and support does not match the level of need. The third—technology transfer—is largely an organizational challenge. As in other areas of rehabilitation medicine research, there is a great need to develop effective linkages among research activities that potentially can yield information relevant to improving rehabilitation services for people with musculoskeletal disabilities.

Recommendations

- Characterize the electrical impulses, hormones, and other physiological signals that regulate the structure and function of the musculoskeletal system.
- Improve existing techniques or develop new ones that will enable more precise characterization of the physiological signals that affect important properties of muscles and connective tissues.
- Define how these physiological signals interact with the molecular mechanisms that regulate the synthesis of proteins by muscle fibers.

- Develop rehabilitative interventions to optimize musculoskeletal function following injury, disease, or invasive therapeutic procedures.
- Define the etiology of fatigue in people with and without neuromuscular impairments and over the course of aging.
- Describe more fully how forces are transmitted from motor units to muscle tendons.
- Define the risk factors associated with different types of musculoskeletal dysfunction.
- Develop and evaluate potential strategies for preventing musculoskeletal disease and injury.

Cancer Rehabilitation

Rehabilitating persons treated for cancer is a major health care priority because of the frequency of the disease and the increasing number of survivors, now estimated to total 6 million. In the near future, one out of a thousand 20-year-olds will be a survivor of childhood cancer.

Cancer and its treatment can result in impairments leading to significant disability. In turn, negative societal attitudes toward cancer patients can exacerbate the effects and transform cancer-related disabilities into handicaps.

Research on the rehabilitation of cancer patients is ongoing, but progress is often impeded by the lack of collaboration with specialists in related areas such as prosthetics and kinesiology. As is true for all rehabilitation medicine, progress also depends on the development of better instruments to quantify functional outcomes, including the impact of treatment on the quality of life.

In head and neck cancer, too little is known about the basic physiology of the functions of taste, smell, speech, and swallowing, as well as the impact of treatments on them. Recent advances in speech restoration, such as the Singer-Blom prosthesis, still fall short of providing full function for the laryngectomy patient, and more work is needed. More practical as well as more aesthetic prostheses need to be developed for people who undergo facial surgery for orbital or maxillary sinus cancer.

Rehabilitation of patients with breast cancer is a high priority, because 10 percent of all women will develop this disease. The trend toward less extensive surgery is well established, but the definition of appropriate rehabilitation techniques has not kept pace with these changes. There is little information, for example, on the benefit of arm and shoulder exercises after conservation surgery with radiation therapy. The long-term effects of radiation therapy, particularly when combined with chemotherapy, must be evaluated, and the proper timing for rehabilitative measures after mastectomy with immediate reconstruction remains to be determined.

Major priorities in the rehabilitation of patients with sarcoma of the extremities include basic research on the biology of bone allografts, on prosthetic materials, and on promoting bone growth along prostheses, as well as on facilitating soft tissue and tendon attachments. At the clinical level, further advances in the use of modular and adjustable prostheses need to be made and optimal postoperative rehabilitation techniques for the limb-salvaged patient have yet to be determined.

Progress in rehabilitation requires better definition and quantification of psychosocial factors that can impede or enhance recovery and social and physical adjustment. Also warranting more research are the vocational and employment problems encountered by people with cancer, both during and after treatment. Much of the research cited in discussions on this topic is nearly two decades old.

Recommendations

- Improve existing biomaterials and develop better ones for implantation devices and prostheses; continue to refine modular implant components that can be tailored to reconstructive methods needed for different anatomic regions.
- Investigate and define deficits in taste, smell, speech, chewing, salivation, and swallowing that result from cancer and cancer treatments.
- Investigate the impact of breast cancer treatments on lymph function.
- Improve techniques for breast reconstruction.
- Define the prevalence and incidence of dysfunctions associated with breast cancer therapies (behavioral and psychological problems, vaginal dryness, hot flashes, lymphedema, and shoulder dysfunction).
- Develop methods to stimulate bone and soft-tissue growth in prosthetic devices.
- Investigate the biology and immunology of osteoarticular allografts.
- Characterize the psychosocial and personality factors, physical problems, and societal factors that influence rehabilitative outcomes for patients who undergo limb-sparing surgery.
- Study and define the pathophysiology of neuropathic and nociceptive pain.
- Investigate new approaches for preventing or alleviating pain in cancer patients.
- Study the psychosocial and vocational adjustments required to enhance the rehabilitation of children and adults with cancer.
- Identify and define the problems of sexual dysfunction caused by cancer and its treatment.
- Evaluate the effectiveness of existing interventions for people with metastatic disease, including methods for managing pain, repairing bones, controlling side effects, and easing psychosocial adjustments.

Geriatrics

Most disabling conditions that require rehabilitation affect older adults disproportionately. A few statistics are illustrative: Three-fourths of all strokes and three-fourths of all amputations occur after age 65; the average age of people who sustain hip fractures is over 70 years; 86 percent of those over 65 have at least one chronic condition; and 52 percent of those older than 75 years are limited in at least one activity of daily living.

Because of their high risk of disability, people aged 65 and older—only 12.7 percent of the general population—constitute 40 percent of the population with disabilities. Given the aging of the U.S. population, this proportion and therefore the total number of older adults with disabilities will likely increase in the coming decades. Averting this likelihood will require significant advances in geriatric rehabilitation and in the prevention of disability.

Rehabilitation should be an integral part of the practice of geriatric medicine, provide the tools to avert or reverse declines in functional capacity caused by disability, and thereby ensure the ability to maintain an autonomous lifestyle. Currently, the number of rehabilitative interventions of proven effectiveness are not commensurate with the rising level of need.

In recent years, basic research on aging has intensified. Investigators are attempting to define the normal processes of aging, as well as the pathologies associated with growing older at the molecular level. Studies using new animal models—from fruit flies to turtles—are yielding insights that, along with findings from other lines of research, may some day make it possible to

distinguish between normal aging and disease.

Although these efforts will greatly enhance the understanding of what it means to grow old, it is already recognized that older adults have physiological and psychological characteristics that distinguish them from younger members of the population. These differences have important implications for rehabilitative interventions. Therapies that are effective for the young patient with cancer or heart disease, for example, are often not directly transferable to the older patient with the same condition.

Similarly, the functional, vocational, and avocational goals of rehabilitation should be tailored not only to the type of disability, but also to the age of the patient. Thus, rehabilitation goals must be defined for the elderly in the context of quality of life. In turn, realistic and personally relevant rehabilitation goals may point the way to new types of interventions.

Intensified research is especially needed in the following areas: natural history of disability in older adults, assessment of functional capacity and performance, prevention of disability, evaluation of the effectiveness of existing and emerging interventions, and organization and delivery of rehabilitation services. Integrating the findings from these diverse lines of research will be necessary to ensure that rehabilitative interventions are tailored to the special needs of older adults.

Recommendations

- Conduct epidemiological studies to determine the relationship between aging and the onset of disabling conditions. Identify factors that influence the progression or regression of functional limitations that commonly occur in old age.
- Identify and define the physiological and environmental risk factors for falls, limited mobility, and diminished control over fine movements.
- Investigate the neuroplasticity of the nervous and muscular systems of older adults and thus determine whether interventions might improve the functioning of older adults with cognitive and neuromotor deficits.
- Identify the factors responsible for the often-found differential between the functional capacity of older adults and their actual level of performance.
- Develop valid, reliable measures of daily function for use in clinical and residential settings.
- Study the influence of social support mechanisms on rehabilitation outcomes.
- Conduct basic research on hormonal, neurochemical, and potential pharmacological agents (such as growth hormone) that might improve the cognitive and physical functioning of older adults.
- Evaluate the effectiveness of rehabilitative interventions for older adults in different settings.

Developmental Issues

The consequences of disability are highly variable; they result from a complex interaction among biological, behavioral, psychological, environmental, and social factors, many of which have been enumerated but remain to be fully understood. Moreover, the nature of this interaction changes over the life span of the individual.

Development and, therefore, change are fundamental processes of living—with or without a disability. In the case of the person with disability, however, developmental issues are likely to be more complex. These issues, though precipitated by pathophysiological changes that result in diminished functional capacity, include health-related concerns that pertain to behavioral, psychological, and social adjustment; educational and vocational

attainment; and environmental modifications to accommodate the functional limitations of people with disabilities. Thus, the search for effective interventions must deal with a dynamic array of factors and needs that change over the life of the person with disability and the duration of disability.

The importance of the developmental perspective becomes clear when considering the estimated 5 percent of the population aged 21 and younger who are estimated to have a disability. Of these 3.2 million children, nearly three-fourths have a physical disability and the remainder have a mental one. Although only 1 in 20 people with disability is aged 21 or younger, this population accounts for the largest proportion of "disability years" (i.e., the number of years lived with disability). According to one estimate, people whose disabilities were manifested before age 16—about 5.6 million people—live with their disability for an average of 50 years, and account for 35 percent of all disability years in the United States.

Although children with disabilities have the same developmental needs as their peers without disabilities, their condition poses challenges to efforts to provide the educational and social experiences critical to preparing responsible, productive adults. Because physical limitations create a sense of being different, psychological issues as well as physical ones must be addressed. Moreover, interventions intended to ensure normal developmental progress must reckon with the limitations and health problems specific to different types of disability.

Rehabilitation medicine research should build the foundation of knowledge that can guide the development of interventions that are age appropriate (i.e., geared to the developmental or life stage of the person with disability). This need is not confined to the young. It applies to everyone with disabilities.

In addition, more research effort should be devoted to identifying the problems associated with the increasing duration of disability, which can have cumulative physiological and psychological effects. Substituting or compensating for lost or diminished function can cause physical stresses that, in the long term, lead to secondary conditions and to additional disability. This phenomenon is evident among the 1.6 million survivors of polio.

The experiences of polio survivors and of other people who have lived for many years with a chronic condition exemplify a set of issues that will become increasingly important over the coming decades. The number of so-called survivors—of severe head or spinal cord injuries, of cancer, of prematurity, of fetally acquired drug addiction, of live-saving heart surgery, and so on—is growing. For many of these people, long-term health problems and psychological issues are virtually unknown.

Recommendations

- Conduct long-term, multifactorial studies of the changing nature of impairments, disabilities, and handicaps over the lifespan.
- Conduct multivariate studies to determine how interactions among biological, psychological, sociological, and environmental risk factors influence the occurrence and course of impairments, disabilities, and handicaps.
- Evaluate the effectiveness of psychological and social support strategies intended to facilitate the psychosocial adjustment of children and adults to permanent impairments and disabilities. Identify the most important elements in this process.
- Define the roles of maternal and environmental risk factors in the pathogenesis of birth defects.
- Elucidate the mechanisms governing bone and muscle development in the

presence of normal and abnormal neural function.

- Develop animal models of common physically disabling conditions to establish a scientific rationale for optimizing rehabilitation strategies.
- Conduct controlled clinical trials to evaluate the short- and long-term efficacy of multivariate treatments (such as the combination of surgical and pharmacological interventions and assistive devices) to reduce impairment and disability.
- Determine the factors that contribute to successful prevocational and career development programs for children with disabilities (i.e., programs that have been shown to be effective in helping these children become independent, self-sufficient adults).

Basic and Clinical Research Training

Rehabilitation medicine research suffers from a severe shortage of highly qualified, experienced basic and clinical scientists and applied technological investigators. Demand is so great and the supply so limited that faculty positions may remain vacant for years. At some major university medical centers, entire departments of rehabilitation medicine have been abandoned. This personnel shortage and the lack of support for research opportunities in the field are the primary obstacles to improving the effectiveness of rehabilitation services in the United States.

Progress in rehabilitation medicine research has lagged behind the pace of scientific advances in other areas of biomedicine. Although advances in acute care medicine have reduced mortality caused by cancer, congenital birth defects, severe brain and spinal cord injury, and other conditions that until recently were nearly always fatal, many of those who have been spared survive with permanent functional impairments and disabilities. These people constitute a large, growing segment of the population that would benefit from a sustained, comprehensive commitment to building the field of rehabilitation medicine research.

Funded primarily by NIH and the National Institute on Disability and Rehabilitation Research, current programs for training in rehabilitation medicine suffer from deficiencies in quantity and scope. Available opportunities are insufficient to cultivate the growth of the cadre of highly qualified researchers essential to building a solid base of knowledge on which to develop effective interventions and services. With rare exception, training opportunities do not have rehabilitation medicine as a primary focus and fail to reflect the field's interdisciplinary composition. Especially neglected is the critical need to train investigators in the basic sciences who are needed to help build the field's theoretical foundation.

Besides the inadequate support, the relative immaturity of rehabilitation medicine as a discipline poses an additional problem. Because senior investigators are few, young researchers interested in entering the field often do not have role models or mentors to help them make the transition and guide their efforts to compete for funding for the research training they may require.

Consequently, the two most productive pathways for cultivating the growth of an emerging discipline—attracting accomplished biomedical and nonbiomedical scientists to the field and providing training opportunities for students and young investigators—remain to be fully developed in rehabilitation medicine.

Recommendations

- Create a Midcareer Rehabilitation Research Development award and other mechanisms and incentives to attract to

the field established basic, clinical, and applied investigators working in areas relevant to the needs of rehabilitation medicine research and to encourage established rehabilitation clinicians to pursue research careers.

- Recruit people with disabilities and members of minorities, ethnic groups, and other populations that are underrepresented in the field.
- Create Young Academic Investigator awards in basic, clinical, and applied rehabilitation medicine research to help recruit and develop junior faculty members.
- Create individual and institutional awards to support the training of medical, graduate, and postdoctoral students in rehabilitation medicine research.
- Create an award to support the development of curriculums and training programs.
- Encourage researchers and academic centers to pursue the various existing career development awards administered by NIH institutes and centers with rehabilitation-related interests.
- Strengthen institutional commitments to rehabilitation medicine research and training.
- Ensure adequate presence of rehabilitation medicine research in the NIH process of peer review of applications for extramural research and training grants.
- Establish Institutional Centers of Excellence for rehabilitation research and training.

Biomechanics, Ergonomics, and Engineering Design

The efforts of research engineers and physical scientists have contributed significantly to major advances in rehabilitative interventions and services. In particular, the application of quantitative analysis, modeling, and device design has significantly expanded the understanding of body motion and function and has led to new approaches to restoring or substituting for lost function. These contributions stem from work in three major categories of research and development: biomechanics, ergonomics, and engineering design.

Biomechanical principles and techniques provide the quantitative means to define the physical elements of human movements. On the basis of precise knowledge of how the body moves, one can design means to supplement or replace lost function. Significant progress has been made in the quantification of muscle function, joint mechanics, and the mechanical properties of soft connective tissues.

Determination of muscle forces, joint positions, and limb loads enables the assessment of the most efficient methods of performing physical tasks. Ergonomic studies yield detailed knowledge of energy expenditures associated with the performance of certain tasks, as well as of the resulting physical stresses on specific musculoskeletal systems. This knowledge can be used to devise measures to reduce the incidence of job-related injuries. Recent work has concentrated on how the forces of exertions, repetitions, and postures combine over time to cause cumulative trauma disorders such as tendinitis, carpal tunnel syndrome, and low back pain. Medical costs and economic losses resulting from lost work time caused by such disorders are estimated to total more than $100 billion annually.

Measurement of metabolic energy expenditure provides important information on ambulation. Moreover, quantitative methods can be used to estimate the additional energy demands, or costs, that might be caused by gait impairments. These measurements can be used to assess

the effectiveness of assistive devices, such as prostheses and orthoses.

A major focus of rehabilitation engineering has been the design of devices and systems to replace lost function. Research and development have been concentrated in the areas of prosthetics and orthotics, assistive devices, urinary incontinence, neural prostheses, wheelchair design, cognitive training, and robotics.

Recommendations

- Develop easy-to-use clinical tools for the quantitative assessment of muscle function, mobility, and postural control.
- Develop quantitative measures for assessing and comparing the functional capacity to carry out routine tasks and the level of performance achieved in doing so.
- Develop procedures and standardized protocols for determining sites of fatigue in the neuromotor systems in people with and without impairments and disabilities.
- Develop techniques for the mechanical testing of tissue properties under physiologically representative conditions.
- Identify and quantify, in people with and without impairments and disabilities and in older adults, the factors and mechanisms involved in performing important motor tasks such as walking, ascending and descending stairs, reaching, sitting, and crouching.
- Determine the effects of the use of mobility aids (i.e., canes, wheelchairs, prosthetic and orthotic devices) on the muscles and joints.
- Plan rehabilitation strategies to assess the potential physiological and metabolic benefits of varying the means and modes of mobility for people with impaired mobility.
- Improve the analytical tools for evaluating the performance of work-related tasks and the potential to reduce work-related injuries.
- Rigorously evaluate the utility, functional impacts, and dependability of assistive devices.
- Optimize the performance properties and biocompatibility of materials used in implanted devices such as artificial ligaments, tendons, and bones; mechanical and fluid conduits; and chronic sensing and stimulation electrodes.

Assessment and Epidemiology

Rehabilitation medicine research needs epidemiological tools and assessment instruments that transfer across disciplinary boundaries and provide information that can be used to build the field's theoretical foundation.

Considerable effort has been devoted to developing methods for measuring and assessing various aspects of impairment, disability, and handicap. At the level of body systems, for example, assessment tools have been developed to measure strength, endurance, energy expenditure, range of motion, muscle activity, and sensory function. Frequently, however, such assessments are based on subjective methods of observation. Although more quantitative tools, such as isokinetic dynamometers, are sometimes used, the methods employed vary so greatly that it is difficult to compare data from different laboratories. An additional challenge is the need to incorporate these tests of neuromuscular function into an integrated, multidimensional analysis that would provide meaningful measures of outcomes. It would then be possible to determine how closely the results of a given assessment correspond to functioning in daily life.

Much of the work on measures of disability falls under the rubric of functional

assessment. In all, more than 40 systems for measuring various aspects of function have been published in the literature. Few, however, have been evaluated for their applicability and methodological soundness as research tools.

Measures of handicap examine such factors as quality of life, sense of well-being, performance of social roles, and work productivity, but only limited research effort has been devoted to developing systems of measurement.

Obstacles and shortcomings also exist in epidemiology. As a result, understanding of the determinants and prognoses of disability resulting from major chronic diseases and impairments has advanced little during the past 25 years. This fact largely reflects the small number of researchers dedicated to medical rehabilitation, the low levels of support for their activities, and their understandable preoccupation with the immediate, practical problems faced by the patients they serve. However, neglecting the epidemiology of impairments, disabilities, and handicaps has limited the development of more effective rehabilitation strategies because it has slowed the evolution of the theoretical foundation on which such strategies should be built.

Classical epidemiology provides a simple, useful model for studying antecedent-consequent relationships of multiple causal factors of disability and the role of rehabilitation as an intervening variable. Many important research questions can be developed around the relationships among these key variables.

Epidemiological investigations such as the Framingham study and the National Health and Nutrition Examination Surveys have been organized around specific diseases or conditions and global health indicators. No large-scale data set has been designed primarily to investigate the distribution and correlates of impairment, disability, and handicap within the population. These data are needed to develop science-based rehabilitation strategies and to evaluate the efficacy and cost-effectiveness of interventions. Research is also needed on intervening factors that influence rehabilitation outcomes.

Recommendations

- Develop the data-collection and surveillance systems necessary to generate epidemiologically sound evidence of the incidence and prevalence of impairments, disabilities, and handicaps.
- Develop and test theoretical formulations of the determinants of impairments, disabilities, and handicaps, and of the course of the progression leading from impairment to handicap.
- Assess patterns and models of care in terms of their impact on the quality of life of people with impairments, disabilities, and handicaps.

Information Resources

One of the great disappointments in rehabilitation medicine is the field's failure to use all the available informational resources to ensure that those in need receive the best and most appropriate services and interventions. The problem lies in the relatively ineffective methods used to disseminate research findings and the other types of information required by researchers, rehabilitation practitioners, people with disabilities, manufacturers of assistive technologies, policymakers, and the many other audiences that regularly or occasionally need information.

These shortcomings are not unique to rehabilitation medicine, but their consequences may be more severe. The multidisciplinary composition of the field and its reliance on interdisciplinary approaches to addressing most issues mean that those in the field face the challenge of integrating a tremendously diverse range of information

presented in widely different formats and levels of technical detail.

Databases are a partial answer to these problems. Access, however, is rarely convenient, and databases contain information that must often be processed before it becomes directly useful to the person seeking it.

These obstacles are surmountable. The fields of information science, information processing, and communication technology are advancing at an unprecedented rate. Computing power increases by a factor of 10 every 4 years, while costs decrease by a factor of 10 every 5 years.

Progress in technology and artificial intelligence will provide rehabilitation medicine with the opportunity to tap into the collective pool of knowledge easily and quickly. Realizing this opportunity could significantly advance the understanding and practice of rehabilitation medicine.

Recommendations

- Build an integrated information resources system.
- Cultivate an awareness, within the rehabilitation medicine research community, of information sources and how to access them.
- Create faster, more accessible, and more user-friendly interfaces.
- Develop ways to increase the utility of available information.
- Increase the accuracy and quality of available information.
- Add new data to the system.

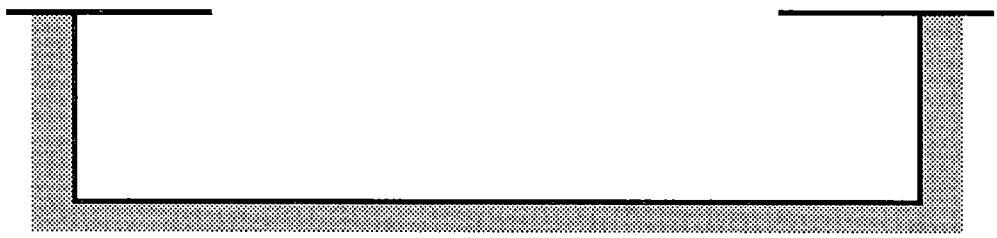
Looking Ahead

This report is a beginning, a building block in the development of rehabilitation medicine research. It is not intended to be a rigid prescription for leading the field into the next century. The problems and challenges are too many, too diverse, and too complex for any one body to reduce to a single prescription.

The needs, priorities, and recommendations presented here can guide and accelerate the evolution and growth of rehabilitation medicine research into a discipline positioned at the leading edge of the biological, behavioral, and social sciences. The aim of this process is, of course, to build the scientific foundation on which to develop treatments that are at the forefront of medical practice and that help achieve the maximal level of functional recovery for people with impairments, disabilities, and handicaps. There is no shortcut to building this foundation. It will require effective interaction between basic and clinical scientists, an efficient process of technology transfer, and a sustained level of financial support for training and research.

Thus, convening other panels to explore further the critical issues and needs identified in this report will be a continuing need. It is necessary, for example, to address methodological issues, to refine and address research training needs in specific areas of rehabilitation medicine, to guide the diversity of research efforts needed to enhance understanding of the mechanics of disabilities and of the natural histories of impairments and disabilities, and to plan the development of the data-collection and surveillance systems needed to improve the epidemiological understanding of impairments, disabilities, and handicaps. Also warranting attention is the troublesome gap that separates the efforts of basic researchers from those of applied and clinical scientists. This "technology-transfer gap" is not unique to rehabilitation medicine research, but its consequences—avoidable delays in using available and emerging scientific knowledge to improve interventions and therefore the lives of millions of people—are especially severe.

Introduction



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Introduction

Overview

Disability is not a new health issue but its incidence and general impact are rapidly increasing. Every day, expectant couples agonize over the small but real possibility that their newborn will have a birth defect. Older adults are aware that vulnerability to activity-limiting conditions increases with age. Drivers of motor vehicles, workers in hazardous occupations, and residents of crime-ridden areas accept, or have little choice but to accept, an elevated injury risk that can result in lifelong physical or mental impairment.

Though often difficult to grasp in the abstract, these and other risks have a very concrete manifestation—the estimated 35 to 43 million people, or 1 in 7 Americans, who have a physical or mental disability. It is no exaggeration to say that most people will experience disability, either directly or in a family member or close friend.

What is new, then, is not the widespread nature of disability and the ubiquity of its risk factors, but rather a rapidly evolving scientific and social understanding of disability. Years of public awareness efforts by representatives of the rehabilitation professions and the independent living and disability rights movements have spawned growing recognition that, by itself, the inability to perform certain tasks without personal or technological assistance does not preclude an affected individual from leading an independent and productive life. Moreover, advocates of people with disabilities have explained that lifelong impairments and their associated physical and mental limitations pose special personal challenges, but the extent to which these limitations preclude living a normal life is determined by a complex interaction of health-related factors and societal attitudes. Often, it is society, not health status, that denies people with disabilities the opportunities to live autonomously—to hold a job or to secure vocational or educational training necessary for employment; to travel to stores, restaurants, and entertainment events; and, in short, to engage in the activities that most people take for granted. These ideas are the underlying tenets of the Americans With Disabilities Act, signed into law by President Bush in 1990. This civil rights law is designed to reduce social and economic barriers confronting people with physical and mental limitations. It is also a powerful impetus for evaluating and strengthening the role of rehabilitation practitioners in helping people with disabilities become active members of society.

Rehabilitation medicine intersects the concerns of traditional medicine and the social determinants that influence human capacity and performance. It is a component of the "healing arts and sciences," but has some unique aspects. The field focuses on optimizing human functioning in

customary social and environmental settings—an outcome that is difficult but necessary to quantify.

This report describes needs and opportunities in the interdisciplinary field of rehabilitation medicine research which provides the underpinnings of successful interventions. Progress in the field depends on advances made across a broad range of areas, from basic biomedical research to engineering. Because inputs from many specialties are required to develop and deliver optimal rehabilitative procedures, research must be multidisciplinary and well integrated.

Specifically, rehabilitation medicine research is the study of impairment, disability, and handicap resulting from illness, injury, and developmental processes that begin before birth and continue until the last stages of life. Its focus is on health-related improvement—physical, cognitive, behavioral, and social—in human functioning. Rehabilitation medicine research explicitly applies new knowledge to the development of medical, behavioral, psychological, social, and technological interventions designed to optimize function following impairment or the occurrence of disability or handicap.

Scope of the Report

This report addresses the question: What research is needed to build a strong scientific foundation to guide the development of effective, cost-efficient medical rehabilitation treatments and services? In June 1990, the National Institutes of Health (NIH) convened a Task Force of more than 100 experts in rehabilitation medicine, an interdisciplinary field with roots in basic and clinical biomedical sciences, the behavioral and social sciences, allied health, nursing science, and health services research. The Task Force examined the adequacy of current efforts to understand the spectrum from impairment to disability and to handicap. It also evaluated ongoing efforts to develop the knowledge necessary to devise health care interventions, social services, and personal health practices to increase the chances for people with disabilities to live autonomously and pursue their personal, social, and vocational interests.

Emphasis was given to four major areas of scientific concentration: neurophysiological dysfunction, musculoskeletal disorders, cancer rehabilitation, and geriatrics. In addition, five panels examined issues that transcend the entire field of rehabilitation medicine: needs and opportunities for addressing issues that arise over the lifespan and development of individuals with disabilities; basic and clinical research training; biomechanics, ergonomics, and engineering design; assessment and epidemiology; and information resources.

Though not explicitly listed in the titles of the Task Force's working panels, injuries and cardiopulmonary, pediatric, and other physical disabilities were considered. However, the Task Force did not evaluate the status of research on mental disabilities, an area warranting analysis by another body, perhaps created under the auspices of the National Institute of Mental Health. Nonetheless, behavioral, psychological, and cognitive issues were not only discussed but given high priority because of their impact on people with physical disabilities. Also outside the Task Force's immediate scope were vision disorders and hearing, speech, and other communication disorders. Disabling conditions in both these categories have been examined in previous initiatives organized by NIH. However, the Task Force did review associated communication difficulties to the extent that they affect the rehabilitation and functioning of people with neck cancer, spinal cord injury, traumatic brain injury, or other disabling conditions.

Evidence of Need

One approach to assessing the need for medical rehabilitation research and its significance is to characterize the field on the

basis of the number of the needs and potential beneficiaries. As a group, the approximately 40 million Americans with disabilities are roughly equal in number to the combined populations of California and Florida, the Nation's most populous and fourth most populous States. The economic consequences of disabilities are staggering. Total direct costs (the sum of expenditures for health care and other services, the value of productivity losses directly attributable to disability, and the value of productivity losses attributable to reduced wage-earning activity by household members who provide assistance to people with disabilities) have been estimated at 6.5 percent of the U.S. gross national product.

Thus, in terms of prevalence and cost, disability ranks as this Nation's largest health problem. It is rarely recognized as such, however, because disability is a potential consequence of hundreds of pathologies or impairments. (Table 1 lists, by categories of disorders, the 15 leading causes of disability among the noninstitutionalized population.) The bulk of research has addressed disability-causing impairments. Comparatively little effort has been devoted to investigating the consequences of these pathologies on the performance of affected individuals. Much biomedical research attempts to elucidate disease processes and to describe, at the most basic level, normal biological functioning. However, this essential research in itself breaks problems into ever-smaller units of analysis, down to the level of individual proteins or other molecules. Anticipated byproducts of the knowledge generated in these pursuits, such as new pharmacological agents, surgical procedures, and other medical therapies and interventions designed to prevent or reverse pathology, can be realized if there is an effective interface between basic research and clinical practice.

Lack of an effective interface has resulted in neglecting of efforts to understand and alleviate the functional consequences of the many disability-causing impairments for which there are inadequate

Table 1.
Leading Causes of Disability in the United States*

Cause of disability	*Prevalence (thousands)*	*Percent*
All conditions	52,718	100.0
Orthopedic impairments	6,987	13.3
Arthritis	6,130	11.6
Heart disease	5,575	10.6
Hypertension	3,506	6.6
Visual impairments	2,900	5.6
Diabetes	2,111	4.0
Mental disorders	1,837	3.5
Asthma	1,783	3.4
Intervertebral disk disorders	1,699	3.2
Nervous disorders	1,601	3.0
Hearing impairments	1,405	2.6
Mental retardation	1,047	2.0
Emphysema	994	1.9
Cerebrovascular disease	939	1.8
Abdominal hernia	595	1.1

**Noninstitutionalized population*

*Source: **Data on Disability From the National Health Interview Surveys, 1983–1985**, National Institute on Disability and Rehabilitation Research, Washington, DC, 1988.*

treatments. Disabilities can result from curative treatments that effectively control a primary condition, such as cancer, but at the price of incurring prolonged or lifelong secondary conditions that significantly diminish functional capacity and quality of life. Present-day medicine does not adequately address the latter issues and problems.

Compared with other areas of biomedical and health-related research, medical rehabilitation research is distinguished by its emphasis on understanding health-related changes in human functioning and performance and the mechanisms by which function improves after the occurrence of disability. Its goals are to develop interventions to maximize functional recovery from any impairment, disability, or handicap. Thus, rehabilitation medicine research attempts to combine and synthesize basic concepts and to integrate them at the level of complexity necessary to improve an individual's day-to-day functioning in his or her normal environment. The products of rehabilitation medicine research, therefore, can—and should—be integrated into the entire treatment process, beginning with acute care and continuing through the duration of any disability.

The importance of expanding efforts to strengthen the scientific underpinnings of rehabilitation medicine and of fostering greater integration of effort in research and treatment is underscored by several trends, which are described below.

Mortality is decreasing, while morbidity and disability are increasing. In all age groups, the prevalence of disability is increasing faster than population growth. For example, between 1959 and 1984, the largest increase in severe disabilities, those that prevent individuals from carrying out their major activities, occurred among people in the prime of working life, between the ages of 18 and 44. The 178 percent increase in the prevalence of severe disability in this age group was four times greater than the percentage increase in population over 25 years. Researchers also report increases in the prevalence of multiple, or coexisting, conditions that limit activity. In an analysis of data from 1969 to 1971, the average number of chronic conditions per person with an activity limitation was 1.32. Ten years later, the average increased to 1.48 conditions, an increase of 12.1 percent.

The factors contributing to these increases are multiple, and most remain to be explained in satisfactory detail. Given the inadequacies of current data-collection and surveillance systems, this void in understanding should not be surprising. Nonetheless, researchers have identified three major underlying causes: increasing prevalence of chronic diseases in U.S. society, increasing survival among people with disabling conditions previously characterized by high mortality, and increasing life expectancy among people with or without disabilities.

Modern medicine's success in averting death from once-fatal conditions has contributed to an increase in the population with disabilities. For example, survival among people who sustain serious spinal cord injuries has risen steadily over the last few decades. In the 1950s, the probability of survival was high only for people with low-level paraplegia. Today, substantial numbers of people with high-level traumatic quadriplegia are surviving, and many are living outside institutions. Similarly, early death is no longer the expected outcome for people born with spina bifida, Duchenne muscular dystrophy, and other life-threatening conditions.

Among the middle-aged and elderly populations, there is a strong inverse relationship between disability and mortality trends for many conditions, including such common diseases as hypertension, diabetes, heart disease, and emphysema. Among middle-aged people, the prevalence of 10 of 11 conditions with historically high

rates of mortality increased between 1958 and 1981. Yet, mortality rates for 8 of these conditions declined, some by as much as 50 percent. However, the number of people reporting that these same conditions caused limitations in their major activity increased markedly—more than 100 percent for some chronic conditions.

As the U.S. population ages, the proportion of the population at high risk of disability increases. On average, U.S. citizens who reach age 65 can expect to live longer than their elderly counterparts in nearly every other nation. Demographic analyses project that the elderly population will increase from 27.5 million in 1985, or 11.5 percent of the total population, to 31.7 million in the year 2020, or 17.3 percent of the population. By the year 2040, more than one person in five will be age 65 or older. Associated with increasing life expectancy and other demographic trends that underlie the growth of the elderly population, both in absolute numbers and as a proportion of the general population, are increasing numbers of people age 65 and older who have chronic diseases and disabilities. More than 80 percent of the people in this age group have one or more chronic physical conditions that can impair function. The risk of disability increases markedly after age 55 and continues to rise with age. By age 75, there is a 50 percent chance that a person will have a disability.

These trends, along with substantial increases in the prevalence of disability among working-age people, pose a number of difficult health and social policy issues. In health care, one proposed goal is to "compress" morbidity and disability, or to increase the number of "years of healthy life." Indeed, the national health objectives for the year 2000, promulgated by the Public Health Service, call for increasing to 65 the number of years of healthy life enjoyed by the average American, as compared with about 60 years in 1987.

Primary prevention, which, through such measures as immunization, seeks to prevent diseases and injuries that can lead to disability, represents one means of accomplishing this objective. However, preventive efforts that interrupt or at least slow the progression to disability after an impairment occurs are also required. Such efforts constitute an important focus of rehabilitation medicine.

Because all disability cannot be prevented, the need for interventions that reduce the level of disability and improve or maintain the functional capacity required to perform personal, social, and vocational roles will remain high for the foreseeable future. Such rehabilitative and habilitative interventions are also a major emphasis of rehabilitation medicine.

Without more effective interventions, the economic costs of disability will rise. Aggregate economic losses due to disability, as noted earlier, have been estimated at 6.5 percent of the gross national product. Disability-related expenditures for working-age people, who comprise 60 percent of the population with disabilities, were estimated to be $169.4 billion in 1986, a nearly ninefold increase since 1970. Public-sector spending accounted for 54 percent of that amount, while the steadily rising private-sector share was 46 percent, up from 38 percent in 1980.

An analysis of spending for health care estimated that the 16 percent of the population with activity limitations totaled $63 billion in 1980, or about 40 percent of all health care expenditures for that year. Research indicates, however, that many of the secondary complications and other health problems of people with disabilities can be prevented by timely and appropriate primary care services. Consequently, inadequate primary care ultimately adds significantly to the Nation's health care bill.

Maintaining the status quo will perpetuate needless underutilization of a large, potentially productive segment of U.S.

society. A not uncommon view holds that people with disabilities are "sick" and therefore unable to provide for themselves. This view has influenced the development of health care and social service programs that, in effect, make people with disabilities the objects of charity. In exchange for social beneficence, however, many people with disabilities have been excused—some have said "disenfranchised"—from the affairs of society.

The disability rights and independent living movements have worked to change this perception, arguing that, given the opportunity and necessary support, people with disabilities are capable of assuming a fully productive role in society. Whether a person with a disability can work, go to a movie, travel to a shopping center across town, or engage in any other activity is not solely determined by his or her functional limitation. Rather, the critical determinants of societal participation and personal autonomy are public attitudes, features of the environment, and the willingness of employers and other elements of society to alter the environment to accommodate the limitations of people with disabilities.

The results of a 1985 survey of 1,000 people with disabilities illustrate the significance of these distinctions. Two-thirds of the respondents between the ages of 16 and 64 were unemployed. However, 65 percent of these people said they would like to be working. Extrapolating this result to the entire working-age population with disabilities yields an estimate of 8 million people who would like to enter the labor force. Barriers to employment included employer discrimination (cited by 25 percent of the working-age respondents) and the lack of accessible or affordable transportation (cited by 28 percent). Among the respondents who were working or had been employed, about one-third reported that their employers had taken measures to accommodate their disabilities. Also illustrating the impact of the social and physical environment is the finding that 56 percent of the respondents reported having difficulty socializing with friends outside the home and attending cultural and sporting events.

Because the ultimate concern of rehabilitation medicine research is human performance and quality of life, the field must also study how social and environmental factors interact with the physical, psychological, and behavioral aspects of impairments and disabilities. Strategies for intervention must be based on knowledge of this complex interaction.

Rehabilitation Medicine Research as a Scientific Discipline

Conceptual Foundation

The field of rehabilitation medicine research requires contributions from a variety of disciplines. Why this is so can be illustrated with the World Health Organization's (WHO) model of impairment, disability, and handicap, as described in the accompanying box. By illustrating the progression to disability and handicap, this model, which was published in 1980 as a trial supplement to the International Classification of Diseases, draws attention both to the causes of pathology and to its consequences. Though the diagrammatic depiction suggests a simple and direct relationship between each stage in the continuum, the underlying concepts recognize the complexity of the interrelationships.

Each stage in the continuum presents a broad range of research questions. As noted earlier, most biomedical research focuses on disease and impairment, the points at which preventive and curative measures can maintain or restore health. Beyond the impairment stage, where the focus expands to functional performance, the scope and intensity of the research effort diminishes

considerably, while the complexity of the questions increases.

Irreversible impairments, such as chronic diseases, loss or malformation of a limb, and paralysis, increase the risk and severity of disability, although not uniformly. Functional limitations imposed by some impairments carry a disability risk of virtually 100 percent. In contrast, some chronic diseases pose substantially smaller risks but, because of their high prevalence, account for large numbers of people with disabilities. For example, among the 29 million Americans with hypertension, about 1 in 8 reports an activity limitation caused by the disorder; among the 29 million people with osteoarthritis, 1 in 5 has an activity limitation. Numerous issues arise between the stages of impairment and disability. What are the physiological mechanisms involved in the progression to disability and how are these mechanisms related to the severity of disability? Beyond physiological processes that cause dysfunction, what role do psychosocial variables play? Why do some people with a specific impairment develop disability, while others with the same impairment do not? Questions such as these address the causes of disability and the corresponding risk factors.

One aim of clinical research is to develop reliable, scientifically valid measures of the limitations associated with a specific impairment, such as the amount of weakness or

Model of the Consequences of Pathology

Disease or Disorder → **Impairment** → → **Disability** → → **Handicap**

Disease or disorder. "Something abnormal occurs within the individual: this may be present at birth or acquired later. A chain of causal circumstances, the 'etiology,' gives rise to changes in the structure or functioning of the body, the 'pathology.' Pathological changes may or may not make themselves evident; when they do they are described as 'symptoms and signs.' These features are the components of the medical model of disease."

Impairment. An abnormality of structure and/or function at the organ level. At this stage, an affected individual becomes aware of the pathology or, in behavioral terms, becomes aware that he or she is unhealthy. Subclasses of impairment include disfigurement and intellectual, psychological, language, aural, visceral, skeletal, and sensory abnormalities.

Disability. Restriction or lack of ability to perform an activity in a manner considered normal, a disability is a disturbance manifested in the performance of daily tasks. Disabilities are the functional consequences of impairments. Principal subclasses of disabilities are concerned with behavior, communication, personal care, locomotion, body disposition, dexterity, and particular skills.

Handicap. A disadvantage resulting from an impairment or a disability, a handicap limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for the affected individual. The nature of and severity of a handicap are determined in large part by the interaction of the adaptation of the person to the social and environmental surroundings and the adjustments made by the society to accommodate an impaired individual. A disadvantage is evaluated in terms of the level of interference with socially expected and so-called survival roles. Measured as such, handicaps largely reflect societal attitudes toward people with disabilities and impairments. Handicaps include physical dependency, lack of mobility, and economic dependency.

Sources: ***International Classification of Impairments, Disabilities, and Handicaps;*** *World Health Organization, Geneva, Switzerland, 1980; and Rowland Chang, Report of the Panel on Physical Medicine and Rehabilitation Research, Washington, DC, 1989.*

stiffness caused by osteoarthritis, and of the effect of these limitations on the performance of tasks. Assessments of impairment, disability, and, as will be explained, handicap require separate measurement systems, and each type of impairment, disability, and handicap may require unique measures to define its impact. Each measurement system, however, must be related to the others. Collectively, assessments should provide information to guide basic research on the underlying pathology of impairment and disability, guide the development of interventions, and evaluate the effectiveness of rehabilitative and habilitative interventions to improve human functioning.

Shifting the focus to the relationship between disability and handicap introduces an additional layer of complexity. Here the unit of analysis is the person with a disability within his or her social and physical environment. Research in this area addresses the interaction of the intrinsic health-related aspects of handicap—impairments and disabilities—with the extrinsic aspects—social attitudes, accessibility and nature of services, and features of the environment, ranging from alterations of curb cuts to devices that aid mobility.

Interventions to reduce handicap can be viewed as enabling an individual to manage everyday needs with the aid of assistive devices, or developing the skills and level of functioning necessary for employment. Thus, the principal aims of handicap-focused interventions are to maximize the potential for performing functional tasks and to improve quality of life.

The concept of quality of life is assuming an increasingly prominent role in all of health care, not just rehabilitation medicine, where reduction of handicap is virtually synonymous with an improvement in quality of life. However, measures of quality of life and related concepts, such as sense of well-being, social-role performance, and work productivity, remain largely experimental and must be developed further. Nonetheless, the emphasis on quality of life in rehabilitation medicine transcends the broad range of potential rehabilitative interventions from those aimed at reducing impairment to those that address the social determinants of handicap.

It is important to study impairment, disability, and handicap from many perspectives—medical, psychological, cognitive, behavioral, social, environmental, and educational—and to integrate the findings. Human performance is the product of a complex array of interacting variables. To evaluate medical interventions solely on the basis of physiological changes is to neglect other important determinants of function and performance, such as an individual's psychological adjustment to disability. In short, the problems and needs of people with disabilities are multidimensional, and so must be the intervention strategies and the research on which they are based.

An Interdisciplinary Science Ready for Growth

Past and present. Traditionally, the locus of medical rehabilitation research has been the handful of departments of physical medicine and rehabilitation at the Nation's medical schools. While these departments and the few other centers of rehabilitation research have made important contributions over the past 50 or 60 years (see box), the field has not received adequate support. Its overall effort has not been commensurate with the rising need, nor has it kept pace with the rate of scientific progress in other fields of medicine. Those who work in medical rehabilitation research point out that the quantity and quality of research in the area has been insufficient.

Rehabilitation medicine is at a critical stage of development. For most of its history, rehabilitation medicine has been the domain primarily of practitioners, as is true of most young fields of medicine. The

Rehabilitation Medicine Research Accomplishments

Though still a young scientific discipline seeking full recognition and adequate support, significant contributions to the treatment and care of people with disabilities have been made in research related to rehabilitation medicine. Past accomplishments also include the development and continuing improvement of assistive devices and posttreatment interventions that have helped many people with disabilities maintain their independence and remain productive members of society.

One of the most obvious examples of the benefits spawned by rehabilitation medicine research are prosthetic and orthotic devices, the products of the combined efforts of engineers, physiatrists, and other rehabilitation researchers. Both basic and clinical research have contributed to the development of new assistive devices and the refinement of existing ones. Basic research, for example, has greatly enhanced understanding of the biomechanics of gait, which, in turn, has led to the improvement of mobility aids and to more precise and more informative assessment measures for diagnosing neuromuscular and musculoskeletal impairments and disabilities.

This synergy in basic, clinical, and applied technological research is also apparent in the area of functional electrical stimulation. Scientists and engineers are collaborating to enhance understanding of the neurophysiological and anatomical control of movement. They are using this information, along with new electronic technology, to develop techniques to restore function to paralyzed limbs.

Other dividends from research related to rehabilitation medicine research include improved methods for treating burns, controlling pain, promoting wound healing, controlling spasticity, managing bowel and bladder dysfunction, and preventing the occurrence of secondary conditions such as contractures and decubitus ulcers. In addition, advances in assessment techniques, a major area of research concentration, are yielding an increasingly comprehensive picture of the biological, behavioral, psychological, and sociological impacts of impairments, disabilities, and handicaps. Further progress in this area will likely lead to innovative intervention and prevention strategies.

It is recognized that the beginnings of many past, as well as future, advances are the products of work done by investigators in disciplines with complementary interests and by rehabilitation medicine researchers. Thus, the pace of future progress will be determined not only by the efforts of rehabilitation medicine researchers, but also by the strength of the connections forged between investigators in a variety of disciplines.

capacity for research has been limited by shortages of personnel trained in the basic or clinical sciences, a dearth of research support, and an absence of direction and coherent funding programs among the few funding sources that do exist. Most researchers now in the field are clinicians or other practitioners who have, in effect, developed their research skills "on the job." Meanwhile, accomplished and prospective researchers with rehabilitation-related interests have tended to avoid the field because of its weak scientific underpinnings, the uncertainty of funding opportunities, and a sense that scientific endeavors in rehabilitation medicine are not perceived as a high national priority. But regardless of the circumstances that have led to the current situation, it is clear that progress in clinical practice has been constrained by the lack of a theoretical foundation and of a sustained, state-of-the-art research program.

The breadth of rehabilitation medicine research is large. The field's interests span

a variety of disciplines from the basic biomedical sciences to the medical and surgical fields, from pediatrics and adult-focused clinical fields to engineering and health services research. Given the lack of focused resources for rehabilitation medicine research, progress has depended largely on the strength of the connections among disciplines.

Unfortunately, these connections are weak. Much current research is relevant to rehabilitation medicine, but rarely is this relationship recognized in a timely fashion by researchers and clinicians. Ideally, advances in basic research, for example, guide clinical investigations of intervention strategies. In turn, the results of clinical studies help define areas in which basic research efforts are needed. Such interactions are spotty at best and, in most university settings, do not exist among the component disciplines of rehabilitation medicine research.

On the basis of a 1983 survey of Federal agencies, the Interagency Council on Handicap Research (now the Interagency Council on Disability Research) estimated Federal expenditures for rehabilitation research to be $198 million. However, the accuracy of this estimate has been challenged. Individual agencies varied widely in their interpretation of the survey definition of rehabilitation research: research that is "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." While agencies identified what they considered to be rehabilitation-related research, some observers within rehabilitation medicine have suggested that many projects were only obliquely related to the goals of rehabilitation research. In a preliminary review of research training programs supported by NIH, this Task Force questioned the relevance of many projects described as being in the area of rehabilitation medicine.

Overall, it appears that only a fraction of the research and research-training programs identified as rehabilitation-related truly qualify as rehabilitation medicine. This is a crucial limitation, and it undoubtedly can be attributed to a variety of factors. One appears to be the difficulty that many researchers have in securing funding specifically for rehabilitation medicine.

Accepting, for the moment, the least restrictive definition of rehabilitation medicine research, the overall research effort is very uneven. Most clinical and basic research is supported in large part by NIH, which estimated 1989 expenditures of $119.3 million to support extramural and intramural research and training in rehabilitation medicine. Most NIH-funded research is clustered at stages antecedent to disability and handicap; that is, at the stages of "disease or disorder" and, to a lesser degree, "impairment." Potentially, studies in any basic science, but especially the biological sciences, can contribute to rehabilitation medicine research, now or in the future. Salient examples include studies of neuronal plasticity and axonal regeneration, biochemical mechanisms of cellular senescence and death, motor pathways in the brain, learning and memory, and developmental processes. In short, many areas of basic biomedical research are addressing issues pertinent to rehabilitation medicine research. Unfortunately, the intensity and scale of the research effort diminish at the point where the basic understanding acquired in these investigations can be applied to the study of human function and performance.

Ongoing research on the functional limitations associated with specific impairments and on the disabilities caused by these limitations is insufficient to identify, assimilate, and advance relevant sectors of research into human biology and behavior.

Moreover, many fundamental questions about the complex factors involved in normal and abnormal functioning—the answers to which would inform the efforts of basic researchers—remain to be addressed.

Proceeding across the continuum from disease or disorder to handicap, one finds an increase in research activity at the stage of handicap. Some of this activity is funded by the National Institute on Disability and Rehabilitation Research (NIDRR), a U.S. Department of Education agency with a budget of $73 million in 1990. Much NIDRR-supported research and development is focused on the "integration of disabled persons into independent and semi-independent community life." Although the agency's mission includes the goal of identifying the causes and consequences of disability, its emphasis is clinical research, including studies of the organization and delivery of rehabilitation services in acute care settings and in the community. Also supporting research with a focus on reducing disability and handicap is the Rehabilitation Research and Development Service in the Federal Department of Veterans Affairs. This agency's primary research interests are prosthetics, amputation, orthotics, spinal cord injury, and sensory aids. The service's 1990 budget was about $20 million.

Though only cursory, this review of rehabilitation research, broadly defined, leads to the same two conclusions that would be drawn from a more detailed examination. First, there are significant gaps in the effort, particularly in the areas of functional limitations associated with impairments and disability; and, second, there is a tremendous need for integration, for making explicit the connections between disciplines and between the various tiers of research activity. Further, more efficient integration and utilization of advances from other disciplines are needed. Too often, ideas and findings directly relevant to the interests of rehabilitation medicine lie dormant far too long.

Building research capacity for the future. Like the practice of rehabilitation medicine, research in the field should be viewed as an integrated problem-solving process. For the most part, current research efforts are fragmented and unsustained. However many disciplines are represented in these efforts, there is not enough interactive collaboration among disciplines on individual projects. This piecemeal approach will impede development of the scientific foundation needed to foster progress in rehabilitation medicine. For example, there is a pressing need for new research paradigms that consider the multifactorial nature of the problems and the need for long-term evaluation. In spite of the magnitude of the associated difficulties of controlling variables for evaluation and of creating experimental and control groups large enough for clinical studies, bold and aggressive efforts that deal with these problems must be encouraged. These difficulties underscore the need to develop new methodologies and sophisticated statistical techniques. Given sufficient research and training opportunities, investigators who can integrate knowledge from several disciplines will likely overcome these methodological challenges.

Challenges abound in rehabilitation medicine, but so do opportunities. Responding to both will require building research capacity in accordance with the field's integrative concepts. That is, investigators—clinical and basic, biomedical and nonbiomedical—must maintain a common focus on human functioning and performance in a societal context. Integration is essential. Therefore, researchers in the field must not only be accomplished in their specialties, but also familiar with the aims and methodologies of others. Basic scientists, for example, should be acquainted with the practice of rehabilitation medicine so

that they can assist in translating laboratory findings into experimental applications for clinical testing and evaluation. In turn, clinical investigators should have working knowledge of one or more basic sciences.

Developing a critical mass of research personnel will mean not only addressing shortages in the constituent disciplines of rehabilitation medicine research, but also cultivating interdisciplinary linkages. Productive working relationships that cut across disciplinary boundaries are so essential that the field's rate of progress ultimately depends on the success of these relationships. Thus, a new type of research specialist is needed, one who is highly qualified to address questions in multiple domains.

Summary

There is an urgent need to develop and validate interventions, to develop measurement instruments and valid models, and to design clinical trials. All are essential to building the scientific foundation on which to develop the optimal rehabilitative treatment strategies. There is no shortcut to building this foundation. It will require effective interaction between basic and clinical scientists, an efficient process of technology transfer, and a sustained level of financial support for training and research.

Technology is not only hardware and techniques, but also the underlying knowledge they embody. Rehabilitation medicine research has the overriding aim of developing the technology that will help people with disabilities gain autonomy and, thus, the opportunity to attain a high quality of life.

About 40 million Americans with disabilities are the potential beneficiaries of improvements in rehabilitative and habilitative interventions that can enhance their performance, maintain a margin of good health, and reduce vulnerability to secondary complications. Even small advances can make a critically important difference in the lives of these people. Moreover, all of society will gain if such measures reduce the waste of human capital that results when the potential of many goes unrealized. If these measures enable more people with disabilities to secure gainful employment or reduce the demand for transfer payments or costly acute care health services, the entire Nation will reap direct economic benefits.

The Task Force offers three general strategies for fostering and supporting the research efforts that will be instrumental in achieving these benefits.

First, a mechanism for "cross-fertilization" should be developed to allow the rehabilitation research community to participate in identifying research priorities in the basic biomedical sciences. The results of research in many scientific areas offer promising leads and opportunities for clinical investigations. Given sufficient support and intensity of effort, some lines of research could yield clinically useful applications in the near future. For example, applications of new synthetic bone materials may allow for earlier mobilization of patients with spine fractures. Neural tissue transplants have shown some promise for enhancing motor recovery by these patients.

Without input from the medical rehabilitation research community, many opportunities might go unrecognized and, therefore, unsupported. One means of fostering cross-fertilization between basic and clinical researchers is to add more medical rehabilitation scientists to the NIH study sections and review committees that evaluate research and training proposals. In addition, establishment of a separate rehabilitation medicine study section would help the field achieve equal standing with the other biomedical sciences that already have their own study sections.

Second, the field must expand its clinical research base by encouraging more investigators to study the functional outcomes of

patients with cancer, cardiovascular disease, and other common impairments. Much of the current research on outcomes in these clinical areas is confined to evaluations using biochemical, physiological, and survival measures. Inadequate attention is paid to functional assessment.

Third, incentives for interdisciplinary clinical research focusing directly on disability and handicap should be created. Much of this research would be long term, focusing on the health-related, psychological, and social aspects of disability and handicap. Moreover, it might require the participation of investigators in a variety of medical and nonmedical disciplines.

Estimates of the Number of Americans With Disabilities

Estimates of the number of Americans with disabilities vary from about 20 million to more than 40 million. This wide range reflects the lack of consistency in definitions of disability used in health surveys. Thus, there is a clear need to standardize disability-related concepts and definitions.

Estimates of the number of conditions causing activity limitations in the noninstitutionalized population are presented in table 2. Many of these conditions are directly in the province of rehabilitation medicine. The estimates are based on the National Health Interview Surveys (NHIS), 1983–1985. The concept of activity limitation corresponds closely to the WHO definition of disability: "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being." According to the NHIS, 32.5 million Americans have an activity limitation. Of these people, 22.4 million are either unable to perform their major activity or are restricted in their ability to carry out their major activity. Major activities are defined according to age: (1) playing for children under age 5; (2) attending school for people aged 5 to 17 years; (3) working or keeping house for people aged 18 to 69; and (4) caring for oneself and one's home for people age 70 and older. About 10 million people are limited in other than their major activity for their age group.

Many people with an activity limitation have more than one condition. Thus, the table reports a prevalence of nearly 53 million conditions that, collectively, are the causes of activity limitation in the affected population of 32.5 million people.

Functional limitation—the ability to perform nine selected tasks or functions—is another concept used to gauge the prevalence of disability in the U.S. population. The Survey of Income and Program Participation, carried out by the Bureau of the Census, estimates that 37.3 million people age 15 and older, or 1 person in 5, have functional limitations. The limitations of 13.5 million, or 36.3 percent of the total, are classified as severe. Examples of functional limitations are difficulty getting into and out of bed, a problem for 2.1 million people; difficulty getting around inside the home, a problem for 2.5 million people; difficulty climbing a flight of stairs, a problem for 18.1 million people; and difficulty walking a quarter of a mile, a problem for 19.2 million people.

Finally, it must be noted that an estimated 2 million people are living in nursing homes, mental health facilities, and other care facilities.

Table 2.
Prevalence of Activity Limitation due to Chronic Conditions, by All Causes of Limitation, Age, and Gender: United States Civilian Noninstitutionalized Population, 1983–1985 (Three-year Average)

All Causes of Limitation	*All Ages*		*Under 18*		*18–44*		*45–69*		*70–84*		*85+*	
	Number of conditions in thousands and percent distribution											
All conditions	52,718	100.0	3,817	100.0	10,895	100.0	25,027	100.0	10,884	100.0	2,097	100.0
Skin and musculoskeletal												
Rheumatoid arthritis	646	1.2	*11	*0.3	121	1.1	388	1.5	118	1.1	*8	*0.4
Osteoarthritis/other arthropathies	5,484	10.4	*14	*0.4	469	4.3	3,099	12.4	1,594	14.6	306	14.7
Intervertebral disk disorders	1,699	3.2	*2	*0.0	668	6.1	904	3.6	117	1.1	*8	*0.4
Osteomyelitis/bone disorders	552	1.0	33	0.9	91	0.8	280	1.1	128	1.2	21	1.0
Bursitis	253	0.5	*1	*0.0	76	0.7	140	0.6	35	0.3	*1	*0.0
Psoriasis and dermatitis	189	0.4	31	0.8	75	0.7	69	0.3	*11	*0.1	*2	*0.1
Skin cancer	44	0.1	–	–	*8	*0.1	20	0.1	*13	*0.1	*3	*0.1
Bone cancer	52	0.1	*1	*0.0	*5	*0.0	24	0.1	20	0.2	*2	*0.1
Other skin and musculoskeletal	573	1.1	*13	*0.3	94	0.9	315	1.3	128	1.2	23	1.1
Impairments												
Absence of arm(s)/hand(s)	35	0.1	*5	*0.1	*10	*0.1	*13	*0.1	*7	*0.1	–	–
Absence of leg(s)	191	0.4	*2	*0.0	33	0.3	93	0.4	55	0.5	*8	*0.4
Absence of fingers, toes, feet	109	0.2	*6	*0.1	39	0.4	49	0.2	*13	*0.1	*2	*0.1
Other absence, NEC	186	0.4	*11	*0.3	47	0.4	88	0.4	39	0.4	*1	*0.0
Complete paralysis of extremities	373	0.7	*10	*0.3	93	0.9	172	0.7	82	0.8	*16	*0.8
Cerebral palsy	177	0.3	86	2.2	72	0.7	18	0.1	*1	*0.0	–	–
Partial paralysis of extremities	380	0.7	*9	*0.2	48	0.4	164	0.7	137	1.3	22	1.1
Paralysis of other sites	122	0.2	*13	0.4	25	0.2	53	0.2	25	0.2	*6	*0.3
Curvature of back or spine	534	1.0	56	1.5	287	2.6	155	0.6	33	0.3	*3	*0.1
Other impairment of back	2,593	4.9	26	0.7	1,154	10.6	1,186	4.7	200	1.8	27	1.3
Spina bifida	36	0.1	*14	*0.4	17	0.2	*5	*0.0	*1	*0.0	–	–
Impairment of upper extremities	822	1.6	35	0.9	361	3.3	341	1.4	73	0.7	*12	*0.6
Impairment of lower extremities	2,791	5.3	183	4.6	1,047	9.6	1,014	4.0	433	4.0	115	5.5
Other orthopedic impairment	211	0.4	*11	*0.3	75	0.7	84	0.3	32	0.3	*8	*0.4
Speech impairment	421	0.8	234	6.1	53	0.5	83	0.3	44	0.4	*7	*0.3
Blind in both eyes	301	0.6	*15	*0.4	53	0.5	88	0.4	100	0.9	46	2.2

See footnote at end of table

Table 2.
Prevalence of Activity Limitation due to Chronic Conditions, by All Causes of Limitation, Age, and Gender: United States Civilian Noninstitutionalized Population, 1983–1985 (Three-year Average)—continued

All Causes of Limitation	*All Ages*		*Under 18*		*18–44*		*45–69*		*70–84*		*85+*	
	Number of conditions in thousands and percent distribution											
Cataracts	572	1.1	*9	*0.2	25	0.2	189	0.8	256	2.3	93	4.4
Glaucoma	312	0.6	*1	*0.0	19	0.2	122	0.5	131	1.2	38	1.8
Other visual impairment/eye disorders	1,715	3.3	141	3.7	404	3.7	575	2.3	438	4.0	158	7.5
Deaf in both ears	221	0.4	31	0.8	56	0.5	62	0.2	50	0.5	21	1.0
Other hearing impairment/ear disorders	1,184	2.2	249	6.5	227	2.1	371	1.5	249	2.3	89	4.2
Digestive												
Ulcers	429	0.8	*6	*0.1	81	0.7	257	1.0	78	0.7	*8	*0.4
Abdominal hernia	595	1.1	*9	*0.2	105	1.0	336	1.3	128	1.2	17	0.8
Enteritis and colitis	138	0.3	*8	*0.2	43	0.4	75	0.3	*10	*0.1	*2	*0.1
Cancer of digestive sites	185	0.4	*1	*0.0	*14	*0.1	114	0.5	48	0.4	*9	*0.4
Other digestive disorders	775	1.5	36	0.9	142	1.3	387	1.5	176	1.6	34	1.6
Circulatory												
Rheumatic fever	204	0.4	*7	*0.2	52	0.5	114	0.5	27	0.3	*3	*0.1
Ischemic heart disease	2,423	4.6	*1	*0.0	97	0.9	1,581	6.3	683	6.3	61	2.9
Heart rhythm disorders	598	1.1	39	1.0	79	0.7	288	1.1	170	1.6	23	1.1
Other heart disease	2,350	4.5	67	1.8	187	1.7	1,230	4.9	714	6.6	151	7.2
Hypertension	3,506	6.6	*10	*0.3	311	2.9	2,313	9.2	780	7.2	92	4.4
Cerebrovascular disease	939	1.8	*6	*0.1	34	0.3	430	1.7	396	3.6	74	3.5
Arteriosclerosis	363	0.7	–	–	*6	*0.1	153	0.6	151	1.4	52	2.5
Phlebitis, varicose veins	470	0.9	*3	*0.1	84	0.8	307	1.2	70	0.6	*7	*0.3
Other circulatory	612	1.2	*4	*0.1	60	0.6	329	1.3	182	1.7	37	1.8
Respiratory												
Chronic bronchitis	301	0.6	40	1.0	41	0.4	151	0.6	62	0.6	*6	*0.3
Asthma	1,783	3.4	608	15.9	547	5.0	493	2.0	127	1.2	*8	*0.4
Hay fever	253	0.5	76	2.0	112	1.0	56	0.2	*9	*0.1	–	–
Sinusitis	135	0.3	*11	*0.3	23	0.2	69	0.3	28	0.3	*4	*0.2

See footnote at end of table

Table 2.
Prevalence of Activity Limitation due to Chronic Conditions, by All Causes of Limitation, Age, and Gender: United States Civilian Noninstitutionalized Population, 1983–1985 (Three-year Average)—continued

All Causes of Limitation	*All Ages*		*Under 18*		*18–44*		*45–69*		*70–84*		*85+*	
	Number of conditions in thousands and percent distribution											
Emphysema	994	1.9	*2	*0.0	29	0.3	650	2.6	297	2.7	*16	*0.8
Lung or bronchial cancer	125	0.2	–	–	*4	*0.0	81	0.3	39	0.4	*2	*0.1
Other respiratory disease	564	1.1	41	1.1	65	0.6	330	1.3	119	1.1	*8	*0.4
Miscellaneous												
Diabetes	2,111	4.0	23	0.6	222	2.0	1,284	5.1	535	4.9	47	2.2
Anemias	168	0.3	29	0.8	46	0.4	57	0.2	23	0.2	*13	*0.6
Kidney disorders	344	0.7	20	0.5	75	0.7	174	0.7	61	0.6	*14	*0.7
Female genital disorders	271	0.5	*12	*0.3	111	1.0	118	0.5	28	0.3	*1	*0.1
Schizophrenia/other psychoses	253	0.5	21	0.5	127	1.2	88	0.4	*13	*0.1	*4	*0.2
Neuroses/personality disorders	410	0.8	54	1.4	158	1.4	168	0.7	26	0.2	*3	*0.2
Other mental illness	601	1.1	269	7.1	124	1.1	162	0.6	44	0.4	*2	*0.1
Alchohol or drug dependency	104	0.2	*10	*0.3	56	0.5	36	0.1	*2	*0.0	–	–
Mental retardation	1,047	2.0	629	16.5	334	3.1	75	0.3	*7	*0.1	*2	*0.1
Epilepsy	444	0.8	78	2.0	244	2.2	105	0.4	*16	*0.1	*1	*0.1
Multiple sclerosis	127	0.2	–	–	53	0.5	66	0.3	*9	*0.1	–	–
Senility	469	0.9	–	–	–	–	81	0.3	201	1.8	187	8.9
Parkinson's disease	146	0.3	–	–	*4	*0.0	53	0.2	74	0.7	*15	*0.7
Other nervous disorders	884	1.7	70	1.8	279	2.6	388	1.6	133	1.2	*14	*0.7
Tuberculosis (all sites)	114	0.2	*3	*0.1	29	0.3	66	0.3	*15	*0.1	*1	*0.0
Other infectious/parasitic diseases	137	0.3	*11	*0.3	55	0.5	45	0.2	22	0.2	*3	*0.2
Leukemia	58	0.1	*9	*0.2	*7	*0.1	29	0.1	*13	*0.1	*1	*0.0
Cancer of female breast	159	0.3	–	–	19	0.2	101	0.4	34	0.3	*5	*0.2
Cancer of genitourinary sites	173	0.3	*2	*0.1	20	0.2	96	0.4	48	0.4	*8	*0.4
Cancer of all other sites, NEC	190	0.4	*10	*0.3	36	0.3	100	0.4	39	0.4	*5	*0.2
Surgical/medical complications	454	0.9	*10	*0.3	96	0.9	240	1.0	96	0.9	*13	*0.6
Other injuries	359	0.7	23	0.6	114	1.0	152	0.6	58	0.5	*12	*0.6
Other ill-defined conditions	1,361	2.6	78	2.0	334	3.1	681	2.7	228	2.1	40	1.9
All other chronic conditions	1,814	3.4	233	6.1	484	4.4	752	3.0	300	2.8	45	2.2

**Figure has low statistical reliability or precision (relative standard error exceeds 30 percent)*

Source: National Health Interview Surveys, 1983–1985: original tabulations from public use tapes

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Neurophysiological Dysfunction

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Neurophysiological Dysfunction

Overview

The human nervous system regulates and controls the functions of the body, and in a broader sense integrates the individual into his or her environment. These regulatory and integrative functions enable humans to perform skilled voluntary movements and, through the various senses, to be aware of their environment. These senses include the special senses, such as vision and hearing, and the cutaneous and proprioceptive senses, which provide information to various perceptual, affective, and cognitive brain systems. Each of these systems is composed of a hierarchy of subsystems, and damage to any of the subsystems may result in extensive functional impairments, many of which require long-term rehabilitation.

The most common causes of neurophysiological dysfunction requiring rehabilitation are stroke, spinal cord injury, traumatic brain injury, and degenerative diseases of the nervous system. A common feature of these pathologic conditions is damage to multiple neural systems, resulting in complex patterns of functional impairment.

While the measurement of the functional status of some neural subsystems is quite advanced, as in the case of visual acuity and peripheral nerve conduction, measurement of the impairments caused by multilevel neurologic disease is comparatively primitive. For example, accurate, reproducible, and clinically meaningful measurements of voluntary movement, postural control, and functional properties of muscles have been difficult to achieve in the clinic.

In the past, the impacts of neurophysiological dysfunction were rarely studied. It was taken on faith that improving organ function would decrease levels of both disability and handicap. Today, consumers and health care insurers are demanding that providers of rehabilitation services document the effectiveness and the efficiency of interventions. This requires measuring levels of impairment, functional limitation, disability, and quality of life—before and after rehabilitation.

Documentation of the effectiveness of interventions is the basis for decisions on whether specific rehabilitation services warrant coverage by public and private insurers. With the enactment of Public Law 101-129, the U.S. Congress and the President have endorsed this approach to financing health care services. Subsequently, Congress established, in Public Law 101-239, a major program of research on the effectiveness and outcomes of health care services, the results of which will be incorporated into clinical practice guidelines that will greatly influence provision of services and reimbursement policies.

Because of the growing emphasis on determining the effectiveness of health services and because assessment is critical to progress in all of rehabilitation medicine, this panel has placed particular emphasis on measurement issues. Current measures of functional limitations, disabilities, handicaps, and quality of life are rudimentary at best, as are measures for assessing the outcomes of rehabilitation services relating to neurophysiological impairments.

Functional assessment of neurophysiological impairments is clearly necessary to measure the impact of interventions on patients. A variety of standardized clinical assessment tools have been developed, such as the Functional Impairment Measure (FIM) of the Uniform National Data System for Medical Rehabilitation and the Patient Evaluation Conference System (PECS). Although the FIM is widely used (64 hospitals in 24 States), it should be noted that there is little explicit connection between either the FIM or the PECS and the pathophysiology of neurologic disease. Moreover, there is little or no use of state-of-the-art measures of function that have been developed in studies of normal physiology.

Thus, major goals for the development of measurement systems for rehabilitation must include not only standardization, but also development of physiologically based measurements that incorporate current knowledge and methods.

The participation of the National Institutes of Health (NIH) in this process is deemed essential. NIH sponsorship and support are required to foster the development and adoption of basic concepts in neurobiology and neurophysiology, as well as the determination of the effectiveness and cost efficiency of rehabilitation services for people with neurophysiological impairments.

Research Accomplishments and Opportunities

Basic Neuroscience and Rehabilitation

Much of the research that provides the physiological substrate for rehabilitation therapy addressing neurophysiological disturbances is, and will likely be, undertaken by basic scientists working outside rehabilitation medicine. However, much more must be done to link this work to rehabilitation research and interventions and to acquaint neuroscience researchers with the needs of rehabilitation medicine. It is essential to identify key areas of neuroscience where advances in fundamental knowledge are deemed critical to developing interventions that correct or ameliorate neurophysiological dysfunction. Perhaps this could be done by a multidisciplinary panel of basic and clinical researchers. It is also important to identify areas in which the basic concepts of neuroscience can be integrated at the level of organ systems and in the whole person.

Discussed below are specific areas of basic neuroscience that appear to be particularly relevant to rehabilitation. Progress in these areas is likely to have a facilitating effect on the development of sound rehabilitative treatments.

Mechanisms of neuronal death in response to diseases and traumatic injuries. Ongoing work relating to the sources of neuronal damage and neuronal death following brain trauma, ischemia, and anoxia has revealed the importance of excitatory amino acids and their potential neurotoxic actions in pathological states. To devise interventions that minimize permanent damage, the mechanisms of action of these

amino acids must be defined in greater detail.

Mechanisms of plasticity. In rehabilitation, it is important to understand the factors influencing long-term neuronal recovery and to establish whether impaired neuronal performance (as distinct from neuron loss) contributes to nervous system disabilities over a prolonged period. In addition, the limits of neuronal reorganization, reconstruction, and recovery following damage from ischemia, anoxia, or trauma must be determined. Altered functional neuronal activity is one of several factors known to be critical to the recovery of neural function after injury. The reorganization of functional connectivity may reflect a variety of intercellular and subcellular adaptations, including altered dendritic and axonal growth and changes in synaptic and receptor density, sensitivity, and spatial organization. The role of the neuroglia in initiating or promoting recovery from neural damage is largely unknown.

Other potentially important mechanisms include neurotrophic factors regulating axonal growth and directional specificity in the central and peripheral nervous systems. While much of the work in this area is currently in the domain of the basic neurosciences, rehabilitation medicine research has a strong interest in and a need to build on the findings.

Neurobiology of skill acquisition and motor learning after injury. The neural alterations that underlie skill acquisition and learning are not well understood. Very little is known about these processes in the normal nervous system, and even less is known about neural alterations in the damaged nervous system, which may involve different recovery mechanisms. Along with neurophysiological recording techniques, new technologies, such as magnetic resonance imaging (MRI) and positron emission tomography (PET), offer promising opportunities to elucidate the mechanisms of learning after neural injury. Studies of whole animal and tissue models employing advanced technologies may also help determine whether these mechanisms can be modified to benefit people with neurological impairments and disabilities. Recent advances in the neuropharmacology of locomotion and in detailing the biochemical and molecular underpinnings of "learning" motor tasks suggest that further progress in these areas could provide the basis for markedly improving the potential for recovery from neural impairments.

Optimal approaches for electrical stimulation of nervous tissue. Since many therapeutic options for treatment of neuromotor impairments now include electrical stimulation of nervous tissue, it is important to understand how various types of electrical stimulation work, and the best way to deliver this stimulation. Currently, the cellular effects of this potentially important intervention are poorly understood, as is its impact on the quality of patients' lives.

Stroke

An estimated 500,000 Americans suffer strokes each year, accounting for about half of all patients hospitalized for acute neurological diseases. About 30 percent die, making stroke the third leading cause of death. The great majority of stroke victims survive, however, and it is estimated that 2.1 million are alive today. A significant proportion of these people require rehabilitation services. Indeed, about one-third of all survivors have permanent disabilities. The social and economic costs associated with stroke are large, though difficult to quantify precisely. Annual economic costs have been conservatively estimated to total $25 billion.

There continues to be considerable debate on what corrective measures in stroke rehabilitation are most important,

how these are best delivered, and over what period of time meaningful progress can continue. Even when the best clinical methods to reduce disability have been applied, however, progress in rehabilitation may be limited because of lack of knowledge about lingering stroke-associated psychological and social problems.

Crucial to the understanding of injury to the central nervous system (CNS) is the concept of brain heterogeneity, or regional specialization. A small lesion in the brain stem may be devastating, while the same sized lesion in the frontal lobes may be clinically insignificant. Likewise, injury to specific areas of the CNS will produce deficits ranging from personality change to paralysis.

New stroke-prevention strategies and new rehabilitative therapies to aid the management of acute and chronic stroke patients are emerging. Methods for selecting the most appropriate patients for carotid endarterectomy have improved, and superior ways to utilize anticoagulation have been developed. The benefits and indications for aspirin administration have been defined more precisely, as has the importance of hypertension control. Although these areas are not uniquely a concern of rehabilitation therapists, continued research is necessary.

Studies of animal models, using hypoxia, focal ischemia, and experimental neurological lesions, and correlating motor, behavioral, and physiological changes with functional recovery are needed. Recent studies have reported that some pharmacological agents can accelerate motor recovery. Meanwhile, the results of research on human subjects indicate that PET, MRI, and single photon emission computerized tomography (SPECT) are useful tools for evaluating the neuroplasticity of motor, language, and cognitive function. Further improvement is likely.

Improvement of rehabilitative interventions addressing acute stroke is hindered by limited understanding of the extremely complex pathophysiology of cerebral ischemia. For example, the selective vulnerability of neurons needs to be explained. Research has shown that some neurons survive an ischemic insult and that areas of the brain differ in ischemic thresholds. Although progressive development of lesions following ischemic insult can occur, the factors that cause this progression are unknown. Once these factors are identified, it might be possible to develop interventions to halt the process.

The necrotic core of an infarction expands into the adjacent areas of an ischemic penumbra. This can lead to a regional increase in tissue pressure due to necrosis and edema and to subsequent reduction of the regional cerebral blood flow to levels below that necessary for survival of adjacent tissue. Strategies to limit the expansion of the infarction and thereby improve functional outcome need to be developed.

Rehabilitation of people with chronic stroke entails remedial intervention to promote recovery of impaired neurons, to enhance neural sprouting or other alternate neural recovery mechanisms, and to facilitate plasticity and motor learning that leads to the acquisition of new strategies for movement. Determining the basic mechanisms that affect neural plasticity and recovery would aid clinical researchers to develop interventions that reduce disability and optimize functional recovery.

Traumatic Brain Injury

More than 2 million people incur head injuries each year. About one-fourth of these require treatment at a hospital, accounting for 12 percent of all injury-related hospitalizations. More than 75,000 (about 4 percent of the total) sustain moderate (45,974), severe (25,239), or very severe (6,710) head injuries. These injuries, cor-

responding to International Classification of Diseases/Abbreviated Injury Scale (ICD/AIS) 3, 4, and 5, result in long-term neurological deficits.

Over the past 20 years, advances in the emergency and acute phases of traumatic brain injury (TBI) management and, specifically, in the area of neurosurgery have significantly improved outcomes for many TBI patients. These improvements have led to increased survival and to levels of functioning higher than those achieved previously. Nevertheless, many TBI survivors have considerable residual disability and handicap.

Perhaps more than any other source of brain impairment, TBI epitomizes the dynamic nature of impairment, disability, and handicap. Over the span of weeks, months, and even years, motor impairments, cognitive and perceptual deficits, memory deficits, psychological imbalance, and sensory impairments may become manifest in the person with TBI. This heterogeneity—in the type of impairment, in the severity of impairment, and in the combination of impairments—results in a unique level of disability for each person with TBI. Moreover, the impairments of some people with TBI are often unrecognized, neglected, or treated inappropriately. The consequence is a worsening level of functional impairment, which leads to disability or exacerbates existing disability and handicap. The complexity of TBI is problematic not only for developing treatment approaches, but also for developing research techniques to disentangle the many factors involved.

Research on rehabilitation outcomes has demonstrated that, rather than the physical impairments, the cognitive and psychosocial consequences of TBI are frequently the sources of the greatest and longest lasting disability and handicap. Although considerable clinical progress has been made in these areas, most treatment modalities have not been evaluated adequately.

This shortcoming is particularly apparent in the area of cognitive rehabilitation, a topic of controversy in the treatment of people with TBI. Cognitive deficits, along with difficulties in psychosocial adjustment and behavioral, personality, and communication problems, are among the most disabling consequences of TBI, affecting decision-making and problem-solving abilities, and the capacity for adapting to the uncertainties of everyday life. Consequently, a goal of rehabilitation programs for people with brain injuries has been to retrain their cognitive processes.

However, there is little evidence that cognitive training has any direct benefit for patients with TBI; nor is there solid evidence that this training is helpful in returning these people to the community. In contrast, there is considerable evidence that some aspects of cognitive retraining, such as memory training, have no effect on the cognition of patients with TBI. Furthermore, studies have shown that people who undergo training cannot generalize learned behaviors to novel tasks.

Nonetheless, cognitive science, a new discipline that merges psychology, neurophysiology, computer modeling, artificial intelligence, and linguistics, should provide powerful new tools with which to address the cognitive deficits of TBI patients. Major advances in neuropharmacology and neuroimaging techniques are also likely to yield important contributions to TBI treatment strategies.

In sum, interventions intended to improve cognitive and behavioral functioning or to facilitate psychosocial adjustment are ripe for systematic exploration and evaluation.

Spinal Cord Injury

Spinal cord injury (SCI) affects between 250,000 and 350,000 Americans, with 6,000 to 10,000 new cases occurring each year. SCI affects not only motor and sensory functions, but also bowel, bladder, and sexual

functions. Consequently, people with SCI may have great difficulty in carrying out even routine activities of daily living. A high cervical injury can cause respiratory dependency, as well as lifelong physical dependency on other individuals.

Improvements in emergency care during the past decade are credited with increasing survival among SCI patients, as well as increasing the incidence of incomplete lesions. (People with incomplete lesions may retain some sensation and motor power.) Growing understanding of SCI complications has improved prevention of renal failure, previously a major cause of death in this population, and led to better management of deep vein thrombosis, skin ischemia, and autonomic and dysfunctional neurogenic bladder. Life expectancy has increased dramatically, and causes of mortality among people with SCI are comparable to those for the non-SCI population.

Support mechanisms for people with SCI have also improved, largely because of the efforts of advocacy groups and the development of a team-based approach to treatment at specially designated spinal cord injury centers. Nevertheless, inadequate financial support systems and attendant care services for those with the most severe disabilities, as well as societal and attitudinal barriers, detract significantly from the quality of life experienced by many people with SCI.

Progress in basic research is contributing to clinical efforts to improve the recovery of function. Growing evidence indicates that more aggressive treatment with scientifically sound procedures can markedly enhance the locomotor potential of many SCI patients. For example, researchers recently reported that administering the steroid methylprednisolone within 8 hours of the occurrence of SCI can improve neurological recovery. In addition, recent advances in the basic understanding of neural control within networks of spinal neurons have been applied clinically to individuals with severe paralysis in the lower extremities. Using strategies similar to those tested in animal models has led to recovery of some motor control, allowing patients to walk with minimal aid from artificial support devices.

These advances and others demonstrate the scientific potential for improving rehabilitative interventions. Unfortunately, any basic science concepts that can help improve recovery of function are not always incorporated into current intervention strategies.

Multiple Sclerosis

Multiple sclerosis (MS) is the most common demyelinating disease of the CNS, estimated to affect between 250,000 and 500,000 people in the United States. MS affects young adults, who nevertheless have a near average life expectancy and, thus, may live for decades with disability. Therefore, the socioeconomic consequences of this illness are considerable.

The cause and cure of MS have been elusive, despite extensive research. Nevertheless, the results of studies have broadened understanding of the nature of autoimmune and viral inflammatory demyelination in the CNS. Such knowledge is essential to efforts to solve the enigma of MS.

Neurogenic Bladder, Bowel, and Sexual Dysfunctions

Neurogenic bladder and bowel dysfunction are common results of neurophysiological disorders. These problems pose specific issues for research and rehabilitation practice, but they must be considered in the context of overall functioning because bladder and bowel dysfunction have significant impact on personal autonomy.

Neurogenic bladder dysfunction and, to a large extent, neurogenic bowel dysfunction have been classified on the basis of measurement of urodynamic and colorectal dynamic characteristics. These classifications, however, have had limited clinical utility for diagnosis or therapeutic management. Greater effort is needed to translate these classification methods into clinically useful tools. In addition, outcome-related research data are not yet standardized with regard to measurements of impairment, disability, and handicap.

Similar obstacles and shortcomings undermine progress toward more effective interventions for addressing sexual dysfunction, a problem for many people with SCI.

Neuromuscular Diseases and the Biology of Nerves and Muscles

Neuromuscular diseases encompass a broad range of inherited and acquired disorders (see table 1). Rehabilitation management of neuromuscular disorders has been based primarily on clinical observation. Evaluations of treatment have yielded little constructive guidance, because many studies are retrospective and fail to follow sound clinical research techniques.

Two avenues of research should be pursued in tandem. Investigations of the natural course of each disease are necessary to improve the currently limited understanding of the underlying pathophysiology. Second, prospective studies of treatment outcomes are essential to enhancing the effectiveness of interventions. Although these disabling conditions are complex, affecting multiple organ systems, investigations should incorporate sound clinical research methodology, including treatment group samples of adequate size, control subjects matched for duration or severity of disease, supervised therapy sessions, a well-articulated hypothesis, valid and reliable measurement

Table 1.
Examples of Neuromuscular Disorders

Affected tissue	*Etiology*	
	Acquired	*Hereditary*
Anterior horn cell	Amyotrophic lateral sclerosis Poliomyelitis Postpolio syndrome	Spinal muscular atrophies
Peripheral nerve and motor nerve roots	Neurotoxic neuropathies Guillain-Barré syndrome	Charcot-Marie-Tooth syndrome
Myoneural junction	Myasthenia gravis Botulism	Hereditary myasthenia gravis
Muscle	Polymyositis	Muscular dystrophies Congenital and metabolic myopathies

criteria for assessing outcomes, and a double-blind system.

Because of the relatively low incidence of each condition, studies that can yield definitive results will likely require national collaboration involving patients at several centers. This is especially true because of the great variability within some conditions. For example, the course and prognosis for people with Guillain-Barré syndrome, an acquired disorder, range from virtually no long-term effects to severe residual disability.

Understanding of the basic mechanisms of muscle contraction and mechanics, muscle function, and neuromuscular fatigue has improved greatly over the past decade. This knowledge should be applied in the development of rehabilitative interventions for people with muscular dystrophy and other neuromuscular disorder that cause weaknesss. Significant progress in the diagnosis and treatment of people with neuromuscular diseases could result from integrating basic concepts of muscle function and adaptation into the development and evaluation of treatment protocols to increase strength, endurance, and coordination.

Much more, however, remains to be learned about nerve and muscle function and dysfunction in general, and about neuromuscular disorders in particular. Prospects for significant advances in the treatment of people with these disorders depend on progress in elaborating the biomechanics of movement and the neural mechanisms that control movement. Research is also needed on developing measures of muscle parameters and function and on optimizing exercise protocols to increase strength, endurance, and coordination.

Recommendations

Stroke

- Most of the prevailing therapeutic techniques used by physical and occupational therapists and prescribed by physiatrists, such as those described by Bobath, Brunnstrom, and Kabat and Rood, have yet to be validated. Controlled clinical trials must be conducted to determine whether these interventions alter important parameters of motion in the gait cycle, enhance voluntary movement of the upper extremities, and clearly increase functional independence. In addition, the development of new therapeutic techniques and assistive devices must be guided by scientific theories and concepts.
- In the course of acute and chronic care, stroke patients are often treated with a number of drugs, including amphetamines, neuroleptics, tranquilizers, antidepressants, and antiepileptics, all of which can affect the central nervous system. Studies in animals and humans are needed to determine whether commonly prescribed drugs impede or enhance recovery of motor or cognitive function.
- Improved and more specific interventions are needed for speech and language impairments, such as aphasia, and for behavioral impairments. In addition, prevailing interventions must be evaluated for effectiveness in both short- and long-term studies.

Several case studies have reported that pharmacological agents activate specific cellular receptors and improve an aspect of language or behavior. For example, bromocriptine has been reported to reduce perseveration, and carbamazepine to reduce violent behavior. The effectiveness of existing and emerging pharmacological techniques and training methods should be established in controlled trials or in multiple single-case studies, with the doses and administration of the drug or the learning paradigm clearly defined.

- Physical and pharmacological measures that modify spasticity should be identified. In addition, techniques that measure the effects of hypertonia across a joint at rest and especially during voluntary activity should be developed.
- Basic and clinical research should focus on identifying pharmacological agents and physical therapies that have the potential to enhance neural plasticity. Experimental interventions arising from this work should be rigorously evaluated to ascertain their impact on levels of impairment and disability. This testing, however, will require reliable, validated measures of physiological and functional outcome, as well as of quality of life.
- Quantitative methods for measuring and evaluating neural and motor deficits must be developed, tested, and validated. Quantitative measures are required for both physical and cognitive disabilities.
  - Motor deficits: Several scales exist for measuring motor impairments, including the NINDS Stroke Scale, Fugl-Meyer Motor Scale, and Hemispheric Stroke Scale. These scales and others should be tested, validated, and compared. Current technology permits many components of existing measurement instruments to be quantified more precisely.
  - Sensory deficits: Lesions of the CNS can result in a variety of deficits in primary sensory processing and in higher level perceptual functions. Measurement instruments capable of differentiating among these deficits are needed.
  - Cognitive deficits: Existing quantitative methods for evaluating language and intellectual capabilities must be refined and validated, and development of new, potentially superior methods should be encouraged.
  - Psychological deficits: Measures of emotional and personality changes that occur after a stroke must be developed and validated.
- The success of stroke rehabilitation is integrally related to, and dependent on, family and social support systems. Greater research effort should be devoted to identifying and characterizing the primary factors influencing psychosocial adjustment.
- Risk factors for poststroke depression and other psychological impairments should be identified and described in detail sufficient to guide development of interventions. Such interventions are needed not only to counter the adverse impacts of psychological impairments on physical rehabilitation outcomes, but also to improve the quality of life of individuals, independent of the treatment of physical impairment or disability.
- Secondary conditions associated with stroke, such as mental and physical fatigue and bowel, bladder, or sexual dysfunction, have a major impact on the quality of life. Research efforts devoted to ameliorating these problems should be comparable to those devoted to other facets of the treatment of stroke patients.

Traumatic Brain Injury

General Priorities

- The basic mechanisms by which human cognition is altered by brain injury should be determined to provide a solid scientific foundation for rehabilitation therapy.
- Rigorous evaluation of existing and emerging therapeutic programs for patients with head injuries is needed.
- Emphasis should be placed on longitudinal studies that track the progress of people with TBI throughout the course of specific rehabilitation

processes and then beyond to assess family and community integration.

Specific Priorities

- Identify and characterize the cognitive and affective disturbances experienced by people who incur mild or moderate TBI, and ascertain the effects of these disturbances on the ability to work and on community integration.
- Develop scientifically sound methods to guide approaches to cognitive remediation after TBI.
- Develop new research paradigms and statistical methods for studying the complex interactions among the multiple impairments (such as spasticity, rigidity, dystonia, ataxia, and weakness) often encountered in people with TBI. The results of studies using these new paradigms and methods should be refined for clinical use and serve as guides for treatment planning and predicting the level of functional motor skills over periods of up to 15 years.
- Determine the efficacy of medications used in the management of post-traumatic epilepsy.
- Define the role of monoaminergic and cholinergic agents and other neuromodulators in promoting recovery of motor function, controlling spasticity, improving behavior and motivation, and countering TBI-caused changes in personality.
- Determine the utility of current and emerging techniques used to promote recovery from a comatose state.
- Determine the efficacy of pharmacological agents in arresting ossification and gather data to determine the optimal time for surgical removal of heterotopic ossifications.
- Develop a comprehensive quantitative assessment tool for evaluating the functional capacity of patients with TBI. The information gathered with this tool would provide an objective basis for determining an individual's capabilities for driving and engaging in other potentially high-risk activities, and it would help define appropriate rehabilitative interventions.

Spinal Cord Injury

General Priorities

- Evaluate the findings of basic neuroscience studies, especially those pertaining to novel pharmacological agents, for their applicability to clinical research, including the development of methods for assessing motor behavior, reflexes, and sensory function.
- Evaluate the effectiveness and efficiency of systems of care and followup. Studies should distinguish between restitution of function initially lost and the use of compensatory strategies.
- Focus greater research attention on identifying approaches for improving the functioning of the whole person and for improving quality of life.

Basic Research Priorities

- Define the effects of gangliosides, exercise, electrical stimulation, and other interventions on the formation of neural networks involved in locomotion and other movements.
- Determine the role of spinal cord regeneration in mediating functional recovery, and define the mechanisms involved in dendritic branching and axonal growth.
- Define the subcellular, cellular, and intercellular mechanisms by which long-term interventions using pharmacological agents, exercise, and electrical stimulation can modulate movement control.
- Characterize the plasticity of cellular receptors that function as neuromodulators or participate in the

neurotransmission of locomotion and other movement.

- Identify neurotrophic factors and other growth factors and mechanisms of intercellular recognition.
- Identify the mechanisms by which supersensitivity and desensitization to neural input occur in response to injury and chronic levels of use or disuse.
- Define the role of circulatory integrity in determining the severity of function loss in response to SCI.

Clinical Research Priorities

- Identify pharmacological agonists and antagonists that can selectively modulate activation and inhibition of the involved motor pools so that the motor deficits caused by specific neural impairments can be addressed.
- Define the mechanism that modulates activation and inhibition of selected neural systems in the spinal cord.
- Characterize the long-term neuromotor adaptation of specific motor networks to chronic pharmacological interventions and identify how the interventions affect measures of functioning in the activities of daily life.
- Characterize the short- and long-term effects of weight-supporting, stepping movements of the leg on locomotor capacity, and determine the neurophysiological and neurochemical mechanisms involved.
- Characterize the short- and long-term effects of sensory and muscle stimulation and of biofeedback on locomotor capacity.
- Investigate the interactive effects of pharmacological, locomotor, and stimulation interventions on locomotor capacity.
- Characterize and define the causes of secondary complications associated with SCI. These conditions include deep vein thrombosis and pulmonary embolism, pneumonia and respiratory failure, heterotopic ossification, urinary tract infection, osteoporosis, disuse atrophy and deconditioning, and cystic degeneration of the spinal cord following trauma.
- Identify the factors that initiate or contribute to spasticity and develop more effective pharmacological, biofeedback, exercise, and surgical interventions to ameliorate spasticity.
- Identify the source and mechanisms of pain in patients with SCI, and develop a sound scientific rationale to guide the improvement of pharmacological and physical interventions to control pain.
- Determine the extent to which strength, flexibility, and pulmonary cardiovascular functional reserve decline as SCI patients age and develop strategies to prevent or mitigate the most critical declines.
- Investigate the mechanisms that underlie sexual dysfunction and infertility in people with SCI and develop and evaluate strategies for restoring or improving sexual function and fertility.
- Develop quantitative measures for assessing the impact of SCI on functioning in daily life and on quality of life, as well as for evaluating the outcomes of rehabilitative interventions and services. Outcome measures such as hospitalization rates, employment status, life expectancies, and psychosocial well-being should be documented for each type of intervention.

Demyelinating Disorders

Basic Research Priorities

- Establish the molecular basis of demyelination, including the roles of cytokines, proteases, free radicals, and other mediators of tissue damage, and the roles of the cellular participants,

such as macrophages, lymphocytes, astrocytes, oligodendrocytes, and endothelial cells.

- Define the role of systemic immune dysregulation in CNS autoimmune disease and the roles of immune-system regulatory molecules in neural conduction.
- Define specific systemic immune abnormalities in patients with MS.
- Characterize the involvement of blood-brain barrier permeability in CNS autoimmune disease.
- Investigate possible deterrents to CNS remyelination.

Clinical Research Priorities

- Develop immunotherapeutic agents directed at the specific immune-system abnormalities caused by MS.
- Develop pharmacological agents to combat demyelination and to enhance remyelination.
- Develop pharmacological agents to enhance conduction through demyelinated nerve segments.
- Improve the correlation between clinical findings, measurements of disability, and lesions imaged by MRI.
- Develop strategies to improve functional use of centrally denervated (sensory and motor) limbs.
- Improve existing treatments for spasticity and investigate new, potentially superior methods.
- Identify the neural mechanisms by which bowel and bladder sphincter dysfunction occurs and develop interventions based on this knowledge.
- Develop strategies for the long-term care of younger individuals in nursing homes, which typically serve older adults.
- Determine the role of family support in rehabilitation and its impact on outcomes.

Neurogenic Bladder Dysfunction

- On the basis of urodynamics and long-term evaluations of clinical parameters and outcome measures, develop strategies for managing dysfunction of the upper motor neuron bladder and the mixed lower motor neuron bladder.
- Evaluate biofeedback as part of neuromuscular reeducation in urinary storage and voiding dysfunction.
- Determine the benefits of and the optimal methods for normalizing high bladder voiding pressures in people with upper motor neuron bladder dysfunctions to prevent upper urinary tract degeneration.
- Investigate the long-term effectiveness of the management of neurogenic bladder dysfunctions.
- Determine the most effective methods for reducing abnormally high tension of the internal and external urethral sphincter.
- Define the anatomical substrates and physiological mechanisms involved in bladder detrusor contraction and the effects of acute and chronic overstretching of the detrusor muscle in normal subjects.
- Develop state-of-the-art diagnostic and therapeutic bladder rehabilitation technology.

Neurogenic Bowel Dysfunction

- Characterize the upper and lower bowel dynamics following spinal cord injury, stroke, and other upper motor neuron conditions, as well as the changes that occur with aging.
- Delineate the role of biofeedback in the retraining of persons with colorectal storage and emptying dysfunctions.

- Conduct long-term trials to evaluate and compare the effectiveness of interventions to correct or ameliorate gastroenteritis and lower bowel dysfunctions. Evaluations should include assessment of impact on levels of impairment, disability, and handicap.

Sexual Dysfunction

- Develop strategies for accurately evaluating upper and lower motor neuron sexual dysfunction.
- Develop methods for normalizing sexual function in men and women.
- Evaluate the long-term efficacy of managing sexual dysfunction.
- Study the impact of physiological sexual dysfunction on emotional state and relationships, and investigate psychosocial adaptations to altered sexual function.

Neuromuscular Diseases and the Biology of Nerves and Muscles

General Priorities

- Quantify the amount of pain, sensory loss, and weakness caused by neuromuscular diseases.
- Identify muscle properties that can be used to predict performance in functional tasks; develop techniques to assess muscle output during normal activities; and develop biomechanical measures for efficient clinical evaluation of movement capabilities.
- Define the needs of ventilator-dependent individuals with amyotrophic lateral sclerosis, Guillain-Barré syndrome, muscular dystrophy, postpolio syndrome, and similar disorders. On the basis of this information, improve currently available respirator support systems.
- Document the degree and frequency of increased weakness among people with postpolio syndrome and other disorders that affect the anterior horn cell, nerves, and muscles; investigate the causes of this problem.
- Document the effectiveness of electrodiagnostic techniques in predicting recovery and the value of this information in guiding intervention strategies.
- Define the responses of muscle to voluntary and electrically induced exercise and to disuse and determine the physiological and molecular triggers that modulate physiologically important muscle proteins.
- Determine the effectiveness of the following interventions in modulating neuromuscular performance: nutritional supplements, pharmacological agents, electrical stimulation, specific exercise routines and associated devices used to improve neuromuscular performance, and devices to improve sensation and lessen pain and contractures.
- Determine the impact of psychological and socioeconomic factors on the progression and treatment of disorders of the anterior horn cell, peripheral nerves, and muscles.
- Determine the value of bedside myometric measuring techniques in predicting the outcome of neuromuscular diseases.

Implementation Strategies

The multidisciplinary nature of rehabilitation medicine research and the complexity of the issues it addresses present both challenges and opportunities for the development of appropriate and productive research and training programs. This is especially true in the area of neurophysiological dysfunction, where the spectrum of research

questions extends from the genetic and biochemical determinants of neurological disorders to the psychosocial factors influencing the reintegration of people with CNS injuries into the community. In turn, rehabilitative interventions, which ultimately are intended to improve the physical, cognitive, behavioral, and social functioning of people with neurophysiological dysfunction, must also address a large and complex array of issues.

Several steps are needed to place the efforts of rehabilitation medicine investigators and caregivers on a solid scientific foundation and to address fully the needs of people with neurophysiological dysfunction.

- *Common language.* Outcome measurements are needed that are acceptable to all disciplines and include common definitions and criteria for evaluating specific types of neurophysiological dysfunction and their impacts on human functioning.
- *Interdisciplinary research.* Understanding of the complex effects of neurophysiological dysfunction requires research approaches that fully integrate current technological capabilities and scientific concepts.
- *Cross-disciplinary opportunities for research training.* Opportunities for basic scientists to train and conduct research in a clinical setting and for clinical scientists to pursue technical research skills in the basic sciences must be formalized and adequately supported.
- *Application to real-life situations.* Rehabilitation research must acknowledge that outcome criteria differ from individual to individual, even when the disability is caused by the same neural impairment.
- *Increased multicenter research.* In many cases, treatment approaches can best be validated or modified through multicenter research efforts.

Musculoskeletal Disorders

Musculoskeletal Disorders

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Musculoskeletal Disorders

Overview

About 23 million people, or 10 percent of the U.S. population, have one or more chronic disorders of the musculoskeletal system—those affecting the structure and function of the joints, muscles, bones and cartilage, ligaments, and tendons. Within this diverse category are such chronic diseases as osteoporosis and more than 100 forms of rheumatic disease, including the various types of arthritis, congenital malformations and defects (such as spina bifida and clubfoot), inherited diseases (such as Duchenne muscular dystrophy and osteogenesis imperfecta), and fractures, sprains, dislocations, and other mechanical defects caused by injuries. Collectively, these disorders affect all age groups, with consequences ranging from pain to severe disability and handicap.

Musculoskeletal disorders are the main cause of disability in the working-age population and are among the leading causes of disability in other age groups. For the entire population, orthopedic impairments and arthritis rank as the top two causes of activity limitation, affecting 9.2 million people (or 28 percent) of the 32.5 million Americans estimated to have an activity limitation, according to the 1983–1985 National Health Interview Surveys. Each year, about 1 person in every 10 incurs a musculoskeletal injury that limits activity or requires medical care. Such injuries account for 36 million visits to physicians and nearly 20 million hospital days; the average hospital stay is about 9 days. The average episode of back pain, which affects an estimated 31 million people each year, results in 12 days of restricted activity. For persons between the ages of 17 and 44, back disorders are the primary cause of disability.

Osteoporosis, one of the most prevalent disorders of the bone and other skeletal support structures, is the leading cause of fractures among women older than 75. Each year, about 200,000 older adults incur a hip fracture—an injury that often precipitates a serious deterioration in health status.

The annual economic costs associated with musculoskeletal dysfunction are estimated to total more than $65 billion, ranking second only to disorders of the circulatory system.

Research Accomplishments and Opportunities

The need for an interdisciplinary research effort to enhance understanding of the etiology of disabilities and to improve rehabilitative interventions that reduce impairments and optimize function is as great in the area of musculoskeletal disorders as it is in other areas of dysfunction. Furthermore, research on handicaps encompasses an even broader sphere of concerns that relate to integrating

people with disabilities into society and that require input from scientists working in many fields. A major aim of this research involves identifying measures that contribute to autonomy and self-sufficiency by enhancing capacity for self-care, mobility, employment, and participation in social and recreational activities.

Control of Movement

Research on motor control ranges from studies of the neural circuitry controlling locomotion in primitive animal models to investigations correlating skilled movements with the activation of specific muscle groups in human subjects. Patterns of muscle activation and their kinematic consequences have been defined in persons without impairments and in those with selected impairments of voluntary movement caused by upper and lower motor-neuron dysfunction. The technologies that facilitated this progress are being used clinically not only to assess musculoskeletal impairments, but also to guide rehabilitative strategies.

Integration of Neural and Skeletal Function With Muscle Function

Considerable progress has been made in integrating knowledge of neuromusculoskeletal function. This progress largely results from technical advances in measurement and recording devices that have increased the capability for gathering detailed biological data, which in turn facilitate more realistic computer modeling of movements.

Numerous movement-related parameters, including joint motion, electromyography of whole muscle or motor units, muscle forces, temperature, and electrocardiograms, can now be quantified. Current techniques for tissue imaging are largely noninvasive and capture data on metabolic processes in localized areas of tissue, including sites of injury. The techniques also yield data on the morphology and biochemistry of muscles and bones and on the movements of individual tendons. Enhanced ability to study movements involved in performing daily tasks should lead to an integrated understanding of neuromuscular skeletal function.

The role of neural and immunological systems in muscle dysfunction. Although the primary tissue directly responsible for movement is muscle, movement dysfunction is usually not the initial result of muscle damage. Although it has long been recognized that nonmuscle tissue is intricately involved in primary movement dysfunction, the nature of this involvement has not been described in detail. For example, there are several immunological disorders that directly affect movement dysfunction or indirectly have adverse and interactive effects on neural, muscular, and connective tissues. Identifying these interactive effects has provided additional evidence of the need to integrate functional studies of movement disorders.

Control of rhythmic movements. Exciting advances have been made in understanding how repetitive movements such as walking, breathing, and chewing are controlled. Animal models of neural networks are providing new insights into the electrophysiological mechanisms that generate rhythmic patterns, and a new challenge is to link musculoskeletal function to the workings of these neural networks. It may be possible to use highly conserved rhythmic neural networks to generate useful movements in cases of severe but not complete interruption of motor pathways. A range of rather nonspecific inputs to neuromotor networks in the spinal cord appears to generate locomotor-like patterns of movement.

Control of the activation of a single muscle or motor pool. Theories of how motor units of a single muscle are organized in the spinal cord and respective muscles are

continually being refined. An extensive body of literature describes the functional and anatomical organization of motor units, and considerable progress has been made in defining the factors largely responsible for excitation patterns and in describing how motor units are recruited in normal locomotion and in the performance of other routine activities. Studies suggest common mechanisms of recruitment among specific motor pools. This built-in order may simplify the task of controlling movement, particularly in people with supraspinal deficits.

Control of synergistic and antagonistic motor pools. Virtually all movements require the control of multiple motor pools, but few studies have quantitatively examined how synergistic and antagonistic motor pools are recruited to excite motor units in normal movements. Nonetheless, it is feasible to use the techniques employed in studies of individual motor pools to begin unraveling the patterns of excitation that control synergistic and antagonistic motor pools. This information is of fundamental importance to efforts to promote the recovery of motor function.

Spasticity. Although some progress has been made in managing spasticity—spontaneous contractions of portions of single muscle, multiple muscles, and multiple body segments—its etiology is largely unknown. Spasticity seems to have many origins, depending on specific neuromuscular disorders and on environmental and personal factors related to physiological state. Current treatment modalities are varied and include exercise, and pharmacological and surgical interventions such as deafferentation and tenotomy. Rarely, however, are these treatments completely successful. Fundamental research on the etiologies of muscle spasticity is essential before there can be significant progress in controlling muscles and enabling performance of useful tasks.

Denervation sensitivity. Enhanced contractile response to acetylcholine and spontaneous contractions (fibrillations) are manifestations of denervation sensitivity. These responses reflect the interdependence of the muscle on motor neurons, but the factors associated with this functional neuromuscular interdependence and the cause of the sensitivity remain to be determined. However, extensive data on changes in membrane properties and on the time course of changes in denervated skeletal muscle fibers exist. It is not known whether denervation sensitivity plays a positive or detrimental role in the long-term homeostasis of muscle fibers and the control of protein metabolism—factors of utmost importance in developing rehabilitation strategies.

Joint Mechanics and Pathophysiology

Biochemical and biomechanical properties of connective tissues. Recent research findings contradict the prevailing notion that the malleability of connective tissues is very limited. In fact, connective tissues have been shown to be biochemically and physiologically dynamic. Studies are needed to characterize the cellular and matrix components of all types of connective tissues and to determine the physical and physiological roles of these components. For example, the influences of the various collagens and proteoglycans and of their organization on the properties of connective tissues have not been determined. On the basis of detailed biochemical knowledge, it might be possible to modify the stiffness or strength of tendons and ligaments by altering the biochemical composition of connective tissues.

In vivo stress-strain properties of connective tissues. The ways in which connective tissues respond to both the amount and pattern of stress and strain can either improve or diminish the functional integrity of the tissues. Properties and responses of

connective tissue should be characterized in people with and without musculoskeletal disorders to determine how specific disorders alter the stress-strain properties of connective tissues.

These properties of bones and ligaments are already being studied *in vivo*, and the adaptive responses of bone to chronic stress and strain have been shown to have a significant impact on functional integrity. The same technology used in these studies can be applied to research on other connective tissues. *In vivo* data on the actual stress-strain characteristics in movement should improve diagnoses of connective tissue disorders and provide information to guide the selection of treatments for people with specific disorders and impairments.

Dynamics of the interactions in joints. Numerous studies of joint mechanics have been conducted. Unfortunately, the precision and utility of many of the results are limited because the investigations were performed with cadaver materials. These limitations can be overcome by using current noninvasive imaging techniques, which enable researchers to study the interactions of joints, muscles, and tendons under normal or near-normal physiological conditions. Such *in vivo* studies would provide important information for improving movement-related rehabilitation strategies.

Studies of the physical and physiological mechanisms involved in the normal articulation of joints have led to more effective internal and external prosthetic devices, thereby creating new opportunities for the rehabilitation of people with arthritic and traumatic joint injuries. A more complete picture of the complexity of joint movement under physiological loads, the patterns of loads on tendons and ligaments, and the location and magnitude of contact forces acting on cartilage should evolve with further refinement of *in vivo* recording techniques. Many studies, including evaluations of the ability of muscle to generate maximal torque (strength) and to maintain selected torques in repeated efforts (endurance), have quantified muscle-joint performance under a variety of conditions. New techniques make it possible to develop controlled, quantitative tests of neuromuscular function under different external loads, velocities, and directions. Although it is technically feasible to develop clinical instruments that relate torque-velocity measurements to the performance of routine daily tasks, such development has not yet taken place.

Mathematical modeling of joint motion. Mathematical models that simulate joints are being used to predict joint forces and motions and to describe the interdependence of joint mobility and the forces incurred by cartilage, ligaments, tendons, and muscles. The robustness of these models is increasing with the growing knowledge of the detailed geometry of joint surfaces and of the material properties of bone, ligaments, and cartilage.

Newly developed technologies and better understanding of musculoskeletal function have helped surgeons plan procedures to correct gait dysfunctions in children with cerebral palsy and select patients for whom certain preventive orthopedic procedures can be successful. Moreover, gait and postural analyses have proved to be valuable tools in studies of balance difficulties in older adults and of factors that increase the risk of falling.

In vivo imaging to study musculoskeletal function. New imaging technologies have greatly enhanced opportunities for indepth studies of musculoskeletal function. The volume and shape of single muscles can be defined quite accurately, and this information can be combined with data on muscle fiber arrangements and the results of biomechanical analyses of joint motion to yield close approximations of a muscle's functional potential. Beyond anatomical

descriptions, *in vivo* measurements of metabolic responses to specific work conditions are also possible. Magnetic resonance imaging (MRI) has been used to estimate relative changes in extracellular and intracellular water content, to predict the relative proportion of fibers expressing slow or fast myosin, and to image muscles and muscular regions activated in a controlled movement. Moreover, MRI and other imaging techniques are useful in localizing specific metabolic consequences of muscular contractions, as well as in defining localized regions of skeletal muscle injury. Full realization of the great potential of these technologies in improving the understanding of normal musculoskeletal function and in optimizing rehabilitative interventions should be a major priority.

Role of activity in pathophysiology. In every situation involving musculoskeletal impairment, choices must be made about when and how much activity to resume during recovery. Despite the importance of this issue, little scientific information is available on which to base a decision. It is not known whether certain types and amounts of activity will slow the worsening of an impairment or in what ways specific activities affect the functional integrity of normal and pathophysiological bones, ligaments, and tendons. Similarly, the ways in which activities modulate the intra- and extracellular components of connective tissues have not been described. It has been shown that chronic exercise after joint surgery strengthens the repaired ligament-bone attachments and can also promote metabolic adaptation in the ligaments, which may increase the potential for repair. However, there is also evidence that excessive levels of chronic exercise can have detrimental effects on bones and connective tissues. The challenge is to determine the optimal activity regimen for a specific type of person, connective tissue, and physiological state.

Immunological disorders of connective tissues and muscles. Abnormalities of the immune system can significantly affect musculoskeletal function because of changes in connective tissue properties in joints, muscles, and skin, as well as in the vascular system. In addition, people with arthritis, lupus erythematosus, scleroderma, and other pathological states associated with immunological abnormalities suffer severe pain, as well as movement dysfunction. It is assumed that at least minimal participation in activities would be beneficial for these people and perhaps slow deterioration of function. Yet decisions on the types and levels of activities most appropriate for people with specific immunological disorders are often made virtually without guidance from sound scientific principles.

Musculoskeletal Biology and Plasticity

Recent studies have found that the structural organization of muscle fibers varies in important ways from muscle to muscle and that these differences have a profound effect on the muscle's force-generating properties. During normal gait, leg muscles are often activated under both lengthening and shortening conditions. Significant technical advances have yielded quantitative data from studies of humans, nonhuman primates, and other mammals on the force patterns of single muscles during normal movements, including locomotion.

Muscle tissue has a remarkable potential to adapt to a wide range of physiological and hormonal stimuli. Researchers have identified and characterized some of the physiological and biochemical stimuli that can modulate the amount and kind of proteins synthesized by muscle fibers. Understanding the modulation of proteins is fundamental to identifying the factors that regulate the physiological properties of muscles, including force, speed, and endurance.

Muscle design, form, and function. Muscle function is significantly affected by the arrangement of fibers within a muscle, the fibers' orientation to tendons and extracellular components, and their interface with adjacent fibers. These characteristics should be taken into account when assessing muscle function and levels of adaptation to atrophy-inducing and hypertrophy-inducing stimuli. In addition, knowledge of a muscle's architecture should be factored into decisions on surgical strategies for tendon transfers. It is important to know, for example, whether the muscle-tendon complex is optimized for force, displacement, or resistance to fatigue. Among synergistic muscles, given a known moment arm length, the relative contributions of individual muscles in a specific type of joint movement can be estimated.

It is clear that the mechanical stress imposed on a muscle fiber can be translated into an increase in net synthesis of muscle proteins, particularly contractile proteins. In cross-section, fibers become larger by assembling new sarcomeres in parallel. Stretch can also stimulate more sarcomeres to be assembled in an *in series* arrangement, resulting in fiber elongation. Synthesis of new sarcomeres *in series* can improve sarcomeric function by maintaining sarcomeres at lengths optimal for producing force. Further enhanced stretch stimulates some fibers that normally express only fast myosin to express slow myosin. Opposite changes occur when mechanical stress or loading on muscle is reduced.

Muscle-tendon dynamics. The contributions of tendinous components of the musculoskeletal system to movements warrant more intensive investigation. Although the potential for the musculotendinous structure to transfer or amplify sarcomeric actions has been studied, important questions about the precise role of tendons in musculotendinous functional units remain to be answered. Because the tendons influence movement control, efficiency, power, and even fatigability, a detailed understanding of their role is critical to improving rehabilitative interventions for people with damaged musculoskeletal tissues.

Control of protein expression. Elucidation of the physiological signals that direct the expression of proteins is a high research priority. Some forms of severe overload are known to increase the proportion of muscle fibers that express slow myosin. In contrast, under the low gravity of space flight, in some muscles the proportion of fibers expressing fast myosin increases. Moreover, it is known that enzymatic activities are coordinated within as well as across metabolic pathways, but the signals that orchestrate the coordination of the many enzymes in the primary metabolic pathways of muscles have not been determined.

The cascade of biochemical events that eventually trigger gene translation and expression also await full description. Although the genes for several protein components (e.g., the genes for fast and slow myosin) of skeletal muscle have been identified, the signals and processes that determine their expression are unknown.

Motor unit properties. The motor unit is probably the most thoroughly described component of the motor system. Detailed descriptions of the physiological and anatomical characteristics of the motor unit provide a solid foundation for explaining why and how muscles produce force at a given speed and over a series of repetitive movements. Further, the properties of the muscle component of the unit have been matched to the electrophysiological properties of the motoneuron. Researchers have determined how these electrophysiological properties relate to the probability that a motoneuron will be recruited during the performance of a well-defined motor task. Detailed understanding of motor unit function and morphology provides the basis for

designing treatment protocols for optimizing neuromuscular function.

Plasticity of musculoskeletal tissues. As described previously, the essential elements of plasticity are the modulation and control of protein synthesis. Regarding the plasticity of musculoskeletal tissues, the primary issue is how the various regulatory signals interact to induce modulation of a protein or family of proteins. For example, chronic increases in thyroid hormone levels in the blood increase the expression of fast myosin, as does the unloading of extensor muscles for prolonged periods. The opposite effect can be achieved with chronic administration of electrical stimuli to the muscle, to some extent by chronic levels of endurance exercise, and by chronic administration of a phosphocreatine analogue in the diet.

There are many examples of musculoskeletal tissues responding to mechanical stress. Myoblasts in culture increase their rate of protein synthesis when the substrate on which they are grown is subjected to cyclic strain. Tendons and ligaments subjected to cyclic loading after injury demonstrate greater ordering of collagen fibrils, thus increasing healing rates. These and other findings indicate the progress that has been made in characterizing the potential of muscle fibers to regenerate after damage caused by mechanical stress. In addition, studies have demonstrated the importance of tissue growth factors that modulate muscle fiber growth. At the cellular level, stress transduction occurs and influences gene expression and, ultimately, cell morphology.

Recent studies of the interaction between the cell and the extracellular matrix have demonstrated that most tissues have specific adhesion receptors that permit transduction of extracellular signals to the controlling machinery of the cell. For example, the integrin superfamily of receptors binds specifically to extracellular matrix proteins such as laminin, fibronectin, vimentin, and merosin. These proteins are involved with and can even control cell morphology, differentiation, malignant transformation, and migration. Increasingly refined knowledge of the molecular basis of cellular responses to mechanical stress has significant implications for rehabilitation.

Control of mitochondrial proteins in muscle is being described in increasing detail. Although enhanced muscle activity increases mitochondrial density, decreasing normal activity levels does not necessarily reduce it significantly. The mitochondrial density of a muscle fiber is one of many factors that determine its resistance to fatigue. With better understanding of the modulation of mitochondrial proteins, it may be possible to reduce muscle fatigue—a limiting factor for many patients with musculoskeletal disorders.

There is increasing evidence of the plasticity of muscle. However, yet to be established for muscles and, just as important, for connective tissues are sound principles for guiding clinical approaches to modulating specific proteins to alter the functional properties associated with them.

Surgical approaches to muscle dysfunction. Significant advances have been made in surgical and postsurgical reparative procedures, resulting in improved functional outcomes for many people with musculoskeletal impairments. Ongoing research is strengthening the scientific foundation for further advances. For example, the results of several studies indicate that it is beneficial to reactivate immobilized joints as early as possible after ligament surgery, and an extensive body of literature is available on the potential role of muscle transplants to replace damaged tissues.

Electrical stimulation. Clinical uses of chronic electrical stimulation to improve muscle function have evolved without convincing scientific evidence of their benefits. Nonetheless, many research centers and

medical clinics have embraced the notion that stimulation can effectively strengthen muscle. It is important to determine whether, and under what conditions, chronic electrical stimulation can improve the output potential of the neuromusculoskeletal system of people with movement-related disorders.

Orthotics and Prosthetics

Orthoses (braces), which protect injured or painful joints or compensate for muscle weakness, and prostheses (artificial body parts) have long been used in rehabilitation medicine. In recent years, lighter, stronger materials have significantly improved both types of devices. For example, prosthetic feet are now made with plastics that store and release energy, which aids controlled mobility. In addition, computer-aided design and manufacturing methods have fostered progress in research to improve below-knee prostheses, especially in socket formation. Little information is available on the adaptive processes that follow when these movement-assistive devices are used. Adaptive responses may have a negative or positive effect on the desired outcome.

Outcome Measurement

Over the last decade, techniques for measuring function, quality of life, and health status have improved markedly. Much of the research leading to these improvements has focused on musculoskeletal disorders, especially rheumatic diseases. New functional assessments, most of which include self-administered questionnaires with excellent reproducibility and sensitivity, capture the impact of musculoskeletal disorders on the ability to function in daily activities, on the capacity for work, and on psychological well-being. The instruments have been incorporated into clinical trials and, to a limited degree, are used in daily practice. Moreover, measures of physical function have been incorporated into the National Health and Nutrition Examination Survey—a step that is expected to yield valuable information on the epidemiology of disability.

Recommendations

Research questions relevant to the rehabilitation of the millions of Americans with musculoskeletal disabilities abound. Yet, in the short term, intensified efforts in three major categories of activity are necessary to build a foundation for future research and to foster synergy among studies already under way. Needs in two of these categories—functional assessment and outcomes research—are being addressed by basic and clinical researchers, although the level of effort and support does not match the need. The third category—technology transfer—is largely an organizational challenge. As in other areas of rehabilitation medicine research, there is a great need to develop effective linkages among research activities that can yield information on improving rehabilitation services for people with musculoskeletal disabilities.

Specific recommendations for research follow.

Biomechanics

Detailed descriptions of normal and abnormal musculoskeletal structures are needed to guide the development of orthotic and prosthetic devices, as well as other rehabilitative interventions. A clearer understanding of the dynamics of muscle fibers and of fiber-to-fiber and fiber-to-tendon interfaces in routine movements is essential. To a large extent, progress in biomechanics will be determined by the rate of success in applying the most advanced biomedical developments to the problems outlined in this chapter.

Bone Biology

Topics warranting intensified research in this important area include bone remodeling; design of orthoses and implants; cellular effects of stress, strain, and other external influences; and osteoporosis. Detailed information is needed on the physiological events triggering the biochemical processes that ultimately affect bone morphology and function.

Biology of Pain

The biomechanical and biochemical determinants of musculoskeletal pain warrant increased research. These factors should be defined in the context of basic neurophysiological events. The aim of this research should be to develop models to characterize the chain of events that cause chronic pain. Greater emphasis should also be placed on the psychological modifiers of pain and on the physiological and behavioral responses to it.

Regeneration and Healing

Biological research should elucidate the roles of physical, biochemical, metabolic, pharmacological, and psychosocial factors in the regeneration and healing of damaged connective and muscle tissues. An understanding of the cellular and intercellular events that influence cellular adaptation, functioning, and survival is fundamental to progress in treating people with musculoskeletal disorders.

Interaction of Impairments

Musculoskeletal disabilities often result from interactions of multiple impairments, but the consequences of individual impairments are rarely limited to the main site of pathology. For example, physical adaptation or compensation may lead to physiological stresses elsewhere in the body that may also affect overall performance. An important line of research, therefore, is the biological description of how specific functional and morphological characteristics of the neuromusculoskeletal system adapt to specific types of impairments. Also needed are studies of the biochemical events that influence adaptations in musculoskeletal tissues. Efforts to increase understanding of the biological elements of impairments should be undertaken from the perspective of the whole person, and issues should be examined in the context of their relevance to the performance of daily tasks.

Control of Movement

More research must focus on the interactions of the neuromuscular and musculoskeletal systems and on how these interactions are translated into specific kinetic and kinematic characteristics of movement. Basic investigations are essential for advances in computer modeling of movements—an approach that might yield considerable insight into the significance of various control features of the neural output to structurally well-defined regions of the musculoskeletal system.

A detailed understanding of neuronal recruitment across motor pools, synergists, and antagonists is key to developing optimal techniques to supplement or even substitute for the neural control of well-defined movements.

Inducing and Controlling Plasticity

Intensified research efforts are needed to determine the potential for inducing and controlling plasticity in all types of connective tissues, particularly the adaptive responses to hormonal influences and physical stress. The potential for inducing and controlling plasticity of motor units needs to be thoroughly defined: One of the most important functional control characteristics to define is how the cross-sectional area of a muscle fiber is determined.

Similarly, an improved understanding of the plasticity of bones, ligaments, tendons, and cartilage is essential.

Functional Assessment

Although important strides have been made in recent years, developing, testing, and standardizing techniques to measure the impact of impairments, disabilities, and handicaps requires more concerted effort. An explicit goal should be to improve understanding of the basic physiology of the musculoskeletal system so that strategies can be developed to optimize function at any given stage of development and level of impairment.

Rehabilitative Interventions

The rehabilitation of people with disabling musculoskeletal conditions spans a diverse array of services, often beginning with acute care and extending to community-based programs. Many interventions have been developed to address problems at each point. Unfortunately, the effectiveness of few of these interventions—medical, behavioral, social, environmental, or vocational—has been evaluated. Not only must individual interventions be evaluated, but alternative approaches for organizing and coordinating the delivery of combinations of needed services must also be rigorously analyzed.

Technology Transfer

Much ongoing biological, psychological, sociological, and health services research yields results with potential clinical applications. These results are rarely or, at best, slowly transferred to clinical investigators. The converse is also true, however. Researchers in clinical rehabilitation medicine rarely communicate the results of their studies to investigators in other disciplines who have allied interests. Efficient mechanisms for cross-disciplinary communication are clearly needed to fully utilize available technical and scientific advances.

Cancer Rehabilitation

Cancer Rehabilitation

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Cancer Rehabilitation

Overview

About half of the 1 million Americans who will be diagnosed with cancer this year can expect to be alive and disease free in 5 years. Three decades of progress in research, early detection, and treatment have increased the number of long-term cancer survivors in the United States to 6 million. In the near future 1 person in every 1,000 aged 20 will be a survivor of childhood cancer.

While early diagnosis and advances in treatment, such as limb-sparing procedures, conservation surgery in laryngeal and breast cancer, and adjuvant chemotherapy for colon cancer, have reduced morbidity and increased patient survival, these gains impose the important responsibility of addressing the long-term rehabilitation needs of survivors. However, the long-term consequences of many innovative therapies are largely unknown.

Both cancer and its treatment can cause impairment that leads to disability. The resultant functional deficits vary widely, but include loss of speech or a limb, incontinence, disfigurement, and dysphagia. In addition, these and other physical disabilities carry an increased risk of psychosocial, vocational, and economic problems that can severely diminish the quality of life. In conjunction with treating the underlying pathologies, rehabilitative interventions seek to enhance or maintain physical, psychological, social, and vocational function. Accomplishing this goal requires an integrated multidisciplinary approach in clinical practice and in the underlying research efforts intended to improve the effectiveness of cancer rehabilitation.

Cancer rehabilitation research must address the unique characteristics of each tumor and its therapy; each poses special challenges for rehabilitation. This chapter examines research issues specific to three major categories of cancer: cancers of the head and neck, breast cancer, and cancers of the bone and soft tissues. Time constraints did not allow the panel to devote detailed attention to other forms of cancer, such as colorectal, genitourinary, and gynecological cancers, which present a subset of different research problems and treatment issues. This chapter does examine, however, several issues relevant to the needs of large numbers of people with any cancer: psychosocial stresses and challenges, pain, sexual dysfunction, and rehabilitation needs associated with metastatic disease.

Research Accomplishments and Opportunities

In fiscal year 1989, the National Institutes of Health (NIH) spent more than $11 million on cancer rehabilitation research. Most of this support was provided by the National

Cancer Institute (NCI). NCI funded about 30 projects focused entirely on cancer rehabilitation, and an additional 145 projects, including clinical trials, that devoted at least 5 percent of the research effort to studying rehabilitation issues.

Besides NIH, other public and private institutions and organizations, such as the American Cancer Society, support research on the rehabilitation of cancer patients. Total expenditures were not tabulated by the panel, but benefits of the overall effort are evident, as innovations stemming from recently published research results are now undergoing clinical evaluation.

About 65 percent of children with cancer are cured, and studies have demonstrated that treatment modifications can minimize cognitive impairments, while maintaining survival rates. About 80 percent of head and neck cancer patients who previously would have lost their voices are candidates for treatment with a tracheoesophageal fistula, which makes understandable speech possible. New materials and methods have made limb-salvage procedures a viable option for many patients with bone and soft tissue tumors. And advances and refinements in conservation surgery of both the breast and larynx have resulted in functional outcomes markedly superior to those achieved with historical methods. Rehabilitation problems remain, such as lymphedema of the arm or rib fractures following breast irradiation.

Although these and other newly developed treatment strategies, such as bone marrow transplantation and biological therapies, are demonstrably beneficial for cancer patients, the full consequences of the curative therapies have yet to be established in followup studies. The number of people treated to date is too small to permit meaningful statistical evaluation of outcomes. Clinical and epidemiological researchers should focus their efforts on describing the functional and psychosocial problems of people who undergo new and emerging treatments. Research on potential rehabilitative interventions should proceed in tandem. At the same time, interventions that address the already-recognized sequelae and functional impairments of cancers and therapies need to be improved. Similarly, the effect of nutritional deficits on rehabilitation outcomes also requires study.

Head and Neck Cancers

About 42,000 new cases of oral cavity, pharyngeal, and laryngeal cancers are diagnosed each year. About half of the people with these conditions are potential 5-year survivors, and the majority of all patients are candidates for rehabilitation.

Survivors of head and neck cancers are often debilitated by the disease and its treatment. Patients are frequently unable to return to work, and many avoid routine activities such as eating in restaurants and attending social gatherings. Some seek seclusion because of changes in their appearance. Smoking and excessive alcohol consumption have been implicated as causative agents for head and neck cancers, and rehabilitation may be complicated if these harmful behaviors are resumed. Because of such behavioral problems, compliance with rehabilitative regimens can be difficult to achieve.

Common posttreatment deficits include impairments of hearing and balance following chemotherapy; loss of taste and smell resulting from radiation therapy and some chemotherapeutic drugs; dysfunction of speech, swallowing, and chewing caused by surgery; and salivary and sensory impairment resulting from irradiation or surgery. Some of these problems are considered in more detail below.

Speech. Radiation therapy eliminates the cancer and preserves the voice in more than 90 percent of patients with early stage laryngeal cancer. For laryngectomy patients,

voice preservation or restoration has been the focus of rehabilitation research during the past 20 years. Patients undergoing total laryngectomy can achieve reasonably good speech with a tracheoesophageal fistula that is maintained by a silicone prosthetic device with a one-way valve to prevent aspiration. Although this instrument represents a major advance, further refinement of the technology is needed to improve the speech quality. Conservation surgery is another promising approach.

The loss of all or a major part of the tongue causes serious speech problems. The type of reconstruction is critical in facilitating tongue mobility and speech following surgery. Investigators have found that tongue mobility is best preserved by a limited resection and primary surgical closure. Recent studies of the combination of laser therapy and radiation therapy report improvement in maintaining tongue mobility in patients with small tongue tumors.

Investigators are developing prostheses that make possible better tongue apposition to oral surfaces, but more work is needed. Limited basic understanding of the neuromuscular function of the tongue has slowed progress in this area.

Swallowing. Among the most devastating consequences of head and neck surgery is difficulty in swallowing, or dysphagia. To assess the degree of swallowing deficit and to evaluate interventions, researchers have developed methods to quantitate swallowing performance with timed videofluoroscopy, scintigraphy, and ultrasonography. Scintigraphy can also be used to detect and quantitate aspiration. In addition, a simple performance scale has been developed to assess the effects of impairments in eating and speech on the overall functioning of head and neck cancer patients.

To prevent swallowing difficulties, many head and neck surgeons have begun using the technique of cricopharyngeal myotomy. A nationwide, prospective, randomized trial is evaluating the effectiveness of this procedure in preventing dysphagia in 400 head and neck cancer patients who have had resections of the supraglottic larynx, base of the tongue, or hypopharynx.

Salivary flow is significantly reduced after surgery and irradiation of either the minor or major salivary glands. Reduced salivation hinders chewing and swallowing, alters taste, and leads to significant dental problems. New methods to protect salivary gland function are being studied, and medications that appear to stimulate salivary flow have been identified.

Appearance. Cancers in the orbit of the eye and the paranasal sinuses often require removing large portions of the face and adjacent skull. Current research focuses both on surgical reconstruction and on improving the synthetic materials used in cosmetic prostheses. To improve stabilization of these prostheses, researchers are trying such techniques as anchoring prostheses to bone. Cosmetic prostheses that match natural tissue in color and opacity could benefit rehabilitation of patients by enhancing their self-esteem. In ongoing work, researchers are developing and evaluating colorants for polymeric prostheses for patients with facial disfigurement.

Hearing and balance. Studies of the safety of chemotherapeutic agents, particularly cis-platinum, used to treat people with head and neck cancers have shown that dose responses are not predictable and impairments of hearing and balance appear to be aggravated by other medications. Cis-platinum analogues, such as carboplatinum, may cause less hearing impairment than the parent compound, but may also be less effective against the tumor. Investigations of the effect of drugs on hearing and balance are continuing.

Breast Cancer

The incidence of breast cancer has been rising steadily over the past decade. It is the most common malignancy in American women, and is second only to lung cancer as a cause of cancer mortality among women. One woman in 10 will get breast cancer in her lifetime. Of the 150,000 new patients diagnosed with invasive breast cancer in 1990, about 70 percent have early-stage (stages I and II) disease. About three-fourths of these early-stage patients will be 5-year survivors.

Increased use of screening mammography and heightened awareness of signs of disease have led to more diagnoses at the earliest stages of disease. Over the past 20 years, several worldwide clinical trials have compared radical mastectomy—formerly the most common type of initial treatment—with less extensive breast resections. These trials have shown that the local control and survival outcome of early-stage breast cancer patients who received limited surgery plus definitive radiation therapy is equivalent to that achieved with those who had radical mastectomy. In 1987, 36.5 percent of all women with stage I disease and 46.9 percent of those under age 50 received lumpectomies. An NIH consensus panel convened in 1990 concluded that not only is breast conservation surgery an appropriate primary therapy for the majority of women with stage I and II disease, but it is preferable even to mastectomy because it preserves the breast while achieving equivalent survival.

Fear of recurrence appears not to vary with type of treatment, but other psychological and sexual reactions seem to be related to the type of therapy. Radical surgery is likely to have a greater impact on a woman's feelings about her body image, physical attractiveness, and sexuality. Lumpectomy followed by radiation therapy may interfere, in the short term, with lifestyle requirements. Moreover, adjuvant chemotherapy or hormone therapy for patients who undergo either surgical procedure can cause adverse side effects that can slow recovery and resumption of normal activities. The impact of treatment side effects and the psychological stresses associated with alteration of the body can result in deteriorating quality of life, a matter warranting further investigation in clinical trials of treatment effectiveness.

Limited breast surgery is associated with several posttreatment problems that may necessitate rehabilitation. Radiation therapy following breast conservation surgery can cause the secondary problem of fibrosis with edema and poor appearance. In addition, a number of patients who undergo radiation therapy experience long-term sequelae such as unusual sensations, breast pain, arm lymphedema, and rib fractures. Eliminating or reducing these complications will require new and different kinds of rehabilitative interventions. As with radical mastectomy, axillary node removal remains an important part of primary treatment with conservation surgery resulting at times in arm edema and shoulder dysfunction. Because a large number have been treated with radical or modified radical mastectomy, many may develop arm lymphedema and decreased shoulder mobility, problems that merit attention in rehabilitation research.

Women who have undergone or will undergo radical mastectomy are candidates for breast reconstruction. Refinements in breast reconstruction techniques, including better prosthetic implants and nipple reconstruction, are needed. Finally, the timing of postoperative exercise programs for these women has not been adequately studied.

Bone and Soft Tissue Cancers

About 60 percent of the 7,800 patients diagnosed each year with primary bone or soft tissue cancers will be 5-year survivors.

Until this decade, the standard treatment for extremity sarcomas was amputation. Today, about 90 percent of patients with extremity soft tissue sarcomas are treated with limb-sparing procedures. These procedures, developed through the combined efforts of orthopedic surgeons and bioengineers, have created the need for new types of rehabilitative interventions. Using computer-based engineering techniques, scientists have developed durable prostheses (80 percent have lasted 10 years or longer). Improvements in performance and longevity of prostheses may result from recent research advances. For example, the new technique of extracortical fixation permits bone to grow directly into the prosthesis through porous or titanium mesh coating. Another bone reconstruction technique under development uses large osteoarticular allografts, although risks of infection and fracture are fairly high. Recent work with tissue typing and immunosuppressants may help overcome some of these problems.

Using large bone transplants to bridge defects and restore musculoskeletal joint function is a logical and appealing approach in limb-sparing surgery. However, the usefulness of the technique is limited by the high risk of significant, often unpredictable complications. Emerging methods, such as better geometric matching of the graft-to-host bone, improved operative techniques, and specially designed fixation devices, have the potential to reduce these problems. Guidelines for selecting and fitting allografts are being developed, along with a system of modular implant components that can be tailored to various reconstructive methods for different anatomic regions.

Using prostheses that expand and adjust as a young patient grows is increasing, but the adequacy of adaptation and the potential long-term sequelae have not been evaluated.

Problems encountered in patients and experiments in rats show that some metal alloys commonly used in implants may cause tumors at the implant site. Preliminary studies attribute tumor development to high nickel, cobalt, or chromium content and to the large surface areas typical of cementless porous implants. In long-term studies of laboratory rats, researchers are investigating the carcinogenic risk of metal alloys on the surfaces of implanted devices. Findings from these studies may lead to better methods to assess the biological suitability and safety of new metal devices proposed for use in human implant surgery.

Pain

Research interest in the pain cancer patients experience has largely emphasized the suffering and discomfort associated with end-stage cancers. Little attention has been paid to the posttreatment pain experienced by patients whose lives have been prolonged by cancer therapy. Data on the prevalence, duration, or severity of treatment-related chronic pain syndromes are extremely limited. Studies conducted in the United States and the United Kingdom reported that less than half of all cancer patients achieve adequate pain control. In addition, small studies conducted at individual pain clinics indicate that about 20 percent to 30 percent of cancer patients referred for treatment suffer from pain related to treatment, not to active disease or other causes. Only rudimentary data are available on how chronic posttreatment pain affects rehabilitation.

According to some estimates, applying current knowledge of pain management could significantly reduce pain in about 95 percent of cancer patients. Considering the suspectedly high prevalence of chronic pain among cancer survivors, this estimate suggests a crucial need for better and wider dissemination of pain management methods. Several efforts are under way,

including statewide information and referral networks, computer-based instructional systems, and national conferences on pain. It should be noted, however, that the effectiveness of many existing pain management techniques has not been scientifically evaluated. Data on the prevalence of posttreatment chronic pain among various categories of cancer patients need to be gathered, along with data on the effects of pain control on the rehabilitation process.

Research on pain management ranges from descriptive studies of pain incidence in adults and children to experimental use of different types of patient-controlled analgesia systems and to clinical evaluations of the efficacy of drugs used alone or in combination. Behavioral techniques, used alone or as an adjunct to drug therapy, are also being examined. In addition, some researchers are attempting to elucidate the roles of pathophysiological and psychological factors known or suspected to influence the occurrence of pain, as well as its severity and duration.

Psychosocial Factors

Cancer survivors, even those who are spared functional impairment or disability, face some adjustment problems. For example, they fear recurrence and the challenge of resuming normal activities during or after a physically demanding treatment period. The severity of these and other problems is often magnified for those who survive with a functional impairment or disability.

Cultural backgrounds can also introduce obstacles to treatment and rehabilitation. The best evidence of this phenomenon is the differences in cancer outcomes for patients in different racial groups. For example, survival rates for whites exceed those for blacks. Factors hypothesized to explain this difference include earlier disease diagnosis in whites and socioeconomic differences. Moreover, cultural values can influence individual perceptions of treatment and its effect on the body. In some cultures, removal of a breast may have stigmatizing implications for the woman. Appreciation of such perceptions could guide selection of the rehabilitative interventions most likely to achieve the outcome desired by patients.

Job discrimination is a complaint of some cancer survivors. For those already employed, such discrimination is manifested in demotion, denial of consideration for a new job, or transfer to an undesirable location. Some survivors also face "job lock"—having a job, wanting to change, but finding it hard to do so because they fear having to disclose their cancer history and risking the loss of health insurance coverage or other benefits.

Children. Advances in the treatment of childhood cancer have resulted in a large and growing population of long-term cancer survivors. Like their adult counterparts, some children survive with functional impairments and disabilities, and psychosocial adjustment can be difficult. Physical sequelae include retarded bone growth secondary to radiation therapy, impaired limbs after salvage procedures, or absence of a limb. Long-term followup studies are beginning to provide information on the lifelong consequences of these and other impairments and on the cognitive, behavioral, and psychosocial effects of the disease and its treatment.

Identifying and monitoring the effects of cancer and its treatment on the neuropsychological development of children is ongoing. Such studies have resulted in treatment modifications intended to reduce processing deficits among pediatric cancer patients and to retain their capacity for educational attainment.

School is a normalizing setting for the child with cancer. Regular school attendance and participation in activities with

peers can counteract the anxiety and depression that often accompany severe illness. Furthermore, the opportunity to receive a complete education in a normal school environment will yield long-term benefits by preparing the childhood cancer patient for a productive adult life. Some children, however, are reluctant to return to school after diagnosis and have difficulty maintaining regular attendance during and after treatment. One ongoing study is testing the effectiveness of a systematic intervention to increase school attendance during cancer therapy and to maintain regular attendance by long-term survivors of childhood cancer. The intervention requires significant parental involvement, as well as that of teachers and peers.

Some studies suggest that adults who have had cancer in childhood may experience discrimination in securing employment commensurate with their training and abilities and in obtaining adequate life and health insurance for themselves and their families. Current studies are evaluating these experiences. Much more research of this type is needed, however. Very little information is available to guide the development of rehabilitative interventions and associated services to help survivors of childhood cancer prepare effectively for all aspects of adult life, including employment, marriage, family life, and social participation.

Support. While behavioral and psychosocial aspects are generally recognized as critical elements of the cancer rehabilitation process in the short and long term, these complex issues have not been adequately studied. Support groups for cancer patients and their families are offered as a service by many institutions and organizations, but these well-intentioned programs often operate without benefit of scientific research. There is virtually no information to help program personnel identify patients who most need such services, nor is there research on the timing, content, or structure of such programs. The panel also identified the need to facilitate access to the health care system and for studies on alternative health insurance programs.

Sexual Dysfunction

An estimated 5 percent of all newly diagnosed cases of cancer, or about 55,000, occur in patients aged 34 or younger. Since many of these patients will be long-term survivors, the effects of therapy on sexuality and reproductive function have great significance.

Both irradiation and chemotherapy can lead to gonadal dysfunction. Infertility, for example, is a major side effect of pelvic irradiation in women. In contrast, childhood cancer patients who are treated with combination chemotherapy have an excellent chance of normal progression through puberty, and most will maintain normal reproductive function. Yet, a significant number of people who undergo chemotherapy experience reproductive problems, with men affected more frequently than women.

For some men, cryopreservation of semen before treatment keeps reproduction options open. While ovarian function appears to be less susceptible to the toxicity of chemotherapy, girls and women should be counseled on the potential for infertility and premature menopause. Estrogen replacement therapy (preferably with cyclical progestin administration) is now widely used in noncancer patients to relieve menopausal symptoms and prevent osteoporosis, but risks and benefits of this form of treatment in cancer patients should be examined more thoroughly.

The decision to use radiation or radical prostatectomy for cancer limited to the prostate should be guided by the likelihood of sequelae, as well as by the need for irradiation of the cancer. In the past, radical surgery has resulted in nearly universal impotence and a significant incidence of

urinary incontinence. Nerve-sparing surgical techniques that preserve potency are under investigation, but the adequacy of tumor control is a concern. Additional research effort should be devoted to developing innovative surgical techniques that significantly reduce the risks of impotence and incontinence. Clinical trials of therapies for prostate cancer now are examining, in addition to other variables, the psychosocial impacts of alternative treatments, including their effects on sexuality.

Gynecological oncologists continue to improve techniques for vaginal and vulvar reconstruction after cancer surgery, but more research is required in this area. A common side effect of gynecological cancer treatment is edema in the lower extremities. Results of research on lymphedema of the arm associated with breast cancer may be applicable to this problem and should be reviewed for their potential usefulness. In addition, cancers and their treatment often adversely affect a person's concept of self as a sexual person who desires and feels comfortable in intimate relationships. Damage to self-esteem and gender identity can have a negative effect on treatment outcomes and quality of life.

Metastatic Disease

Many patients with metastatic disease, particularly of the breast, thyroid, and prostate, may live with their disease for many years. Maintaining optimal function in these patients may be greatly facilitated by appropriate rehabilitation techniques. However, rehabilitation is often complicated by ongoing or periodic chemotherapy or palliative radiation therapy, necessitating measures that address the side effects of these treatments. In addition, pain control is likely to be an important objective. If pain control is not accomplished, the success of other rehabilitative interventions may be limited.

Bony metastases to the femur and humerus are not only painful, but frequently result in pathological fracture. Stabilization of the bone by intramedullary rods and bone cement before fracture may preserve function and prevent disability. More extensive procedures, such as total hip replacement, are appropriate for some cancer patients, and rehabilitative techniques are similar to those for other patients with comparable problems. More research is needed on the timing of stabilization procedures, particularly when combined with radiation therapy.

The vertebral column is the most common site of bony metastases, which often result in severe pain and neurological deficits. One of the most exciting new developments in this area is the technique of vertebral replacement by prosthetic vertebrae or an acrylic plate. The biomechanics of reconstruction vary and are in the early stages of development. When spinal cord compression has already occurred, the rehabilitation principles applicable to other patients with spinal cord injury are used. Further research is needed in this area, particularly on wheelchairs and mobility devices, self-care aids, techniques for bowel and bladder control, and prevention of complications in paralyzed body parts.

Resection of some solitary brain metastases is being performed more frequently and with increasing success. Rehabilitating these patients follows procedures used for people who have incurred stroke and other types of brain injury. Considerable strides are being made in this area, but much remains to be done. For example, muscle atrophy associated with high-dose steroid therapy and some chemotherapy agents may be an additional problem for the cancer patient. Little basic or clinical research has been done on this problem.

The psychosocial needs of the patient with metastatic disease are ordinarily greater than those of the patient for whom cure is

expected. Requiring refinement are counseling techniques that help people deal with the possibility of a prematurely shortened lifespan but encourage them to participate, as their functional capacity allows, in the activities of life and its pleasures. Improved strategies for counseling family and friends are also needed.

Recommendations

Because of the prevalence of cancer and the increasing number of cancer survivors, improved cancer rehabilitation interventions should be a major national priority. The nature of cancer and its treatment can result in impairments leading to significant disability. In addition, discriminatory societal attitudes toward people diagnosed with cancer can significantly reduce the opportunity for a decent quality of life:

Transcending research priorities in the field of cancer rehabilitation include the need to:

- Develop instruments and measures for assessing functional outcomes;
- Develop new materials and bioengineering techniques to fabricate prostheses that improve functioning and reduce the risk of complications;
- Use existing national clinical trial mechanisms, such as NCI-sponsored cooperative groups and the Community Clinical Oncology Program, to evaluate rehabilitative interventions; and
- Assess the impact of nutrition on the achievement of functional potential.

Recommended research priorities in the specific areas examined by the panel are presented below.

Head and Neck Cancers

Little is known about the basic physiology of taste, smell, speech, and swallowing and about the effects of cancer treatment on these sensory functions. Clinical trials of existing and emerging rehabilitative interventions for people with head and neck cancers warrant greater emphasis. Recent advances in speech restoration, such as the tracheoesophageal fistula, still fall short of achieving full function for the laryngectomy patients. More practical as well as more aesthetic prostheses need to be devised for patients who have had large portions of their faces removed for orbital or maxillary sinus cancer.

Basic Science Research

- Develop better materials for implants or prostheses.
- Conduct studies of specific biological deficits of taste and smell caused by cancer treatments such as radiation therapy.
- Improve understanding of how the tongue works as a complex neuromuscular unit.
- Increase research on the physiology, biomechanics, and pathophysiology of swallowing, using such techniques as timed videofluoroscopy and scintigraphy.

Clinical Research

- Evaluate functional capacity of taste and smell, pre- and posttherapy.
- Improve chewing function with and without prostheses and refine methods for vascularized bone grafts and osseointegrated implants.
- Improve tongue mobility to overcome speech and swallowing disabilities.
- Preserve or restore salivary gland function or substitute new synthetic substances and delivery systems.
- Evaluate emerging surgical techniques (e.g., myotomy and neurectomy) and behavioral interventions intended to maximize swallowing.

Breast Cancer

Rehabilitation of women after breast cancer treatment is a high priority, because 10 percent of the female population will develop this disease. The evolution of less extensive surgical procedures has not eliminated the need for rehabilitation nor the need for research to develop more effective interventions. Major clinical problems, including lymphedema, are encountered by both lumpectomy and mastectomy patients. Basic science and clinical investigators must strive to solve these common problems, and they must address the new challenges posed by innovative therapies.

Basic Science Research

- Develop new prosthetic materials for breast reconstruction.
- Conduct laboratory studies on the physiology of lymphatic flow and on methods for reestablishing normal function (e.g., lymphatic and/or lymphatic-venous anastomosis).

Clinical Research

- Evaluate and improve techniques for breast reconstruction.
- Evaluate the influence of chemotherapy and radiation therapy side effects on rehabilitation, and evaluate new strategies, such as aerobic conditioning, for reducing or controlling side effects.
- Study and define the physical, psychological, behavioral, and social problems associated with long-term sequelae of mastectomy and those associated with limited surgery plus radiation therapy; develop better methods for preventing or ameliorating these problems.
- Evaluate the long-term sequelae of adjuvant hormone (tamoxifen) therapy, such as vaginal dryness and hot flashes, and of adjuvant chemotherapy alone and in combination with radiation therapy.
- Evaluate strategies for preventing or treating lymphedema and shoulder dysfunction, and devise more effective interventions.

Bone and Soft Tissue Cancers

Innovative developments in bone and sarcoma management have helped improve the functional capacity of patients. Successes to date, however, are incomplete; further improvement will require research contributions from a variety of disciplines.

Basic Science Research

- Test the carcinogenicity of prosthetic materials, and develop efficient screening methods.
- Develop new and refine existing bone replacement materials and cements.
- Develop methods for attaching soft tissue to bone-joint prostheses and for stimulating bone growth directly into prosthetic components.
- Devise better methods for fixing bone transplants during tumor surgery.
- Investigate biology and immunology of osteoarticular allografts to reduce infection and fracture rates.

Clinical Research

- Investigate potential for using established surgical techniques in innovative ways.
- Continue to develop modular prosthetic components that permit surgeons to construct prostheses at the time of surgery and so eliminate the need for time-consuming custom fabrication.
- Design adjustable and expandable prostheses for growing children.
- Evaluate the problems and variables influencing the physical rehabilitation of patients who undergo limb-sparing surgery, who have different needs than

amputees, the current model for rehabilitation in this area.

- Refine implantation techniques for large bone allografts.

Pain

Methods that prevent or alleviate the pain of patients are among the most pressing needs in cancer rehabilitation. Available pain management techniques can be effective for many patients, but most cancer specialists and general health care practitioners have little experience with these newer techniques. New methods for treatment are also needed, but progress is impeded by limited understanding of the pathophysiology of pain.

Basic Science Research

- Conduct pathophysiological studies of neuropathic pain (due to destruction or perturbation of neural tissue) and nociceptive pain (due to primary stimulation of pain fibers).

Clinical Research

- Design and conduct longitudinal studies to define the epidemiology of chronic posttreatment pain, including its duration and its impact on the patient.
- In controlled, randomized clinical trials, evaluate existing and emerging therapies for managing posttreatment pain.
- Evaluate effects of combined pain therapies.
- Examine current methods of training health care professionals who work with patients who have posttreatment pain and use this information to correct training inadequacies.

Psychosocial Factors

Embedded in the concept of medical rehabilitation is the tenet that successful rehabilitation addresses all aspects of the individual's life. As such, psychosocial and vocational adjustment is equally as important as physiological functioning. This is an especially important area for cancer rehabilitation research. For example, much of the research literature describing the vocational experiences of adults who have had cancer is nearly two decades old.

Basic Science Research

- Develop measurement techniques for assessing psychosocial determinants of human functioning and quality of life. In this area, perhaps more than in any other, there is a need for valid and reliable instruments.

Clinical Research

- Identify, evaluate, and define the ethnic and cultural factors that influence adaptation to cancer and the success of treatment.
- Test interventions to improve school attendance and performance by children with cancer.
- Study long-term effects of childhood cancer on the physical status and psychosocial adjustment of surviving adults.
- Evaluate methods to help patients understand, overcome, and navigate the complexities of the health care delivery system.
- Investigate the role of support groups and evaluate the effectiveness of various counseling and educational strategies.
- Develop interventions to decrease the economic and vocational problems associated with cancer and to overcome barriers to successful employment.
- Evaluate the feasibility of an assigned insurance risk pool for cancer patients who cannot obtain adequate health insurance coverage.

Sexual Dysfunction

Issues of sexuality are important in both physical and psychological rehabilitation.

Future research must recognize this dual perspective when addressing problems of sexual dysfunction.

Clinical Research

- Develop interventions to ameliorate *physical* problems associated with sexual dysfunction in patients with breast, gynecological, genitourinary, or rectal cancers.
- Develop interventions to alleviate *psychological* problems associated with sexual dysfunction in cancer patients.

Metastatic Disease

The problems of people with metastatic disease can be even more complex and more severe than those experienced by other cancer patients. Improving the rehabilitation of people with metastatic disease requires a focused research effort.

Basic Science Research

- Study the effect of high-dose steroid therapy and of certain chemotherapeutic agents on neuromuscular physiology.
- Continue laboratory studies on the pathophysiology of pain in metastatic disease and on the effectiveness of analgesic agents when used alone and in combination with behavioral methods.

Clinical Research

- Develop better methods for stabilizing long bones affected by metastatic disease and for coordinating surgical procedures with radiation therapy.
- Continue developing techniques for vertebral replacement.
- Establish criteria to select candidates for resection of brain metastases; develop better rehabilitative methods for patients who undergo this procedure.
- Continue studies on approaches to controlling the side effects of treatment; continue research on the impact of side effects on rehabilitation.
- Improve counseling techniques for patients with metastatic disease and for their families and friends.

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Geriatrics

Overview

Most disabling conditions that require rehabilitation affect older adults disproportionately. A few statistics illustrate this fact: three-fourths of all strokes and three-fourths of all amputations occur after age 65; the average age of people who sustain hip fractures is over 70; 86 percent of those over age 65 have at least one chronic condition; and 52 percent of those over age 75 are limited in at least one activity of daily living.

Because of their high risk for disability, people age 65 and older, who make up only 12.7 percent of the general population, comprise 40 percent of the population with disabilities. Given the demographic aging of the U.S. population, it is likely that this proportion and, therefore, the total number of older adults with disabilities will increase in coming decades. Averting this likelihood will require significant advances in geriatric rehabilitation and in disability prevention. Given the inevitability of aging, benefits spawned by progress in both domains will be reaped not only by today's older adults, but also by the youngest among us—the older adults of the future.

Perhaps the most telling example of what can be accomplished comes from the area of stroke rehabilitation, where interventions have been found to benefit between 80 percent and 90 percent of stroke survivors. Research has established that poststroke rehabilitation is cost-effective. It also helps survivors attain higher functional levels than are possible without rehabilitative therapy. Greater success has also been achieved with people who undergo unilateral below-the-knee (BK) amputations, the great majority of whom are older than age 65. With prosthetic training, 75 percent of unilateral BK amputees are able to walk independently. The predominant cause of amputation, however, is peripheral vascular disease, which often necessitates subsequent amputation on the contralateral side. Unfortunately, only about half of bilateral BK amputees and less than 50 percent of unilateral above-the-knee (AK) amputees will walk with a prosthesis.

Incidence of Parkinson's disease peaks between the ages of 60 and 69 years, resulting in 40,000 to 50,000 new cases each year. While drug treatment has led to significant improvements in Parkinson's disease patients, physical interventions also may be helpful. Arthritis is the most common chronic illness in the geriatric age group. Rehabilitation techniques are used to maintain function of arthritic joints, enhance mobility, and prevent deterioration. Finally, although a minority of patients with spinal cord injuries are elderly, one study showed that over 73 percent of persons suffering such injuries after age 60 were able to return home after undergoing rehabilitation.

The nature of one's disability *per se* is not as important as the impact of the condition on the person's independence. Especially

among the elderly, disabilities are associated with higher mortality, increased health problems, and increased expenditures for health care. Certain disabilities, such as reduced mobility, incontinence, and reduced capacity for self-care, often translate into increased dependency and, consequently, increased risk of institutionalization.

Rehabilitation should be an integral part of geriatric medicine, providing the tools to avert or reverse declines in functional capacity caused by disability, and thereby ensuring the opportunity to live independently. Currently, the number of rehabilitative interventions of proven effectiveness is not commensurate with the rising need. Indeed, the interface between geriatrics and rehabilitation is so necessary and so important that the modest development of geriatric rehabilitation is of great concern.

Older adults have different physiological and psychological characteristics than younger people. Moreover, disability in older people often results from primary conditions, such as stroke, interacting with secondary conditions, such as physical deconditioning. These differences have important implications for rehabilitative interventions. Therapies that are effective for the young patient with cancer or heart disease, for example, often do not directly transfer to the older patient with the same diagnostic condition. Drug testing is a case in point. Trials of many new drugs are conducted on populations of young subjects. From the results of these trials, however, one can rarely predict the iatrogenic complications so often experienced when medications are administered to the elderly.

Similarly, the functional, vocational, and avocational goals of rehabilitation should be tailored not only to the type of disability but also to the age of the patient. (See chapter on Developmental Issues.) Realistic and personally relevant rehabilitation goals may point the way to new types of interventions for older adults.

Effective geriatric rehabilitation requires contributions from a broad range of scientific disciplines. It also requires integrating these diverse inputs to ensure that rehabilitative interventions are tailored to the special needs of older adults.

Research Accomplishments and Opportunities

Natural History of Disability in Older Adults

Current understanding of disability in the context of aging is limited. Prevalence data clearly indicate that the risk of activity limitation increases sharply after age 65 and especially after age 75. Research has implicated a variety of factors, including disease severity, comorbidity, nutritional state, and psychosocial variables, that affect recovery from acute illness. However, the specific roles of these and other variables, working alone or together, in recovering functional capacity after the onset of disability remain to be elucidated. Also requiring further investigation is the finding that in many elderly people, levels of performance in carrying out activities of daily living fall below their functional capacity to carry out those activities. The reason for this gap is unknown.

Although rates of disability increase with age, epidemiological studies also indicate that the course of disability and aging is not one of inevitable deterioration. The conditions and functional capacity of some patients with disability remain stable for extended periods, and, according to one study, about 20 percent of older persons with a given level of disability will actually improve their function over time. Even the oldest adults can improve functionally. For example, strengthening exercises greatly

improved mobility in a sample of nonagenarians with leg weakness.

The existing research literature on the natural history of impairment and disability in older adults provides important leads for more detailed investigations. Clearly, prospective studies are needed to disentangle the relationships among risk factors and etiological factors involved in the development of disability and to identify so-called protective factors that can reduce the probability of becoming functionally limited. On the basis of this knowledge, new approaches to the primary and secondary prevention of disability could be developed and incorporated into clinical strategies for maintaining the functional health of older persons.

Assessment of Functional Capacity and Performance

Issues related to the assessment of function and the evaluation of rehabilitation outcomes have been neglected in geriatric rehabilitation research. This is not to say that instruments for each task do not exist. On the contrary, many instruments have been developed to screen for a variety of functional impairments. However, the sensitivity, validity, and reliability of these instruments in rehabilitation settings have not been closely examined. In addition, most scales for measuring physical and cognitive function have been developed for younger persons. Thus, very few scales are useful for determining the need for and appropriateness of rehabilitation for older adults with functional impairments.

Transcending issues requiring investigation include the timing of assessments. In clinical practice, followup measurements of function are rare. While repeated measurements are necessary to ascertain changes in function and the effectiveness of interventions, existing instruments are too limited and too insensitive to assess the array of physical, psychological, and social variables known to, or suspected to, influence the impact of disability and the potential for functional recovery. A few measurement scales incorporate patient values or preferences in assessing the impact of disability, and some assess mood and cognitive state in older individuals. Very few adequately assess social or environmental support for elderly individuals.

Some of the shortcomings of existing instruments can be corrected through validity and reliability testing. However, the robustness and utility of these instruments could be greatly enhanced with more detailed knowledge of the factors (physical, cognitive, mood, personality, social, environmental) that together determine the disability of the individual and influence the outcomes of rehabilitative interventions. Current research does not address all the factors that influence human function, thus limiting progress in developing comprehensive functional assessment inventories.

Intervention Issues

Obviously, primary prevention measures that protect against potentially disabling impairments and secondary prevention approaches that interrupt or slow the progression from impairment to disability are the most desirable strategies for maintaining a high functional capacity in older adults. Effective interventions for preventing disabling conditions are best built on knowledge of the pathological process at the molecular, cellular, and organ levels. For example, while growth hormone production generally declines after age 30, abnormally low levels of growth hormone have been identified as a cause of severe weakness in older adults. Building on this finding, a recent trial in which synthetic growth hormone was administered to a sample of hormone-deficient older adult men reported marked improvements in the strength and functional capacity of most subjects. Though

a number of questions and issues, including drug side effects, remain, this development may open a new avenue to preventing disability in some older people. Other ongoing research has identified modifiable risk factors for disability in older persons. These risk factors include leg weakness and inappropriate prescribing of drugs. Several clinical trials are evaluating interventions to prevent or reduce frailty and related disability.

For the foreseeable future, however, effective primary prevention strategies are likely to be few, and rehabilitation will remain the primary means of maintaining or restoring functional capacity in older people with disabilities. Yet, many rehabilitation interventions for this population have been empirically derived and have never been evaluated in controlled studies to establish their effectiveness. In addition, many factors influencing disability status in older adults have raised many questions about the appropriateness of certain rehabilitative interventions for this population.

An immediate priority for clinical researchers is to evaluate the effectiveness of both existing interventions and promising interventions suggested by the results of recent studies. Examples of the latter are preventive approaches learned from studies of fall prevention and mobility impairment and of the rehabilitation of fall victims. Research on disability risk factors and on the modifiability of those risk factors should point the way to other promising rehabilitative interventions, which will also require careful evaluation.

Examples of existing modalities requiring evaluation in controlled trials are biofeedback, electrical stimulation, and neuromuscular facilitation, all used in rehabilitating stroke patients. Current modalities for urinary and fecal incontinence also await clinical studies to establish their efficacy and to identify their potential risks. Similarly, assistive devices intended to improve mobility, such as wheelchairs and prosthetic and orthotic devices, warrant critical evaluation. Results of these studies would have immediate use, guiding, for example, the interventions to improve the mobility of people who sustain hip fractures. Moreover, there is a need to evaluate the additive effects of combined interventions, such as those used for many people with Parkinson's disease. A substantial number are treated with medications, but may also undergo physical rehabilitation and nutritional intervention. Are these approaches complementary, or would a different combination lead to better functioning? In addition, there are questions of timing, particularly in rehabilitating patients with chronic, degenerative disorders. What is the optimal time for amputating the limbs of elderly patients with peripheral vascular disease? And following amputation, is immediate prosthetic fitting and weight bearing preferable to delayed fitting and weight bearing?

Although unique problems arise with specific disabling conditions, many issues in geriatric rehabilitation research have transcending significance. Much evidence attests to the preventive and rehabilitative value of regular exercise and good nutrition, but specific guidance is lacking. Basic and clinical research should establish the extent to which diet and exercise can modify age-related changes in muscle. Nutritional parameters predicting rehabilitative outcomes need to be identified and interventions developed on the basis of this information. The role of exercise also requires further elaboration. For example, the types and amount of exercise that are effective in reversing the physiological changes (deconditioning) that result from acute or chronic inactivity should be established. Once incorporated into interventions, this information will do little good if the intended beneficiaries do not follow the prescribed exercise regimen. Thus, there is also need for research to identify

motivational and behavioral strategies that foster compliance in elderly people, including those with cognitive impairments.

Cognitive retraining methods and approaches to pain management are also used widely, since a variety of conditions cause cognitive deficit and pain is a frequent complaint of older adults. However, the theoretical foundation underlying both categories of rehabilitative interventions needs further development. Recent research suggests that environmental modifications to increase or decrease sensory stimulation may help enhance cognitive functioning, but further investigation is required. In addition, rehabilitation practice would benefit greatly from the results of studies for developing useful measures of rehabilitation potential in patients with dementia and other cognitive disorders. In the area of pain management, one of several needs is to establish the relative roles of psychological and physical rehabilitation interventions. Another is to ascertain the usefulness of personality profiles in determining the appropriateness of behavioral and psychological interventions, as suggested in some studies. Moreover, research is needed to determine the extent to which depression or dementia can contribute to pain.

Recent research strongly indicates that depression can significantly affect function. A study published in 1989, for example, reported that "depression and chronic medical conditions had unique and additive effects on patient dysfunctioning." Mental health is an important facet of disability. Further research is needed to delineate the role of treatment for depression and other mental disorders in the rehabilitation of patients with physical disabilities.

Finally, salient criteria by which to evaluate the outcomes of rehabilitative interventions for older patients should be developed. Such criteria might include the degree to which an intervention improves a person's ability to maneuver in the home, to attend to personal hygiene needs, and to travel by public transportation. Also important are the effects of interventions on cognitive functioning and on psychological status. Moreover, interventions should be categorized and evaluated according to specifically defined purposes—treating an impairment, disability, or handicap.

Rehabilitation Process and Service Delivery

Questions about the appropriateness of current approaches to designing and delivering health care and rehabilitation-related social services to older persons are intricately related to issues concerning rehabilitative interventions. These questions are treated separately here, but their direct relevance to the goal of improving intervention effectiveness is implied throughout the discussion.

The traditional approach of clinical medicine has been to treat people according to diagnostic category. Private and public health care insurance also adheres to this categorical approach in determining a claimant's eligibility for services. Thus, whether an older adult with disability is reimbursed for rehabilitation services depends not on the pattern of disability and the potential for functional recovery, but on the categorical diagnosis of the impairment. Two single-site randomized trials evaluated the alternative approach of treating patients by functional impairment rather than by diagnostic condition. The studies reported significant benefits for subjects who underwent geriatric assessments and then received rehabilitation services in specialized inpatient units staffed by geriatric rehabilitation teams. The results raise the question of whether the pattern of disability might be more important than the diagnosis in determining eligibility for rehabilitation services. This issue merits further research.

Much work needs to be done to identify the appropriate setting for delivering

rehabilitative services to older patients. For instance, it is possible that some geriatric assessment and rehabilitation services that traditionally have been provided in hospital or rehabilitation-unit settings might also be appropriately delivered in adequately staffed nursing facilities. Although some studies indicate that inpatient rehabilitation improves function in frail older adults, more research is needed to determine the components of rehabilitative care that are most critical in determining outcome.

Preventing institutionalization of older adults has become an overriding social goal. Thus, community-based care and home care are the preferred alternatives. However, none of the options is monolithic; considerable variation exists within each, and the determinants of what constitutes quality care in each setting have received scant research attention.

Also warranting increased research attention is the process of executing rehabilitation. The essence of the process is teamwork, requiring regular interaction among patient, physicians, and other members of the team, which might include, among others, nurses, social workers, occupational therapists, psychologists, physical therapists, and recreational therapists. In addition, the family of the patient should participate in consultations. Effective communication and close coordination of actions are critical to achieving the best rehabilitative outcome for the patient. The special needs of the older patient, however, are often slighted in this process. There is a bias toward the irreversibility of conditions that occur in old age. Therefore, the teamwork approach of rehabilitation medicine, in general, and geriatric rehabilitation, in particular, poses a number of questions: How can varying disciplinary perspectives be integrated? What is the optimal number of team members? What organizational approaches and communication methods are most efficient? What is the specific role of each team member or each discipline? What are the most effective methods for eliciting patient and family input?

Outside the immediate rehabilitation setting, there are additional questions. Research is needed to establish the roles of family and friends in providing support and to identify the most effective ways to provide that support. Moreover, the relevance of the independent living movement to elderly persons with disabilities is ill defined. Independent living centers have helped many young people with disabilities achieve autonomy, but the themes stressed by the centers may need to be revised when applied to older people with disabilities.

Access to health care services is a major social policy issue, but one particularly important to the population with disabilities. Much discussion of this issue focuses on reducing unnecessary or inappropriate patient care. The resultant cost savings, it is believed, will make health care more affordable, thereby advancing efforts to increase access to services. Very little discussion, however, addresses the question of whether services and interventions known to be effective are reaching the intended beneficiaries. Studies of people with disabilities indicate that many do not receive adequate primary care, frequently resulting in serious, but often preventable health problems. An investigation of a sample of outpatients aged 65 and older suggests that many did not receive appropriate rehabilitation services because their need for these services was not identified by attending physicians. These findings point to a problem of underutilization of appropriate services. They also illustrate the importance of educating the broader health care community on the role of rehabilitation.

Recommendations

Natural History of Disability

Basic biological, epidemiological, and clinical studies are needed to clarify the multifactorial

relationship between aging and disability. Research issues warranting intensified efforts are listed in order of priority:

- Prospective epidemiological studies, along with expanded analysis of established databases, are essential to disentangle the relationship between age and disabling conditions. Comorbidity and social-support, environmental, nutritional, and psychosocial factors should be evaluated to determine their roles in the onset of disability or as etiological agents. Identifying factors that determine the rate of progression or even regression of functional impairment and disability over time should be emphasized. Also critical are investigations to determine whether the age of onset of a morbid condition or degenerative disorder affects its degree, pattern, or course of disability in the elderly.
- Biomechanical and basic biological investigations should elucidate the pathophysiological mechanisms that increase the risk of repeated falls and mobility impairment, including gait disorders, patterns of muscle atrophy and weakness, abnormalities in blood pressure homeostasis, changes in nervous system control of postural reflexes and gait, and sensory and cognitive deficits.
- Investigators should identify the factors underlying the often incongruent relationship between the functional capacity of older people and their actual levels of performance in daily activities.
- Studies are needed to identify predictive markers of disability to facilitate intervention before the onset of functional impairment.
- Cross-national and cross-cultural studies are needed to investigate differences in the pattern and course of disability in older persons of different ethnic and cultural backgrounds.

Assessment of Functional Capacity and Performance

Much geriatric rehabilitation research and, ultimately, all of geriatric medicine would benefit greatly from robust measures of the functional capacity and performance levels of elderly people in a variety of domains (physical, cognitive, mood, social, and environmental). Particular measurement attributes to be embodied in assessment instruments include sensitivity to change over time; reliability of measures across raters and over time; range of performance measured in terms of preventing threshold effects; usefulness across different methods of administration; usefulness during different phases of rehabilitation; and relevance to functioning outside clinical settings. Instruments that possess all these attributes would be valuable for baseline assessments and for outcome assessments.

Developing these critically needed instruments will require research in the following areas, listed in order of priority:

- The validity, reliability, and relative merits of various methods of functional assessment should be evaluated and compared in a variety of clinical and residential settings. These methods include performance-based measures, self-report measures, proxy responses, current measures of observed timed performance, and performance measures graded on interval scales.
- Research is needed to explain the influence of education level, gender, race, and nationality on disability, and to develop valid, reliable measures of these variables and include them in functional assessment instruments.
- The influence of both formal and informal support mechanisms on functional capacity and levels of performance warrants greater research attention.

- The key physiological and biomechanical components of functional performance need to be determined.
- Controlled clinical studies should be conducted to ascertain the attributes of physical, cognitive, and affective functioning that can be used to identify older persons needing rehabilitation; variables predicting patient motivation to participate in rehabilitation; and variables predicting successful rehabilitation outcomes.
- Research is needed to determine whether the validity and reliability of assessment instruments could be improved by making them impairment specific, factoring in patient utilities, or by simultaneously assessing both functional ability and social and environmental support.

Intervention Issues

Projected increases in the size of the population aged 65 and older, both in absolute numbers and as a proportion of the general population, imply an increasing need for geriatric rehabilitation services over the next several decades. Meeting this need effectively and efficiently will require a two-pronged research effort: evaluating and improving existing interventions and developing new interventions based on new knowledge generated by studies in the fields of biomedicine, social science, and other rehabilitation-related disciplines. The following research recommendations are offered in order of priority:

- A comprehensive clinical research program is essential to evaluate the effectiveness and outcomes of existing rehabilitation techniques, procedures, and programs for targeted groups of older patients with specific functional impairments or patterns of disability. (See the first recommendation in the next section.)
- Research on methods to correct gait, balance, and strength disorders or to enhance the functioning of older persons with these disorders should be expanded.
- Research to identify and explain the disability correlates of cognitive impairment is needed, as are studies of interventions to reduce the need for care and to increase independence and personal safety.
- The usefulness of various rehabilitation counseling methods intended to help older people with disabilities become involved in meaningful vocational or avocational activities should be evaluated.
- The impact of maintenance rehabilitation on sustaining gains achieved with acute rehabilitation services should be evaluated.
- Increased emphasis should be placed on basic research on hormonal, neurochemical, or pharmacological agents that may be able to improve strength, repair damaged neurons, or generally assist the rehabilitation process through a variety of physiological mechanisms.
- As epidemiological, basic, and clinical research uncovers the factors that influence the course of functional impairment and disability, new strategies for interventions should be devised and then evaluated in controlled studies. Emphasis should be placed on promising interventions for the primary prevention of disabilities.
- Studies are needed to determine if anticipatory rehabilitation can improve recovery and restoration of function after primary medical and surgical interventions.

Rehabilitation Process and Service Delivery

A constellation of rehabilitation-related services has evolved in this country, but

with little regard for the relationship among the various service components. In addition, new programs and approaches to service delivery are emerging as existing ones are being revised. Many important topics, ranging from the functioning and organization of the rehabilitation team to the accessibility of services, warrant comprehensive study. Research issues most salient to the growing population of older adults are listed in order of priority:

- Further research is needed to determine whether the pattern of functional disability is more useful than categorical diagnosis in determining eligibility for rehabilitation services and ascertaining which older patients are most likely to benefit from these services.
- Process and outcome research is needed to evaluate the critical components and effectiveness of the "team approach" to geriatric rehabilitation, just as it is for rehabilitation practices used with younger populations.
- Health service researchers and clinical investigators should evaluate the appropriateness of different settings for delivering rehabilitative services to elderly people with specific types of functional impairment or disability.

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Developmental Issues

Overview

Disability is neither monolithic nor static. Its causes number in the thousands, and its consequences are highly variable, the products of a complex interaction involving biological, behavioral, psychological, environmental, and social factors, many of which have been enumerated but remain to be fully understood. Moreover, the nature of this interaction changes over the lifespan of the individual with disability. Thus, the needs of a young child who was born with a limb deformity and who may never be able to walk are quite different from those of an adult or an adolescent who is not capable of ambulating independently. This is an obvious conclusion—development and, therefore, change are fundamental processes of living, with or without a disability. In the case of a person with disability, however, developmental issues are likely to be more complex.

Change is a core principle of rehabilitation medicine. This panel evaluated issues that are relevant to living with a disability across the individual's lifespan. These issues, though precipitated by pathophysiological changes that result in diminished functional capacity, include health-related concerns that pertain to behavioral, psychological, and social adjustment; educational and vocational attainment; and environmental modifications to accommodate the functional limitations of people with disabilities. The emphasis is on developmental issues, rather than developmental disabilities, a term that refers to disabilities with onset before age 22.

Consistent with rehabilitation medicine's whole-person focus, the panel's review places health within the influence of psychosocial and environmental factors. The search for effective interventions—medical, behavioral, psychological, social, educational, and environmental—must deal with a dynamic array of factors and needs that change over the lifetime of the person with disability and over the duration of the disability.

Particular attention is paid to the developmental issues involved in the rehabilitation of children with disabilities. About 5 percent of the population aged 21 and younger are estimated to have a disability. Of these 3.2 million children, nearly three-fourths have physical disabilities and the remainder have mental disabilities. Although only 1 in 20 people with disabilities is aged 21 or younger, this population accounts for the largest proportion of "disability years," or the number of years lived with disability. According to one estimate, people whose disability was manifested before age 16—about 5.6 million people—live with their disability for an average of 50 years, accounting for 35 percent of all disability years in the United States.

Over this average span of five decades, the person whose disability occurred early

in life will go through many developmental transitions. Like those without disabilities, children who have functional limitations are, in effect, in training for adulthood. This preparation is a composite of activities and experiences—at home, at school, with peers and adults, in organized and informal recreational endeavors, and so on. Through a variety of quality experiences, it is hoped, children will mature into competent adults, equipped with the skills and knowledge so they will contribute to society as parents, workers, community members, and, perhaps, leaders.

It is critical to remember that children with disabilities are, first and foremost, children. They have the same developmental needs as their peers without disabilities. The presence of a disability, however, can pose challenges to provide the educational and social experiences deemed critical to the preparation of responsible, productive adults. Because physical limitations create a sense of being different, psychological issues must be addressed in tandem with physical ones. Psychological strategies will be necessary to help children cope with social stresses and adjust to the physical and environmental challenges posed by their limitations. Finally, interventions intended to ensure normal developmental progress must reckon with the limitations and health problems specific to different types of disabilities.

Rehabilitation medicine research should build the foundation of knowledge to guide the development of age-appropriate interventions—geared to the developmental or life stage of the person with disability. This need is not confined to the young. It applies to all people with disabilities, including older adults. As the Task Force panel on geriatric rehabilitation also pointed out, the functional, vocational, and avocational goals of rehabilitation should be tailored not only to the type of disability, but also to the age of the person with disabilities. Realistic and personally relevant rehabilitation goals will point the way to appropriate interventions.

In addition, more research effort should be devoted to identifying the physiological and psychological problems associated with the increasing duration of disabilities. Substituting or compensating for lost or diminished function can cause physical stresses that, in the long run, lead to secondary conditions and additional disabilities. This phenomenon is evident among the 1.6 million survivors of polio. Many who had been ambulatory with the aid of braces and crutches are now reporting increased weakness and fatigue, resulting in more limitations on activity and a need for more assistive equipment. Thus the normal aging process, which presents its own set of health-related issues, occurs in combination with processes specific to disability.

The experiences of polio survivors and other people who have lived for many years with a chronic condition exemplify a set of issues that will become increasingly important over the coming decades. The number of so-called survivors—of severe head or spinal cord injuries, of cancer, of prematurity, of fetally acquired drug addiction, of life-saving heart surgery, and so on—is growing. Many of these people will experience long-term health problems and psychological effects about which virtually nothing is known. What, for example, will be the long-term needs of the 40,000 infants born this year with congenital heart defects? Only a short time ago, early death was the likely outcome of congenital heart disease. Tomorrow, emerging surgical procedures and other interventions may permit the repair of even more complex lesions. Yet we are ill prepared to address the special needs of these people from birth through adulthood.

General Research Needs

There is growing recognition of the importance of the changing multifactorial nature of disability and its consequences. In turn,

this recognition has heightened awareness of the need to develop multivariate perspectives in rehabilitation medicine, both in research and in practice. Moreover, it is clear that the development of rehabilitative interventions should be guided by age-specific information. Because of age-related pharmacodynamic differences, for example, drug therapy effective in middle-aged adults may be ineffective in the young or the elderly. If the drug is not clinically evaluated in these age groups, not only could its ineffectiveness in these groups go unrecognized, but potentially dangerous side effects could also go undetected. In addition, gender-related and ethnic differences—two other neglected areas—can also undermine the generalization of anticipated treatment benefits.

Unfortunately, we lack the information and surveillance systems needed to develop a comprehensive understanding of the changing complexity of disability and the relative importance of factors underlying this change. Current data collection systems, for example, provide the equivalent of snapshots of the population with disabilities. People with disabilities are categorized according to age, disabling condition, or functional limitation. Not surprisingly, epidemiological studies of this data yield an essentially static representation of disability in the U.S. population. In addition, these analyses are limited by the surveys' lack of conceptual clarity and continuity in the definition of disability. Therefore, there is considerable variation among estimates of the incidence and prevalence of disabilities. (See chapter on Assessment and Epidemiology for a more detailed discussion of these issues.)

Perhaps more important than these methodological problems are two additional shortcomings in current data collection systems. First, the lack of longitudinal surveillance undermines efforts to understand the changing nature of disability over the lifespans of affected individuals. Static descriptions of disease and disability in the U.S. population do not permit tracking of the progression from impairment to disability, or of the occurrence of secondary conditions in people with preexisting disabilities. Consequently, little information is available on factors that increase the risk of impairment and the potential for disability; and efforts to prevent impairment and disability are developed empirically rather than on the basis of sound epidemiological analysis.

The paucity of knowledge about risk factors also belies the limited scope of disability surveillance. It is now widely acknowledged that impairments, disabilities, and handicaps are the products of interacting biological, social, and environmental variables. It is also widely recognized that the outcome of rehabilitation and the likelihood that a person with a disability will be able to live autonomously and productively are partially determined by predisability factors, including the person's socioeconomic status and level of education. However, there has been little systematic effort to gather data to ascertain the relative contributions of factors that affect the occurrence of disabilities and that determine the level of functioning ultimately achieved by affected individuals. Thus, for example, we cannot determine the direction of causality in the relationship between disability and socioeconomic status. The prevalence of disability among people in low-income groups is significantly greater than it is among those in high-income groups; yet whether low socioeconomic status increases the risk of disability or disability increases the likelihood of living in poverty is unknown.

A longitudinal surveillance system, one that captures data on health-related and social variables, would greatly benefit research on the nature of disability and its impact on important age-specific behaviors. Also needed are studies to evaluate whether and how certain key behaviors in people with disabilities differ from those of people

in the same age group but without disabilities. The combination of multivariate longitudinal and comparative studies would aid in the determination of (1) whether important biological, psychological, and behavioral parameters of disability change; (2) how and when these changes occur; and (3) whether the relative importance of disability-related changes, and therefore their impact on human functioning, varies from one stage of life to the next. Without this type of information, we will be slow to develop effective interventions that address the most important consequences of disability and that are matched to the major developmental needs of the individual. In addition, developmentally relevant information on the consequences of disability would serve as the basis for standardized measures to assess functioning over time and to evaluate short- and long-term rehabilitation outcomes.

Condition-specific Issues

Research on the natural history of impairments and disabilities can yield information on the causes and mechanisms of dysfunction and on the likely course of the pathophysiology. This information is critical in developing prevention strategies, as well as medical interventions to reduce the severity of disability and the risk of associated secondary conditions that can cause additional disability.

Natural history studies have not paid sufficient attention to secondary conditions, especially those associated with the duration of disability and those that appear to arise from the treatment of the primary condition rather than from the condition itself. For example, braces and crutches are often used to help children with neurological impairments achieve ambulation. In adulthood, however, many of these individuals develop problems, presumably from musculoskeletal stresses caused by long-term use of these devices. Similar problems have been reported in people who have propelled their wheelchairs for years. Although options for achieving mobility are limited, it is important to understand the pathophysiology caused by long-term use of assistive technologies. This knowledge could guide the timing of interventions and, perhaps, lead to new approaches to preventing secondary conditions or to new devices that pose a lower risk of complications.

The biological determinants of impairment and disability and, more recently, the influence of certain behaviors on health, have been the principal subjects of research on pathophysiology. Yet, mounting evidence demonstrates a strong link between biology and ethnic, cultural, socioeconomic, and psychological characteristics. Many details of this complex relationship remain to be filled in. The scope of research on the natural history of impairment and disability should be enlarged to examine how social and other nonbiological factors influence the body.

In addition, there should be close coordination between researchers studying long-term effects with multiple adaptive phases and those studying short-term effects. For example, many rehabilitation practitioners encourage young children with motor impairments to walk with the aid of orthotic devices, regardless of the metabolic requirements or the number of hours spent in therapy. However, children as young as 18 months of age can be taught to maneuver a powered wheelchair, allowing self-initiated mobility much earlier in life. Critics of the early use of wheelchairs argue that this practice may discourage attempts to ambulate independently later in childhood. Proponents claim that the mobility achieved with powered wheelchairs enables children with motor impairments to begin exploring their environment closer to the time when children without impairment are mastering the ability to walk. These proponents suggest that early mobility and the opportunity to explore may

play important roles in the cognitive and mental development of young children.

Too little is known about the neurobiological development of children with disabilities to resolve this controversy. There is a clear need for natural history research that factors in developmental issues such as the one given in the example. Because disability influences many aspects of human behavior, it is critically important to understand these influences in detail at each stage of development.

The issues described here, as well as others, are addressed in more detail in the following discussion of four types of conditions that cause childhood disability. These conditions are only examples; the exclusion of the many other conditions that cause disability does not mean that the panel ascribes lesser importance to those conditions.

Birth Defects

Disorders associated with premature birth and abnormal growth *in utero* rank among the major causes of childhood disability. (Congenital malformations, which also contribute significantly to morbidity and mortality among infants and children, are not discussed here.) It has become dogma that poor maternal medical care and insufficient nutrition are the major determinants of these disorders; however, this has not been clearly established, nor demonstrated to be equally important for all ethnic, cultural, and socioeconomic groups. Efforts to develop intervention and prevention programs are hindered by a lack of specificity in our understanding of the roles of "good nutrition" and particular nutrients in successful pregnancy outcomes.

Similarly, the elements of prenatal care that are directly linked to successful pregnancy outcomes have yet to be delineated, both in general and for specific population groups. Issues requiring further investigation include the management of pregnancy-related maternal diseases, such as hypertension, and the ways in which various treatment strategies affect the survival of the fetus and, ultimately, the functioning of the infant.

Well-designed, carefully controlled studies have greatly enhanced our understanding of the deleterious effects of smoking and alcohol consumption during pregnancy. Other hypothesized risk factors should also be evaluated in rigorous, well-designed studies.

Considerable concern has been expressed over the potentially adverse effects of exposure to environmental and occupational pollutants during pregnancy. To date, however, there is little hard evidence that these substances contribute significantly to childhood disabilities. Therefore, it seems unwarranted to emphasize research on the actions and control of these putative fetotoxic agents when more clearly associated factors remain to be studied and controlled.

Cerebral Palsy

Cerebral palsy (CP) is motor dysfunction secondary to brain malformation or injury that occurs *in utero* or perinatally. Over the past few decades, the incidence of CP has persisted at 2.5 to 3.0 per 1,000 live births, despite advances in obstetrical and neonatal care that have reduced the incidence of perinatal asphyxia, kernicterus, and other traditional etiologies of neurological impairment. CP, which results in lifelong disability but usually does not have a progressive course, appears to have many causes. The steady incidence of the condition despite improvements in neonatal care suggests that an increasing number of cases are prenatal in origin.

Many streams of research are pertinent to determining the causes of CP and to developing rehabilitative interventions that effectively address CP-caused functional limitations. The questions to be answered cut across the traditional disciplinary

boundaries that separate biological sciences, clinical sciences, epidemiology, allied health sciences, health services research, social sciences, and education research.

Basic research is needed to determine the causes and mechanisms of brain malformation in the context of developmental neurophysiology and the physiology of pregnancy. The role of genetic factors, acting either directly on the fetus or indirectly through maternal reproductive function, has never been systematically explored.

A host of issues in clinical obstetrics and neonatology await sustained attention. For example, the pathophysiology in neonatal asphyxia is poorly understood, which impedes efforts to develop interventions. Similarly, the roles of spinal cord malformation and injury in CP remain to be elucidated, as do the mechanisms of autonomic dysfunction. Better diagnostic methods for assessing the biological and anatomic correlates are needed. Developmental issues include determination of the critical mechanisms governing the interaction of bone and muscle development in the presence of normal and abnormal neural function.

Answering these and other important questions will require population-based studies and scientifically valid models of multifactorial interaction. More sophisticated experimental designs and methods of statistical analysis may be necessary to unravel the complex array of factors that influence the level of functioning achieved by people with CP. Useful conceptual models for addressing this difficult problem may exist in economics, political science, anthropology, and other fields that deal with issues and phenomena with interacting dependent and independent variables.

Neural Tube Defects

Neural tube defects are a group of congenital malformations ranging from encephalocele and anencephaly to myelodysplasia. In the United States, the annual incidence of neural tube defects is about 1 case per 1,000 live births, and the prevalence is about 0.45 cases per 1,000 people. Most neural tube defects, particularly the myelodysplasias, result in disturbed brain and spinal cord function, with a variety of manifestations. Over the last decade or so, improved initial stabilization of newborns, better technical options for management, and greater social acceptance of people with disabilities have led to improved prognoses for people with even the most challenging conditions. In addition, multicenter studies, such as those being conducted by the International Myelodysplasia Study Group, have significantly enhanced our understanding of the etiologies of neural tube defects. Many questions and challenges for rehabilitation medicine remain, however.

In utero management of encephaloceles and myelomeningoceles is a potentially important clinical option. In animal studies, *in utero* treatment of spine defects and encephaloceles produced much better results than did treatment of these lesions after birth. Investigation of the utility of this approach in animal models should continue and, if the results warrant, the techniques should be evaluated in human studies.

A recent study of children with myelomeningoceles reported improved muscle function when prelabor cesarean section was used for delivery. The method appears to protect exposed functioning nerves from the trauma associated with the rupture of membranes, labor, and passage through the vaginal canal. This work has not been replicated, however, and further studies of this approach should be undertaken.

A variety of surgical interventions for treating neural tube defects now exists. For example, a recent survey of pediatric neurosurgeons found a wide variety of approaches to managing Arnold Chiari malformation. However, very few surgical

techniques for any of the congenital malformations have been evaluated for short-term and long-term effectiveness. Controlled clinical trials are needed to establish the appropriate method and timing of such treatment.

A better understanding of the neuromuscular factors that control hip position in posture and during walking and other routine movements would benefit efforts to develop more effective surgical interventions. People with midlumbar neural tube defects vary greatly in their ease of walking, vulnerability to hip dislocation, and general response to hip surgery. More detailed information about the neuromuscular factors affected by surgical intervention would help refine the criteria for surgery and might lead to more effective rehabilitative interventions.

For those patients who are marginal ambulators, we must develop scientific criteria for determining whether aggressive surgical and rehabilitative interventions are most appropriate for maintaining ambulation or whether wheelchair use is preferable. Evaluative studies are also needed to assess the comparative costs and benefits of the methods now used to manage the neurogenic bladder and bowel.

Knowledge of the physiological mechanisms that lead to decubitus ulcers in children with insensate skin is increasing, but understanding of the interaction among organic, psychological, and environmental factors that lead to skin breakdown is limited. Such understanding is fundamental to the design of successful prevention strategies.

Duchenne Muscular Dystrophy

Basic and clinical researchers have made great strides toward understanding the pathogenesis and treatment of Duchenne muscular dystrophy (DMD), an X-linked, recessive, physically disabling condition of childhood. Comprehensive investigation of the natural history of muscle weakness in DMD patients has led to methods for judging the effectiveness of drug therapy and other interventions in modifying strength and functional parameters, as well as other outcome measures.

The recent isolation of the defective gene in DMD and the identification of its protein product, dystrophin, has had a major impact on the diagnosis of this condition. Accurate detection of female carriers of the defective gene is now possible, as are *in utero* tests to distinguish DMD from Becker muscular dystrophy.

Although the exact physiological role of dystrophin has not yet been determined, clinical applications are emerging. In a recent animal study, myoblasts from a normal mouse were injected into a dystrophic, dystrophin-deficient mouse. The healthy transplanted myoblasts fused with dystrophic muscle fibers and produced dystrophin. This finding has led to a multicenter clinical trial of human muscle transplants and other approaches for dystrophin replacement. These experimental therapies may alter the course of what has been a uniformly fatal disease.

Clinical and basic scientists often use insufficiently standardized quantitative methods for estimating dynamic strength, movement control, and fatigability. Existing methods must be refined to permit accurate testing of muscles in young children and adults. Furthermore, research on all neuromuscular diseases would benefit from better biochemical tests and functional assessment methods for measuring metabolic and adaptive responses to muscular enzyme deficiencies. Basic mechanisms of functional adaptation should be studied to identify processes that are condition specific and those that can be generalized across diseases, recovery states, and ages. In the clinical area, researchers should evaluate the

effects of exercise training on people with neuromuscular disorders. We do not fully understand how much and what kind of exercise is optimal for a patient with a given neuromuscular or musculoskeletal disorder, or when it is appropriate.

Pediatric Pain

Over the past two decades, there has been a growing appreciation that pain in children is complex and different from pain in adults. Contrary to historical notions, newborns are physiologically capable of perceiving pain, and even every young children experience the physical and psychological dimensions of pain.

The pain experienced by children is affected by the nature and extent of tissue damage and is modified by a host of internal and environmental factors, including developmental level. Many nonpharmacological approaches, including relaxation, distraction, guided imagery, and hypnotic-like suggestions, appear to be more effective with children than with adults. Methods that had been used only with adults, such as biofeedback, transcutaneous electrical stimulation, and acupuncture, are now being applied to children with pain problems, complementing the more traditional approach of distraction achieved through play, art therapy, and music.

Most pain during childhood is thought to be acute, caused by injury-related tissue damage and medical procedures such as operations, blood samplings, lumbar punctures, and intravenous and intramuscular administrations. Although chronic pain is experienced with cancer and sickle cell anemia, chronic debilitating pain is not acknowledged to be a major health problem for children.

Although there has been some progress in understanding and treating pain in children, many issues and questions remain to be resolved. The incidence and prevalence of acute, recurrent, and chronic pain in infants, children, and adolescents are unknown, as is the relationship, if any, between pain experienced in childhood and recurrent pain experienced in adulthood. The effectiveness of most techniques for managing pain in children has not been evaluated. Rehabilitation practitioners, as well as other clinicians, require guides for pain assessment and management. Thus, careful documentation of the nature of children's pain complaints and the effectiveness of therapeutic interventions should be made a routine part of clinical practice.

Cross-cutting Issues

Disability can have extremely disruptive effects on most aspects of human behavior. Disability-caused limitations not only restrict functional activity, but also can filter all of life's experiences. Affected individuals must learn to accommodate their limitations through substitution, compensation, adaptation, and coping.

The aim of rehabilitation medicine is to help people with disabilities achieve the maximum feasible level of functioning. In effect, rehabilitative interventions and related services are intended to equip people with the means to live autonomously and productively. This goal cannot be accomplished if the sole focus of rehabilitative efforts is to improve the biological correlates of health. Although biological health is extremely important, it must be factored into a complex equation of human functioning that includes many other independent and dependent variables—social, psychological, and environmental. All of these variables must be addressed in rehabilitation medicine research. Moreover, the significance of these variables for functioning must be assessed in an age-related context, over the duration of the disability, and in all the important spheres of activity—home, school, work, and the community.

Despite the heterogeneity of conditions that cause disability, condition-specific variables are often not the primary determinants of functioning and social integration achieved by individuals with disabilities. Among people who acquired their disability as adults, for example, socioeconomic, educational, and occupational status prior to disability are strong predictors of how successfully an individual adjusts to disability. Similarly, problems encountered during rehabilitation, such as depression, social alienation, marital and familial strife, or poor performance in school, appear to cut across conditions. Risk factors for these problems appear not to be related to the disabling condition *per se*, but rather to such variables as the age of onset, the condition's course and prognosis, its functional impact, and the obviousness of the physical impairment to others.

Both change and continuity are important elements of the rehabilitation process. For example, efforts to promote the physical, emotional, cognitive, and educational development of children with disabilities must be matched to goals appropriate for the children's life stage. The degree to which these goals are accomplished, however, will influence the level of functioning and independence achieved in adulthood.

Below, we discuss a variety of cross-cutting issues relevant to development of rehabilitative interventions that will enable people with disabilities to achieve autonomy and become fully integrated into society.

Social Integration

The goal of rehabilitation is full integration into the community, which requires a variety of personal, social, and vocational skills. However, the initial focus of rehabilitative efforts often must be the mastery of routine activities such as bathing, grooming, eating, and personal health care. Without control over the activities of daily living—achieved independently or with assistance—participation in other endeavors, personal and social, becomes more difficult and more prone to disruption. For example, if a person cannot routinely carry out all the tasks involved in getting ready for work—from eating breakfast to meeting transportation schedules—then that person will have trouble maintaining a regular work schedule.

Rehabilitation must also help people with disabilities to reestablish a balance in their relationships with family members, friends, and coworkers. Maintenance of these relationships entails the performance of certain roles—for example, the role of parent, mate, or sibling—and the management of personal affairs, such as financial matters. Here, too, adjustments are necessary on the part of the person with disabilities and, often, on the part of family members and close associates.

Opportunities to participate in personally and financially rewarding activities are essential for full integration into the community and for developing a sense of purpose. In the context of community integration, rehabilitation serves to enable—to provide the training, assistive technologies, and other means to attain the level of functioning that permits vocational and avocational choices. Whether these choices are available, however, depends largely on the attitudes of society and its willingness to make environmental modifications to accommodate the special needs of people with disabilities.

Within this three-tiered framework of human activity—personal affairs and activities, familial and peer relationships, and community participation—questions for medical rehabilitation research abound. Moreover, there are three major categories of research topics: people with disabilities; institutions and members of the larger society, including teachers and providers of health care and other services; and features

of the physical environment, which can either impede or facilitate social integration. The many issues in this large and varied research domain can be addressed independently, but the true significance of the findings will be determined in the context of the whole person—how they relate to the functioning of people with disabilities in their environment.

Family and friends. The impact of disabilities extends to the families and friends of affected individuals. The families of children with disabilities, for example, often incur a large financial burden from continuing medical care, specialized equipment, and, perhaps, architectural modifications to accommodate the children's functional limitations. Financial strains compound the emotional stresses often involved in adjusting to a family member's disability. Not surprisingly, marital friction and sibling maladjustment are common.

If the individual with a disability is a parent or mate, a new balance among family members' roles and expectations must be established. Family members may be required to adjust their schedules and commitments to be available to provide assistance to the parent or mate. This accommodation often leads to resentment. If the person with a disability is unable to work or loses his job, the need to meet financial obligations forces additional adjustments and creates new strains.

In short, disability is extremely disruptive to the family, and few families are prepared to address the many challenges it poses. Despite growing evidence of familial difficulties, no systematic effort has been made to identify and describe the types of stresses experienced by different family members at different points in the disability process.

Counseling and other types of services are available for the families of people with disabilities. Unfortunately, these services were not developed from scientific understanding of the diverse needs of family members and of people with disabilities. We do not know, for example, what types of family-focused interventions will facilitate functional improvement and psychosocial development in children with disabilities. Thus, we do not know whether existing programs and services intended to achieve these aims are effective.

Educational and vocational training. In children, the overall developmental process is influenced by the interaction among features of the disability, the child, the family, and the broader social environment. Of particular importance are experiences in school and with peers. Within these contexts the following developmental tasks are commonly addressed: separation from family and integration into the peer group and the larger society; acquisition of social skills and community values; development of a sense of accomplishment; learning socially acceptable behavior; and acquiring the behaviors, knowledge, and skills that will ultimately result in self-sufficiency and independence.

In other words, the intended benefits of education are the same for children with disabilities as they are for children without disabilities. So is the ultimate goal of education: to help prepare children for many of the roles and responsibilities they will be expected to assume in adulthood. Given the ongoing debate on how to address the oft-cited shortcomings of this Nation's educational system, it is clear that the path to this goal is not straight.

For children with disabilities, the debate on educational approaches also includes questions on the appropriateness of mainstreaming children with disabilities into the classroom or, alternatively, providing specialized instruction in separate settings. Public policy favors mainstreaming. The Education for All Handicapped Children Act, passed in 1975, established as goals the completion of high school by all

children with handicaps and the provision of education in the least restrictive environments possible; however, the law also provides for special education services when deemed necessary.

In 1990, 15 years after the passage of the landmark legislation, there is still no definitive evidence on the relative merits of either approach, and school districts vary greatly in their placement policies. Thus, we cannot ascertain whether mainstreaming provides children with the experiences that will foster their maturation into productive adults or whether this approach results in repeated experiences of failure and inadequacy that ultimately hinder the transition to self-sufficiency. It is possible that special education may be more appropriate at one stage of development and mainstreaming may be more appropriate at another. Moreover, the timing of the approaches may vary with the type of disability or with the personality characteristics of the children. Many questions about educational strategies await answers.

Apart from issues pertaining to educational settings and approaches, there are questions about the role of the school, or perhaps ancillary training programs, in preparing children and adolescents with disabilities for independent living. Here, specialized training, dictated by the needs and challenges associated with the type of disability, is likely to be needed.

Vocational training is a widely recognized need for children and adults with disabilities. However, it is a largely unmet need. For example, the U.S. Office of Special Education Services estimates that of the more than 300,000 students with disabilities who complete high school each year, only about one-fifth become fully employed. Moreover, only between 2 percent and 5 percent of those in special education have vocational components in their special education plans.

The need for career guidance for children and adolescents with disabilities has been emphasized by many authors. Within the field of vocational rehabilitation there is general agreement on the following points:

- The process of career development has many attributes applicable to most people with disabilities.
- Vocational challenges are important in the development of vocational maturity and increase the potential for future employment.
- Early job experiences provide an important framework for the vocational development of people with disabilities.
- Vocational training for children and adolescents with disabilities generally begins too late in life.
- Disabling conditions are associated with delayed social maturation and with low expectations for employment, both on the part of adolescents with disabilities and on the part of society.

These conclusions underscore the need for career development services early in the schooling of adolescents with disabilities, before the age of 16, the age of eligibility for vocational counseling in the existing vocational rehabilitation system. The Adolescent Employment Readiness Center, a demonstration project under the auspices of the Children's National Medical Center in Washington, D.C., is offering career development services to adolescents between the ages of 12 and 20 with disabilities and chronic illnesses. More projects of this type are needed. The results would help guide the development of a vocational rehabilitation system more closely aligned with the needs of adolescents with disabilities.

Vocational issues are not confined to children and adolescents with disability. The working-age segment of the population with disabilities is the primary target of publicly funded vocational rehabilitation

programs jointly financed by the Federal and State governments. A 1987 survey found, however, that only 10 percent of the eligible people in this age group used these programs, and about half of the participants said vocational services were of little or no value in helping them secure employment.

The composition and timing of vocational rehabilitation are critical issues. For example, people who sustain serious spinal cord injuries, primarily men between the ages of 16 and 30, are sometimes unreceptive to vocational counseling, at least initially. Before incurring their disabilities, many of these people led physically active lives, and most are not interested in occupations that will accommodate their physical limitations. Typically, this perspective changes over time, and young adults with spinal cord injuries modify their vocational interests to include jobs that can be performed from wheelchairs.

Initial vocational training needs will vary according to the life stage of the individual with disability, the age of onset, the type of disability, and the amount and type of occupational experience prior to disability. In addition, people who have progressive conditions or who incur disability-exacerbating secondary conditions are likely to require retraining at different stages of the disability process.

Although the inadequacies of vocational rehabilitation services partially account for high unemployment among the population with disabilities, the attitudes of society, the hiring practices of employers, and the work disincentives in disability programs contribute significantly to the problem. Even individuals who have been trained for suitable vocations tend to earn less than the average person and to be employed less often than would be expected. In addition, the eligibility requirements and earned income limitations of the Medicare and Social Security Disability Insurance programs are often described as deterrents to vocational rehabilitation, thereby fostering lifelong unemployment. Research and demonstration projects are needed to identify strategies for promoting job placement and retention among people with disabilities.

Composition, Organization, and Delivery of Services

As the duration of disability increases, the risk of worsening impairment and of secondary conditions also increases. Deterioration of functional status magnifies existing needs and often creates new ones, such as for assistive technologies or in-home care. Because a decline in health can precipitate depression, which in turn can lead to further deterioration of function, psychological counseling and social support services may be needed.

Most people prefer to remain in their homes, rather than to be placed in institutions. Thus, innovative community services to address the long-term needs of people with severe disabilities are needed. Continuity of services is also important. For example, people with disabilities have difficulty finding primary health care after leaving rehabilitation. Many of the secondary conditions of people with disabilities can be prevented with timely and appropriate primary care. For example, in a sample of working-age people with physical disabilities who lived in the Washington, D.C., area, nearly one-fourth of those hospitalized during the previous 12 months said hospitalization would have been unnecessary if they had had timely access to a health care provider who was knowledgeable about their disability. Inadequate primary care ultimately adds to the Nation's health care bill.

Several factors determine access to health care. Insurance coverage is an obvious one. Because of higher than average rates of poverty and unemployment among people with disabilities, financial access to

health care is a significant problem in this population. Moreover, many people with disabilities who have private policies are likely to be underinsured. Increasingly, private insurers are refusing to provide coverage for preexisting conditions, including disabilities. Insurance problems aside, people with disabilities often have difficulty finding physicians who are knowledgeable about their health needs and special problems. In addition, many assistive technologies that can be instrumental in promoting greater self-sufficiency are excluded from public and private insurance coverage because these devices are not considered medically necessary.

Many people who acquired their disabilities in childhood are poorly prepared to negotiate the Nation's complex health care system when they reach adulthood. Nor is the system prepared to facilitate the transition from pediatric care to adult care. For example, physicians may be experienced in treating people who incur a disability in adulthood, but this experience does not prepare them to address the needs of young adults with childhood-onset disabilities.

Lack of information on the timing and effectiveness of interventions further confuses efforts to provide coordinated and comprehensive health care services. Clinical researchers have not fully evaluated the application of assistive devices to promote functional activity; for example, the costs and benefits of various methods for achieving ambulation or mobility have not been determined. A critically important question is whether early gains in functional activity eventually lead to musculoskeletal or neurological problems and, ultimately, a decline in function.

Research Priorities

Many specific research issues have been identified in the preceding sections of this chapter, but the overall aim of the discussion is to create a framework for studying impairments, disabilities, and handicaps as dynamic health-related phenomena that can influence all aspects of human behavior and well-being. There is a critical need not only to improve our knowledge of the biological, behavioral, psychological, and sociological impacts of these entities, but also to understand their impact in a changing age-related context. This understanding is essential to developing rehabilitative interventions that optimize the functioning of the whole person, enabling the individual with disabilities to perform activities and carry out roles that, together, contribute to a high quality of life.

Pursuing the following research priorities would greatly improve our understanding of the developmental issues associated with impairments, disabilities, and handicaps.

- Conduct long-term multifactorial studies of the changing nature of impairments, disabilities, and handicaps over the lifespan.
- Conduct multivariate studies to determine how interactions among biological, psychological, sociological, and environmental risk factors contribute to the onset of impairments, disabilities, handicaps, and secondary conditions.
- Identify psychological strategies and support mechanisms to ensure the sound mental health and successful adjustment in children with impairments and disabilities and in adults aging with impairments and disabilities.
- Determine the role of maternal and environmental factors in the pathogenesis of birth defects.
- Elucidate the mechanisms governing the interaction of bone and muscle development in the presence of normal and abnormal neural function.
- Develop animal models of common physically disabling conditions to establish a scientific rationale for optimizing selected rehabilitation strategies.

- Conduct controlled clinical trials to establish the short- and long-term efficacy of multivariate treatments such as surgical, pharmacological, and other therapeutic interventions directed at reducing impairments and disabilities.
- Identify the factors that contribute to optimal educational, prevocational, and career development programs for children with disabilities. Such programs should ultimately lead to self-sufficiency, independence, and employment in adulthood.

Basic and Clinical Research Training

Basic and Clinical Research Training

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Basic and Clinical Research Training

Overview

Rehabilitation medicine is an emerging interdisciplinary field at a critical stage of development and opportunity; it must mature rapidly to meet the rising demand for rehabilitation services that several trends portend. The aging of the U.S. population, the increasing average life expectancy, and the life-extending advances in acute care medicine are among the forces leading to increases in the prevalence of disabilities across all age groups. Progress in basic, clinical, and applied technological rehabilitation research is essential to guide development of needed therapies and services that can help ensure autonomy and the opportunity to achieve a high quality of life for the tens of millions of Americans with disabilities.

On the one hand, there is cause to be optimistic about the prospects for meeting this need. Significant advances in many biomedical fields and in the social and behavioral sciences point the way to major improvements in rehabilitative and preventive interventions. Rehabilitation medicine is poised to benefit from such breakthroughs in basic research as our increasingly refined knowledge of the genetic determinants of disease and of the functioning of the cell and its components; improvements in drug design; advances in the miniaturization of ever more powerful and ever more versatile electronic devices; and a growing, integrated understanding of the biological, psychological, social, and environmental underpinnings of health and quality of life.

On the other hand, there is cause to be pessimistic about whether rehabilitation medicine can capitalize on these and other scientific advances. Rehabilitation medicine research suffers from a severe shortage of highly qualified basic and clinical scientists and applied technological investigators.

The shortage of rehabilitation medicine scientists and the lack of support for research opportunities in the field are the primary obstacles to improving the effectiveness and efficiency of rehabilitation services in the United States.

Progress in rehabilitation medicine research has lagged behind advances in other areas of biomedicine. This disparity has had an ironic result. As noted in previous chapters, advances in acute care medicine have reduced mortality caused by cancer, congenital birth defects, severe brain and spinal cord injury, and other conditions that until recently were nearly always fatal. Many of those who have been spared from death survive with permanent functional impairments and disabilities. These people constitute a large and growing segment of the population that would benefit from a sustained comprehensive commitment to building the field of rehabilitation medicine research.

Neglected Opportunities

The need for scientific research in rehabilitation medicine is pressing. The field's basic, clinical, and applied technological research interests are wide ranging, yet all topics are subsumed under rehabilitation medicine's transcending aim of improving human functioning. Some questions are already being investigated in fields that are relevant to rehabilitation science and medicine. Others are receiving, at best, limited research attention.

Because of the severe shortage of independent investigators in basic, clinical, and applied rehabilitation medicine research and the paucity of support, it is likely that only a few of these questions, even those with the highest priority, will be addressed comprehensively in the current research and training milieu. This is not to say that relevant advances will not be made, but they are likely to be piecemeal rather than consistent and sustained. Moreover, translation of salient findings from basic research to clinical or technological applications will be slow, delaying delivery of improved rehabilitative interventions that could enhance the functioning and the quality of life of people with disabilities.

Who Does Rehabilitation Medicine Research?

Although the goals and characteristics of rehabilitation medicine distinguish it from other research areas, the field's identity is a composite of interacting and complementary medical and nonmedical disciplines. Like other areas of science, rehabilitation medicine research requires investigators who are accomplished in one or more specialties. Indeed, independent investigator-initiated research projects can go a long way toward answering questions related to reducing or preventing functional impairments, disabilities, and—in people who already have disabilities—secondary conditions. But rehabilitation medicine research, more than other areas, also requires investigators who can cross disciplinary boundaries. Interdisciplinary collaborations are essential to address the complex, multifactorial issues that are inherent in the study of human functioning.

The foundation of rehabilitation medicine is basic research conducted in a host of disciplines, including not only the basic and clinical biomedical sciences but also epidemiology, psychological and behavioral sciences, health services, allied health sciences, nursing science, bioengineering, and ergonomics. Scientists and professionals in each of these fields offer perspectives that are unique, and, when properly melded, these perspectives will foster synergy in rehabilitation medicine research.

Current Situation

Historical Background

A few academic departments of physical medicine and rehabilitation in medical schools have organized programs that have trained a small pool of physician-scientists in the basic and clinical research skills necessary for rehabilitation medicine research. More recently, some of these departments have expanded their training programs by networking with physician-scientists from other medical specialties, epidemiologists, basic medical scientists, bioengineers, and scientists from the allied health fields. Although these developments represent important steps and the number of qualified medical students and resident physicians attracted to rehabilitation medicine has grown, research fellowship training positions are still few. Because of the dearth of experienced independent investigators in rehabilitation medicine, many of the programs have recruited and retained their own trainees for faculty positions. The demand for experienced independent

investigators in rehabilitation medicine research is so great and the supply so limited that vacant faculty positions may remain unfilled for several years. At some major university medical centers, the departments of rehabilitation medicine have been abandoned entirely.

As embryonic and limited as these initiatives are, the few research training programs in academic departments of physical medicine and rehabilitation represent the bulk of the training efforts in the field. But the most severe obstacle to increasing the supply of qualified scientists in the field has been that, in other biomedical and nonbiomedical disciplines, pathways to research careers in rehabilitation medicine are virtually nonexistent.

A small number of young investigators in recent years have completed research training in departments of physical medicine and rehabilitation, but most researchers with an interest in rehabilitation have been forced to develop their expertise and methodological proficiency on the job. A review of these researchers has identified three groups:

1. Basic scientists and engineers who have received formal research training but who lack the clinical expertise and experience that fosters the application of research results.
2. Physiatrists and other rehabilitation-related specialists who have received no formal research training.
3. Clinical scientists who have received research training in an area that afforded little or no exposure to rehabilitation problems and issues.

In recent years, an important additional pathway to rehabilitation medicine research has evolved. Health services researchers, psychologists, economists, and other social and behavioral scientists have begun to study the determinants and consequences of disabilities in personal and societal contexts, focusing on issues related to quality of life.

Current Support for Research Training

The bulk of support for research training in rehabilitation-related fields has come from two sources: the National Institutes of Health (NIH) in the Department of Health and Human Services, and the National Institute of Disability and Rehabilitation Research (NIDRR) in the Department of Education. Until 1986, when the NIDRR created its Career Development Research Award, neither funding source had provided for a centralized training focus in rehabilitation medicine.

NIH. Through individual awards, grants to institutions, and its own intramural training programs, the NIH is credited with training an entire generation of biomedical scientists, helping the United States maintain its preeminent international position in biological and medical research. In 1988, the NIH allocated $245.7 million for training—$45 million in the form of individual awards and $200.6 million to institutions. The allocation accounted for 4.4 percent of the more than $5.5 billion the NIH spent on extramural grants and contracts. In 1979, when extramural support totaled about $2.6 billion, the NIH spent $149.3 million on training, accounting for 5.8 percent of the total. Perhaps the most notable feature of the 10-year period between 1979 and 1988 is the decline in the number of individual awards. The 1,944 individual awards made in 1988 were fewer than the total made 10 years earlier by 11.5 percent. The number of institutional awards, however, increased by 11 percent to 1,404.

Among the categorical institutes and major centers of the NIH, allocations for research training as a proportion of total extramural funding in 1988 ranged from 2.4 percent to 11.7 percent.

Table 1.
FY 1989 Rehabilitation Medicine Research Supported by the NIH (basic and clinical research training)

	Total	Extramural		Intramural		Grants
		Major	Minor	Major	Minor	
NIA	$327,961	$274,775	$53,186	—	—	6
NCI	379,482	379,482	—	—	—	9
NICHD	55,409	55,409	—	—	—	1
NCNR[1]	12,500	—	12,500	—	—	3
NIAMS	376,008	376,008	—	—	—	6
NIDCD	385,877	385,877	—	—	—	6
CC	31,200	—	—	31,200	—	—
Total	$1,697,512	$1,600,626	$65,686	$31,200	—	33

[1]*NCNR has three active training awards, but only one received funds from FY 1989 allocations.*

How do allocations for training in rehabilitation-related research compare with these NIH-wide averages? Preliminary data made available to the task force indicate that the NIH spent nearly $1.7 million in 1989 for 33 basic and clinical research and training grants in the five major areas of rehabilitation medicine examined by the Task Force. (See tables 1 and 2.) The allocation accounted for 2.1 percent of the $80.4 million that the NIH identified as supporting extramural and intramural research and training in rehabilitation medicine. The 32 extramural awards for research training represented 2.2 percent of all extramural awards listed as being in the area of rehabilitation. This proportion is half the NIH-wide average of 4.4 percent in 1988, and falls below the low end of the range (2.4 percent) for the institutes and centers. It seems reasonable to assert that during rehabilitation medicine's capacity-building phase, a larger proportion (between 5 percent and 10 percent) of the extramural budget should be allocated for research training, but not at the expense of current research programs in the area.

On reviewing program and project descriptions by training award recipients, Task Force members noted that some of the programs and projects appeared to be only marginally related to the needs and interests of rehabilitation medicine. Thus, the amount of support going for training in rehabilitation medicine, as opposed to loosely defined rehabilitation-related research, is likely to be less than the amounts reported in tables 1 and 2.

NIDRR. In 1986, the NIDRR established training in rehabilitation research as a priority, creating a program of career development awards intended to attract new investigators and enhance the research credentials of those already in the field. While recognizing the need for research training in all of the constituent disciplines of rehabilitation medicine, the agency has chosen to concentrate its limited training dollars on providing opportunities for physicians and other clinicians in rehabilitation-related specialties.

The NIDRR appropriates funding for its Research Career Development Awards to academic institutions, primarily departments of physical medicine and rehabilitation. The 3-year training grants, averaging about $180,000 annually, have been awarded to 11 centers, which in 1989 were supporting about 30 investigators.

The institute also awards 1-year research and training fellowships to individuals. In 1989, 12 Switzer Fellowships were awarded. Recipients included predoctoral and postdoctoral students as well as midcareer rehabilitation researchers and clinicians. The fellowship program's total allocation in 1989 was about $300,000.

Table 2.
Total FY 1989 Rehabilitation Medicine Research Expenditures Supported by NIH Institutes, Centers, and Divisions

	Neurophysiological dysfunction	*Musculoskeletal disorders*	*Cancer rehabilitation*	*Geriatrics*	*Developmental issues in rehabilitation*	*Basic and clinical research training*	*Institute total for rehab. medicine research*
NINDS	$9,516,073	—	—	—	—	$129,075	$9,645,148
NIA	—	—	—	$10,148,013	—	327,961	10,475,974
NHLBI	—	$508,984	—	—	—	—	508,984
NCI	—	—	$10,643,636	—	—	379,482	11,023,118
NICHD	110,804	—	—	—	$7,059 074	55,409	7,225,287
NIDR	—	92,486	74,967	784,804	4,335,435	—	5,287,692
NCRR	2,251,515	1,872,217	19,274	1,253,526	465,766	—	5,862,298
NCNR	—	816,577	203,565	455,886	242,674	12,500	1,731,202
NIAMS	456,995	13,634,509	157,104	9,867,252	197,720	376,008	24,689,588
NEI	1,892,045	—	—	—	—	—	1,892,045
NIGMS	—	—	—	—	45,000	—	45,000
NIDCD	604,406	—	—	86,737	113,855	385,877	1,190,875
CC	160,800	295,400	195,500	17,400	94,900	31,200	795,200
NIH Total	$14,992,638	$17,220,173	$11,294,046	$22,613,618	$12,554,424	$1,697,512	$80,372,411

In addition, the NIDRR helps support 38 Rehabilitation Research and Training Centers, most at academic institutions. Research training opportunities vary from center to center, but they tend to be concentrated in the areas of applied and clinical research, focusing on issues related to the organization and delivery of rehabilitation services and to the integration of people with disabilities into the community.

At the 17 Rehabilitation Engineering Centers supported by the NIDRR, emphasis is given to the development of assistive technologies and other techniques and hardware that can be incorporated into the service delivery system. Training opportunities are largely in the form of assistantships given to graduate and undergraduate students.

Training opportunities through other Federal agencies that fund rehabilitation-related research, such as the Veterans Administration (VA), the National Science Foundation, the National Aeronautics and Space Administration, and the Social Security Administration, are extremely limited. For example, the VA, which allocated about $20 million for rehabilitation-related research and development in 1990, does not have a training program in the field. Career development awards are available through the agency's Medical Services Division, a unit separate from Rehabilitation Services, but very few active or prospective rehabilitation medicine researchers have attempted to tap into this potential source of training support.

Inadequacies of Current Mechanisms

Support for basic, clinical, and applied technological research training in rehabilitation medicine suffers from deficiencies in quantity and scope. Available training opportunities are insufficient to produce the cadre of qualified researchers essential to building a solid base of scientific knowledge on which to develop effective interventions and services for people with disabilities. With one exception, training opportunities do not have rehabilitation medicine as a primary focus, and they fail to reflect the field's interdisciplinary composition. Especially neglected and most critical is the need to

train investigators in the basic sciences, who are needed to help build the field's theoretical foundation.

At the NIH, training grants are awarded on the basis of the perceived needs of the major institutes and centers. Just as in competition for research awards, the institutional or individual candidates most likely to succeed in securing training grants are those whose proposed projects correspond most closely to the priorities of the awarding institute or center. Because of the cross-cutting nature of rehabilitation medicine, proposals from departments and individuals in the field may not fit squarely within an institute's or center's category of needs. Moreover, because of the underrepresentation of rehabilitation medicine researchers on NIH study sections, which review proposals for research and training awards, the special needs and characteristics of the field are not likely to be taken into account during the review process.

The relative youth of rehabilitation medicine as a research discipline poses an additional problem. Senior investigators are few. As a result, young clinical researchers, applied scientists, and basic researchers who are interested in entering the field often do not have role models or mentors to help them make the transition and to guide them in their efforts to compete for funding for research training. This presents a circular irony.

To develop more researchers, a "breeding stock" of accomplished scientists is needed to nurture the field's development. Incentives and opportunities for established basic, clinical, and applied scientists must be created to encourage these researchers to make a midcareer switch to rehabilitation medicine. No such mechanism now exists. Consequently, the two most productive pathways for cultivating the growth of an emerging discipline—attracting accomplished biomedical and nonbiomedical scientists to the field and providing training opportunities for students and young investigators—remain to be fully developed in rehabilitation medicine.

Research Training Goals

Severe shortages of basic, clinical, and applied scientists exist in physiatry and other rehabilitation-related specialties and subspecialties, such as neurophysiology, biochemistry, exercise science, psychology, epidemiology, bioengineering, nursing science, physical therapy, occupational therapy, and speech pathology. Steps to remedy these shortages must not be taken in isolation, because the larger scientific domain of rehabilitation medicine will not benefit commensurately. Strengthening the scientific foundation of rehabilitation medicine requires that training and recruitment measures within the constituent specialties be integrated under rehabilitation's transcending objective of improving human functioning.

The panel identified four major goals that it believes are critical to increasing the quantity and quality of rehabilitation medicine research and, ultimately, to improving the effectiveness of rehabilitative interventions and services.

1. Increase the number of new and established investigators entering the field, and increase the diversity of research specialties represented in the field. This can be accomplished by creating new research training programs and by significantly expanding existing ones. Research training opportunities should be available to students and junior faculty members in the basic, clinical, social, behavioral, nursing, and allied health sciences; in epidemiology; in bioengineering; and in health services research. To attract senior investigators to study rehabilitation-related problems, incentives will be needed, as will mechanisms to foster networking among established investigators. Increasing research capacity and competency in rehabilitation

medicine will require a long-term commitment of resources.

2. Increase the participation of population groups that are now underrepresented in the field. Currently, only about 60 black physicians are among the some 3,200 board-certified physiatrists in the United States. Other minorities and ethnic groups, as well as people with disabilities, women, and the economically disadvantaged, are not adequately represented in the field of rehabilitation medicine. Many of these groups are at higher than average risk for certain types of impairment and disability. Researchers from these groups, therefore, could contribute significantly to planning and implementing measures to address these particular disabilities.

3. Create research incentives and enhance the priority of rehabilitation medicine research. Clearly, the field cannot expand and diversify its pool of investigators if prospects for future funding are lower than in other areas of science. Because of rehabilitation medicine's discipline-spanning interests, research proposals from investigators in the field often present a quandary for reviewers and, ultimately, sponsoring organizations that have more narrowly defined interests and priorities. This seeming lack of correspondence can place rehabilitation medicine research proposals at a double disadvantage. The first difficulty is one that confronts most researchers: only a small proportion (less than 25 percent at the NIH) of peer-approved research proposals actually receive funding. The second difficulty stems from the lack of rehabilitation medicine focus at the NIH. Nonetheless, many NIH centers and institutes have rehabilitation-related interests. Formal measures to expand the missions of these units to embrace the goals of rehabilitation medicine research would improve prospects for funding quality research proposals in the field.

4. Increase opportunities for single-investigator and collaborative interdisciplinary studies of rehabilitation-related problems and issues. The importance of issues in rehabilitation medicine, the field's multidisciplinary composition, and its unique emphasis on human functioning all warrant a commitment of support for research, as well as research training. Such support is needed to foster the field's growth during a critical stage of development.

These goals and the recommendations below for measures to accomplish them are necessarily broad: they apply to all of rehabilitation medicine as platforms on which to build areas of research excellence. However, elaboration of the details of implementation and of the areas warranting a concentration of training effort are best left to those with expertise in the major areas within the broad field of rehabilitation medicine research, such as those reviewed by the Task Force's science panels. An example of a research training program geared to a specific area of endeavor is the recommended initiative for rehabilitation engineering described in the box on p. 130.

This panel recommends the creation of an ad hoc committee to review and evaluate existing training programs for rehabilitation research offered by the NIH, NIDRR, VA, and other relevant agencies and organizations. On the basis of this detailed review, the committee should identify specific, high-priority training needs to be addressed with the general award mechanisms and training approaches recommended by this Task Force. It should also elaborate on the implementation of the needed programs. Because of the specialized needs of some areas of rehabilitation medicine, however, the ad hoc committee may determine that additional mechanisms and approaches are necessary, which it should identify during its deliberations. This effort will require separate workshops involving researchers and educators in rehabilitation medicine and

outlying disciplines. It will also require the close cooperation of the NIH and other agencies and organizations that sponsor training programs in basic and clinical rehabilitation medicine research.

Because training issues are so critical to ensuring progress in rehabilitation sciences and, ultimately, in rehabilitative interventions and services, periodic review of the effectiveness and productivity of new training programs would be helpful. An advisory oversight committee could perform this role.

Recommendations

Recruitment and Training Programs for Senior and Young Scientists

Attract established basic, clinical, and applied scientists to study problems relevant to rehabilitation medicine. Although the number of senior scientists in the field of rehabilitation medicine research is low, many established investigators working in rehabilitation-related areas can be recruited to collaborate with existing research groups, to increase scientific productivity in the field, and to serve as role models and mentors for young trainees. To carry out this recommendation, the following steps are necessary:

- In medical research centers and other research institutions, chairmen of departments of rehabilitation medicine or the heads of rehabilitation medicine research groups should identify accomplished investigators with rehabilitation-related research interests and recruit them to participate in collaborative studies.
- Incentives to aid in networking of established scientists should be provided. Academic departments of rehabilitation medicine and other institutional units with rehabilitation-related interests should create programs or centers for

Training Programs in Rehabilitation Engineering

It is common to find engineers working as principal investigators or as collaborators on rehabilitation research projects. Unfortunately, the level of this engineering work has not been consistently at the postdoctoral level, which is typical of engineering research in other areas of biomedicine.

Part of the reason for this disparity is the preference for simplicity among rehabilitation researchers and patients. However, another reason for the technology gap is the simple fact that very few U.S. universities offer a Ph.D. in rehabilitation engineering.

A modest program of 5-year institutional training grants should be sufficient motivation for universities to address the need for doctoral training in rehabilitation engineering. Each grant would provide the resources necessary to support eight graduate students and the development of relevant graduate courses (for example, orthopedic engineering, biodynamics, biosystems analysis, and sensory aids design). The estimated budget for a training grant is presented below.

8 graduate students × $12,000 per year × 5 years	=	$ 480,000
4 courses × $10,000 per year × 5 years	=	200,000
Ph.D. thesis supplies and laboratory resources	=	320,000
5-year total	=	$1,000,000

interdisciplinary research. This will require the allocation of additional institutional and outside support to rehabilitation groups. Flexibility in the administration of these funds is necessary, so that they can be used both to attract investigators and to support rehabilitation research trainees who can benefit from collaborating with outside groups with rehabilitation-related interests. Interdepartmental appointments for faculty members are recommended.

Create midcareer rehabilitation research development awards. These awards would encourage established independent researchers in basic, clinical, or applied sciences to enter the field of rehabilitation medicine research. The program should be designed to enable investigators unfamiliar with rehabilitation medicine research to work on basic, clinical, or technological issues in rehabilitation. The main features of the awards should be as follows:

- Eligibility: Midcareer faculty members in basic, clinical, or technological areas within or related to rehabilitation.
- Sponsor/mentor: An appropriately qualified clinical scientist (if applicant has a basic science background) or basic scientist (if applicant has a clinical background).
- NIH support: Partial salary support for 2 years; annual research support of about $20,000.
- Institutional support: Half of the faculty member's time must be reserved for research in the newly chosen area; joint appointments upon completion of training should be encouraged.

Create young academic investigator awards in basic and applied rehabilitation medicine research. These awards would attract junior faculty members in the biological sciences, engineering, and related areas to careers in rehabilitation medicine research. The main features of the recommended awards should be as follows:

- Eligibility: (1) Young faculty members in rehabilitation-oriented clinical specialties and (2) young faculty members in engineering or in cellular biology, molecular biology, or other basic science departments with research interests relevant to rehabilitation medicine.
- Sponsor/mentor: For clinicians, a basic scientist who has strong expertise in a rehabilitation-related discipline and who, preferably, has peer-reviewed research funding; for basic scientists, a clinical researcher in rehabilitation medicine.
- Requirements: Research plan and, as appropriate, coursework in a basic science area, clinical research and practice, and scientific methodology.
- NIH support: Partial salary support for 3 to 5 years and modest research support.
- Institutional support: Space and access to research facilities; nonresearch commitments limited to no more than 20 percent of the researcher's time.

Create young investigator awards in clinical rehabilitation medicine research. These awards would be made to medical research centers, nursing schools, and other health professional schools. The institutions would use the awards to train highly qualified young faculty members in clinical rehabilitation medicine research or in allied areas such as occupational therapy, psychology, health services research, and the behavioral sciences. The main features of the recommended awards should be as follows:

- Eligibility: Young faculty members in any rehabilitation-related clinical field.
- Sponsor/mentor: A clinical researcher in a rehabilitation-related area.

- Requirements: Research plan; coursework in an area of basic science and in scientific methodology.
- NIH support: Partial salary support for 3 to 5 years and modest research support.
- Institutional support: Space and access to research facilities; nonresearch commitments limited to no more than 20 percent of the investigator's time.

Recruitment and Training Programs for Students

Create individual and institutional awards to support research training of students in graduate schools and medical schools. Strengthening and diversifying the pool of investigators in rehabilitation medicine research depends heavily on the field's success in attracting highly qualified trainees. The recommended awards, in the form of individual fellowships or institutional grants, would be given to graduate students in epidemiology, the biological sciences, nursing science, allied health sciences (especially occupational therapy, physical therapy, and speech pathology), behavioral science, social science, and engineering. Because the need for physician-scientists in rehabilitation medicine is acute, the awards would also include summer research fellowships for students in medical school. Award recipients should demonstrate how the coursework and research in their particular specialty will be directed to the study of human functioning—physical, psychological, behavioral, social, or vocational. Each awardee must have a sponsor who is an established investigator in rehabilitation medicine. The anticipated outcome of such programs is continuation of rehabilitation-related research training at the postdoctoral level.

Create individual and institutional awards to support research training of postdoctoral students. These awards, in the form of individual fellowships or institutional grants, would enable young basic, clinical, and applied scientists interested in rehabilitation medicine research to undertake 5 years of postdoctoral study to prepare for careers in the field. These awards would offer two pathways for career development:

- *Basic research.* This option would provide the recipient with the time, support, and mentorship necessary to develop the specialized knowledge and acquire the methodological skills that are essential for a successful career in basic rehabilitation medicine research. Candidates should have a doctoral degree and a demonstrated interest in rehabilitation-related issues that can be studied in the laboratory. Candidates should also have a research plan and a mentor who is an established investigator in rehabilitation medicine research.
- *Clinical and applied research.* This option would provide the recipient with the time, support, and mentorship necessary to develop the specialized knowledge and acquire the methodological skills necessary to become a successful clinical investigator or applied scientist in rehabilitation medicine research. The awards would enable recipients to investigate a well-defined clinical or technological problem in rehabilitation medicine under the sponsorship of an established investigator in rehabilitation medicine. Research and training should be conducted in an interdisciplinary environment. For young clinical investigators in rehabilitation medicine or a rehabilitation-focused specialty, the awards would reduce the clinical service responsibilities that now make it difficult for aspiring clinical scientists to devote time to developing the research expertise and experience necessary to become successful independent investigators.

Other Measures To Enlarge and Diversify the Pool of Qualified Researchers

Use existing NIH training and research awards. Many aspects of rehabilitation medicine research are relevant to the missions of the NIH's categorical institutes and centers. Rehabilitation researchers and centers should be encouraged to pursue National Research Service Awards and various career development awards administered by institutes and centers with rehabilitation-related interests. Such awards include the Fogarty Award, the FIRST Award of the National Institute of Neurological Disorders and Stroke (NINDS), the Javits Award of the NINDS, the Clinical Investigator Award, the Merit Award, the Research Career Development Award, the Physician-Scientist Award, and training grants such as the T-32 and F-series awards. The NIH should take the following steps to encourage greater participation by the rehabilitation medicine research community in these and other award programs:

- As appropriate, revise award announcements to encourage rehabilitation specialists to compete for research and training grants.
- Ensure that award announcements and related informational materials are disseminated to medical school and university departments with research interests relevant to rehabilitation.
- Direct institutes and centers with professed rehabilitation-related interests to include rehabilitation research as an explicit program objective.

Strengthen institutional commitments to rehabilitation medicine research and training and foster more interaction within the field. As is true of other emerging scientific disciplines, the quantity and the quality of rehabilitation medicine research are low. This deficiency is understandable in light of the dearth of support for investigators, the low priority that most medical schools and other institutions place on rehabilitation medicine research, the field's low prestige among other research disciplines, and the lack of incentives to attract investigators. Institutions in general, and institutional units with rehabilitation-related interests in particular, must demonstrate a commitment to rehabilitation research.

- Institutions applying to NIH for institutional research and training grants in the field should be required to document their investment of people and resources in rehabilitation medicine research.
- The leaders of rehabilitation medicine departments and other academic units with rehabilitation-focused research programs must be encouraged to provide the resources and incentives necessary to engage faculty members in clinical and laboratory research.
- Leaders and organizations in the field should devote greater effort to encouraging communication and networking among clinical investigators and other researchers in the field. Potential mechanisms include annual conferences and workshops on rehabilitation medicine research, which in addition to fostering interaction would give the field greater visibility. Trainees attending conferences and workshops would have the opportunity to exchange ideas with senior scientists in the field and to develop contacts beneficial to their emerging research efforts.
- Rehabilitation departments should develop an outside advisory council or other mechanisms for subjecting departmental research to external peer review.

Recruit people with disabilities and members of minorities, ethnic groups, and other population segments that are now underrepresented in the field. The NIH should develop long-term programs

designed to encourage people with disabilities, blacks, Hispanics, native Americans, Asian Americans, and members of other important population groups to pursue careers in rehabilitation research. Important additional target groups include women and members of economically or socially disadvantaged groups. Recommended actions include the following:

- Recruit qualified members of these target groups to serve on peer review panels and NIH advisory councils.
- Develop outreach programs to encourage high school and college students to consider careers in the field.
- Provide resources and incentives for rehabilitation medicine research programs at universities to hire high school and college interns who are members of the target population groups.

Create an award to support development of curriculums and training programs in rehabilitation medicine research. With the intended increase in the number and quality of training programs in the field, this award would provide salary support and funding for development of instructional materials by established rehabilitation medicine researchers in biomedicine, engineering, public health, allied health sciences, and other academic and professional areas. At present, curriculums to support training in rehabilitation medicine research are few.

Development of quality training programs in rehabilitation medicine research at academic institutions will be challenging because of the field's multidisciplinary composition. Supporting the development of curriculums and training programs is essential to meeting the critical need for well-trained investigators and educators in rehabilitation medicine research. Award candidates would be expected to have comprehensive knowledge of one or more basic, clinical, or applied science specialties in rehabilitation medicine and a working knowledge of issues outside their research domains. Candidates should also be experienced educators. In addition to the qualifications of the applicants, awards should be made on the basis of assessments of the quality and innovativeness of the proposed training curriculums. Each applicant's institution should also be required to submit a plan describing the institutional support and resources that will be committed to the development of the proposed research training program.

Peer Review Representation at the NIH

Ensure that proposals for rehabilitation medicine research and rehabilitation medicine research training receive adequate review. The dearth of rehabilitation researchers on the peer review panels or study sections of the NIH Division of Research Grants and on the advisory councils of the categorical institutes and centers exacerbates problems in securing NIH support for research and training in the field. Many rehabilitation research topics reside at the boundaries of the research missions of individual units or intersect the research domains of several units. Without adequate representation of rehabilitation researchers on existing study sections, the importance of high-priority issues in the field is not likely to be recognized, and quality proposals for research or training projects are likely to go unfunded.

The Task Force recommends that the NIH and its organizational units take the following actions:

- Form a separate Rehabilitation Research Study Section with a membership that reflects the field's multidisciplinary composition.
- Incorporate members with rehabilitation expertise into existing study sections, especially those that review

applications for training grants and program projects.

- Ensure representation of the rehabilitation research community on the advisory councils of the individual categorical institutes and centers.

Centers of Excellence in Rehabilitation Research and Training

Establish Centers of Excellence in Rehabilitation Research and Training. Centers staffed by highly competent and adequately equipped groups of researchers have proven to be effective research and training mechanisms, especially in interdisciplinary areas of study. In rehabilitation research, centers possessing a critical mass of basic and clinical scientists would provide not only badly needed leadership to the field but also stable, high-quality environments for training. The purview of the research collaborations at the centers, which would be broader than the single-focus perspective of existing NIDRR centers, would be sufficiently comprehensive to embrace the many biomedical, behavioral, psychological, social, and environmental issues associated with impairments, disabilities, and handicaps. While the NIDRR centers concentrate primarily on secondary conditions, improving function in people with the most severe disabilities, and integrating people with disabilities into the community, the proposed NIH Centers of Excellence in Rehabilitation Research and Training would focus on the many issues related to the progression from impairment and pathology to handicap and the reduction of functional impairment and disability. For example, the proposed centers would be appropriate sites for essential, but so far neglected, epidemiological studies of the population with functional limitations. Thus, the Task Force sees a clear distinction between the research emphases of the proposed NIH centers of excellence and those of the NIDRR centers. It also sees the roles of the two types of centers as complementary, necessitating close communication between them.

The Task Force strongly endorses the creation of Centers of Excellence in Rehabilitation Research and Training, and it recommends that the following guidelines be used in their development:

- Eligibility criteria for center awards should require that the applying institution:
  - Have existing NIH awards, other Federal grants, or peer-reviewed foundation grants for rehabilitation research.
  - Specify an interdisciplinary core group of productive researchers in the basic and clinical sciences who have programs and activities relevant to rehabilitation.
  - Document the commitment of space and resources to be provided by the institution.
  - Document its existing research training curriculum and describe how the proposed center and its affiliation with other institutional units will enhance rehabilitation medicine research and training.
  - Describe its clinical resources, including patient population, and document its excellence in rehabilitation medicine.
- The missions of the centers must explicitly include training as well as research.
- Care should be taken in the development of the centers to achieve complementarity with the NIDRR centers and to avoid duplication of effort.
- Centers of Excellence in Rehabilitation Research and Training should undergo peer reviews equivalent in rigor to peer reviews of other NIH centers, such as those on stroke, spinal cord injury, diabetes, and rheumatoid arthritis.

- As a network of centers of excellence evolves, NIH and other sponsors of rehabilitation research should take steps to avoid inequities in the distribution of support, especially for investigator-initiated research. Institutions that do not have centers must have the opportunity to develop rehabilitation research expertise through other funding mechanisms.

Biomechanics, Ergonomics, and Engineering Design

Biomechanics, Ergonomics, and Engineering Design

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Biomechanics, Ergonomics, and Engineering Design

Overview

The inclusion of engineering and the physical sciences in rehabilitation medicine research has contributed to major advances in rehabilitative interventions and services. In particular, the application of quantitative analysis, modeling, and device design has significantly expanded our understanding of body motion and function and has led to new approaches to restoring or substituting for lost function. These contributions stem from work in three major categories of research and development: biomechanics, ergonomics, and engineering design.

Research Accomplishments and Opportunities

Biomechanics

Biomechanical principles and techniques provide the quantitative means to define the physical elements of human movements. Using a precise knowledge of how the body moves, researchers can design means of supplementing or replacing function lost because of injury or disease. Significant progress has been made in the quantification of muscle function, joint mechanics, and the mechanical properties of soft connective tissues.

Joint mechanics. Using gait analyses combined with anatomical studies, *in vitro* studies of the mechanical properties of tissues, and modeling efforts, researchers have assembled a detailed, though incomplete, picture of the biomechanics of the hip and the knee. Less progress has been made in defining the biomechanics of the shoulder and hand. The forces on the ligaments, joint cartilage, and bones have been measured or predicted. These results have guided the design and development of artificial joints.

Spine mechanics. Because of its uniqueness and its central importance to the functioning of the body, the spine constitutes a separate area of biomechanics research. *In vitro* and modeling studies have defined the normal functioning of the spine. Research emphasis has been placed on describing the complex anatomy and mechanics of the intervertebral disc, especially the lumbar spine. These studies are contributing to our understanding of why certain loads and postures are associated with a high incidence of pain and disability in the work force. A second area of biomechanical study has been the mechanics of the whole spine relative to the curves in the different segments. Information from this line of research is a prerequisite for developing rehabilitative interventions for people with scoliosis and other spinal deformities.

Soft- tissue mechanics. Studies have focused on the effects of disease, disuse, and denervation on the mechanical properties of soft tissues. Elucidation of a muscle's length-tension and force-velocity properties during gait contributes to the understanding of how muscles actually function *in vivo*. More detailed knowledge of the mechanics of soft tissues is likely to be gathered with ultrasound techniques that have recently been applied to this area of investigation. Other types of noninvasive scanning techniques are being developed to improve the accuracy of diagnoses of multiple sclerosis and related disorders.

Clinical measurements. Rapid advances in electronics technology and computer science have led to the development of many instruments that can be used in rehabilitation medicine research and clinical practice. These devices are used to measure strength, joint mobility, balance, coordination, and other properties of motion that are necessary to define a patient's level of impairment.

Gait analysis. The basic instrumentation for measuring the mechanics of walking was developed during the late 1940's in collaborative research projects involving engineers and orthopedic practitioners. More recently, cinephotography and manual extraction of data points from film have been replaced by digital cameras and computer methods for automated motion analyses. In addition, improvements in electronics have enhanced the utility and sensitivity of dynamic electromyography in studies of muscle function. Technical developments in force plate design and mathematical modeling have resolved the significance of the ground reaction forces experienced by the limbs. Footswitch systems now define the temporal-distance characteristics of the stride. Such advances have permitted definition of the basic motions and force patterns of normal gait.

Systems for analyzing gait are now used clinically in the diagnosis of gait disorders and to measure the effectiveness of interventions. In the treatment of people with cerebral palsy, gait analysis can be used to guide surgical planning. Advances in computer techniques for automating data reduction and in the use of artificial intelligence to aid logical interpretation of results promise to facilitate the use of motion analysis as an important tool for clinical assessment.

Ergonomics

Determination of muscle forces, joint positions, and limb loads permits assessment of the most efficient methods of performing physical tasks with the least effort. Detailed knowledge of the energy expenditures associated with the performance of certain tasks, as well as of the resultant physical stresses on specific parts of the musculoskeletal system, can be used to devise measures to reduce the incidence of job-related injuries. Ergonomic principles include the optimization of body mechanics to avoid injury: for example, keeping the mass of an object close to the body's center of gravity and using lower-extremity strength to assist the back muscles in lifting. Recent work has concentrated on how the forces of exertions, repetitions, and postures combine over time to cause a variety of cumulative trauma disorders, such as tendinitis, carpal tunnel syndrome, and low back pain. Medical costs and economic losses resulting from lost work time caused by such disorders are estimated to total more than $100 billion annually. It is estimated that the safety of a large majority of manual jobs in the United States could be improved by ergonomic applications.

The measurement of metabolic energy expenditure provides important information on ambulation. Moreover, quantitative methods can be used to estimate the additional energy demands, or costs, that might be caused by gait impairments. These

measurements can be used to assess the effectiveness of assistive devices—prostheses, orthoses, crutches, wheelchairs—and other rehabilitative interventions.

Engineering Design

A major focus of rehabilitation engineering has been the design of devices and systems to replace lost function. The research and development of rehabilitation devices has been supported primarily by manufacturers and by Federal agencies, including the National Institutes of Health, the National Institute on Disability and Rehabilitation Research, the Veterans Administration Medical Centers, the National Science Foundation, and the National Aeronautics and Space Administration. Research and development have been concentrated in the five areas described below.

Prosthetics and orthotics. For three decades following World War II, there was an intensive effort to design functionally effective and mechanically efficient artificial limbs. Very serviceable artificial limbs resulted. In recent years, however, as needs became more subtle and agencies were reorganized, prosthetics research has become a lower priority. Responsibility for further progress shifted to the prosthetics industry, composed mostly of small companies with correspondingly small budgets for research and development.

Recently, the Department of Veterans' Affairs reinstituted an extensive program in prosthetics development and amputee services. This has resulted in the Seattle Foot and several other designs of dynamic prosthetic feet that utilize modern energy-storing materials. New interface materials for leg sockets are currently being explored. A major effort is being directed toward the use of computer-aided design and manufacturing (CAD/CAM) for automatic socket fabrication. A significant development in upper-extremity prosthetics is myoelectric control for more responsive hand and elbow control. Preliminary designs of sensory feedback devices are also progressing.

With the exception of work focusing on the needs of children with disabilities, research on orthotics has not attracted the same level of support accorded to prosthetics research. The major accomplishment of orthotics research has been the introduction of vacuum-forming plastics to reduce weight and improve comfort, fit, and appearance. Further weight reductions have been achieved with the application of new composite materials. These materials, however, require complicated fabrication methods. Several advances have been made in the areas of pediatric prosthetics and orthotics, areas given relatively high priority by Federal funding agencies. Contoured seating to accommodate the limitations of people with severe deformities or spasticity has also been a major focus of research efforts. Several seating devices are now commercially available, but the versatility of these products is limited.

Assistive devices. Numerous devices have been developed to assist people with disabilities in eating, dressing, bathing, and other essential activities of daily living. Kitchen aids for cooking and a variety of assistive devices for writing, reaching, and communicating have enabled people with high levels of paralysis to perform meaningful work.

The application of robotics to assist people with disabilities has enormous potential. Although robots have found a place in industry, the demands for safety, reliability, and low cost have limited their use by people with disabilities. For example, workstations with robotic arms permit people with limited strength and arm motion to work more effectively in an office environment. Other recent developments include new gripper systems for the terminal devices of prosthetic arms and new sensors that help in navigating a motorized wheelchair.

Urinary incontinence. Some 12 million Americans suffer from urinary incontinence, a debilitating condition that can cause great physical discomfort and emotional stress. Many people suffering from incontinence lose self-esteem and isolate themselves for fear of embarrassment. They may leave their jobs and avoid social situations.

Urinary incontinence is a major cause of institutionalization among older adults. About 55 percent of all nursing home residents suffer from chronic urinary incontinence. In older adults, incontinence increases the risks of developing cystitis, depression, and decubitus ulcers, which are associated with skin breakdown.

A broad range of conditions contribute to the etiologies of incontinence. These include birth defects, pelvic or spinal injuries, multiple sclerosis, polio, infections, cancer, pregnancy, and degenerative muscle weakening associated with aging. A variety of interventions, from highly absorbent undergarments to mechanical, surgical, and pharmacological interventions, have been developed to manage urinary incontinence. Although many of these interventions have been beneficial to people with the condition, all have shortcomings.

Neural prostheses. Restoring function in people who have suffered strokes or incurred spinal cord injuries is a long-pursued goal of rehabilitation engineers and their collaborators. Much emphasis has been placed on functional neuromuscular stimulation (FNS). In paralyzed individuals, muscle tissue is usually normal and can be used to move otherwise paralyzed limbs if selective activation of the muscles can be achieved. Similarly, sensory receptors in the skin, muscles, and joints remain functional and might be used to provide information on pain, heat, touch, and position. Clinical applications in this area depend on technical progress in developing more reliable and more selective bioelectrical interfaces and on improved understanding of the neurophysiological and anatomical control of movement.

Advances in FNS have enabled people with paralyzed hands to grasp objects. Work has moved out of the laboratory, where demonstration systems were evaluated on volunteers, to actual home and work environments. Currently, about 20 people with spinal cord injuries routinely use FNS systems based on percutaneous electrodes. One individual has had a fully implanted FNS system for 4 years.

In the lower extremities, electrical stimulation is used routinely to maintain muscle mass. With more advanced FNS systems, paraplegic individuals have walked up to 1,000 yards. Further research and development will make this form of restoration more practical and available to a larger number of people.

Control of bladder emptying by electrical stimulation of the sacral roots has been investigated in the United States, Canada, and Great Britain. Bladder continence can be restored in some individuals through selective stimulation of the sphincter, and incomplete bladder emptying can be achieved upon voluntary command. Electrical stimulation is also being examined as a means for restoring sexual and bowel function. Continuing research should lead to more natural and more reliable control of genitourinary function.

Broader and more refined applications of FNS to restore function are closely tied to progress in several areas of science and engineering, including biomaterials, electrode design, and the design of safe and effective stimulation techniques.

Mobility. Wheelchair design has progressed dramatically over the last 30 years. Cane-backed chairs have been replaced by low-profile "sport" chairs. Chair weight has been reduced from 75 pounds to less than 35 pounds, while maneuverability and durability have been greatly improved.

Several designs of motorized chairs are commercially available, and there are portable motors that can be attached to specially designed manual chairs for dual use. Other motorized chairs have been designed to improve efficiency, and more intelligent digital controllers have been developed. Vans, lifts, and special driving systems are commercially available for wheelchair-dependent people, permitting them to travel comfortably in their communities.

Cognition training. Computer programs have recently been developed to help people with brain damage interact more fully with their environment. These interactive training devices are designed to enhance remaining cognitive processes rather than to restore or compensate for lost cognitive abilities. A variety of training protocols are being studied that have the potential to enhance memory, speech, way finding, and other cognitive functions.

Research Priorities and Recommendations

Progress in each of the areas described above has been impeded by gaps in knowledge. For each of the three major research categories, the panel identified several topics that warrant more intensive study and increased funding. Within each category, these research priorities are listed in the order of the importance ascribed to them by the panel.

Biomechanics

Quantitative measurement of function. More accurate and more sensitive methods for quantifying slight to moderate functional impairments are needed. Most assessment methods now used are too coarse to measure subtle yet clinically significant changes in function. Also needed are practical methods for the systematic evaluation of position changes, balance maneuvers, and other determinants of mobility.

To quantify the degree of functional impairment, the basic physical requirements for the performance of routine daily tasks must be determined and compared with the physical capacities of the individual. This information would help guide the development of strategies to overcome or compensate for the impairment.

Quantitative measurement of muscle fatigue. Improved techniques for identifying the sites of muscle fatigue during functional activities are needed. A more detailed understanding of the relationship between local muscle fatigue and central fatigue in upper motor neuron disorders is necessary to improve treatments.

Tissue properties under physiological loads. Most of the available information on the mechanical properties of tissue systems has been gathered in studies performed under nonphysiological conditions. Emphasis should be placed on developing new techniques for *in situ* evaluation of tissue properties, permitting assessment in natural or near-natural conditions. In addition, quantitative, valid, but noninvasive techniques must be developed to permit study of the effects of aging and other physiological processes on the mechanical properties of tissue systems. Such techniques would likely result in improved diagnostic tools, and the resultant information would benefit planning of treatment interventions and preventive strategies.

Mobility impairments in older adults. Many older adults are limited in their ability to walk, ascend and descend stairs, maneuver around obstacles, reach, kneel, crouch, and respond adequately to postural changes. For example, more than 2 million noninstitutionalized persons aged 65 and older have difficulty getting in and out of chairs and beds; nearly 3 percent of this

group and 9 percent of those older than age 84 need assistance.

Biomechanics research is needed to quantify these complex physical tasks, reducing them to their basic functional elements and assessing the degree to which impairment of each of these elements contributes to overall functional impairment.

The effects of weight bearing on upper extremities. The use of walking aids, such as canes and crutches, and wheelchairs can lead to muscle strain and joint deterioration in shoulders, elbows, and wrists. Research is needed to define functional tolerances, to prescribe preventive therapies, and to improve assistive devices.

Standardized clinical testing. Technological innovations have improved clinical measurements in rehabilitation medicine. However, it is difficult to quantify the efficacy of each innovation because training techniques, research protocols, and outcome criteria vary by investigator, by institution, and by region. Well-designed multisite studies could contribute to the development of standardized techniques and outcome measures that would permit more definitive and more widely applicable evaluations of the efficiency and effectiveness of interventions.

Effects of clothing on biomechanics and the utility of functional aids. There has been surprisingly little research on the design of clothing that facilitates movement and prevents the breakdown of skin tissue. Nor has there been systematic evaluation of the designs of common utensils used for self-care, such as toothbrushes, eating and drinking utensils, and reading glasses. Modifications that make these basic devices easier to use would increase the independence of people with disabilities.

Ergonomics

Physiological costs of ambulation. Improving the mobility of people with disabilities is a major goal of rehabilitation programs. Nevertheless, the decision to provide ambulation training and the extent to which walking is considered useful is usually determined subjectively. Further research on the physiological demands and energy costs of ambulation—before and after treatment—is essential to developing objective guidelines on anticipated functional performance in the home, community, and vocational environments.

Innovations in rehabilitation engineering technology have led to many new designs for orthoses, prostheses, wheelchairs, and other devices for improving mobility. Additionally, new physical therapy training and techniques such as electrical stimulation are now prescribed to improve ambulation. Many of these devices and treatments are widely used even though they may be very costly and their effectiveness has not been demonstrated in controlled studies. There is an urgent need to determine whether such interventions significantly reduce energy expenditure, significantly increase mobility, and are cost effective.

Worksite evaluation. Federal agencies such as the Occupational Safety and Health Administration and the National Institute on Safety and Health, as well as unions and private industry, need analytical tools for evaluating the worksite and the worker with the aim of preventing injuries. Worksite evaluations are now conducted with subjective tools; objective methods are needed, for example, to establish safe guidelines for lifting and carrying.

Recent Federal legislation forbids job discrimination against people with disabilities. For the goals of this legislation to be realized, studies are required to define objectively the work capacity of people with different types of disabilities, ensuring that the job-related tasks they perform will be within their tolerances.

Engineering Design

Evaluation of the effectiveness and efficiency of assistive devices. Rehabilitation professionals are often concerned about prescribing "appropriate technologies." That is, they are concerned about performance specifications as well as cost, safety, reliability, and durability. Unfortunately, rehabilitation researchers often start with an available technology and then search for a practical application. This approach sometimes leads to new devices or procedures that are totally inappropriate. The preferred approach is first to identify a need and then to study technologies that will satisfy the need.

Unfortunately, there are many impediments to the development of an effective research and development process that results in a sufficient number of affordable products of proven efficacy. Among the impediments identified in a study of the rehabilitation technology industry were the small size and financial instability of most firms, which, as a result, allocate few resources for research and development. At the consumer end, problems include high prices—partly the result of small sales volumes—and the restrictions of public and private insurers, which deny reimbursement for many types of devices because they are not deemed "medically necessary." Other impediments include the lack of a coherent service delivery system and the lack of awareness of existing products, on the part of both consumers and rehabilitation professionals.

Scientifically valid evaluations of the effectiveness of available and emerging assistive technologies are needed. In addition, people with disabilities should have the opportunity to air their views on the performance of commercially available devices. The NIH or other organizations charged with evaluating assistive technologies could sponsor a monthly newsletter that would report the results of product evaluations and publish consumers' opinions of existing products and their suggestions for improvements. These inputs would inform the research and development efforts of manufacturers and rehabilitation engineers.

Biomaterials research. Prototype rehabilitation devices and design concepts often cannot be realized or optimized because suitable biomaterials are lacking. In recent years, the development of lightweight, high-strength composite materials and new surface treatments for biomaterials has progressed significantly, but further improvements are needed. Research on biomaterials should focus on the following:

- Composites for low-stress, high-cycle applications.
- Chronic sensing and stimulation electrodes for applications in the peripheral and central nervous systems.
- Chronic percutaneous materials systems (mechanical and fluid conduits).
- Active (electro- or chemostrictive) muscle replacement materials.
- Materials for ligament and tendon prostheses.
- Materials for the replacement of massive bone loss.

Advanced design of orthoses and prostheses. With the introduction of new composite materials and high-temperature thermoplastics, the use of orthotics has expanded well beyond the scope of conventional bracing. Lightweight, custom-molded materials are being applied to various parts of the body for support and immobilization; examples include plastic foot orthotics for pronation control, body jackets, spinal orthotics, and positioning splints for limb contracture and tone control. These materials could also be used to control musculoskeletal conditions such as severe valgus and varus deformities of the knee in people with degenerative arthritis. These applications would require new methods

for fitting these prosthetic and orthotic devices to accommodate time-varying deformations occurring at the interfacing surfaces.

Neural coding and signal processing. Quantitative analyses of biological signals are needed to establish a basis for artificially controlling biological systems. Specific areas warranting increased research are described below.

- *Quantitative analysis of electrical and vibrational signals from skeletal muscles.* These signals can be used to monitor muscle activity and, subsequently, to control orthotic devices. For example, a person with muscle weakness might be provided with a servomotor, which assists or performs body movements. The motor could be controlled by amplitude and frequency modulation of the electrical signals normally produced by the subject's muscles, as determined from an electromyogram. Another potential application is the use of electrooculogram signals from eye muscles as a means of communication by people who are otherwise completely paralyzed. Other applications meriting research include prosthetic control, environmental control, evaluation of muscle performance, relation of motor unit properties to gross motor function, optimization of exercise protocols, evaluation of muscle injury, and diagnosis and prognosis of muscle disease.
- *Quantitative analysis of electrical and magnetic signals from the central and peripheral nervous system.* This area of research includes analysis of signals recorded noninvasively or via implanted electrodes. Matrix electrodes implanted in the brain or spinal cord may provide insight into interneuronal communication, opening avenues for rehabilitation applications in motor and pain control.
- *Evaluation of electrical stimulation patterns.* Research is needed to determine the potential for stimulating nerves and muscles with computer-controlled electrical signals to enhance muscle function and slow muscle atrophy.
- *Development of sensory substitution techniques.* Providing sensory feedback for an insensate limb can be a crucial step in returning function to the limb. Afferent information is a key element in motor control and reflex actions; therefore, methods for gathering this information require further development.

Control mechanisms for bowel and bladder dysfunction. Improvements in existing methods and devices for managing urinary incontinence are needed, as are new types of technology. Existing methods and devices either do not provide satisfactory control or pose significant risks of side effects and complications.

Interactive environments. Mobility requires that the mass and inertia of body segments be supported and moved by the skeletal system through muscular actions. Functional impairments stem from reduced muscular strength, limited range of motion, increased latencies in motor response times, inappropriate sequencing of body-segment motions, or combinations of these and other mechanisms.

Through biomechanical analyses, it may be possible to isolate the physical components of a complicated physical task. Quantitative understanding of mobility impairments is essential to developing architectural and other environmentally appropriate designs to foster greater mobility and greater independence for people with these impairments. For example, thorough determination of critical environmental features is necessary to guide the design of beds, stairs, inclinators, hand tools, materials-handling devices, and workplace layouts that are truly assistive and accessible.

Improved materials, designs, and energy supplies for power-assisted devices. An estimated 60,000 people depend on powered wheelchairs or myoelectric arms for mobility. Any general failure in the materials or power supply can strand the user, a major worry of users. In addition, the cost of batteries is prohibitive for many: The typical wheelchair battery requires daily recharging, which destroys the battery in about a year. The annual national cost of replacing these batteries is about $7.2 million.

The deep-discharge lead-acid battery is preferred by most powered wheelchair users. It can be recharged 300 to 500 times before failing and costs about 24 cents per recharging cycle. However, it is spillable and is an explosion hazard because the electrolyte is free floating and must be vented. Most airlines refuse to transport lead-acid batteries because of this hazard.

The deep-discharge gel-electrolyte battery system for electrically powered wheelchairs is also popular. It is maintenance free and nonspillable. However, its maximum lifespan is 100 to 300 recharging cycles, with an average cost of 80 cents per cycle.

New power sources should be investigated, including nickel-hydrogen batteries, which are expected to have a long life and a recharging-cycle cost comparable to that for lead-acid batteries. Nickel-hydrogen batteries are also maintenance free and nonspillable. In addition, more efficient motors and controllers should be developed for both wheelchairs and myoelectric arms. Finally, frame designs should be reevaluated to consider the potential advantages, including weight reduction and increased durability, of using composites and other new materials.

Robotics to supplement the functioning of people with disabilities. Most of the robots used in industrial applications are designed to replace or assist human operators. Robots for people with disabilities are designed to improve human performance of tasks made difficult or impossible by functional limitations. Therefore, better human-machine interfaces are needed to ensure a good match between the capabilities of the user and the capabilities needed for control and operation of robotic devices.

In addition, industrial robots usually perform single preprogrammed tasks, whereas robots for people with disabilities must perform a variety of daily-living tasks. In most rehabilitation applications, the control algorithm can be a combination of preprogrammed activities with interim modifications by the user. Hence, the control system should have the capacity to "learn" from previous activities and to adapt to new situations.

Four features of interface designs require further development:

- Input controls, including voice recognition.
- Sensory feedback, especially tactile feedback.
- Artificial intelligence, especially the capability to "learn" sequences of common movements.
- Safety, especially the ability to recognize and avoid high-risk movements.

Augmentative communication aids. Communication aids are commercially available for people with quadriplegia or other neuromuscular disorders affecting speech and hand dexterity. A variety of video scanning and icon display formats have been tried, but none of the commercially available devices achieve the desired word-processing speeds.

More efficient methods for selecting letters and words are needed. It may be possible, for example, to devise a simpler alphabet in which commonly used letters are represented by two or three straight segments of a seven-segment display. The letters could then be defined by two or three facial movements.

Assessment and Epidemiology

Assessment and Epidemiology

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Assessment and Epidemiology

Overview

Issues concerning assessment and epidemiology have been identified in each science area examined by the Task Force. Within each, there are specific needs to be addressed. However, a variety of problems and needs pertaining to assessment and epidemiology span the entire field of rehabilitation medicine research, reflecting the field's multidisciplinary composition and its fundamental concern with improving human functioning. Clearly, rehabilitation medicine research requires epidemiological tools and assessment instruments that transfer across disciplinary boundaries and provide information that can be used to build the field's theoretical foundation.

This chapter addresses topics and needs that are applicable to all of rehabilitation medicine research.

Assessment

Introduction

Considerable effort has been devoted to developing methods for measuring and assessing various aspects of impairment, disability, and handicap. Measures of a variety of specific components of human performance have been devised. At the level of body systems, assessment tools have been developed to measure, for example, strength, endurance, energy expenditure, range of motion, muscle activity, and sensory function. Frequently, however, such assessments are based on subjective observational methods, as is true in the case of manual muscle testing and other manual techniques. Although more quantitative, automated tools such as isokinetic dynamometers are sometimes used, the precise methods employed vary so greatly that it is difficult to make comparisons of data from different laboratories. An additional challenge exists in incorporating these neuromuscular function tests into an integrated, multidimensional analysis that would provide meaningful measures of outcomes. It would then be possible to determine how closely the results of a given assessment correspond to functioning in daily life.

Much of the work on measures of disability falls under the rubric of functional assessment. Among measurement systems that have gained some degree of acceptance is the Functional Independence Measure (FIM), a descriptive, criterion-referenced scale. Direct observational methods for assessing human performance and a few other methods, such as gait analysis systems, have also been developed and promoted. In all, more than 40 systems for measuring various aspects of function have been published in the literature. Few, however, have been evaluated for their applicability and methodological soundness as research tools.

Measures of handicap examine such factors as quality of life, sense of well-being, social role performance, and work productivity. Only limited research effort has been devoted to developing systems for measuring handicap.

Research Priorities

Research needs relating to assessment fall into six general categories. The foremost research priority is the thorough evaluation of existing and newly developed rehabilitation outcome measures. In particular, the meaningfulness, reliability, validity, and precision of these measures must be ascertained.

Measurement of the Effects of Rehabilitation Interventions

A diverse array of therapeutic processes, tools, and modalities is used in the care of people with impairments or disabilities. Collectively, these interventions are intended to reduce impairment, disability, and handicap. While precise measurement of intervention outcomes is often difficult, it is necessary, nevertheless, to determine efficacy (that is, the probability of benefit to patients from a specific intervention under ideal conditions of use) and effectiveness (that is, the probability of benefit to patients from a specific intervention under average conditions of use). Therefore, formalized measurement systems are required to evaluate often complex rehabilitation techniques so that a "dose" of a particular type of therapy, such as gait training or training on using a wheelchair, can be characterized. Standardized interval measures of such interventions as vocational counseling should also be developed along with a system of descriptors to characterize the different rehabilitation programs and settings in which interventions are applied.

Formal measurement systems will permit meaningful comparisons of the effects of the same intervention administered in different amounts or levels of intensity, as well as comparisons across different types of interventions and different rehabilitation settings.

New and More Precise Measures of Disability

Traditional measures of disability assessment are based on observations and self-reporting of activities. The primary outcome indicator is an individual's level of dependence or independence. More precise, quantitative measures of disability are needed, as are new measures that characterize other aspects of function and performance. These measures would be adjuncts to existing measurement approaches, examining different dimensions and supplementing information obtained with more traditional measures.

Innovative Measures of Handicap

A plethora of measurement tools to investigate disability exist; sorting and integrating aspects of these measures would aid efforts to develop meaningful measures of handicap. Existing measures of handicap are inadequate. While measures of remunerative activity and other indicators of an individual's productivity are available, tools for assessing social role performance (e.g., facets of parenting or spousal relationships) are lacking.

Improved Measures of Social and Physical Environment

The observed performance of people with disabilities is a composite of endogenous factors (e.g., impairments, emotional status, age) and exogenous factors (i.e., products of the social and material environment). For example, the reliability of personal-care assistants for a person with substantial motor impairment can substantially influence that individual's productivity and health maintenance behaviors. Further, architectural barriers in or around the home and in the community can decisively influence the

individual's community participation and access to health care.

The role of environmental factors has been neglected in research because of the lack of indices and measures examining their impact. Such indices and measures would quantify the influence of environmental factors on disability, on handicap, and on responses to rehabilitative interventions.

Development and Evaluation of Standardized Measures of Subjective Well-being

Disability and handicap are most often characterized in objective terms that do not recognize the psychological and behavioral underpinnings of human functioning. Ignored, for example, are the influences of individual perceptions, personal value judgments, and feelings. Broadly considered, these and other dimensions are facets of the phenomenology known as subjective well-being. Since many rehabilitation interventions are expressly intended to enhance the individual's subjective well-being, appropriate measurement of this outcome is necessary. Although some existing scales examine subjective well-being—operationalized as, for example, expressed satisfaction with life, perception of the degree to which life is controllable, and predominant emotional state—these measures have been developed in contexts other than rehabilitation. The sensitivity of such scales to rehabilitation issues requires exploration. Development of measures more appropriate to rehabilitation may be necessary.

Development and Evaluation of a Set of Generic Rehabilitation Outcome Measures

A hierarchy of measurement tools building on the concepts of impairment, disability, and handicap is needed to assess status and response to rehabilitation therapies and to determine cost-effectiveness and cost-benefit relationships. Specific measures that are distinctly relevant to impairment, disability, and handicap must be developed, tested, and proven to adequately operationalize each rehabilitation outcome.

Fields within rehabilitation, such as geriatrics and rheumatology, have developed a multitude of approaches to measure function. However, little integration of knowledge and approaches from those fields has occurred, even though issues of measurement are similar in many areas of rehabilitation. Key variables of human performance must be identified, especially those relating to basic aspects of survival and environmental interaction. Determination of these key variables will permit the development of a core set of generic measures for comparing the effectiveness of rehabilitation interventions across studies, as well as across groups differing in types of impairment, disability, or handicap. The reliability and validity of these tools must be subjected to appropriate scrutiny. Disease- or condition-specific supplements should also be developed and evaluated to complement this core set of measures.

Implementation Strategies

There is a compelling need for implementation strategies designed primarily to standardize and classify existing and future measures and definitions pertinent to assessment. Without clearly defined steps to accomplish the priorities identified here, it is unlikely that important research needs will be met.

Experience clearly attests to this assertion. Other groups and individual researchers have identified many of the same research priorities. Despite this seemingly broad consensus, relatively little progress has been made. To overcome this inertia, we strongly urge that steps be taken to carry out

the three key implementation strategies described below.

Develop and apply standards for the design and evaluation of measures of rehabilitation outcomes. Consensus on the criteria and minimum standards that any measurement tool must achieve is essential. These standards should address validity, reliability, precision, and sensitivity. Moreover, the relevance of measurement approaches in assessing impairments, disabilities, and handicaps should be established.

It is anticipated that many medical rehabilitation research studies will evaluate interventions in multicenter clinical trials. To ensure reliability in assessment, emphasis must also be placed on training team members in the skills necessary for performing assessment and collecting valid, reliable data on rehabilitation outcomes.

Establish a task force to develop and improve core rehabilitation outcome measures. The need to integrate measures of function has long been recognized. A mechanism must be created to achieve this integration and the field-wide consensus it will require. Perhaps a standing task force, charged with the responsibility of fostering development and adoption of a core set of generic measures of rehabilitation outcomes, should be established. Initially this group would evaluate existing measurement tools, identify the key variables within each that pertain to function, and develop the core set of generic measures. As a standing task force, this group would also have responsibility for monitoring changes in assessment needs and for revising and updating the core set of measures accordingly. The task force could also assume responsibility for the development of standards for the measurement of impairment, disability, and handicap. Success in this effort would serve as a foundation for further study of measurements of quality of life, a concept that is receiving increasing attention from health services researchers, policymakers, and insurers.

Develop an international classification scheme for rehabilitation outcomes. Fundamental to the study of rehabilitation is a common classification scheme of impairment, disability, and handicap, comparable to the World Health Organization's (WHO) International Classification of Diseases, 9th edition (ICD-9). There is a growing need internationally for a common nosology, which might advance efforts to develop common functional measures for epidemiological and intervention studies.

Existing classification schemes, such as the WHO's trial International Classification of Impairments, Disabilities, and Handicaps (see Introduction) and one developed by Saad Nagi, serve as useful first steps toward common language for describing rehabilitation outcomes. The confusion and controversy that arise with the use and interpretation of these classification schemes strongly indicate the need for improvement or alternative approaches.

The ICD-10 is due for publication in 4 years. Therefore, it would be timely to reach a consensus on the development and testing of an international classification scheme for rehabilitation outcomes, which could be appended to the ICD-10.

Epidemiology

Introduction

Understanding of the determinants and prognoses of disability resulting from major chronic diseases and impairments has advanced little during the past 25 years. This is largely due to the small number of professionals dedicated to medical rehabilitation, meager support for their activities, and their understandable preoccupation with the immediate, practical problems faced by the patients they serve. This emphasis on day-to-day problems has limited the development

of more effective rehabilitation strategies because it has slowed the evolution of the theoretical foundation upon which such strategies should be built.

Classical epidemiology provides a simple but useful model for the study of antecedent-consequent relationships involving multiple causal factors of disability and the role of rehabilitation as an intervening variable. Many important research questions can be developed around the relationships among these key variables.

Application of the epidemiological model to rehabilitation research allows analysis of the differential distribution of a specific disease consequence—for example, a specific impairment, such as muscle weakness, or a specific disability, such as inability to walk—in terms of three major sets of variables:

- *Host factors*, which encompass the characteristics of the individual with the disease;
- *Agent factors*, which describe the condition causing the impairment or disability; and
- *Environmental factors*, which pertain to the physical and social surroundings in which the impairment or disability is produced.

Epidemiological investigations such as the Framingham study and the National Health and Nutrition Examination Surveys have been organized around specific diseases or conditions and around global health status indicators. No large-scale data set has been designed primarily to investigate the distribution and correlates of impairment, disability, and handicap within the population. These data are needed to develop science-based rehabilitation strategies and to evaluate the efficacy and cost-effectiveness of interventions. Research is also needed on intervening factors that influence rehabilitation outcomes.

Research Priorities

Research needs relating to epidemiology fall into three general areas:

- Development of epidemiologically sound evidence of prevalence and incidence of impairment, disability, and handicap;
- Development and testing of theoretical formulations regarding the patterns of development, major determinants, and course of impairment, disability, and handicap; and
- Investigation of patterns and models of care.

Prevalence and Incidence of Impairment, Disability, and Handicap

Collect more accurate data, and broaden the populations and outcomes considered. Because of past difficulties with conceptual definitions, measurements, and samples studied, reliable information is limited on the distribution of impairments, disabilities, and handicaps among population groups differing in age, sex, race, culture, and geography. Further, the scope of existing research is limited to a narrow band of outcomes (e.g., performance of customary activities of daily living). More comprehensive epidemiological information is needed to understand the broad manifestations of impairment, disability, and handicap (e.g., occupational and avocational activities, productivity, social interaction, performance of societal roles). Such information is required for a variety of population groups. This theme is also strongly emphasized in the chapter on developmental issues.

Much research has focused on unrepresentative patient populations, leading, at times, to erroneous estimates of incidence of disease consequences. Just as the incidence of disease states shows marked divergence in various population groups, it can also be expected that resultant rehabilitation needs will vary according to

socioeconomic, environmental, cultural, and gender differences and, perhaps, genetic variations. Consequently, the mix and importance of the specific rehabilitation needs of these populations will vary, influencing the provision and effectiveness of rehabilitation services. Data are available on the incidence and prevalence of individual disease states for many conditions, but information for specific population groups is often not available.

Develop national injury surveillance systems. National standardized surveillance systems to monitor disability-causing injuries need to be developed. While many different types of injury surveillance programs are under way at the local, State, and regional levels, none is truly national, and many are limited in scope or overlapping in function. A standardized, national surveillance system to monitor the epidemiology of trauma-related disabilities will be a more cost-effective approach to collecting information, will gather important information about the natural history of injury-related disabilities, and will facilitate the design of new intervention strategies.

Use of existing data-collection mechanisms to gather such data is also encouraged. For example, items addressing issues related to impairment, disability, and handicap should be included in future National Health Interview Surveys.

Reduce respondent burden. Respondent burden refers to the demands that research places on potential participants. Nonparticipation and incomplete data in epidemiological research are not random. People who are frail or ill may be less likely to participate. Research on factors that limit participation and development of mechanisms to reduce respondent burden is needed.

Investigate minority, newly identified, and low-incidence disease populations. People with disabilities who are members of racial and ethnic minority groups tend to have the greatest difficulty in accessing rehabilitation care. This is particularly true for those who are poor. People with AIDS and with substance abuse also have access problems associated with poverty. The impairments and disabilities of some of these minority groups are a direct result of substance abuse. Difficulties in securing care or reluctance to seek services arise, in part, because the cultural backgrounds and values of minority populations often diverge substantially from those of providers of rehabilitation services.

Investigations of newly identified populations with primary or secondary impairments, disabilities, and handicaps should be conducted. New and better treatments have prolonged the lifespan of those with severe illnesses. However, treatments themselves may result in secondary impairments that change or become more pronounced during the aging process. Examples of these populations include the following groups:

- Premature and low-birthweight infants,
- Adults with developmental disabilities,
- Long-term survivors of childhood cancer,
- Adult survivors of earlier therapies (e.g., bone cancer therapies),
- Individuals with AIDS, both infant and adult onset,
- The oldest old who have survived catastrophic illness or events, and
- Individuals with chronic exposure to environmental or occupational toxins.

Theoretical Formulations

Investigate the factors influencing the relationships among disease, impairment, disability, and handicap. The presence and degree of disability and handicap are often poorly explained by the primary underlying disease or impairment. To understand the individual consequences

of pathology and to guide development of problem-solving responses, it is essential to identify the impact of factors that may modify the relationships among impairment, disability, and handicap. Factors meriting more detailed study are described below.

- Comorbidity, or concomitant diseases and impairments, may influence outcome. For example, the prospect of ambulation for an amputee can be limited by the presence of vascular disease causing cardiomyopathy and endurance limitation. Can therapy for the cardiac condition improve an amputee's ability to walk and work with a prosthesis?
- Nutritional status has been shown to influence recovery after hip fracture and cancer rehabilitation. Can greater emphasis on nutrition result in greater gains in rehabilitation?
- Psychological status also influences outcome. Cognitive impairment substantially reduces the ability to apply standard rehabilitation therapies. Is there a modifiable component of cognitive impairments caused by delirium or confusion in the acute phase of disability? Similarly, depression, common among stroke patients, may influence the ability to participate in therapy, and once identified, hasten improvement.
- Lifestyle factors antecedent to impairment, such as smoking or substance abuse, may influence recovery or the path from disease to disability.
- Social support has been identified as a major influence on the success people with disabilities have in reentering the community. To what extent might marginal social supports be buttressed or enhanced? What can society do to create social supports that are lacking?
- Environmental factors influence the capacity of people with disabilities to function independently. Key among these factors are architectural barriers and barriers to using public transportation.
- Demographic factors, such as age, gender, race, and socioeconomic status, may alter the course of impairment and disability.
- The availability of health care services and the ability of providers to tailor services to the needs of people with disabilities can confound the natural history of disabilities.

Investigate factors that predict level of recovery and adaptation after the onset of new disease or injury. Many psychological, social, and environmental factors may explain the diverse patterns and degree of recovery following the onset of new disease or injury. The elucidation of important prognostic factors in recovery following hip fracture, stroke, and other conditions will facilitate the design of new rehabilitation strategies.

Investigate the cycle of comorbidity and the progression from impairment to disability. Research is needed to identify the role that various comorbid states play in the temporal progression of impairment and disability. For example, onset of Parkinson's disease causes restricted mobility. Restricted mobility in turn leads to deconditioning and general weakness that lead to further restricted activity, depression, and social isolation. The result is worsening disability and handicap status.

Develop theoretical models to describe the relationship between disorders and interventions. Theoretical mathematical descriptions of individual and population behaviors should be developed. These models would foster the development of testable hypotheses on the impact of interventions on the consequent behavior of the individual or, in the case of social and policy interventions, on the behavior and attitudes of the community. Such models could also

be used to test the relative effects of interventions, the results of which could point the way to multivariate clinical studies. Examples of questions that could be examined in this manner include: How does the recovery of walking ability for only in-home distances affect the probability that gainful employment will occur? Does the introduction of an incentive policy for supported work programs require a change in access to sponsored transportation in order to succeed? Does strengthening a quadriceps muscle to 70 percent of normal predict return of knee stability in a model of ambulation? Clarification and classification of key rehabilitative outcomes will be required for the development of such theoretical models.

Patterns and Models of Care

Investigate patterns of rehabilitation care. Studies of patterns of rehabilitation care received by individuals are needed to increase understanding of rehabilitation outcomes. Information is needed on the manner in which care is accessed and initiated, on the types of institutions providing care, on the types of care available in various geographic areas, on the cost of care, and on the sources of payment for care. Research is also needed on socioeconomic and other key factors associated with the receipt of different types of care. This information would enhance understanding of the causes underlying variations in rehabilitation outcomes.

Develop models of rehabilitation provider-patient relationships. Nursing researchers have conducted several studies on models of care and caregiver-patient relationships. A determination of the applicability of this work to rehabilitation and of the need for studies specific to rehabilitation is required.

Summary of Research Recommendations

Assessment

Research Priorities

- Develop quantitative measurement systems for assessing rehabilitation therapies.
- Develop new and more precise measures of disability.
- Design innovative measures of handicap.
- Develop improved measures of social and environmental factors that affect rehabilitation success.
- Develop and evaluate standardized measures of subjective well-being.
- Develop and evaluate a core set of generic rehabilitation outcome measures.

Implementation Strategies

- Develop and apply standards for design and evaluation of rehabilitation outcome measures.
- Establish a mechanism to develop and revise core measures.
- Develop a practical classification scheme for rehabilitation outcomes that can be applied in the widest possible range of venues.

Epidemiology

Research Priorities

Development of epidemiologically sound evidence of prevalence and incidence of impairment, disability, and handicap

- Gather more accurate data and broaden populations and outcomes considered to include people and issues pertinent to rehabilitation medicine's goals and interests.

- Develop national injury surveillance systems.
- Reduce respondent burden.
- Investigate minority and low-incidence disease populations.

Development and testing of theoretical formulations regarding the determinants and course of impairment, disability, and handicap

- Investigate the factors that influence the relationships among impairment, disease, and disability.
- Investigate the factors predictive of level of recovery and adaptation after the onset of new disease or injury.
- Investigate the cycle of comorbidity and the progression from impairment to disability.
- Develop theoretical models of relationships between disorders and interventions.

Investigation of patterns and models of care

- Investigate characteristics of rehabilitation care and their relationship to outcome.
- Investigate existing models of care, review research on caregiver-patient relationships, and determine the applicability of this work to rehabilitation and the need for studies specific to rehabilitation.

Information Resources

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Information Resources

Overview

One of the great disappointments in rehabilitation medicine is the field's failure to use all of the informational resources available to ensure that those in need receive the best and most appropriate services and interventions. The problem lies in the relatively ineffective methods used to disseminate research findings and the other types of information required by researchers, rehabilitation practitioners, people with disabilities, manufacturers of assistive technologies, policymakers, and numerous other audiences with regular or occasional need for rehabilitation-related information. (See table 1.)

These shortcomings are not unique to rehabilitation medicine. Their consequences may be more severe, however. The field's

Table 1.
Users of Rehabilitation-related Information

- Researchers and educators
- People with disabilities or functional limitations and their families, friends, and advocates
- Professionals serving persons with disabilities
  - Rehabilitation professionals (regular need for information)
  - Other medical and nonmedical professionals (occasional need for rehabilitation information)
  - Paraprofessionals and special educators
- Students
- Policymakers and planners (local, State, and Federal levels)
- Agencies, organizations, and institutions
  - Government agencies and programs
  - Disability organizations
  - Nondisability organizations
- Third-party payers
- Employers
- Manufacturers and distributors
  - Disability-related products
  - Mass-market products
- Media
- Attorneys
- General public

multidisciplinary composition and its reliance on interdisciplinary approaches to addressing most problems and issues mean that information users face the challenge of integrating a tremendously diverse range of information. They confront other problems as well. Information is rarely available when it is needed and, if it is available, it is not likely to be in a readily accessible and understandable form. Because of the multiplicity of disciplines in the field, information must be presented in different formats and in different levels of technical detail.

As in other areas of research, the need for rapid access to information has never been greater. It takes too long to find usable material in books and journals, and there are simply more publications than most clinicians and scientists can comprehend. Add at least a year's delay in getting material published and further delays in dissemination after publishing and the problem is compounded.

Databases are a partial answer to this problem. Access, however, is rarely convenient except, perhaps, for the most experienced researchers or reference librarians, who also have the requisite accounts, passwords, access terminals, and user protocols and query language. Even if these obstacles are overcome, difficulties remain. As their name implies, databases contain only data, which often must be processed before they become useful to the person seeking the information.

These problems are correctable. Information science, information processing, and communication technology are advancing at an unprecedented rate. Computing power increases by a factor of 10 every 4 years, while costs decrease by a factor of 10 every 5 years.

Progress in technology and artificial intelligence will provide those in the field of rehabilitation medicine with the opportunity to tap into the collective pool of knowledge as easily as, and perhaps more quickly than, consulting with a colleague in the hallway. Realizing this opportunity would significantly advance the understanding and practice of rehabilitation medicine.

Improving access to information will require efforts in four areas:

- Development of information to fill existing gaps;
- Development of information system interfaces that are truly easy to use;
- Development of efficient mechanisms for searching among databases; and
- Development of systems to interpret or translate information into forms usable by individuals with different levels of expertise and different language requirements.

This chapter presents specific recommendations for accomplishing these important tasks. It begins by assessing the current situation: needs for rehabilitation-related information, sources of this information, and methods of accessing these sources. The capabilities of new and emerging information technologies are then discussed, creating the context for the recommendations that follow.

It should be noted that the panel focused primarily on addressing the needs of the rehabilitation medicine research community. However, as indicated in the sampling of users presented in table 1, the need for rehabilitation-related information is shared by many audiences. Thus, the panel's recommendations are also responsive to this broader need.

Current Situation

Types of Information Needed

Information needs are as varied as the users. Table 2 profiles some of the types of information required by different users. In almost

Table 2.
Categories of Rehabilitation-related Information

- Disabling conditions and potential interventions
  - Nature of disability
  - Coping techniques
  - Patient recovery expectations
  - Techniques for improving compliance
  - Patient outcome preferences
  - Statistics
    - Incidence and prevalence
    - Rare conditions
    - Disability statistics broken down by ethnicity and socioeconomic status
    - Current demographic trends
    - Prevalence of patients with specific conditions, e.g., fractures in paraplegics or adults with cerebral palsy
- Research
  - Recent research developments
  - Research needs assessment from clinicians and clinician researchers
  - Bibliography of current grants and grant programs (government, foundations, etc.)
- Referral sources, other information sources and experts
- Interventions available; program models; best practices
  - Management protocols for patients
  - Methods to assess, treat, teach
  - Treatment, management, effectiveness, and cost-benefit information
  - Technical aspects of treatment
  - Review articles
  - Models for case management
  - Practice guidelines
  - Ethics in service industry
- Technologies available
- Services available
  - National/State/local
  - Education/information and referral
  - Transportation (geriatrics, disabled)
  - Community resources
    - Type and location of rehabilitation services available (with detailed description)
      - What specialists exist
      - What facilities are/are not accessible
- Rights and legislation
  - Laws and regulations
  - Precedents
  - Advocacy resources
- Sources of financial assistance to individuals (public/private)
  - Insurance issues
  - Third-party reimbursement programs and policies
- Sources of financial support for programs, organizations, investigators
  - Bibliography of current grants and grant programs (government, foundations, etc.)
- Publications covering a topic
  - Bibliographies
- Patient utility or preferences for treatment
- Outcome measures
- Agencies involved in rehabilitation

all cases, an information category is useful to several different groups. For example, information on available interventions and summaries of research findings published during the last few years, two separate categories of information, would be of interest to researchers, practitioners, and consumers. The same information, however, may be required at three different levels of detail or in three different formats to meet the needs of each of the three audiences.

To accomplish their objectives, individuals must not only gather information from several different categories, but they also must integrate the items with the array of information they find. Thus categories of information can be subjective. For example, a person searching for information on spinal cord injury would much prefer to go to a centralized source of information on this topic rather than to search for relevant items within each of the categories presented in table 2.

Currently, information pertinent to the field is contained in a wide variety of mutually incompatible databases and formats, preventing systematic exploration within or across categories. To meet information needs effectively and efficiently, sophisticated mechanisms must be developed to permit information searchers to move easily among information categories and sources.

Sources of Information

In describing the current state of information resources in the field of rehabilitation medicine, a number of dimensions must be examined. These include the types of data and information currently being collected, the networks through which the information is available, the organizations dispensing the information, and the various techniques for accessing the information.

Most of the rehabilitation-related information now available is in the form of databases, the majority of which are bibliographic in nature. They include very large databases, such as MEDLINE and COMPENDEX, with well over 2 million entries each, and smaller, more specialized bibliographies, which collectively cover almost every area of rehabilitation. Of the 90 journals specifically relating to rehabilitation, 31 are indexed in MEDLINE, 30 in other sources, and 29 are not indexed in any source. (See tables 3, 4, and 5.) An additional 58 journals indexed in MEDLINE each year publish more than 16 articles relating to rehabilitation.

Information on assistive devices and other types of technologies and products is also abstracted in databases such as ABLEDATA and Accent on Information. Population databases, which make up a third major category, are usually based on national census information or survey research. Table 6 provides a sampling of databases relating to rehabilitation.

Accessing Information

Most of the databases listed are accessible through national information networks or bibliographic services such as BRS (formerly Bibliographic Retrieval Services), AbleNet, Compuserve, SpecialNet, The Source, Prodigy, and Series. In addition, there are numerous electronic bulletin boards dispersed throughout the country, providing information varying widely in searchability and quality.

Although databases, information networks, and electronic bulletin boards are the products of the "information age" in which we live, these services are used by a disappointingly small number of people. There are several reasons for this situation. First, the majority of information seekers who might have use for these services are not aware of their existence. Second, most people do not possess the necessary equipment to access these services. Third, mastery of the skills and knowledge necessary to use

Table 3.
Core Rehabilitation Journals Indexed in MEDLINE

Acta Belgica Medica Physica
Advances in Clinical Rehabilitation
American Annals for the Deaf
American Journal of Occupational Therapy[1]
American Journal of Physical Medicine and Rehabilitation[1]
American Rehabilitation
Archives of Physical Medicine and Rehabilitation[1]
Brain Injury
Canadian Journal of Occupational Therapy[1]
Clinical Orthopedics and Related Research
Decubitus
Exceptional Child
International Disability Studies
International Journal of Rehabilitation Research
International Rehabilitation Medicine
Journal of the American Paraplegia Society
Journal of Burn Care Rehabilitation[1]
Journal of Communication Disorders
Journal of Rehabilitation Research and Development
Journal of Speech and Hearing Disorders
Journal of Speech and Hearing Research
Mental Retardation
Pain
Paraplegia
Physical Therapy[1]
Prosthetics and Orthotics International
Rehabilitation
Rehabilitation Nursing
Research in Developmental Disabilities
Scandinavian Journal of Rehabilitation Medicine
Vopr Kurortol Fizioter Lech Fl (Problems Health Resorts, Physiotherapy, and Exercise Therapy [Russian])

[1]*Indexed in Cumulated Index to Nursing and Allied Health.*

Table 4.
Core Rehabilitation Journals Indexed in Sources Other Than MEDLINE

Australian Occupational Therapy Journal
British Journal of Occupational Therapy[1]
Canadian Journal of Rehabilitation[1]
Clinical Kinesiology[1]
Clinical Management in Physical Therapy
Journal of the Association of Children's Orthotic-Prosthetic Clinics
Journal of Hand Therapy
Journal of Head Trauma Rehabilitation
Journal of Health Trauma Rehabilitation[1]
Journal of Orthopedic and Sports Physical Therapy[1]
Journal of Rehabilitation[1]
Journal of Rehabilitation Administration
Journal of Visual Impairment and Blindness
Journal of Visual Rehabilitation
New Zealand Journal of Physiotherapy[1]
Occupational Therapy Journal of Research[1]
Occupational Therapy in Mental Health[1]
Occupational Therapy Practice
Paraplegia News
Physical and Occupational Therapy in Geriatrics[1]
Physical and Occupational Therapy in Pediatrics[1]
Physiotherapy[1]
Physiotherapy Canada[1]
Physiotherapy Practice[1]
Psychosocial Rehabilitation Journal[1]
Rehabilitation Digest
Rehabilitation Psychology[1]
Sexuality and Disability[1]
Topics in Acute Care Trauma Rehabilitation[1]
Topics in Geriatric Rehabilitation[1]

[1]*Indexed in Cumulated Index to Nursing and Allied Health.*

each of these services can be a daunting and frustrating task, and the requisite skills and knowledge are usually not transferrable from one database or network to the next. Fifth, a considerable number of people are non-English speaking, and some cannot read. Sixth, the costs of some of these services are prohibitive for many. Finally, the information retrieved from these services often is not in a form that is usable or under-

Table 5.
Rehabilitation Journals Not Indexed in Bibliographical Sources

American Archives of Rehabilitation Therapy
American Children's Prosthetics and Orthotics
AOPA Almanac (American Orthotic and Prosthetic Association)
Assistive Technology
Augmentative and Alternative Communication
British Journal of Rehabilitation
Clinical Rehabilitation
Cognitive Therapy
Computer Applications in Occupational Therapy (newsletter)
Contemporary Perspectives in Rehabilitation
Critical Reviews in Physical Medicine and Rehabilitation
Current Concepts in Rehabilitation Medicine
Disability Studies Quarterly
Industrial Rehabilitation Quarterly
International Rehabilitation Review
IRMA Monograph Series (International Rehabilitation Medicine Association)
Journal of Cardiopulmonary Rehabilitation
Journal of Disability Policy Studies
Journal of Neurologic Rehabilitation
Journal of Prosthetics and Orthotics
NARIC Quarterly
Pediatric Habilitation
Pediatric Physical Therapy
Physical Medicine and Rehabilitation: State of the Art Reviews
Rehab Briefs (reviews)
Rehabilitation Nursing
SOMA—Engineering for the Human Body
Springer Series on Rehabilitation
Trends in Rehabilitation

standable. This factor greatly diminishes the incentives for overcoming the six preceding obstacles.

While most people think of on-line access when the term "information system" is used, most of the information conveyed electronically is in the form of bibliographic references to other documents. The actual content or detailed information is still generally stored and accessed in print form. In reality, then, most rehabilitation-related information is not disseminated through computers. Instead, it is distributed through more traditional means such as the following:

- Professional organizations
- Manufacturers
- Trainers and educators
- Peer support groups
- Public and private rehabilitation agencies
- Government programs
- Disability information and referral centers
- Journals
- Newsletters
- Conferences
- National disability organizations
- Public media

At this time, these information channels are the only ones capable of providing integrated, across-topic, or interpreted information. Yet, the problems associated with the information sources listed are well

Table 6.
A Sampling of Rehabilitation-related Databases

ABLEDATA and Hyper-ABLEDATA
Accent on Information
AGELINE
Combined Health Information Database
COMPENDEX Engineering Index
Cumulated Index to Nursing and Allied Health
ERIC Clearinghouse on Handicapped and Gifted Children
Excerpta Medica
Linguistic and Language Behavior Abstracts
MEDLINE
OTSource
Psychological Abstracts
RehabData
RESNA/TRACE Service Delivery Directory
Science Citation Index
Sports Database
VA Rehabilitation R&D Database
Population databases
National Ambulatory Medical Care Survey
National Health and Nutrition Examination Surveys
National Health Interview Survey
National Hospital Discharge Survey
National Medical Expenditure Survey
United Nations Disability Statistics Data Base (95 countries)

known. It is difficult, for example, to maintain surveillance over all these channels; to integrate information presented in different sources, formats, or media; and to locate all the necessary items of information when they are needed. These and other long-standing problems are solvable with electronic information technologies, the inadequacies of current electronic information systems notwithstanding. Expected advances and improvements can dramatically change how people in the rehabilitation field get their information.

Ease of access and cost are the two most important factors influencing the success of information searches. Unfortunately, there usually is an inverse relationship between these two components and the comprehensiveness and reliability of the information obtained. That is, the easiest and cheapest methods usually produce the poorest information. As a result, the sources of information most people use rarely contain the best information available. In regard to electronic information technology, efforts must be made to reduce user costs; however, the greatest gains will be made by simplifying the methods of information access.

Future Trends

The term "information explosion" is often used to describe the ever-increasing amounts of information available to the public through television, movies, newspapers, magazines, and other media. As applied in the scientific community, however, the term describes the exponentially increasing amount of information known about physiological and biochemical processes, and the incidence, diagnosis, transmission, and treatment of disease. Unfortunately, the "information explosion" all

too often produces data that are not directly usable by professionals or consumers.

New technologies and the increasing information-processing potential they embody present the opportunity not only to correct the problem of unusable data, but also to enhance and augment the capabilities of rehabilitation medicine research. The new tools will accumulate, structure, manage, display, and disseminate information in ways that will make it far more accessible and useful to increasing numbers and types of people.

With continuing improvement, expert systems will be able to manage information, carry out automated information searches, and serve as an active repository of specialist expertise to aid human decisionmaking. Emerging interface systems and approaches will dramatically increase the options for accessing, organizing, and displaying information and for communicating with other researchers. Examples include touch screens, handwriting interfaces, and computers that respond to spoken commands. Combined with the advances in "naturalizing" computer languages, much more "friendly," practical, and useful computer and information access will be possible. Moreover, the trend is toward alternative access methods, which would make the use of information technology much easier for people with sensory and motor limitations.

Optical storage and video display technologies are expanding the use of computers as information and education tools. These technologies permit individuals to interact with a computer to find specific information and then present this information in graphic form. This technology presents new opportunities for absorbing and transferring information, which would appeal especially to the generations that have grown up with computers and television. Advances in high-density storage devices and high-speed communication networks will enable large amounts of information to be sent from one site to another, no matter how remote. These technologies will also make it possible to provide printed and audiovisual responses to information queries at a level appropriate to the user's specificity of need and sensory and motor abilities.

Use of computer and video teleconferences is growing, and researchers are examining how to use these approaches most effectively. In addition, computer bulletin boards are becoming a communication and information-exchange tool for an increasing number of people. The popularity of these technologies or more sophisticated versions of them will continue to grow as telephone companies and others develop markets for professional, business, and home use.

The ability of the field of rehabilitation medicine to use these advances will be directly related to its success in developing information-storage and access techniques that are appropriate and effective in rehabilitation settings. The high costs of new technologies must also be reckoned with if the field is to take advantage of the tremendous new potential for accessing and using information. The challenge ahead lies in identifying new developments that will deliver the information in the most meaningful ways and finding sustained funding mechanisms to support the assembly, maintenance, and widespread use of the information base.

Anticipated Benefits

Harnessing the power and applications of new and emerging information technologies would foster progress in rehabilitation medicine in several critically important areas. Anticipated benefits include the following:

- Better research with fewer duplicative efforts and more efficient and effective collaborations.
- Improvement in rehabilitation practice, resulting from better and more timely

communication of new techniques and practices.

- Increased independence for people with disabilities as a result of better delivery of services and better access to information on treatments and services.

Obstacles

A finely tuned information resources system would have a major positive impact on rehabilitation medicine. However, several obstacles must be overcome before this potential can be realized.

First, by its very nature, the field is diverse, and users will need different types of information presented in different ways. Any information system must deal with this diversity, for it cannot be assumed that dissemination directed at any one group, such as physicians, will necessarily "trickle down" to other groups. Currently, most information is not available in user-appropriate formats.

Second, although there are a multitude of information sources, most are too scattered for the average person to find. In fact, some of the information is so hard to find that the term "fugitive literature" has been coined to describe its elusiveness. Most people are aware of only a small fraction of the different information sources relevant to their situation; they also have no means of accessing the information.

Third, if existing information systems were tied together and people understood how to access them, the sheer volume of information would be overwhelming. In fact, even without access to the multitude of information sources, most researchers and practitioners are overwhelmed by the amount of information they do have available. Yet, they often have difficulty finding the answers to their questions.

Fourth, gaining access to these systems takes too much time and expertise. Although some information sources are developing more user-friendly interfaces, most databases still require a thorough knowledge of key words and specialized search language in order to conduct meaningful or targeted searches. These difficulties limit researchers' willingness to search beyond all but the most easily accessible resources, usually journals, books, and other traditional sources of information that are nearby.

Fifth, much information is not available in useful form; nor is it of high quality or sufficiently detailed. Despite the huge amount of information available, significant gaps exist.

Finally, with the ever-increasing amounts of information available, it will become more difficult to evaluate conflicting information. In the end, appropriate interpretation of the available data will depend on the expertise and evaluative capability of the reader.

Recommendations

Build an Integrated Information Resources System

Existing information resources in the field of rehabilitation medicine should be linked to form an integrated network. This does not mean creating a large, single entity. Effective linkages among the various systems would permit each to retain its unique expertise and to concentrate on assembling information in its specialty. Information resources here mean publications, nonelectronic databases, and people, as well as electronic databases. Specific recommendations follow:

- Develop a directory of all existing information systems related to rehabilitation (print, electronic, and people).

- Develop a means of tying together widely disparate information resources, including the following:
  - demographic information;
  - bibliographic products;
  - information on practices and treatments;
  - service delivery programs and specialists;
  - introductory and overview information on impairments, disabilities, and handicaps associated with specific disease conditions;
  - crisis management information; and
  - research findings.
- Develop a clearinghouse, or common reference point, for securing information on other information-resource programs and services.
- For each Federal interagency panel on issues relating to rehabilitation, designate an information-resource contact to facilitate contact with, submit queries to, and provide related material to the panels;
- Within the National Institutes of Health, designate a person or office to become knowledgeable about information sources in rehabilitation and to act as a central point of contact for research-specific information.
- Develop a uniform or compatible taxonomy of disability and data-storage formats to facilitate the sharing of information between different databases and to ease access to multiple databases.
- Develop data translation algorithms to allow cross-linking and searching of databases with differing taxonomies.
- Develop tools to permit practitioners to enter status and outcome-measure data and receive information on treatments.
- Develop a means to tie individual experts and expert teams into the information system, making them accessible to other researchers and to practitioners. (A model is the National Cancer Institute's Physicians Data Query, or PDQ.)

Develop an Awareness of Information Sources and Means of Access

A primary reason for poor utilization of existing knowledge and information services is lack of awareness of their existence. Steps should be taken to acquaint researchers, practitioners, people with disabilities, and others with the available information resources. Such efforts should include development of a direct, easy means to access these resources. Specific recommendations follow:

- Conduct a national promotional campaign to acquaint people with rehabilitation-related information resources and create an information resources directory.
- Develop a central number and referral point for people seeking rehabilitation-related information.
- Ensure that funders of databases and information programs require these services to develop and carry out promotional and educational activities aimed at increasing awareness.
- Include a page in all Request for Proposal packets providing new investigators with information on available information resources and how to access them. This would not be a comprehensive listing, but a listing of key sources and of ways to find out about other resources.
- Develop a mechanism to ensure that rehabilitation clients and their families and friends are aware of the available information resources.

Create Faster, More User-friendly, and More Accessible Interfaces

Perhaps the single greatest barrier to using an information system once its existence is known is the time and expertise needed to access the system. Practitioners routinely consult their colleagues and spend time researching journals, but fail to access much of the information (databases and journals not in their collection) because of the amount of work involved. In addition, researchers, practitioners, and consumers with disabilities may have difficulty accessing some types of information resources. Specific recommendations follow:

- Investigate and develop techniques to access information more quickly.
- Develop interfaces that are intuitive to nontechnical users. This includes development of methods for natural language inquiries and development of active interaction and query assistance, i.e., where the information resource actually questions and assists the inquirers in defining their question.
- Develop information systems that are easily accessible, understandable, and affordable for people with disabilities.
- Develop a method for integrating information on a given topic and presenting this information in user-appropriate formats. This is especially critical in the area of pediatric rehabilitation.
- Develop low-cost information systems, such as library-based, "free" access information systems.
- Develop techniques for translating data and information. This includes translating information to make it understandable to people with different levels of technical expertise, different levels of language proficiency, and different languages. It also includes translation into different formats, such as braille or speech, for those who require it.
- Develop training programs on how to use information systems for researchers, practitioners, people with disabilities and their families and friends, third-party payers, and policymakers. These programs should include technical assistance and training for consumer organizations that receive large numbers of inquiries but may have only minimal access to, or skill in using, information resources.
- Investigate the factors that may discourage use of information resources, including cultural barriers, types of disability, rural location, and limited or no access to technology.
- Investigate how television-based information systems of the future can be used effectively to disseminate rehabilitation information. This includes research on electronic telephone book technologies.
- Study the use of artificial specialists in settings where human specialists are not available. An example is knowledge robots, or "knowbots," that could be programmed to search multiple databases for relevant information.

Develop Ways To Increase the Utility of Available Information

The value of information is determined by its relevance and usefulness to the user. As already noted, much rehabilitation-related information is not disseminated in ways that makes it useful and meaningful for its many potential audiences. One approach to correcting this problem would be to store a much broader range of predigested information in the system and to make it accessible with simple retrieval procedures. Another approach would be to utilize people or "knowbots" to collect the relevant

information and digest or interpret it for the inquirer. Specific recommendations follow:

- Develop information systems that provide more than just bibliographic information.
- Develop "knowbots" to help in the search for, collection of, and eventually the interpretation of information from diverse sources.

Increase the Accuracy and Quality of Information

A major concern is the inevitable collection of inaccurate or useless information as the size and number of databases and other information resources increase. Improving the quality of the clinical literature is vitally important. However, while we work toward the goal of improving the overall quality of information available, we must continue to disseminate the best information we have at the moment. It is also important to ensure that the best information is also the most accessible to the information seeker. Specific recommendations follow:

- Improve the quality of published medical rehabilitation research by fostering the adoption of improved peer review criteria, such as those promoted by the *British Medical Journal.*
- Evaluate existing sources to determine accuracy, utility, and accessibility.
- Determine what data are currently being collected, what they are being used for, and where gaps (unmet needs) exist.
- Provide sustained, long-term support for information resources of demonstrated quality and utility.

Add New, Needed Data and Information to the System

The current information resource suffers from gaps in several important areas. Recommendations to fill these gaps follow:

- Create a patient registry that includes demographic information, data on the patient's functional status and rehabilitation outcome, and the variables and measures used in evaluating the patient.
- Create a database that contains the *final results and findings* of studies funded by public grants and contracts. Databases of proposal abstracts exist, but there is no central repository for information on outcomes, methods, and other topics of interest to researchers. This could be accomplished by requiring that a summary abstract of results, along with a reference to documentation of the full results, be a mandatory part of all final reports to funders.
- Create a database of funding sources for (1) research programs; (2) service delivery and other rehabilitation-related programs; and (3) services and devices for people with disabilities.
- Provide support for a planned study of disability by the Statistics Panel of the National Research Council.
- Include questions on the need for and use of rehabilitation services in the Post-Census Disability Survey currently being planned by the U.S. Bureau of the Census.
- Conduct research on the development of automatic reporting systems for collecting data on disability and impairment. Such systems would ensure comprehensive and consistent collection of patient data, which in turn would be fed immediately into a central database, with appropriate provisions for privacy.

Appendix A

Appendix A

The Dimension of the Problem in Medical Rehabilitation

Roberta B. Trieschmann, Ph.D.

The problem of physical disability in America is recent. Before World War II, death was a natural part of life—one that affected individuals of all ages, not just grandparents. Children and adults died of injuries and diseases, and pneumonia was known as the old person's friend. Occasionally, individuals defied the odds and survived major illnesses or injuries with severe physical impairments, but life with a disability was usually confined to the home, and invalids were not expected to participate in the normal rituals of life like work, marriage, raising children, or participating in the community. The *Random House Dictionary* defines the noun invalid as an "infirm or sickly person; a person who is too sick, weak, or old to care for himself; a person disabled by sickness or old age, i.e., a hopeless invalid." Invalid, as an adjective, is defined as "not valid; without force or foundation; indefensible; deficient in substance or cogency; weak, void or without legal force." These concepts shaped the existence of people with disabilities in the 1930's, 1940's, and 1950's, and sometimes still do today. Thus the dimension of the problem of physical disability before World War II was minimal. The life expectancy was 1 to 3 years after spinal cord injury, for example, and families were expected to care for persons so injured at home until they died.

The development of the sulfanilomides and antibiotics in the 1930's transformed medicine. Before their invention, physicians watched helplessly as patients died, and their role was often limited to comforting the sick and providing solace to the family. However, these pharmaceutical miracles provided an opportunity to "do something," to *cure* diseases and infections, and to save lives. People survived major illnesses and were less likely to die of infections and complications secondary to severe trauma. By the end of World War II, military hospitals were filled with thousands of severely disabled men, heroes to the Nation, but heroes with amputations, paralyses, disfigurements, and a variety of musculoskeletal and neurological impairments. There was certainly no role for these people in society, and thus the dimension of the problem of physical disabilities meant custodial care.

Although they lived in the hospital, these men were young and vital, and with their Veterans' Administration (VA) compensation payments, they ventured out into the world with an "eat, drink, and be merry, for tomorrow we die" attitude. Eventually school, dating, marriage, moving out into the community, and work became natural

parts of life again. Joined by the survivors of the polio epidemics of the 1940's and the 1950's, these persons, by their sheer numbers, could not be hidden in back bedrooms or confined to hospitals any longer. Consequently the dimension of the problem of physical disability became one of community integration.

During the 1940's and 1950's, meanwhile, medical rehabilitation programs to manage physical disability developed and extended beyond the VA into the civilian world. Because cure was not the issue in these cases, many professional disciplines were involved in addition to physicians. Thus, nurses, physical and occupational therapists, psychologists, social workers, vocational counselors, prosthetists and orthotists, speech pathologists, and rehabilitation engineers formed the interdisciplinary team that has become the cornerstone of all medical rehabilitation practice. Simultaneously, the Federal Government began to finance programs of medical research, both basic and clinical, that were aimed at understanding the pathophysiology of disease and injury. The focus was on curing and saving lives. New pharmacological agents, surgical procedures, and technological advances in the diagnosis and treatment of disorders expanded the power of the medical profession to prevent death. More people survived with physical impairments and an altered ability to resume the normal features of premorbid function.

By the end of the 1950's, the dimension of the problem of physical disability had grown to include research into more effective acute medical management and prevention of complications; development of rehabilitation programs in civilian hospitals; education of health care professionals in disability management; and vocational rehabilitation programs. Life expectancy after a spinal injury, for example, was now estimated to be 20 years or more, but no one knew for sure. Discharge became the rule rather than the exception, although hospitalization often lasted a year or more. However, financial survival for those without service-connected disability payments from the VA was grim, and consequently a patchwork quilt of social welfare legislation was passed in an attempt to ensure the survival of those who could not work. Nevertheless, in true American tradition, people were expected to earn their own way, and vocational rehabilitation programs were inaugurated to help. In actuality, however, most persons with disabilities received double messages from society: The expectation of invalidism was still the predominant attitude, but the requirement of self-sufficiency was implicit in most of the social welfare and rehabilitation programs.

In the 1960's and 1970's, spectacular advances in medicine resulted in a larger population of persons surviving the acute and chronic stages of physical illness and injury, and thus the number of persons with disabilities increased. The dimension of the problem of physical disability now became long-term survival physically, psychosocially, and financially. But by the 1970's, those with physical disabilities were not content to be grateful for mere survival as second-class citizens, and they began to challenge society's requirement that they achieve financial independence without equal access to society's opportunities and without the right to self-determination. They had been fully willing to accept responsibility for their own lives, but only if given access to a full range of choices as to how they would live their lives.

But their choices were limited by society's attitudes, inaccessible environments, and draconian regulations that required sustained financial destitution as a prerequisite for public assistance. Unfortunately, in many instances, the legislation actually penalized persons for striving to be financially independent. The financial disincentives to productivity were described to legislators and policymakers, and the inde-

pendent living movement gained momentum as persons with disabilities requested the opportunity to provide needed services that were ignored by the rehabilitation establishment. At this point, the dimension of the problem expanded to include the right to first-class citizenship.

It was also during the 1970's that the systems concept of medical management of high-cost disabilities (such as spinal cord injury) was being demonstrated at selected centers around the United States. Thus, within the civilian sector the Model Regional System for Treatment of Spinal Cord Injury (currently supported by the National Institute on Disability and Rehabilitation Research) provided for coordination of emergency medical services, acute treatment of spinal injury, rehabilitation, and followup in the community. It was demonstrated that the cost of spinal injury could be reduced through such a system by prevention of unnecessary medical complications and by timely, expert rehabilitation; as a result, the length of hospitalization could be reduced to 3 or 4 months in uncomplicated cases of paraplegia and quadriplegia. By the late 1980's, this concept had been extended to traumatic brain injury.

Consequently, the dimension of the problem of physical disability was becoming one of the growing numbers of people who were living with a disability, the cost of initial hospitalization and lifetime care, and the role that society was expected to play in long-term care. The American public had always generously supported the concept of saving lives; however, such generosity was noticeably lacking once the life had been saved. This issue continues to be unresolved.

Now the dimension of the problem of physical disability has mushroomed. Advances in medical technology and effective dissemination of information to emergency medical services have increased the number of persons surviving trauma or illness with very severe impairments (e.g., respirator-dependent quadriplegia). Previously these persons died at the scene of the accident or soon after. The issues of their quality of life and their right to end their lives have added ethical, legal, and emotional dimensions to the problem of disability.

At the same time, because of excellent care in the early stages, more persons are surviving with less severe disabilities, but with disabilities nonetheless. Neonatal intensive care units have saved the lives of many infants who used to die and who now survive with massive disabilities. In the latter years of life, a larger proportion of our senior citizens are surviving with varying degrees of impairments, and almost everyone can count on living with a physical disability for some period before dying. Furthermore, a sizable population of persons with spinal injury, polio, and cerebral palsy of 30, 40, and 50 years' duration are aging with their disabilities. So medical technology has extended the dimension of physical disability at both ends of the continuum: the survival of more people with very severe disabilities and the survival of many into old age. Both of these possibilities were inconceivable as recently as 25 years ago.

For a half-century, the primary emphasis in medical science has been to cure disease and therefore save lives. Based on the belief that with sufficient resources, everything could be cured, billions of dollars have been devoted to this cause. There have been many dramatic successes in this battle with death, but the problem of physical disability is the byproduct of this success. Once the life is saved, support for research into strategies to promote health, wellness, and productivity in those whose life has been saved has been less enthusiastic. This problem of what happens later—after discharge from the acute medical wards—has not been considered to be as legitimate a concern for medical science. In fact, many do not consider it an appropriate concern at all.

Yet with rising health care costs and massive Federal deficits, there are calls for reexamination of the priorities in our health care system. Daniel Callahan in *What Kind of Life: The Limits of Medical Progress* (1990) and *Setting Limits: Medical Goals in an Aging Society* (1987) states that we must reorient our emphasis from a strictly "curative" approach to a "caring" one. Because there are natural limits to the extent to which we can prevent death, we must acknowledge this fact and establish a more balanced set of priorities for medical research and clinical practice. This Task Force is not suggesting that we not save lives, but rather insisting that resources be devoted to those whose life has been saved. As a Nation, we can no longer afford to ignore how people with disabilities will manage to live after their life has been saved because these postacute consequences have a serious impact on their health and eventual consumption of further health care resources.

Physical disability in the United States today has become a problem because of an unbalanced approach to medical research and practice. Millions of lives have been saved at an ever-increasing cost. But society's refusal to acknowledge the physical, emotional, and financial realities of these saved lives has added billions of dollars of unnecessary cost to the health care and social welfare systems every year.

Appendix B

Appendix B

Task Force on Medical Rehabilitation Research

June 28-29, 1990
Hunt Valley Inn,
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Adjunct Associate Professor, Pediatrics and Neurological Surgery
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Through the Looking Glass
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Basic and Clinical Research Training

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Appendix C

Appendix C

Reviewing Organizations

American Academy of Dermatology, Inc.
Evanston, IL

American Academy of Neurology
Minneapolis, MN

American Academy of Orthopaedic Surgeons
Park Ridge, IL

American Academy of Otolaryngology
Washington, DC

American Academy of Pediatrics
Elk Grove Village, IL

American Academy of Physical Medicine and Rehabilitation
Chicago, IL

American Association for Advancement of Science
Washington, DC

American Association for Cancer Research
Philadelphia, PA

American Association for Medical Systems and Informatics
Washington, DC

American Association of Colleges of Nursing
Washington, DC

American Association of Electromyography and Electrodiagnosis
Rochester, MN

American Association of Neuroscience Nurses
Chicago, IL

American Association of Retired Persons
Washington, DC

American Association of Spinal Cord Injury Nurses
Jackson Heights, NY

American Association of the Deaf-Blind
Silver Spring, MD

American Cancer Society
Atlanta, GA

American Cleft Palate Association
Pittsburgh, PA

American College of Mohs Micrographic Surgery and Cutaneous Oncology
Evanston, IL

American College of Physicians
Philadelphia, PA

American College of Rheumatology
Atlanta, GA

American College of Sports Medicine
Indianapolis, IN

American College of Surgeons
Chicago, IL

American Congress of Rehabilitation Medicine
Chicago, IL

American Deafness and Rehabilitation Association
Little Rock, AR

American Diabetes Association
Alexandria, VA

American Geriatric Society
New York, NY

American Hearing Research Foundation
Chicago, IL

American Heart Association
Dallas, TX

American Heart Association, Stroke Council
Richmond, VA

American Hospital Association
Chicago, IL

American Neurological Association
Minneapolis, MN

American Nurses Association
Kansas City, MO

American Occupational Therapists Association
Rockville, MD

American Organization of Nurse Executives
Chicago, IL

American Osteopathic Association
Pamona, CA

American Osteopathic College of Rehabilitation Medicine
Des Plaines, IL

American Paralysis Association
Springfield, NJ

American Physical Therapy Association
Alexandria, VA

The American Physiological Society
Bethesda, MD

American Psychological Association
Washington, DC

American Radium Society
Philadelphia, PA

American Society for Head and Neck Surgery
Seattle, WA

American Society for Pharmacology and Experimental Therapeutics
Bethesda, MD

American Society for Therapeutic Radiology and Oncology
Reston, VA

American Society of Clinical Oncology
Chicago, IL

American Society of Colon and Rectal Surgeons
Palatine, IL

American Society of Hematology
Thorofare, NJ

American Society of Nephrology
Washington, DC

American Society of Pediatric Hematology and Oncology
Chicago, IL

American Speech-Language-Hearing Association
Rockville, MD

American Spinal Cord Injury Association
Chicago, IL

American Tinnitus Association
Portland, OR

American Urological Association, Inc.
Baltimore, MD

Arthritis Foundation
Atlanta, GA

Association for Academic Physiatrists
Cincinnati, OH

Association for Advancement of Behavior Therapy
New York, NY

Association for Research in Otolaryngology
Boston, MA

Association of American Cancer Institutes
Tucson, AZ

Association of American Medical Colleges
Washington, DC

Association of Community Cancer Centers
Rockville, MD

Association of Rehabilitation Nurses
Skokie, IL

Autism Society of America
Washington, DC

Brain Tumor Cooperative Group
Barrow Neurological Institute
Phoenix, AZ

Cancer Care, Inc.
New York, NY

Cancer and Leukemia Group B
Dana-Farber Cancer Institute
Boston, MA

Candlelighters Foundation
Washington, DC

Centers for Disease Control
Atlanta, GA

Central Institute for the Deaf
Saint Louis, MO

Children's Cancer Study Group
School of Medicine
Pasadena, CA

Children's Hospital and Medical Center
Seattle, WA

Council of Nurse Researchers
Seattle, WA

Council of State Administrators of Vocational Rehabilitation
Washington, DC

Cystic Fibrosis Foundation
Bethesda, MD

Deafness Research Foundation
New York, NY

Eastern Cooperative Oncology Group
Wisconsin Clinical Cancer Center
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Encore, Inc.
New York, NY

Epilepsy Foundation of America
Landover, MD

Equal Employment Opportunity Commission
Washington, DC

European Organization for Research and Treatment of Cancer
Brussels, Belgium

Friends of NIDCD
Narberth, PA

Gynecological Oncology Group
Philadelphia, PA

Head Trauma Association
(American Trauma Society)
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The Heart and Lung Institute at St. Vincent's, Inc.
Jacksonville, FL

Huntington's Disease Foundation of America
New York, NY

Intergroup Rhabdomyosarcoma Study
Virginia Commonwealth University
Richmond, VA

Juvenile Diabetes Foundation
New York, NY

Leukemia Society of America
New York, NY

Lupus Foundation of America
Washington, DC

The Miami Project to Cure Paralysis
Miami, FL

Midwest Nursing Research Association
University of Nebraska
Omaha, NE

Muscular Dystrophy Association
New York, NY

National Academy of Sciences
National Research Council
Washington, DC

NASA-Commercial Development Division
Washington, DC

National Alliance of Breast Cancer Organizations
New York, NY

National Association for Independent Living
Alexandria, VA

National Association of Rehabilitation Facilities
Reston, VA

National Coalition for Cancer Survivorship
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National Coordinating Council on Spinal Cord Injury
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National Council on Disability
Washington, DC

National Head Injury Foundation
Southboro, MA

National Hospice Organization
Arlington, VA

National Institute on Disability and Rehabilitation Research
Washington, DC

National League for Nursing
New York, NY

National Leukemia Association, Inc.
Garden City, NY

National Multiple Sclerosis Society
New York, NY

National Organization for Rare Disorders
New Fairfield, CT

National Rehabilitation Hospital
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National Retinitis Pigmentosa Foundation, Inc.
Baltimore, MD

National Science Foundation
Washington, DC

National Spinal Cord Injury Association
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National Stroke Association
Englewood, CO

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Social Security Administration
Baltimore, MD

Society for Neuroscience
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Society of Gynecologic Oncologists
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Society of Head and Neck Surgeons
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Society of Pelvic Surgeons
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Society of Surgical Oncology
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Society of Urologic Oncology
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Southwest Oncology Group
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Dear Dr. Medgyesi-Mitschang:

The American Academy of Dermatology, through its Council on Research, welcomes this opportunity to comment on the draft report of the Task Force on Medical Rehabilitation Research which you sent to J.G. Smith, Jr., President (1990) of the American Academy of Dermatology. This letter emphasizes potential interactions between dermatology and rehabilitation research which should be explored as part of comprehensive efforts on rehabilitation research considered and outlined very well in your important and proactive document.

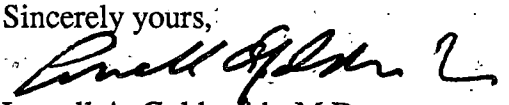
There are, at least, two important interfaces between dermatology which have not been significantly explored in the report which are important with respect to skin disability: 1) disabilities causing marked impairment of skin function related to genetic and acquired diseases directly affecting the skin and, 2) the prevention and treatment of skin ischemia and "Decubitus Ulcers". A comprehensive rehabilitation research plan should address both of these interfaces and the American Academy of Dermatology welcomes the opportunity to be one of those interfaces between the rehabilitation and the dermatology research communities.

There are dermatological diseases including psoriasis, atopic dermatitis, lupus erythematosus, scleroderma and severe genetic diseases such as ichthyosis, epidermolysis bullosa and the ectodermal dysplasias which limit as many as 1 in two hundred Americans (Table 2, p. 36, rehabilitation report). Also to be included are the patients with the cutaneous consequences of severe burns which markedly impair skin function. Individuals with all these conditions, in addition to their physical and medical treatments, need a comprehensive social, behavioral and psychological approach with contributions by both dermatological and rehabilitation experts. Specific areas of research of a combined nature should include, control of body temperature which is affected in several of these disorders and the development of shoes and other materials to decrease shear-induced blistering in epidermolysis bullosa.

Skin ischemia is given some discussion (pp.,31,48) but is not mentioned under the discussion of secondary complications of Spinal Cord Injury (p.53). Skin ischemia and decubitus ulcers are still major health problems in terms of their frequency and ultimately

their monetary implications (JAMA, 264:2905-2909, 1990). Recent increases in understanding and methodology related to skin sensation, skin vasculature and the culturing of skin cells makes new preventative and therapeutic approaches to this vexing condition now possible. These research opportunities should be a significant part of a national plan in rehabilitation research and is another important interface between dermatology and rehabilitation.

Sincerely yours,



Lowell A. Goldsmith, M.D.
James H. Sterner, Professor of Dermatology
Chair, Department of Dermatology
University of Rochester
School of Medicine and Dentistry

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December 20, 1990

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Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

The American Academy of Neurology's Section on Neurologic Rehabilitation welcomes the opportunity to review and comment on the Task Force on Medical Rehabilitation's Report.

The Task Force's Report is to be highly commended for their excellent and thorough report addressing crucial elements which will impact the future of neurorehabilitation research, the advancement of basic and clinical rehabilitation neurosciences, and the care of patients with neurologic impairments, disabilities, and handicaps. The following points are designed to emphasize certain areas and be additive to other areas of the report.

1. Develop (through priority funding and other mechanisms) the crossover of scientists in rehabilitation related fields to focus more directly on relevant rehabilitation research. There are many scientists in fields such as neurology, internal medicine, oncology, geriatrics, orthopedics, urology, psychology, nursing, etc., that have research interests that can be applicable to rehabilitation research. Adding incentives such as priority funding would potentially stimulate their interests more directly into rehabilitation research. This strategy would supplement the supply of currently available rehabilitation research scientists.

2. To develop mechanisms to encourage scientists in rehabilitation related research (see number 1 above) to train potential rehabilitation scientists in rehabilitation research. This recommendation is predicated on the fact that there are few role models for research training in established rehabilitation programs. Therefore, established scientific role models from other fields with rehabilitation related interests could serve as mentors for young scientists who are interested in rehabilitation research, both at the clinical and basic level.

3. The assessment and epidemiologic research efforts should also emphasize the many disabling conditions that are progressive. The premise being that even though disabling conditions are progressive, patients can still be helped functionally by rehabilitation intervention, the team approach, and rehabilitation technology research. The prevention of secondary disabilities needs considerable research efforts and is an important aspect leading to the progression from impairment to disability and handicap.

4. Assessment tools need to be developed to allow the measurements of functional differences in rehabilitation methodology that are aimed at reducing disability of progressive illnesses. For example, progressive illnesses are associated with progressive decreases in function. However, the rehabilitation intervention, the functional loss may be much less than without rehabilitation intervention.

5. Develop and implement neurorehabilitation clinical research methodology which may be more applicable to rehabilitation multidisciplinary research than the standard clinical trials. For example, single case study methodology currently gaining favor in neuropsychology research may be applicable to other rehabilitation research areas. Establishing priority funding for outcome assessment may stimulate more energy and effort into this area. Currently, much of this research is stifled by an attitude that, "Why work on assessment and outcome measures since grants are so difficult to be funded in this area?"

6. Encourage the development of clinical research programs within non-academic rehabilitation centers and hospitals. Try to establish a link between academic research centers and non-academic rehabilitation centers so that the enormous volume of clinical material in non-academic centers becomes accessible to researchers in academic centers. In addition, encourage the development of research programs in non-academic centers, either directly or indirectly through liaisons with academic centers. This recommendation is predicated on the fact that most academic centers are divided into departments and the best rehabilitation programs are successful because they break down "departmental barriers." Successful rehabilitation centers in the private sector are an ideal source of research studies in interdisciplinary team effectiveness. However, rehabilitation researchers are more likely to be found at academic centers where departmentalization is often an impediment for true interdisciplinary multispecialty interaction. Successful pilot projects in the private sector may serve as useful models to apply in academic institutions. This concept is a reversal of standard research methods where pilot projects are often initiated in universities and then transferred to the private sector.

7. Establish clinical research training in private sector centers as well in addition to centers, since the majority of rehabilitation efforts are focused outside of academic centers. These private sector rehabilitation centers usually have significant computer capabilities to conduct clinical research and would serve as an excellent base for clinical research training.

We trust that the above recommendations will serve to emphasize the AAN Neurorehabilitation Section's enthusiastic support of the task force's report and its readiness to participate in the process leading its implementation.

Sincerely,

Jack S. Burks, M.D.
Chairman, AAN Section on Neurorehabilitation

JB/DT/ajd

American Academy of Orthopaedic Surgeons

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December 19, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

On behalf of the American Academy of Orthopaedic Surgeons, I would like to thank you for the opportunity to comment on the Report of the Task Force on Medical Rehabilitation Research. Your quick turnaround time will prevent our Academy from undertaking a formal review of this lengthy report. However, I have looked over the section on musculoskeletal disorders and found it informative and of potential use to our fellowship. I will pass the report on to the appropriate leaders of the Academy for their information.

I look forward to receiving the final report. Please keep us in mind when developing similar studies in the future. We would be pleased to provide expert representation on appropriate panels or task forces.

Sincerely,

Nancy Peacock Heath

Nancy Peacock Heath, PhD
Director, Center for Research
Department of Health Policy and Research

NPH:sn

cc: Thomas C. Nelson
Rebecca Maron
Joseph Buckwalter, MD
B. Kaye Boles, PhD

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

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December 28, 1990

Suzanne Medgyesi-Mitschang, M.D.
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda MD 20892

Dear Doctor:

I am sorry for the tardiness of this commentary relating to the pre-publication draft copy of the report of the Task Force on Medical Rehabilitation Research. Unfortunately it was sent to our former address and just now forwarded to me.

On quick review of this well-done document, I am struck by the apparent absence of any reference to the role of hearing impairment.

In particular, in the section on geriatrics, it would seem appropriate to include direct reference here to the role that hearing loss might play in the impairment of cognitive functioning of older adults. After all, approximately 50% of those reaching the age of 75 have at least socially-inadequate hearing. When investigating the neuroplasticity of the nervous system of older adults, specific reference, I believe, should be made to the adequacy of hearing.

For some years now, I have questioned the appropriateness of audiology being placed under the direction of Rehabilitation Medicine in hospitals in this country. I have questioned this at as high a level as the JCAH, and years ago was told that speech therapy is like physical therapy, and should go under Rehabilitation Medicine. Audiology was brought in under the same cover without adequate understanding, I feel, of the lack of training that rehabilitation medical experts have in this critical area. I would think it appropriate for physicians of my specialty to be involved in this most-needed rehabilitation effort. The thirteenth institute at the NIH is the NIDCD, and I believe, should be

involved in this effort. The role of otolaryngologists and speech pathologists in the rehabilitation of elderly patients, with or without stroke, who have impairment in speech and swallowing functions, is self-evident.

Thank you for the opportunity of reviewing this important document. I would be happy to elaborate on any of the foregoing.

Very truly yours,

Jerome C. Goldstein, M.D., F.A.C.S.
Executive Vice President

JCG:db

cc: Robert Ruben, M.D.
James Snow, M.D.
Jay Moskowitz, Ph.D.

AMERICAN CANCER SOCIETY® NATIONAL OFFICE

January 2, 1991

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang

Thank you for giving me the opportunity to review the draft copy of the report of the Task Force on Medical Rehabilitation Research. I realize that the deadline for comments has passed. Unfortunately the draft reached my office while I was traveling. I hope it is not too late to send a few comments.

On page 10, under "Cancer Rehabilitation", the often quoted prediction that "In the near future, one out of a thousand 20-year-olds will be a survivor of childhood cancer", is included. This prediction was made by Dr. Anna Meadows at Children's Hospital in Philadelphia in approximately 1978. It might be worth checking with Dr. Meadows to see if she still uses the same numbers. The outcome of treatment for childhood cancer has changed since 1978. This formula may need to be updated.

In the section on "Breast Cancer" on page 78, it states that "Refinements in breast reconstruction techniques,....., are needed. Finally, the timing of postoperative exercise programs for these women has not been adequately studied."

Recently I attended an American Cancer Society workshop on breast reconstruction. In listening to the experts, I concluded that the timing of the reconstructive surgery, itself, has not been adequately resolved. There was quite a bit of controversy about this issue; some surgeons advocating doing the reconstruction at the time of the original surgery, others advocating waiting until the original surgical incision is healed.

At the bottom of page 82 the statement is made that "The psychosocial needs of the patient with metastatic disease are ordinarily greater than those of the patient for whom

cure is expected." This seems obvious, but I wonder if it has been demonstrated to be true. The psychosocial needs are certainly different. Issues of survivorship such as uncertainty, body image, productivity, fatigue, employability, insurability, etc. are paramount for the curable patient. The patient with metastatic disease is dealing with pain, suffering, functional limitations and loss and grief, to name a few. That sentence jumped out at me as possibly being one of those assumptions we make as health professionals that has more to do with our feelings and concerns than with the needs of patients. Just a thought for your consideration.

On a more general note, I would like to make a semantic observation. Throughout the manuscript, the terms rehabilitation medicine and medical rehabilitation are used. It was not clear to me how the designation, "medical" differs from rehabilitation. In the preface it states that "The report represents the combined contributions of more than 100 clinicians and researchers with expertise in a wide range of medical, biological, allied health and social sciences." I see that nurses are included in the list of Task Force members. I assume that they are included in the category of allied health. I would like to point out that this is a categorization that is not widely accepted by nurses, the largest group of health professionals. Since nurses play such a big role in rehabilitation, it might be worth mentioning this discipline of clinicians and researchers separately in that sentence. Just adding one word could make a big difference to a large group of health professionals who will benefit greatly from reading this report and the changes in rehabilitation that it will generate.

Thank you for giving me an opportunity to review and comment on the report. I have learned a lot by reading it and I am sure it will be a useful foundation for much needed change.

Sincerely,

Trish Greene, RN, MSN
Vice President for Nursing

TG:em

cc: Gerald Murphy, MD
Morton Bard, PhD
Daniel Nixon, MD

JL-1719

AMERICAN CANCER SOCIETY® NATIONAL OFFICE

JOHN LASZLO, M.D.
Senior Vice President
for Research

January 03, 1991

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

We greatly appreciated the pre-publication draft copy of the report of the Task Force on Medical Rehabilitation Research that was conducted during 1990. It's an excellent study and I was particularly interested in the sections on cancer. When it comes out in final form, I'd appreciate a copy or two if you can spare them. I just wanted to drop you a note to let you know the studies were much appreciated.

Sincerely,

John Laszlo

John Laszlo, M.D.

JL/dk

American College of Mohs Micrographic Surgery and Cutaneous Oncology

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December 11, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Medgyesi-Mitschang,

Dr. Jay Moskowitz recently sent me the pre-publication draft of the report of the Task Force on Medical Rehabilitation Research and I briefly reviewed it. The only omission that came to my attention was no mention of dermatology and skin cancer. The incidence of skin cancer, if not the most rapidly increasing, then it is certainly one of the most rapidly increasing forms of morbidity in the country today. As a clinician I find myself wondering more and more where it is all coming from. Fortunately, most of the surgery needed to rid the patient of cancer is not debilitating, but certainly sometimes is. One of the main areas of need is in helping people readjust to lifestyles that does not include exposure to the sun. For most of us this seems simple and straightforward, but to many people it is an impossible task. Most of the work in this general area should probably be devoted to prevention. Nevertheless, the need for rehabilitation once the harm has been done is probably going to increase with the incidence of skin cancer itself. I don't propose solutions or answers, but simply wanted to bring this to your attention. Kind regards.

Sincerely,

M. Braun

Martin Braun, M.D.

MB:mcr

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AOTA The American Occupational Therapy Association, Inc.

December 19, 1990

Jay Moskowitz, Ph.D.
Associate Director for
Science Policy and Legislation
National Institutes of Health
Bethesda, MD 20892

Dear Dr. Moskowitz:

The American Occupational Therapy Association, Inc. (AOTA) is pleased to have the opportunity to review and comment on the prepublication draft of the report of the Task Force on Medical Rehabilitation Research. In reviewing the report, AOTA would first of all like to applaud, as well as support, the Task Force's move to develop linkages among the basic sciences, clinical sciences, and bioengineering. Such linkages will provide the necessary bridge between biomedical research and the functional consequences of disabilities.

AOTA along with its sister organization the American Occupational Therapy Foundation (AOTF) hold as its highest priority research, and particularly research which focuses on rehabilitation, outcome data and the standardization of assessment tools.

It is a pleasure to learn that the areas identified by the Task Force as critical to the development of rehabilitation research as a scientific discipline closely mirror the priorities of AOTA and AOTF. Quantitative measures of impairments, disabilities and handicaps, and of the outcome of rehabilitative interventions; the development of standards and guidelines for the design and application of evaluation tools; and the evaluation of the effectiveness of existing and emerging rehabilitation procedures are the focus of a number of our programs.

One such program is the jointly funded Center for Research Traditions in Measurement at the University of Illinois at Chicago's Department of Occupational Therapy. Its mission is "To foster and develop research on occupational performance (i.e., function in work, play, and daily living tasks), occupational dysfunction, and the efficacy of services to enhance functional performance. . . ." In October, 1991 the AOTA and AOTF are sponsoring a conference on measurement to be held at this Center. The overall aim of this symposium will be to bring together a critical mass of scholars who will systematically share and discuss issues and concepts related to functional measurement in occupational therapy and to generate a monograph that will document the presentations and deliberations of the symposium.

In addition, funds are being sought to convene an interdisciplinary conference for the purpose of developing long-range strategies that would facilitate rehabilitation research in occupational therapy, and promote research by occupational therapists and their scientist colleagues in related disciplines. The long-term goal is to increase the number of scientists both within the field of occupational therapy and in related disciplines who are committed to studying those broad concepts of rehabilitation that yield strategies for ensuring higher levels of function, greater personal autonomy, and more

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satisfying adaptation to altered living and work environments, if necessary. This long-term goal would be supported by the preparation and distribution of a manual of conference proceedings which would present a model to be used by allied health disciplines to strengthen the commitment to research and scholarship within their own fields. The model would be of assistance to other disciplines making a transition from the practical application stage to the scientific-productive state.

The AOTF is also supporting the professions need for outcome data by convening a task group within the next three months to develop strategies to address the development of an outcome data base. Panel members will include leaders in the field familiar with occupational therapy practice data collection and analysis, statisticians and persons with expertise in outcome research.

In the area of evaluation tools the AOTA and AOTF supported the development of OT FACT (Functional Assessment Compilation Tool) a software program which provides a format for systematically collecting, compiling and reporting on assessment data which has been gathered from existing instruments into a system which provides an overall functional performance profile of an individual. OT FACT is based on AOTA's Uniform Terminology, an accepted standard for describing functional assessment.

The Task Force's identification of a critical shortage of highly qualified and experienced faculty, clinical scientists, and applied technological investigators is one the profession of occupational therapy is also facing and certainly a factor that has impeded our efforts in the area of rehabilitation research. Both the AOTA and AOTF are working to promote the development of strategies which would improve the knowledge, attitudes and skills related to research in the undergraduate and graduate curricula, and which would promote the development of those skills among faculty in academic programs.

In reviewing the Task Force's report AOTA was indeed pleased to see so many parallel concerns and the potential for initiatives between the report recommendations and the concerns of AOTA. Again, we appreciate the opportunity to review and comment on the report, are pleased to have had occupational therapists as members of the Task Force and look forward to future opportunities for support and collaboration.

Sincerely

Jeanette Bair

Jeanette Bair, MBA, OTR, FAOTA
Executive Director

/sl

apta American Physical Therapy Association
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December 21, 1990

Dr. Susan Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

On behalf of the American Physical Therapy Association (APTA), I want to thank you for forwarding the draft report of the Task Force on Medical Rehabilitation Research. The report was reviewed by Dr. Sherry Keramidas and other members of our staff. We were very pleased to see the scope and depth of issues addressed by the Task Force and the comprehensive directives identified to meet the significant challenges that lie ahead.

The report frequently cites the need to involve many professions and disciplines. However, the strong emphasis on physical medicine, which typically connotes a medical subspecialty, does raise some concerns. Physical therapist researchers have made important contributions to understanding disabilities and to rehabilitation. With the strong and growing emphasis on research training within the physical therapy profession, physical therapists are likely to play an even greater role in the future. Finally, it is important to note that physical therapists are direct providers of patient care. In 41 states physical therapists can evaluate without physician referral; in 24 states they also can treat without physician referral. As such, physical therapists can be key links in the management of clinical research. Thus, we hope that efforts to train clinician researchers includes a strong focus on physical therapists.

The APTA looks forward to working closely with the National Institutes of Health in pursuing the important research objectives identified in this report. I hope you will contact Sherry Keramidas, Ph.D., Associate Executive Vice-President here at APTA, and continue to call upon us as you begin to develop programs in the rehabilitative sciences.

Sincerely,

William D. Coughlan

William D. Coughlan, CAE
Executive Vice President/
Chief Executive Officer

The American Physiological Society

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Please Reply To:

January 14, 1991

Dr. Jay Moskowitz
Associate Director for
Science Policy and Legislation
National Institutes of Health
Bldg., 1, Room 137
Bethesda, Maryland 20892

Dear Jay:

Thank you for providing me with a pre-publication draft copy of the report of the Task Force on Medical Rehabilitation Research that was based on a meeting held June 28-29, 1990. I regret that I was unable to comment on the report prior to the December 20 deadline. But, indeed, my comments were minimal. The report looks excellent and provides an excellent framework for the pursuit of medical rehabilitation research. Indeed, I am certain that this report helped contribute to the legislation that was introduced and signed by the President on November 16, which established a National Center for Medical Rehabilitation Research within the National Institute of Child Health and Human Development. It is my hope that the scientific community will be able to work within the framework of this report to improve our understanding of physical disabilities with the goal of alleviating some of the suffering associated with them.

Thank you again for providing me with a copy of the report. I appreciate the opportunity to work with you and other members of the NIH community in developing policy statements that will benefit the scientific community and the U.S. population.

With best wishes for the new year.

Sincerely yours,

Martin Frank, Ph.D.
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American Psychological Association

Advancing psychology as a science, a profession, and as a means of promoting human welfare

December 21, 1990

Jay Moskowitz, Ph.D.
Associate Director for
Science Policy and Legislation
National Institutes of Health
Bethesda, MD 20892

Dear Dr. Moskowitz:

Thank you for sending us a press-ready copy of your report of the Task Force on Medical Rehabilitation Research, along with your letter of December 6 addressed to Dr. Raymond D. Fowler, Chief Executive Officer of the American Psychological Association and received by us on December 11.

Responding for Dr. Fowler and myself, and recognizing that you need to have all further input by December 20, we have no specific comments on the report except to offer our congratulations on a very attractive and thorough-looking document.

Sincerely yours,

Lewis P. Lipsitt

Lewis P. Lipsitt, Ph.D.
Executive Director for Science

LPL/ref

cc: Dr. Raymond D. Fowler

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American Speech-Language-Hearing Association
10801 Rockville Pike • Rockville, Maryland 20852 • (301) 897-5700 (Voice or TTY)

December 18, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

On behalf of the American Speech-Language-Hearing Association (ASHA), the national scientific and professional association representing over 62,000 speech-language pathologists and audiologists, I would like to thank you for the opportunity to comment on the draft copy of the report of the Task Force on Medical Rehabilitation Research.

The Association commends the Task Force on the development of a document that brings together many aspects of the diverse field of medical rehabilitation research.

Because almost 40% of ASHA's membership is employed in healthcare facilities, and many specifically in rehabilitation facilities, a large proportion of our professionals is involved in medical rehabilitation endeavors, including research. As defined by the Task Force, medical rehabilitation research "... is the study of impairments, disabilities, and handicaps resulting from illnesses, injuries, and developmental processes that begin before birth and continue until the last stages of life. It focuses on health-related improvement in human functioning -- physical, cognitive, behavioral, and social." Such a definition, broad in scope, would include communication behavior and disorders within its boundaries. ASHA would support such a broad-based definition. It is a conceptually encompassing and cohesive definition, which deals with the myriad aspects of rehabilitation. As the Task Force recognizes, medical rehabilitation research requires an interdisciplinary research undertaking.

Also, from the perspective of clinical practice, communication disorders has been traditionally included among the members of interdisciplinary rehabilitation teams. Many illnesses, diseases, congenital disorders, or injuries result in disturbed or impaired functions. A prominent goal of medical rehabilitation is to restore or improve these disturbed functions. 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. A good example is traumatic brain injury, which damages the neurological system which, in turn, can manifest in motor disturbance (including speech), sensory disturbance (including hearing and balance), and higher cortical function disturbance (including language).

Benefits also accrue to research when an interdisciplinary approach is used. Researchers from different disciplines bring their respective expertise to investigating/solving problems. This cross-fertilization can result in

creative solutions that would not have occurred without all participants. Of course, it is recognized that every problem does not require the inclusion of every rehabilitation specialty. Designing a prosthetic device for an amputee would not require the expertise of a speech-language pathologist; designing an augmentative communication device for an individual with cerebral palsy certainly would.

Therefore, ASHA sees the benefits of including the rehabilitation aspects of communication sciences and disorders within medical rehabilitation research.

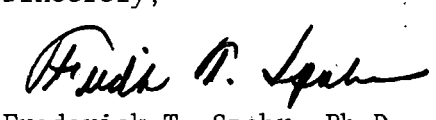
The Task Force indicated that communication disorders were largely beyond their scope and had been "... examined in previous initiatives by NIH." They did consider, however, communication difficulties associated with neck cancer, traumatic brain injury, spinal cord injury, or other disabling conditions. This restricted view, excluding communication disorders from medical rehabilitation, is also seen in the definition contained in P.L. 101-613, which states that medical rehabilitation is "... the rehabilitation of individuals with physical disabilities resulting from diseases or disorders of the neurological, musculoskeletal, cardiovascular, pulmonary, or any other physiological system." P.L. 101-613 establishes a new structure, the National Center for Medical Rehabilitation Research (NCMRR) within the National Institute of Child Health and Human Development, to manage medical rehabilitation research.

ASHA supports the current structure within which communication sciences and disorders are supported at NIH. Although research and training funding for communication sciences and disorders is spread across several institutes, it is focussed primarily in the National Institute on Deafness and Other Communication Disorders (NIDCD). ASHA fully supports the NIDCD and believes it must be permitted to continue to develop unencumbered. NIDCD is only two years old and, naturally, is still in its growth stages. Its intramural and extramural programs are not yet fully developed. Therefore, although ASHA conceptually sees the possible benefits of including the rehabilitative aspects of communication sciences and disorders with medical rehabilitation, ASHA would not wish to see such inclusion occur at the expense of NIDCD. The disadvantages outweigh the possible advantages of such an inclusion.

Of course, ASHA hopes that, in matters of mutual interest and concern, NIDCD and NCMRR would collaborate. Separate structure does not mitigate against shared function, especially when an enhanced product results from the collaboration. That the Director of NIDCD is an ex officio member of the NCMRR Advisory Board provides one mechanism for cooperative efforts and an inter-NIH Committee to explore collaborative efforts might be another. In addition, both NIDCD and NCMRR require adequate levels of funding support to ensure that they are able to achieve the goals outlined in their respective research agendas.

If ASHA can provide assistance as the National Center for Medical Rehabilitation Research is implemented, it will be happy to do so.

Sincerely,



Frederick T. Spahr, Ph.D.
Executive Director

College of Medicine

ARIZONA
CANCER CENTER

The University of Arizona
1515 N. Campbell Avenue
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FAX (602) 626-2284

January 4, 1991

Suzanne Medgyese-Mitchang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, Maryland 20892

Re: Review of "Report of the Task Force of Medical Rehabilitation Research"

Dear Dr. Medgyese-Mitchang:

Dr. Sydney Salmon asked me to review this document and send my comments to you. I apologize for the delay, but I did not get the document until right around the holidays. I have only reviewed the Cancer Rehabilitation section, as that is the area I am most familiar with. This section was of great interest to me, because I have always felt that rehabilitation and cancer survivorship are closely related and overlap in many areas. This section provided a global overview of progress related to cancer rehabilitation, and only touched on specific areas related to cancers of the head and neck, breast, bone, and soft tissues. A strength of this section was its emphasis on the need for prospective research in the area of long-term effects of cancer. The authors also recommended taking the developmental stage of patients into account when suggesting interventions for rehabilitation.

There were a few weaknesses of this section. The definition of cancer survival was not clear and appeared to based on the traditional definition of being 5 years or more out from treatment. Within the past few years, the working definition of cancer survivorship now states that survival begins at the time of diagnosis and continues through and beyond treatment.[1] This definition implies that cancer rehabilitative measures should begin at the time of diagnosis and not when permanent disability is discovered.

The authors of this section concentrated on cancers that, more often than not, result in some permanent, and often visible, physical disability. Other much more common cancers with potential long-term effects were not addressed at all. These include lung cancer, colorectal cancer, gynecologic cancers and certain lymphomas.

I was surprised to see that there was no mention of either primary or secondary cancer prevention as a focus of cancer rehabilitation. It is known that individuals with a history of cancer is at higher risk for another recurrent of primary cancer.[2] With a long-term survivors at our institution, we are continually stressing the importance or primary prevention at early detection measures.

Overall, I feel this is a worthwhile document. Hopefully, my comments will arrive in time for you to utilize them in your revisions. If you have any questions about my remarks, please call me at (602) 626-7254.

Sincerely,

Lois J. Loescher, M.S., R.N.
Advanced Research Specialist

LJL:lh

cc: Sydney E. Salmon, M.D.
David S. Alberts, M.D.

References:

1. Mullan, F. Seasons of Survival: Reflections of a Physician with Cancer. New Eng Journ Med, 313:270-273, 1985.

2. Loescher, LJ, Welch-McCaffrey, D, Leigh, SA, et al. Surviving Adult Cancers, Part I: Physiologic Effects. Anals of Int. Med. 111:411-432, 1989.

Robert G. Petersdorf, M.D.
President

January 4, 1991

ASSOCIATION OF
AMERICAN
MEDICAL COLLEGES

ONE DUPONT CIRCLE, NW
WASHINGTON, DC 20036
TELEPHONE (202) 828-0460

Jay Moskowitz, Ph.D.
Associate Director for
Science Policy and Legislation
National Institutes of Health
Bethesda, Maryland 20892

Dear Jay:

Several members of the AAMC staff have reviewed the prepublication draft of the Report of the Task Force on Medical Rehabilitation Research. I am not sure that we have done it justice, given the length of the document and the short deadline. However, the Association had no trouble in formulating a consensus position on it.

The Task Force Report reflects an extraordinarily broad and comprehensive set of aspirations for the field of rehabilitation medicine, even to the point of encroaching on well established territorial boundaries of established fields and disciplines. This expansive concept of the legitimate ambit of research in medical rehabilitation does not seem necessary and could cause non-productive and needless "turf" disputes. The Report's vision of the proper scope for the field, of the challenges that it will face and of the unmet needs of the disabled is breathtaking. The assignment to develop a comprehensive blueprint for a long range research effort has surely been met.

The NIH will, of necessity, play a large role in the implementation of this sweeping plan. The Report's chapter on Basic and Clinical Research Training puts its finger on the most crucial first step---a major expansion, from---sadly---the presently very small cadre of scientists needed to convert vision to reality. The AAMC would endorse most of the recommendations of the Task Force related to training: the interagency committee (p. 129); the research career development and young academic investigators awards (p. 131); the expansion of the representation of rehabilitative medicine in individual and institutional training awards, both pre-and post-doctoral (p. 132); and the establishment of Centers of Excellence in Rehabilitative Research and Training (p. 135). To mount a research program of the scope and depth envisioned by the Task Force

requires, as was recognized, a training effort of unprecedented proportions. Moreover, attracting high quality candidates into the field in the required numbers will require unusually successful recruitment.
The AAMC would raise a note of caution on the matter of peer review representation at the NIH. Under the recently adopted procedure that converts raw priority scores into percentile rankings, the governing premise is that every discipline, field or specialty recognized by the establishment of a peer review committee for it, is inherently of the same intrinsic scientific merit. An application in molecular biology rated at the 10th percentile is of identical intrinsic scientific merit as another at the 10th percentile in, say, medicinal chemistry or physical biochemistry or nutrition or nursing research or rehabilitation medicine. As a consequence, any discipline, field or specialty that has a "study section" dedicated to it has thereby an entitlement to a share of the NIH extramural grant appropriation. The Task Force implicitly acknowledges that the quality of research in this field leaves something to be desired, when it argues so persuasively for a much improved and expanded training effort. The AAMC concurs and for that reason would have reservations about establishing a separate study section for this field at this time. The Association would, however, endorse the proposals (p. 135) to incorporate individuals with expertise in the field into existing initial review groups and national advisory councils that consider applications for research in rehabilitative medicine.

Thank you for the opportunity to review this proposal. If the Association can be of further assistance, please call upon us.

Warmest personal regards,

Robert G. Petersdorf, M.D.

City of Hope

NATIONAL MEDICAL CENTER

DIVISION OF NURSING

December 17, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institute of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang,

I received the prepublication draft copy of the report of the Task Force on Medical Rehabilitation Research convened by NIH. I reviewed the document in my role as chairperson of the Research Committee for the Oncology Nursing Society and for my own interest as a researcher. I am very impressed by the report and found the information to be quite comprehensive and timely as well as identifying priorities for future research and practice.

I wanted to make two comments specific to the content:

1) I am extremely pleased to see the discussion regarding pain as a major factor influencing rehabilitation for the cancer patient. All of the comments in the report regarding cancer pain are consistent with the recently published Oncology Nursing Society Position Paper on Pain.

2) I was surprised to see that pain was not discussed in the section on Geriatrics. Our research and the work of others has identified pain as a major factor in the elderly and one which significantly impacts function, ability to seek rehabilitation and overall quality of life.

I look forward to receipt of the final report and when it is available, I will see that it is circulated to the Oncology Nursing Society.

Sincerely,

Betty R. Ferrell Ph.D., F.A.A.N.
Associate Research Scientist
and Chairperson, Oncology Nursing
Society Research Committee

BF:ba
cc
Pearl Moore
ONS

COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

Post Office Box 3776
Washington, DC 20007
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Executive Director
Joseph H. Owens, Jr.

December 18, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Medgyesi-Mitschang:

The Council of State Administrators of Vocational Rehabilitation appreciates the opportunity to review the draft report of the Task Force on Medical Rehabilitation Research convened by the National Institutes of Health.

We are most pleased to see the broad range of disciplines consulted and included in the planned research. This interdisciplinary approach has been the undergirding principle of rehabilitation and we believe the inclusion of biological, psychological, social behavioral and allied health sciences will strengthen rehabilitation medicine as a leading clinical program.

The overriding research needs agreed upon by the Task Force are both insightful and timely, reflecting questions encountered by rehabilitation medicine in its expansion over the past several years. Evaluating the effectiveness of rehabilitation procedures, developing a "common language" and developing improved quantitative measures will also directly benefit the State-Federal Vocational Rehabilitation Agencies in their service delivery programs. An example of this is the proposed section on epidemiology. State Agencies, in assisting their respective states in health planning for inpatient and outpatient rehabilitation programs, need accurate data on incidence and prevalence rates of disabling conditions.

For years, State Agencies have worked with universities and legislatures to develop clinical training programs to meet shortages in rehabilitation manpower. The potential of adding research components, on the scale outlined in the Task Force Report, would strengthen training programs and improve the capability of rehabilitation to respond to the complex and diverse issues associated with disabilities and handicaps.

Sincerely,

James B. Griffith

James B. Griffith
President

Dr. Jay Moskowitz
Associate Director for
Science Policy and Legislation
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, Md. 20892

Dear Dr. Moskowitz:

Your letter and prepublication draft copy of the report of the Task Force on Medical Rehabilitation Research was forwarded to my office by the Office of the Associate Commissioner for Disability for comment very close to your December 20th deadline. This, as well as the staffs' holiday vacations precluded our being able to respond. We appreciated the opportunity for review and hope you will keep us abreast of any future activities that grow out of the Task Force. Thank you for sharing the report with us.

I am the agency representative in matters pertaining to Medical Rehabilitation Research and look forward to hearing from you. In my absence, you may call Ms. Frederica Harrison, LCSW, Associate Chief Medical Director for Evaluation and Development. She can be reached on FTS-646-1973 or 301-966-1973.

Sincerely.

Edward N. Brown Jr. M.D.

for John H. Mather, M.D.
Chief Medical Director

cc:
Dr. Suzanne Medgyesi-Mitschang

Eastern Paralyzed Veterans Association
Executive Office

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Member Chapter of Paralyzed Veterans of America

EPVA

December 18, 1990

Dr. Suzzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

Thank you for the opportunity to review the report of the Task Force on Medical Rehabilitation Research. It is a comprehensive and well-prepared research plan. The Task Force can take pride in its efforts, an important step in meeting the challenge of the changing health care needs of the disabled, impaired and aged population groups. I am limiting my comments to the section on spinal cord injury.

There are two statements on page 48 that I believe are somewhat misleading. The first is "Life expectancy has increased dramatically and causes of mortality among people with SCI are comparable to those for the non-SCI population". Causes of mortality among the SCI population are approaching those for the non-SCI population but are not comparable. The SCI population is at higher risk of developing genito-urinary, respiratory and skin complications than the non-SCI population. These complications may have an affect on the aging process and the causes of mortality.

The second misleading statements is, "Using strategies similar to those tested in animal models has led to recovery of some motor control, allowing patients to walk with minimal aid from artificial support devices". The statement exaggerates the outcome of a few studies in highly selective SCI sub-population groups.

The research priorities on pages 52-53 are excellent. I offer several additional areas for consideration.

- Evaluate the effectiveness and efficiency of alternative long term care settings and social support systems.
- Identify and evaluate the economic consequence of spinal cord injury and its secondary co-morbidities.
- Identify and evaluate alternative third party payment methods and financial support systems.
- Identify and investigate metabolic changes secondary to spinal cord injury.

I look forward to receiving a copy of the final report.

Sincerely,

Vivian Beyda, Dr.P.H.
Director
Research and Education

VB:lcb

HARVARD MEDICAL SCHOOL

JOSEPH B. NADOL, JR., M.D.
WALTER AUGUSTUS LECOMPTE PROFESSOR
AND CHAIRMAN
DEPT. OF OTOLOGY AND LARYNGOLOGY

MASSACHUSETTS EYE AND EAR INFIRMARY

CHIEF OF OTOLARYNGOLOGY
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243 CHARLES STREET
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617-573-3652

January 5, 1991

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

Thank you for the opportunity to review the prepublication draft of the report of the Task Force on Medical Rehabilitation Research that was convened by the National Institutes of Health, June 28-29, 1990.

Although judged to be outside the Task Force scope were "vision, disorders in hearing, speech, and other communication disorders" (page 24), I cannot fail to comment that by omitting disorders of hearing, balance, and speech, an immense segment of debilitating disorders are omitted from the report. The percentage of the US population that is so affected certainly exceeds the 4-6% for other disorders mentioned in the overview.

The tremendous impact of hearing loss, either partial or complete, particularly in children, upon future intellectual development should not be underestimated. In addition, many man hours are spent on "rehabilitation" of hearing loss with very little in the way of objective parameters by which to judge the effectiveness of such treatment. It would be my impression then, that at least some comment of the impact of deafness and communication disorders should be mentioned in the area of neurophysiologic dysfunction.

In the area of geriatrics, again, there is little to no mention about two common disorders: progressive hearing loss affecting at least one third of the individuals over the age of 70 years, and vestibular disorders resulting in falls and serious impairment and severe limitations in mobility in the aged.

The frequency and debilitating nature of disorders of hearing, balance, and human communication and a lack of effective parameters to evaluate the utility of rehabilitation in these areas, I believe, deserve greatly increased emphasis in any report concerning medical rehabilitation research.

Sincerely yours,

Joseph B. Nadol, Jr., M.D.

JBN/alz
enclosure

The Heart and Lung Institute
at St. Vincent's, Inc.
1800 Barrs Street
Post Office Box 2982
Jacksonville, Florida 32203
904-387-7563

December 20, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Doctor Medgyesi-Mitschang:

Dr. Moskowitz sent me a pre-publication draft copy of the Task Force on Medical Rehabilitation Research. The report is very interesting and seems to represent concerns from a broad spectrum of disciplines.

Our Institute is particularly interested in rehabilitation of patients who suffer from heart disease. I noted in your summary statistics on page 37 (table 2) that over 4 million people suffered from heart disease in the 1983-85 reporting period. We are actively pursuing a program of cardiac rehabilitation that may have a significant impact on coronary restenosis rate, as well as allowing the patient to monitor their own "heart health". This research lead to a dramatic reduction in the extent of heart muscle damage in those patients who suffer recurrent heart attacks.

I am very interested in the N.I.H. level of concern in this problem. Our institution is uniquely qualified to answer the question of the impact of rehabilitation on patients with heart disease. We would be willing to share this information and our plan for future research in cardiovascular rehabilitation, if you feel that our efforts will provide constructive input to the global rehabilitative program.

I can be contacted at (904) 387-7563. If there is a working group or planning conference where we can participate, we would be delighted to help in any way that we can. It is our hope that we can make a significant impact in this crucial area of patient care.

Sincerely,

William A. Monaco, Ph.D.
Research Director
The Heart and Lung Institute
at St. Vincent's, Inc.

WAM/nac

THE JOHNS HOPKINS MEDICAL INSTITUTIONS

Joseph T. Coyle, MD
Distinguished Service Professor of Child Psychiatry
Director, Division of Child Psychiatry
Professor of Psychiatry, Neuroscience,
Pharmacology and Pediatrics

December 17, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Medgyesi-Mitschang,

We thank you and Dr. Moskowitz for providing the Society for Neuroscience with a draft of the report of the Task Force on Medical Rehabilitation Research. As President-Elect, I took the opportunity to review the document and was quite impressed with the breadth and depth of the analysis. The balanced view of the importance of basic research, particularly in Neuroscience, conjoined with clinical investigation, indicates a commitment to the development of a scientifically basic clinical discipline. Thank you for apprising the Society of this important document.

Sincerely,

Joseph T. Coyle, M.D.
President-Elect, Society for Neuroscience

cc: Nancy Beang

600 North Wolfe Street, Baltimore, Maryland 21205 (301) 955-3550

midwest nursing research society

December 26, 1990

Jay Moskowitz, Ph.D.
Associate Director for Science
Policy and Legislation
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Moskowitz:

Congratulations to the Task Force on Medical Rehabilitation Research on a comprehensive and well done job in generating the report. It will set research priorities for the years to come.

Sincerely,

Mara M. Baun, D.N.Sc., F.A.A.N.
President

MMB/ss

NATIONAL COALITION FOR CANCER SURVIVORSHIP

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December 11, 1990

Dr Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr Medgyesi-Mitschang:

Thank you for the opportunity to review the report of the Task Force on Medical Rehabilitation Research. The Task Force is to be commended for their beginning work on such an enormous undertaking. For purposes of this review I have commented on the Cancer Rehabilitation Section.

In my opinion:

1. The section is limited to a focus on three types of cancer and fails to address the scope of problems generated by other types, e.g. leukemia, Hodgkins, GU, GYN, colon, etc. that are equally problematic.

2. The predominant unit of analysis presented here is the bodily dysfunction of the individual. Additionally the report should address the profound psychosocial rehabilitative needs of patient, the family, partners of patients and the community? What about shifting the unit of analysis somewhat to the social rehabilitative context?

3. The information needs outlined for preparing children for life after cancer also apply to adults, e.g., for managing employment, marriage, family life, social participation, etc. after cancer, p. 81.

4. Acquiring and maintaining health care insurance is a major problem for most cancer survivors. This issue must be highlighted and not just passed off to creating a "special" high risk pool.

5. The report should address the need for psychological counseling (therapy) for patients and families in crisis, and in the long-term management of depression, anxiety, fear, worry, and the many social problems that coping with cancer presents. More work must be done in understanding interventions that are effective for patients and families who need treatment. Thank you for your interest in exploring the utility of support groups which are useful for some people and in managing some types of problems.

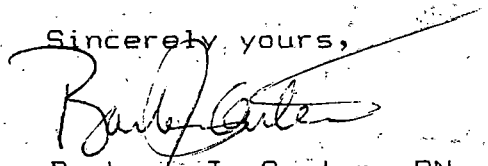
6. I would suggest that you include discussion of chronic fatigue, spiritual distress, and coping with the possibility of death in the discussion. The later two items are usually ignored in "medical" literature.

I appreciate the efforts of the Task Force to include an interdisciplinary purview. A review of the credentials of the panelists however shows that nursing, social work, theology, and law are under represented. In the future I hope to see more interdisciplinary panelists included.

Thank you for your interest in the cancer survivorship movement and for the opportunity to comment on the Cancer Rehabilitation Section of the Task Force Report. I look forward with enthusiasm to receiving a final copy of the report.

Best wishes for a joyous holiday season!

Sincerely yours,



Barbara J. Carter, RN, DNSc
Board of Directors, and
Chair, Research Committee

National Council on Disability
800 Independence Avenue, S.W.
Suite 814
Washington, DC 20591

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An Independent
Federal Agency

January 2, 1991

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, Md. 20892

Dear Dr. Medgyesi-Mitschang:

Please express my gratitude to Dr. Jay Moskowitz for sending the National Council on Disability a prepublication copy of the report of the Task Force on Medical Rehabilitation Research.

The National Council on Disability supports the Task Force in its effort to identify a broad research agenda for the field, especially basic research in a broad range of scientific disciplines. The National Council was also pleased to note the number of Task Force members who are or have been recipients of National Institute of Disability and Rehabilitation Research (NIDRR) funding. Both NIH and NIDRR have been involved in quality research to improve rehabilitation practices. The National Council believes that the NIH Institutes will benefit from coordination among the various rehabilitation research efforts located within the Institutes.

The National Council on Disability also strongly supports the process initiated by NIH to include individuals with disabilities in the research planning effort.

I look forward to our continued involvement in the rehabilitation planning and implementation activities of the National Institutes of Health.

Yours sincerely,

Sandra Swift Parrino

Sandra Swift Parrino
Chairperson

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

December 20, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

Please express my gratitude to Dr. Jay Moskowitz, Associate Director for Science Policy and Legislation, for sending the National Institute on Disability and Rehabilitation Research (NIDRR) a prepublication copy of the report of the Task Force on Medical Rehabilitation Research. I appreciate having the opportunity to comment on the prepublication draft of the report.

I commend you and the Task Force for undertaking the difficult task of outlining the field of medical rehabilitation research, as well as identifying a broad research agenda for the field. The NIDRR endorses the intention of the NIH to support "a solid program of basic research in a broad range of scientific disciplines" that will enhance the work of rehabilitation medicine practitioners.

I was particularly pleased to note that such a high percentage of the Task Force members were also recipients of research funding support from NIDRR. We appreciate your acknowledgement of the quality of research supported by NIDRR and of the outstanding medical and other rehabilitation research contributions of these investigators. Your acknowledgement indicates that both NIH and NIDRR recognize and fund the leading researchers in the field.

The overall quality of the recommendations contained within the report of the Task Force is quite good. Perhaps because a significant number of the researchers were supported by NIDRR, a considerable number of the recommendations relate to areas in which the NIDRR has an ongoing research program. Consequently, a number of the issues identified by the Task Force are ones that NIDRR will pursue in both its long-range planning for disability and rehabilitation research, as well as the development of research priorities in the near future.

At NIDRR, we hope that your report will focus the attention of the various Institutes of the NIH on the need to develop a larger cadre of trained and committed rehabilitation medicine researchers across the Institutes and in the related basic sciences. In the past, excellent research leading to improved rehabilitative practices has been supported by such varied components of the NIH as the NINDS, NIAMS, the Neural Prosthetics Laboratory, the NIA, and the NIMH, among others. We believe that an effort to promote and coordinate medical rehabilitation research in each of the NIH Institutes will augment the knowledge base for applied researchers and will lead to benefits for individuals with disabilities.

At the same time, NIDRR needs to emphasize that there are many important areas of disability and rehabilitation research that are not addressed fully by the Task Force report. These include such areas as disability and rehabilitation research in sensory and communication impairments, mental retardation, mental illness, behavioral disorders, environmental modifications, service delivery systems, independent living programs, knowledge utilization and information dissemination, assistive technology, consumer empowerment, and disability policy and demographics. These issues, among others, continue to be of major concern to NIDRR.

Finally, I was pleased to see that you have begun a process to include individuals with disabilities in the planning process. NIDRR has found it invaluable to involve persons with disabilities in all aspects of disability and rehabilitation research. We strongly urge other research entities to adopt a similar policy.

I look forward to continued coordinated activities around areas of mutual concern.

Sincerely,

William H. Graves

William H. Graves
Director

NATIONAL MULTIPLE SCLEROSIS SOCIETY
205 EAST 42 STREET, NEW YORK, N.Y. 10017-5706 (212) 986-3240
FAX (212) 986-7981

December 13, 1990

THOR HANSON
Vice Admiral, U.S. Navy (Ret.)
President & C.E.O.

Direct Line
(212) 351-2260

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang,

I appreciate the opportunity to review the draft copy of the report of the Task Force on Medical Rehabilitation Research.

I just have a couple points on the Multiple Sclerosis sections:

- Your Table 2 on page 38 gives the number 127,000 as a prevalence for multiple sclerosis, a number we believe very low. It is also inconsistent with the number you use in the section on multiple sclerosis on page 48 -- "between 250,000 and 500,000 in the United States." -- a number we believe to be much more accurate.

  Recommendation: Incorporate the larger number in the table.

- The Clinical Research Priorities for Demyelinating Disorders listed on page 54 are appropriate but really concentrated on the medical model of rehabilitation; the list could benefit with the addition of other items more like the last two of your list; examples might be work on psychosocial issues such as vocational rehabilitation, employment programs, activities of daily living, etc.

I hope this input will useful.

All best wishes.

Sincerely,

Thor Hanson

Thor Hanson

cc: Jay Moskowitz, Ph.D.

National Retinitis Pigmentosa Foundation, Inc.

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Director of Science

Jeanette S. Felix, Ph.D.

RP Foundation Fighting Blindness

January 7, 1991

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

I appreciated receiving a copy of the report of the Task Force on Medical Rehabilitation Research from Dr. Jay Moskowitz. It is truly an impressive undertaking that deserves much praise and encouragement toward a full completion of the project.

In reviewing the contents of the report, I was struck with the scarcity of data and references to conditions resulting in visual impairment. Visual loss, especially the inherited retinal degenerative diseases with which the RP Foundation concerns itself, is often a severe disability which interferes or interrupts work and career development. I urge you to give this topic more attention in future studies.

Developing technology in various fields, but especially in optics for defense purposes, may provide devices useful to people who require special light enhancement, magnification, or acuity correction. Likewise, information resources available to the young and aged populations of visually impaired need to be better coordinated and refined. Although small private foundations like our own attempt to contribute to this need, our resources are devoted almost entirely to research and cannot sustain a truly adequate information/referral program nationwide.

Thank you for the opportunity to comment on this excellent report.

Sincerely,

Jeanette S. Felix

Jeanette S. Felix, Ph.D.
Director of Science

JSF/jb

ONCOLOGY NURSING SOCIETY

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(412) 921-7373

December 18, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Mitschang:

The draft copy of the report of the Task Force on Medical Rehabilitation was reviewed by Deborah Mayer, ONS Past President and the Chairperson of the Oncology Nursing Society Task Force on Rehabilitation of Persons With Cancer. The following are her comments:

1. Although budgeted dollar amounts are listed on the Task Force Report, the percentage of budget this represents is not. The amount of funding allocated to such a broad and important topic is very small relative to other foci.

2. Little mention is made for the routine and uniform assessment of all cancer patients relative to rehabilitation needs. This should be linked to a health care system database to more accurately document and monitor the rehabilitation needs of various populations. We currently do not have a good database to project problems and needed resources to address them.

3. The needs of the health system to address long term and late effects of the cancer patient are not mentioned. Who, where, and how often will follow-up be conducted for this high risk population? No mention is made about prevention and early detection of secondary malignancies as well as other health-oriented issues.

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4. The pain section is good; however, the problem of fatigue is never mentioned and may be as significant or more of a problem than pain is in this population.

5. Overall, there is a very "medical model" orientation (or as I refer to it as "body parts") to the report. The focus was on head and neck, breast and bone, and soft tissue cancers. They are fine in and of themselves, but what of all the other cancers and problems experienced. This kind of report could influence where funding is allocated. Were these topics prioritized? Another example of the medical orientation is under sexual dysfunction "an estimated 5% ...occur in patients aged 34 or younger. Since many of these patients will be long-term survivors, the effects of therapy on sexuality and reproductive function have great significance." (p. 81) What of those over age 34? The rest of the section is very pathophysiologically oriented.

I hope these comments are helpful.

Sincerely,

Pearl Moore

Pearl Moore, RN, MN
Executive Director

mld

P.S. Enclosed is a copy of the ONS Position Statement on Rehabilitation of Persons With Cancer.

Enclosure

Rehabilitation of Persons With Cancer: An ONS Position Statement

DEBORAH MAYER AND LINDA O'CONNOR

It is estimated that almost one million persons will be newly diagnosed with cancer in 1989. Approximately half of the individuals diagnosed with cancer will be alive five years or more, with many considered cured of their disease. As a result, concerns over issues of survivorship and living with the effects of cancer and its treatment are of increased concern to healthcare professionals. Focus should be broadened beyond the prevention, early detection, and treatment of this disease to include the structure, process, and outcome of rehabilitation in the care of the individual with cancer. Rehabilitation is a process by which individuals, within their environments, are assisted to achieve optimal functioning within the limits imposed by cancer.

Barriers

Historically, rehabilitation has not been included as a systematically or consistently integrated process in cancer care. Philosophical and attitudinal differences among health professionals and the public are a major obstacle. Lack of coordinated care and poor interdisciplinary collaboration, lack of adequate reimbursement for services, and a paucity of research supporting the efficacy of rehabilitation interventions also contribute.

Structure

Rehabilitation services will be available to address the physical, psychological, spiritual, social, vocational, and educational potential of the individual.

A team of oncology and rehabilitation care providers and volunteers is needed to provide these services. The most important members of this team are the individuals with cancer and their families. The other team members include, but are not restricted to: nurses; physicians; physical, occupational, and recreational therapists; social workers; speech pathologists; dentists; nutritionists; psychologists; clergy; and volunteers. One of these health professionals must assume responsibility for the coordination of care. Significant contributions are made by all members of the team; however, the nurse is most often the key link in coordinating these services. The structure of this program may range from a formal rehabilitation service to a network of individuals or organizations available to provide this care.

Process

Services are provided according to the preventive, restorative, supportive, or palliative needs of the individual.

The rehabilitation assessment is initiated at the time of diagnosis. Reassessment occurs periodically throughout the individual's lifetime. This assessment is conducted within a holistic framework which evaluates the individual with cancer in the context of the family and community. Interventions should be goal-oriented and have measurable outcomes. Referrals to available resources are based on the identified preventative, restorative, supportive, or palliative needs. Selected information is available on various national, regional, and local resources that currently exist and is published annually in the *Oncology Nursing Forum.*

Outcome

Individuals achieve optimal functioning within the limits imposed by their cancer.

A definition of optimal functioning is based on a realistic appraisal by the individual and the rehabilitation team. Variables that may influence an optimal functional status include type and extent of disease and treatment, concurrent illnesses or disabilities, age, physical and psychosocial abilities, physical environment, and the utilization of appropriate, available resources.

Recommendations

1. Research will be funded and conducted to build systematic and cumulative knowledge of rehabilitation interventions best suited to the individual with cancer.
2. Cancer education curricula will include rehabilitation of individuals with cancer.
3. Cancer publications and standards will address cancer rehabilitation.
4. Cancer legislation will reflect rehabilitation issues.
5. Reimbursement for rehabilitation services to individuals with cancer will be provided.
6. Inter- and intra-organizational efforts will be conducted on an ongoing basis to heighten awareness about cancer rehabilitation.
7. Collaborative interdisciplinary rehabilitation efforts are to be fostered. ONS

Deborah K. Mayer, RN, MSN, OCN, is the biological response modifiers clinical coordinator at Massachusetts General Hospital in Boston, MA. Linda O'Connor, RN, MEd, OCN, is pediatric hematology/oncology nurse clinician at Baystate Medical Center in Springfield, MA. Both Mayer and O'Connor are ONS Board members and were participants at the August 1988 Cancer Rehabilitation Invitational Conference. *This position paper was an ONS Board outcome of the 1987-1989 President's Grant,* Addressing Barriers to Successful Cancer Rehabilitation, *funded by Smith Kline & French. Prior to the Board's March 1989 approval, this paper was reviewed by Susan Baird, Anne Bavier, Patricia Cotanch, Dolores Esparza, Arlene Fleck, Dorothy Gordon, Karen Hassey, Susan Heiney, Marcia Lampert, Susan Leigh, Patti McCollom, Deborah McGuire, Pearl Moore, Marcia Rostad, Nora Stearns, Diane Van Ostenberg, and Pam Watson. (The statement was approved by the ONS Board of Directors on March 13, 1989.)*

SOCIETY FOR NEUROSCIENCE
11 Dupont Circle, N.W. • Suite 500 • Washington, D.C. 20036 • 202-462-6688

December 13, 1990

Jay Moskowitz, Ph.D.
Associate Director for Science
Policy and Legislation
Department of Health and Human Services
National Institutes of Health
Bethesda, Maryland 20892

Dear Dr. Moskowitz:

Thank you very much for the prepublication draft copy of the report of the Task Force on Medical Rehabilitation Research. A copy has been sent to our President-Elect, Dr. Joseph Coyle, and any comments will be forwarded by December 20th.

Thank you again.

Sincerely,

Nancy Beang
Executive Director

Paralyzed Veterans of America
SPINAL CORD RESEARCH FOUNDATION

December 21, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

I would like to contribute several items for consideration for the report of the Task Force on Medical Rehabilitation Research. My comments pertain to the section on Spinal Cord Injury in the chapter on Neurophysiological Dysfunction, pgs. 52-53.

1) The effects of aging following chronic spinal cord injury is an area urgently in need of attention from researchers. Preliminary evidences suggests that following injury, spinal neuron function may deteriorate significantly as a function of the aging process.

2) The neural basis of gastrointestinal dysfunction following paralysis, especially control of bowel function, is a major concern to those with spinal cord injury.

3) An understanding of the condition known as "autonomic dysreflexia", and potential treatments, would be extremely important. This condition is apparently a reflex response to bladder or bowel distension and can result in extreme cardiovascular changes, including body temperature, heart rate and blood pressure. This condition is life-threatening.

4) The neural control of body temperature in quadriplegics. High-level quadriplegics often are unable to be outside in hot weather because of their inability to regulate temperature.

5) The special neurological problems of pregnant women with spinal cord injury, such as autonomic dysreflexia during childbirth.

6) There is a tremendous need for a comprehensive neurological database on spinal cord injury; including the secondary complications of injury, the number of individuals with certain injury levels and durations, and the neurological consequences of the different levels and types of injuries.

7) There is a great need for a comprehensive, informative neurological functional assessment test for humans following spinal cord injury.

8) The occurrence of simultaneous head and spinal cord injury is often overlooked. However, the incidence and special problems associated with this dual injury need to be addressed.

9) The neural control of bladder function following paralysis. Bladder and kidney infection are a constant risk.

Thank you for the opportunity to provide these additional research concerns on spinal cord injury.

Sincerely,

Cheryl M. Chanaud

Cheryl M. Chanaud, Ph.D.
Associate Director of Research
Medical and Research Affairs Department

CMC:JEN

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December 18, 1990

Jay Moskowitz, Ph.D.
National Institute of Health
Building One Room 103
Bethesda, Maryland 20892

Dear Dr. Moskowitz,

I am writing with reference to the NIH Report of the Task Force on Medical Rehabilitation Research. I would like to comment on two themes which are carried throughout the report .

The first point is that it is very difficult to define rehabilitation as a discipline, and this makes it dangerous to establish a separate rehabilitation institute. As a separate institute it is very possible that areas of interest which come under the auspices of rehabilitation might better be reviewed and administered by other institutes.

The second point is that a major weakness in rehabilitation medicine is the area of technology transfer. A great deal of scientific information is already available to rehabilitation medicine professionals and is not being integrated into rehabilitation training and research. What guarantees can the new institute make that current areas of science will be applied to rehabilitation training?

Overall, I applaud the task force for their thorough and insightful job.

Sincerely,

Richard L. Lieber, Ph.D.
Associate Professor of Surgery

UNIVERSITY OF Miami
SCHOOL OF MEDICINE

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HEAD AND NECK SURGERY

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December 17, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Medgyesi-Mitschang:

This document addresses a hitherto largely ignored problem in Biomedical Research, that is rehabilitation of the patient disabled by disease or by treatment for disease. In particular, the oncology patient frequently requires major rehabilitative efforts to return to a functional and psychologically normal state during and following treatment. As noted in this brief, the areas in which this problem is most acute include patients with head and neck cancer, breast cancer and musculoskeletal tumors. In addition however, the long-term morbidity from extensive gastrointestinal resections for malignant and pre-neoplastic diseases must not be forgotten. To the patient who has undergone subtotal colectomy with ileoproctostomy for polyposis or multiple primary cancers may be disabled by chronic diarrhea. Control of diarrhea in such patients deserves further investigation in an effort to make these patients more functional.

Much has been done in the area of rehabilitation of patients with gastrointestinal stomas, but this research needs to be further pursued. While the Koch pouch and continent pelvic pouches have made major inroads towards realizing the goal of restoring continence to patients undergoing ablative colorectal surgery, these procedures are still plagued by imperfections and complications. Further work is required to reduce the morbidity associated with these and to speed the time to functional recovery.

This document represents an encouraging start to reducing societal morbidity related to disease and treatment related disability. Hopefully it will result in a greater proportion of peer reviewed research funds being directed towards these problems.

Sincerely,

F. L. Moffat, M.D., F.R.C.S.(C.)
Assistant Professor of Surgery
SSO Review Representative

Alfred S. Ketcham, M.D.
Chief, Division of Oncology
Professor of Surgery
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December 11, 1990

Dr. Suzanne Medgyesi-Mitschang
National Institutes of Health
Shannon Building, Room 218
9000 Rockville Pike
Bethesda, MD 20892

Dear Doctor Medgyesi-Mitschang:

Jay Moskowitz, Ph.D. submitted the report of the Task Force on Medical Rehabilitation Research held June 28-29, 1990 in Hunt Valley Inn, Maryland, for my review and comment. I have reviewed the subject of cancer rehabilitation and specifically wish to comment on some of the statements under the heading "Head and Neck Cancer" on page 76 through 77.

Although the wording is suscinct and brief, rehabilitation of head and neck cancer patients is a complex issue that involves professionals of numerous medical and paramedical disciplines. The accuracy of the statements regarding laryngeal cancer could be argued; nevertheless, they may stay as they are.

On the second paragraph, on page 77, mention is made to tongue mobility after surgery, and this statement is less than accurate. Certainly the lesser the resection, the better will be the function, though it has not been proved that primary surgical closure is beneficial for rehabilitation. The second sentence is somewhat outrageous because laser therapy and radiation therapy in combination for small tongue cancers is definitely an over treatment, the morbidity of the added radiation therapy should be avoided whenever possible; either surgery alone (preferably) or radiotherapy alone should be used.

On the last paragraph, on the first column, under the heading "swallowing", the issues regarding cricopharyngeal myotomy bear little on scientific facts; although the RTOG has presently a protocol where in a randomized study it is intended to determine the validity of this surgical adjuvant; in my opinion this has failed to address the issues.

In the next paragraph: Cisplatinum as a drug causes more hearing problems than balance problems, but this is not as important in Head and Neck cancer patients as in patients with other type of tumors that receive much higher dosis of Cisplatinum over prolongued periods of time.

I do not know what the readership will be who is going to read your report, but I am afraid that some of the comments may be misinterpreted by non experts and produce more damage than benefit, and more heat than light.

Sincerely yours,

H. Goepfert

Helmuth Goepfert, M.D.
Professor and Chairman
Department of Head and Neck Surgery

cc: Charles W. Cummings, M.D.

HG/emh

Appendix E

NATIONAL INSTITUTES OF HEALTH AMENDMENTS OF 1990

49-139 - 90 (613)

Public Law 101-613
101st Congress

An Act

Nov. 16, 1990
[S. 2857]

To amend the Public Health Service Act with respect to certain programs for the National Institutes of Health.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

National Institutes of Health Amendments of 1990. Medical research. 42 USC 201 note.

SECTION 1. SHORT TITLE.

This Act may be cited as the "National Institutes of Health Amendments of 1990".

SEC. 2. ESTABLISHMENT OF NATIONAL FOUNDATION FOR BIOMEDICAL RESEARCH.

Title IV of the Public Health Service Act (42 U.S.C. 281 et seq.) is amended by adding at the end thereof the following new part:

"PART H—NATIONAL FOUNDATION FOR BIOMEDICAL RESEARCH

42 USC 290b.

"SEC. 499A. ESTABLISHMENT AND DUTIES OF FOUNDATION.

"(a) IN GENERAL.—The Secretary shall establish a nonprofit corporation to be known as the National Foundation for Biomedical Research (hereafter in this section referred to as the 'Foundation'). The Foundation shall not, except for the purposes of the Ethics in Government Act and the Technology Transfer Act, be an agency or instrumentality of the United States Government.

"(b) DUTIES.—

"(1) ESTABLISHMENT OF FUND FOR ENDOWING RESEARCH POSITIONS AT NATIONAL INSTITUTES OF HEALTH.—

"(A) The Foundation shall establish a fund whose primary purpose shall be to provide endowments for positions at the National Institutes of Health to conduct biomedical research. Such positions may be held by scientists without regard to whether the scientists are employees of the Federal Government.

"(B) In addition to the purpose described in subparagraph (A), the fund established under such subparagraph may be expended to recruit scientists to hold the positions endowed by the fund.

"(C) The purposes for which an endowment under subparagraph (A) may be expended include support for the staffing, equipment, and quarters for the biomedical research conducted by scientists holding endowed positions under such subparagraph.

"(2) APPLICABILITY OF CERTAIN STANDARDS REGARDING NONFEDERAL RESEARCHERS.—In the case of scientists holding endowed positions under paragraph (1)(A) who are not employees of the Federal Government, the Foundation shall negotiate a memorandum of understanding with the Director of the National Institutes of Health, subject to the approval of the Sec-

retary, that specifies that any such scientist shall observe the ethical and procedural standards regulating research and research finding (including publications and patents) that are followed by scientists conducting research as employees of such Institutes, including standards under this Act, the Ethics in Government Act, and the Technology Transfer Act.

"(3) ADDITIONAL DUTIES.—The Foundation shall provide for biennial audits of the financial condition of the Foundation.

"(c) BOARD OF DIRECTORS.—

"(1) COMPOSITION.—

"(A) The Foundation shall have a Board of Directors (hereafter referred to in this section as the 'Board'), which shall be composed of ex officio and appointed members in accordance with this subsection. All members of the Foundation shall be voting members.

"(B) The ex officio members of the Council shall be—

"(i) the Chairman and ranking minority member of the Subcommittee on Health and the Environment (Committee on Energy and Commerce) or their designees, in the case of the House of Representatives;

"(ii) the Chairman and ranking minority member of the Committee on Labor and Human Resources or their designees, in the case of the Senate; and

"(iii) the Director of the National Institutes of Health.

"(C) The ex officio members of the Board under subparagraph (B) shall appoint to the Council 9 individuals from among a list of candidates to be provided by the National Academy of Science. Of such appointed members—

"(i) 4 shall be representative of the general biomedical field;

"(ii) 2 shall be representatives of the general biobehavorial field; and

"(iii) 3 shall be representatives of the general public.

"(2) CHAIR.—The ex officio members of the Board under paragraph (1)(B) shall designate an appointed member of the Board to serve as the Chair of the Board.

"(3) TERMS AND VACANCIES.—

"(A) The term of office of each member of the Board appointed under paragraph (2)(C) shall be 5 years, except that the terms of offices for the initial appointed members of the Board shall expire as determined by the ex officio members and the Chair.

"(B) Any vacancy in the membership of the Board shall be filled in the manner in which the original position was made and shall not affect the power of the remaining members to execute the duties of the Board.

"(C) If a member of the Board does not serve the full term applicable under subparagraph (A), the individual appointed to fill the resulting vacancy shall be appointed for the remainder of the term of the predecessor of the individual.

"(D) A member of the Board may continue to serve after the expiration of the term of the member until a successor is appointed.

"(4) COMPENSATION.—Members of the Board may not receive compensation for service on the Board. Such members may be

reimbursed for travel, subsistence, and other necessary expenses incurred in carrying out the duties of the Board, as set forth in the bylaws issued by the Board.

"(d) INCORPORATION.—The initial members of the Board shall serve as incorporators and shall take whatever actions necessary to incorporate the Foundation.

"(e) NONPROFIT STATUS.—The Foundation shall be considered to be a corporation under section 501(c) of the Internal Revenue Code of 1986, and shall be subject to the provisions of such section.

"(f) EXECUTIVE DIRECTOR.—

"(1) IN GENERAL.—The Foundation shall have an Executive Director who shall be appointed by the Board and shall serve at the pleasure of the Board. The Executive Director shall be responsible for the day-to-day operations of the Foundation and shall have such specific duties and responsibilities as the Board shall prescribe.

"(2) COMPENSATION.—The rate of compensation of the Executive Director shall be fixed by the Board.

"(g) POWERS.—In carrying out subsection (b), the Foundation may—

"(1) operate under the direction of its Board;

"(2) adopt, alter, and use a corporate seal, which shall be judicially noticed;

"(3) provide for 1 or more officers, employees, and agents, as may be necessary, define their duties, and require surety bonds or make other provisions against losses occasioned by acts of such persons;

"(4) hire, promote, compensate, and discharge officers and employees of the Foundation;

"(5) prescribe by its Board its bylaws, that shall be consistent with law, and that shall provide for the manner in which—

"(A) its officers, employees, and agents are selected;

"(B) its property is acquired, held, and transferred;

"(C) its general operations are to be conducted; and

"(D) the privileges granted by law are exercised and enjoyed;

"(6) with the consent of any executive department or independent agency, use the information, services, staff, and facilities of such in carrying out this section;

"(7) sue and be sued in its corporate name, and complain and defend in courts of competent jurisdiction;

"(8) modify or consent to the modification of any contract or agreement to which it is a party or in which it has an interest under this subtitle;

"(9) establish a mechanism for the selection of candidates, subject to the approval of the Director of the National Institutes of Health or the Administrator of the Alcohol, Drug Abuse, and Mental Health Administration, for the endowed scientific positions within the organizational structure of the intramural research programs of the National Institutes of Health and the Alcohol, Drug Abuse, and Mental Health Administration and candidates for participation in the National Institutes of Health Scholars program;

Government contracts.

"(10) enter into contracts with public and private organizations for the writing, editing, printing, and publishing of books and other material;

"(11) take such action as may be necessary to obtain patents and licenses for devices and procedures developed by the Foundation and its employees;

"(12) accept, hold, administer, invest, and spend any gift, devise, or bequest of real or personal property made to the Foundation;

"(13) enter into such other contracts, leases, cooperative agreements, and other transactions as the Executive Director considers appropriate to conduct the activities of the Foundation; Government contracts.

"(14) appoint other groups of advisors as may be determined necessary from time to time to carry out the functions of the Foundation; and

"(15) exercise other powers as set forth in this section, and such other incidental powers as are necessary to carry out its powers, duties, and functions in accordance with this subtitle.

"(h) ADMINISTRATIVE CONTROL.—No participant in the program established under this part shall exercise any administrative control over any Federal employee.

"(i) FUNDING.—

"(1) AUTHORIZATION OF APPROPRIATIONS.—Subject to paragraph (2), for the purpose of carrying out this part, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 1991 through 1995.

"(2) LIMITATIONS.—

"(A) Amounts appropriated under paragraph (1) or made available under subparagraph (C) may not be provided to the fund established under subsection (b)(1)(A).

"(B) For the first fiscal year for which amounts are appropriated under paragraph (1), $200,000 is authorized to be appropriated.

"(C) With respect to the first fiscal year for which amounts are appropriated under paragraph (1), the Secretary may, from amounts appropriated for such fiscal year for the programs of the Department of Health and Human Services, make available not more than $200,000 for carrying out this part, subject to subparagraph (A).".

SEC. 3. ESTABLISHMENT OF NATIONAL CENTER FOR MEDICAL REHABILITATION RESEARCH.

(a) IN GENERAL.—Subpart 7 of part C of title IV of the Public Health Service Act (42 U.S.C. 285g et seq.) is amended by inserting after section 451 the following new section:

"NATIONAL CENTER FOR MEDICAL REHABILITATION RESEARCH

"SEC. 452. (a) There shall be in the Institute an agency to be known as the National Center for Medical Rehabilitation Research (hereafter in this section referred to as the 'Center'). The Director of the Institute shall appoint a qualified individual to serve as Director of the Center. The Director of the Center shall report directly to the Director of the Institute. 42 USC 285g–4.

"(b) The general purpose of the Center is the conduct and support of research and research training (including research on the development of orthotic and prosthetic devices), the dissemination of health information, and other programs with respect to the rehabilitation of individuals with physical disabilities resulting from

diseases or disorders of the neurological, musculoskeletal, cardiovascular, pulmonary, or any other physiological system (hereafter in this section referred to as 'medical rehabilitation').

"(c)(1) In carrying out the purpose described in subsection (b), the Director of the Center may—

"(A) provide for clinical trials regarding medical rehabilitation;

"(B) provide for research regarding model systems of medical rehabilitation;

"(C) coordinate the activities of the Center with similar activities of other agencies of the Federal Government, including the other agencies of the National Institutes of Health, and with similar activities of other public entities and of private entities;

"(D) support multidisciplinary medical rehabilitation research conducted or supported by more than one such agency;

"(E) in consultation with the advisory council for the Institute and with the approval of the Director of NIH—

"(i) establish technical and scientific peer review groups in addition to those appointed under section 402(b)(6); and

"(ii) appoint the members of peer review groups established under subparagraph (A); and

"(F) support medical rehabilitation research and training centers.

The Federal Advisory Committee Act shall not apply to the duration of a peer review group appointed under subparagraph (E).

Government contracts.

"(2) In carrying out this section, the Director of the Center may make grants and enter into cooperative agreements and contracts.

"(d)(1) In consultation with the Director of the Center, the coordinating committee established under subsection (e), and the advisory board established under subsection (f), the Director of the Institute shall develop a comprehensive plan for the conduct and support of medical rehabilitation research (hereafter in this section referred to as the 'Research Plan').

"(2) The Research Plan shall—

"(A) identify current medical rehabilitation research activities conducted or supported by the Federal Government, opportunities and needs for additional research, and priorities for such research; and

"(B) make recommendations for the coordination of such research conducted or supported by the National Institutes of Health and other agencies of the Federal Government.

"(3)(A) Not later than 18 months after the date of the enactment of the National Institutes of Health Revitalization Amendments of 1990, the Director of the Institute shall transmit the Research Plan to the Director of NIH, who shall submit the Plan to the President and the Congress.

"(B) Subparagraph (A) shall be carried out independently of the process of reporting that is required in sections 403 and 407.

"(4) The Director of the Institute shall periodically revise and update the Research Plan as appropriate, after consultation with the Director of the Center, the coordinating committee established under subsection (e), and the advisory board established under subsection (f). A description of any revisions in the Research Plan shall be contained in each report prepared under section 407 by the Director of the Institute.

"(e)(1) The Director of NIH shall establish a committee to be known as the Medical Rehabilitation Coordinating Committee (hereafter in this section referred to as the 'Coordinating Committee'). Establishment.

"(2) The Coordinating Committee shall make recommendations to the Director of the Institute and the Director of the Center with respect to the content of the Research Plan and with respect to the activities of the Center that are carried out in conjunction with other agencies of the National Institutes of Health and with other agencies of the Federal Government.

"(3) The Coordinating Committee shall be composed of the Director of the Center, the Director of the Institute, and the Directors of the National Institute on Aging, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Heart, Lung, and Blood Institute, the National Institute of Neurological Disorders and Stroke, and such other national research institutes and such representatives of other agencies of the Federal Government as the Director of NIH determines to be appropriate.

"(4) The Coordinating Committee shall be chaired by the Director of the Center.

"(f)(1) Not later than 90 days after the date of the enactment of the National Institutes of Health Revitalization Amendments of 1990, the Director of NIH shall establish a National Advisory Board on Medical Rehabilitation Research (hereafter in this section referred to as the 'Advisory Board'). Establishment.

"(2) The Advisory Board shall review and assess Federal research priorities, activities, and findings regarding medical rehabilitation research, and shall advise the Director of the Center and the Director of the Institute on the provisions of the Research Plan.

"(3)(A) The Director of NIH shall appoint to the Advisory Board 18 qualified representatives of the public who are not officers or employees of the Federal Government. Of such members, 12 shall be representatives of health and scientific disciplines with respect to medical rehabilitation and 6 shall be individuals representing the interests of individuals undergoing, or in need of, medical rehabilitation.

"(B) The following officials shall serve as ex officio members of the Advisory Board:

"(i) The Director of the Center.

"(ii) The Director of the Institute.

"(iii) The Director of the National Institute on Aging.

"(iv) The Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

"(v) The Director of the National Institute on Deafness and Other Communication Disorders.

"(vi) The Director of the National Heart, Lung, and Blood Institute.

"(vii) The Director of the National Institute of Neurological Disorders and Stroke.

"(viii) The Director of the National Institute on Disability and Rehabilitation Research.

"(ix) The Commissioner for Rehabilitation Services Administration.

"(x) The Assistant Secretary of Defense (Health Affairs).

"(xi) The Chief Medical Director of the Department of Veterans Affairs.

"(4) The members of the Advisory Board shall, from among the members appointed under paragraph (3)(A), designate an individual to serve as the chair of the Advisory Board.".

42 USC 285g-4 note.

(b) REQUIREMENT OF CERTAIN AGREEMENTS FOR PREVENTING DUPLICATIVE PROGRAMS OF MEDICAL REHABILITATION RESEARCH.—

(1) IN GENERAL.—The Secretary of Health and Human Services and the heads of other Federal agencies shall—

(A) jointly review the programs being carried out (or proposed to be carried out) by each such official with respect to medical rehabilitation research; and

(B) as appropriate, enter into agreements for preventing duplication among such programs.

(2) TIME FOR COMPLETION.—The agreements required in paragraph (1)(B) shall be made not later than one year after the date of the enactment of this Act.

(3) DEFINITION OF MEDICAL REHABILITATION.—For purposes of this subsection, the term "medical rehabilitation" means the rehabilitation of individuals with physical disabilities resulting from diseases or disorders of the neurological, musculoskeletal, cardiovascular, pulmonary, or any other physiological system.

Approved November 16, 1990.

LEGISLATIVE HISTORY—S. 2857 (H.R. 5661):

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SENATE REPORTS: No. 101-459 (Comm. on Labor and Human Resources).
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