

# Research Plan for the National Center for Medical Rehabilitation Research

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## Research Plan

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*The statements, conclusions, and recommendations contained in this document reflect both individual and collective opinions of the symposium participants and are not intended to represent the official position of the U.S. Department of Health and Human Services, or the National Institutes of Health.*

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## Foreword

The National Advisory Board on Medical Rehabilitation Research (NABMRR) was established by the National Institutes of Health (NIH) at the direction of the United States Congress. The Board was assigned the task of providing general guidance to the National Center for Medical Rehabilitation Research (NCMRR) of the National Institute of Child Health and Human Development (NICHD) of the NIH. Research supported and coordinated by the NCMRR will ultimately result in improved individual functioning through better medical treatment options for people with disabilities and provide new technical devices to make possible and to improve performance on daily activities. The goal of the Board is to extend the excellence in biological science fostered by the NIH to the rehabilitative sciences that focus on improving function and enhancing the quality of life for people with disabilities.

This Research Plan for Medical Rehabilitation Research, prepared at the request of Congress, will describe a framework for defining and developing the field of rehabilitative sciences and will describe research opportunities for the NCMRR and other agencies funding medical rehabilitation research. Advice and suggestions provided by individuals with disabilities, scientists and service providers will be incorporated into the plans of the NCMRR and other Federal agencies' in developing research initiatives, research training, research coordination, conferences, and other special activities

This report presents the Advisory Board's first review of medical rehabilitation research. Much of this Research Plan is based upon the NIH Report of the Task Force on Medical Rehabilitation Research, a conference proceeding that reports the findings of more than 100 scientists, practitioners and consumers with expertise in the field of medical rehabilitation who met at Hunt Valley, Maryland in June, 1990. (Theodore M. Cole and V. Reggie Edgerton, Report of the Task Force on Medical Rehabilitation Research, Hunt Valley Inn, Hunt Valley, Maryland, 1990.)

The views expressed in this document are those of the Director, National Institute of Child Health and Human Development and the National Advisory Board on Medical Rehabilitation Research, and do not necessarily reflect the positions or judgements of the National Institutes of Health, the Department of Health and Human Services, or the Administration, which must weigh competing requirements of multiple programs and activities.

People who experience disability early in life adapt to societal and environmental demands (challenges) through a habilitation process, an initial learning of skills that allows an individual to function in society. People who are disabled later in life modify their skills through the rehabilitation process, learning new ways of doing things that they did before becoming disabled.

Although this document will use "rehabilitation" to mean both processes, the distinction between habilitation and rehabilitation is important and should be kept in mind.

## Glossary

**Disability** - limitation in performing tasks, activities and roles to levels expected within physical and social contexts.

**Function** - the performance of an action for which a person or thing is especially fitted or used.

**Habilitation** - an initial learning of skills that allows an individual to function in society

**Impairment** - a loss or abnormality at the organ or organ system level of the body

**Pathophysiology** - the interruption of, or interference with, normal physiological and developmental processes or structures.

**Rehabilitation** - restoring or bringing to a condition of health or useful and constructive activity.

**Societal Limitations** - restrictions attributable to social policy or barriers (structural or attitudinal) which limit fulfillment of roles or deny access to services and opportunities associated with full participation in society.

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School of Medicine  
Miami, Florida

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College of Associated Health Professions  
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Chicago, Illinois

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State University of New York at Buffalo  
Director Emeritus  
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Vero Beach, Florida

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Baltimore, Maryland

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State University of New York  
Buffalo, New York

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National and International Affairs  
World Institute on Disability  
Oakland, California

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Spina Bifida Association of America  
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Orthopedic Biomechanics Laboratory  
Mayo Clinic  
Rochester, Minnesota

**Roberta B. Trieschmann, Ph.D.**

Consulting Psychologist  
President RBT Associates, Inc.  
Scottsdale, Arizona

**Theodore Cole, M. D.**

Professor  
Department of Physical Medicine and  
Rehabilitation  
University of Michigan Hospitals  
University of Michigan  
Ann Arbor, Michigan

**George A. Zitnay, Ph.D.**

President  
National Head Injury Foundation, Inc.  
Washington, D.C.

**National Advisory Board on Medical Rehabilitation Research  
Ex-Officio Members**

**Duane Alexander, M.D.**

Director  
National Institute of Child Health and  
Human Development  
Acting Director  
National Center for Medical  
Rehabilitation Research  
National Institutes of Health  
Bethesda, Maryland

**James L. Green, M.D.**

Acting Director  
Rehabilitation Research and Development Service  
Department of Veteran Affairs  
Washington, D.C.

**Praxedes Belandres, M. D.**

Physical Medicine Department  
Walter Reed Army Medical Center  
Department of Defense  
Washington, D.C.

**Ada Sue Hinshaw, Ph.D., R. N.**

Director  
National Center for Nursing Research  
National Institutes of Health  
Bethesda, Maryland

**Nell Carney**

Commissioner  
Rehabilitation Services Administration  
Office of Special Education and  
Rehabilitative Services  
U. S. Department of Education  
Washington, D.C.

**Michael S. Kaplan, Ph.D., M.D.**

Director of Physical Functioning Program  
National Institute on Aging  
National Institutes of Health  
Bethesda, Maryland

**Peter Frommer, M.D.**

Deputy Director  
National Heart, Lung and Blood Institute  
National Institutes of Health  
Bethesda, Maryland

**Lawrence Shulman, M.D., Ph.D.**

Director  
National Institute of Arthritis and  
Musculoskeletal and Skin Diseases  
National Institutes of Health  
Bethesda, Maryland

**Murray Goldstein, D.O., M.P.H.**

Director  
National Institute of Neurological  
Disorders and Stroke  
National Institutes of Health  
Bethesda, Maryland

**James B. Snow Jr. , M.D.**

Director  
National Institute on Deafness and  
Other Communication Disorders  
National Institutes of Health  
Bethesda, Maryland

**William H. Graves, Ed. D.**

Director  
National Institute on Disability and  
Rehabilitation Research  
Office of Special Education and  
Rehabilitative Services  
U. S. Department of Education  
Washington, D.C.

**National Advisory Board on Medical Rehabilitation Research  
Staff**

**Duane Alexander, M.D.**

Director  
National Institute of Child Health and  
Human Development  
Acting Director  
National Center for Medical  
Rehabilitation Research  
National Institutes of Health  
Bethesda, Maryland

**Danuta Krotoski, Ph.D.**

Chief  
Basic Medical Rehabilitation Research Branch  
National Center for Medical  
Rehabilitation Research  
National Institutes of Health  
Bethesda, Maryland

**Cheryl Chanaud, Ph.D.**

Applied Medical Rehabilitation Research Branch  
National Center for Medical  
Rehabilitation Research  
National Institutes of Health  
Bethesda, Maryland

**Louis Quatrano, Ph.D.**

Chief  
Applied Medical Rehabilitation Research Branch  
National Center for Medical  
Rehabilitation Research  
National Institutes of Health  
Bethesda, Maryland

**David B. Gray, Ph.D.**

Acting Deputy Director  
National Center for Medical  
Rehabilitation Research  
National Institutes of Health  
Bethesda, Maryland



## Executive Summary

Disability has a major economic impact on our society and can have a devastating effect on persons with disabilities, their families, and their communities. Between 35 and 43 million Americans have one or more conditions that result in a limitation of life activities. The annual economic costs exceed \$170 billion. Major functional limitations of people with disabilities include restricted mobility, reduced sensory capacities, communication problems and intellectual deficits. Health problems associated with chronic disorders have created an increased set of challenges for the health care system.

In recognition of the rights of people with disabilities, the Americans with Disabilities Act (ADA) was signed into law by President Bush in July of 1990. Implementation of the provisions of this law is progressing in the areas of employment, transportation, public accommodation and communication. Subsequent legislation (P.L. 101-613) established the National Center for Medical Rehabilitation Research (NCMRR) as part of the National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). The formation of the NCMRR reflects the realization that the health care of people with disabilities needs to be improved for people with disabilities to join their fellow Americans in living productive, meaningful and enjoyable lives.

The mission of the NCMRR is to enhance the quality of life for people with disabilities. This will be accomplished through the support of research on restoration, replacement, enhancement, or prevention of the deterioration of functions. This research will be conducted by scientists who are interested in and have the technical expertise to improve the knowledge base in the field of rehabilitation, improve clinical practice, and develop new technical devices for people with disabilities. Recent advances in the behavioral, biological and engineering sciences provide exciting opportunities for the rehabilitative sciences.

The legislation that established the NCMRR required that the Director of the NIH establish a National Advisory Board on Medical Rehabilitation Research and that this Advisory Board assist the Director of the NICHD in the formulation of a plan for medical rehabilitation research to guide the new Center's activities. In addition, the legislation directed that the research plan review medical rehabilitation research in other Federal agencies and the coordination of this research, which would be a responsibility of the NCMRR. This document fulfills that charge and is the result of a cooperative effort of the National Advisory Board on Medical Rehabilitation Research and the Director of the NICHD. In preparing it, the Advisory Board sought and received advice expressed by hundreds of scientists, rehabilitation specialists, and people with disabilities who presented testimony at three field hearings or wrote letters to the NCMRR. In addition, the Medical Rehabilitation Coordinating Committee, discussed herein, was consulted regarding the Research Plan.

This Research Plan for Medical Rehabilitation Research provides a conceptualization of disability that builds on the strengths of existing scientific principles and social values. The focus is on the person with a disability and how that person adapts to functional limitations in his or her family, work and local community. The conceptual model recognizes that rehabilitation is a process that extends over varying lengths of time and has different outcomes. The model provides for five overlapping domains of research that are relevant to studying disability. These are pathophysiology, impairment, functional limitation, disability and societal limitation. The latter domain provides an essential link between the individual's adaptation to disability and society's barriers to people with disabilities that prevent them from having an opportunity to achieve and enjoy a high quality of life.

Bringing the health related problems of people with disabilities to the attention of America's best scientists is an important prerequisite for reducing the individual and societal costs of disability. Adapting rigorous scientific methods to the integrated study of the person who is disabled from birth or through injury or disease or aging will provide a new generation of effective rehabilitation therapies and devices. Medical rehabilitation research has not yet developed as a mature science because it has lacked a focus and an identity of its own. Inadequate funding of rehabilitation research, the lack of measurement tools, scant

epidemiological data, and scarcity of well trained and productive rehabilitation scientists have contributed to the slow progress in improving rehabilitation for people with disabilities.

Research initiatives and opportunities recommended by the Director of the NICHD and the Advisory Board are meant to address the problems of advancing the science of medical rehabilitation. These recommendations are presented in seven general categories - - - mobility; behavioral adaptation; whole body system response; technical devices; measurement, assessment and epidemiology; treatment evaluation; and training research scientists. Within each of these categories are at least four primary initiatives and five opportunities for Federal agency support of medical rehabilitation research. Children, women, and minorities with disabilities are singled out for special attention. The problems associated with growing older with a disability are addressed as a topic for special consideration by the rehabilitation research community.

In the first year of operation, the NCMRR funded seven institutional training grants for the purpose of improving the quality and quantity of individuals who can conduct excellent research studies on the problems of people with disabilities. In the current fiscal year institutional training grants at six additional sites will be funded. Three requests for applications were issued and will result in support for several research projects in each of the following areas: prosthetic and orthotic devices; reproductive functioning; and bowel and bladder management. In addition, investigations initiated by scientists interested in studying rehabilitation will be funded through the regular mechanisms used by the NIH to support research. Conferences will be held to address scientific issues in the areas of improved diagnosis of musculoskeletal disorders; new developments in prosthetic and orthotic devices; basic research and clinical interventions for people with osteogenesis imperfecta, and rehabilitation treatments for chronic pain.

Cooperative activities among the NCMRR and the various Federal agencies involved in medical rehabilitation research have begun to take place. A memorandum of understanding for cooperation and interaction was agreed on by the NCMRR and the National Institute on Disability and Rehabilitation Research. A Medical Rehabilitation Coordinating Committee was appointed by the Director of NIH. This committee will work to develop a method of reporting, coordinating and developing medical rehabilitation research initiatives at the NIH. The NCMRR will assist several other NIH Institutes in providing support for medical rehabilitation research projects that were initially submitted to them. The NCMRR, through its membership on the Interagency Committee on Disability Research chaired by the Director of the National Institute on Disability and Rehabilitation Research, will work to coordinate medical rehabilitation research in other Federal agencies.

The National Advisory Board on Medical Rehabilitation Research and the Director of the NICHD are optimistic that the NCMRR can foster excellence in medical rehabilitation research. If the goals for research focused on function described in this Research Plan are to be fulfilled, then the ensuing years will require the continued efforts and goodwill of those who worked to set the ambitious agenda as well as a serious commitment of the scientific community to use the tools of science for the improvement of the quality of life for people with disabilities.

## Introduction

"It seems to me that this interface between medical rehabilitation and the disability movement is extremely important. It provides a research and program thread that runs from patient-doctor relationships, financial transactions, roles, processes, sharing versus possession of knowledge, empowerment, decision-making, to political action." (Written communication taken from correspondence submitted to the NCMRR for the public hearings.)

Enactment of the Americans with Disabilities Act in 1990 (ADA) demonstrated this country's commitment to providing people with disabilities equal access and opportunity to employment, transportation, public accommodation and communication. Other Federal laws address education, housing and health care for people with disabilities. But before people with disabilities will be able to truly enter the social and economic mainstream of American society, they will need to maximize their ability to function physically and behaviorally. Increased attention of the medical research community to the rehabilitation and health of individuals with disabilities is needed. In recognition of this need, legislation (P.L. 101-613) passed shortly after the ADA establishing a National Center for Medical Rehabilitation Research (NCMRR) at the preeminent medical research facility in the world, the National Institutes of Health (NIH). The mission and opportunity for this Center is to combine, in a synergistic manner, the NIH's proven ability to attract the best and brightest minds in medical research with the important task of developing better rehabilitation treatment and assistive devices for people with disabilities. In this way, rehabilitation research that derives from the NCMRR is a natural precursor to fulfillment of the goals embodied in the Americans with Disabilities Act.

In addition to establishing the NCMRR within the National Institute of Child Health and Human Development (NICHD) at the NIH, P.L. 101-613 charged the Director of the NICHD with developing "a comprehensive plan for the conduct and support of medical rehabilitation research." The research plan, to be developed in consultation with the National Advisory Board on Medical Rehabilitation Research, was to "identify current medical rehabilitation research activities conducted or supported by the Federal Government, opportunities and needs for additional research, and priorities for such research," as well as make recommendations for coordinating such research. The Director of NICHD asked the Board to assume primary responsibility for developing this Plan, an assignment the Board enthusiastically accepted.

In developing this Plan, the Board heard presentations from representatives of the relevant NIH Institutes and Federal agencies on their activities in support of medical rehabilitation research. The Board also reviewed the NIH Report of the Task Force on Medical Rehabilitation Research. In a series of three widely publicized field hearings in Houston, Texas; Seattle, Washington; and Bethesda, Maryland, the Board heard first-hand testimony from scientists, professional and advocacy organizations, and persons with disabilities on the needs and opportunities in rehabilitation research. Finally, through its own extensive discussions, the Board synthesized this information, placed it in the context of a conceptual model of the medical rehabilitation process, and formulated its recommendations and priorities for medical rehabilitation research. The resulting Report and Research Plan reviews progress in medical rehabilitation, provides an overview of the scope of problems associated with disability, suggests a conceptual framework for understanding disability and the rehabilitation process, describes barriers to current efforts in medical rehabilitation research, lists general and specific goals for the NCMRR, and offers a vision for future directions in medical rehabilitation research.

The NCMRR will support research on restoring, replacing or enhancing the function of children and adults with disabilities, and will coordinate research in these areas conducted at NIH and elsewhere. Medical rehabilitation research is directed towards restoration or improvement of functional capability lost as a consequence of injury, disease, congenital disorder or natural aging process. The mission of the NCMRR is to improve the ability of medical rehabilitation to restore or improve function through research on: 1)

mobility; 2) behavioral adaptation to functional loss; 3) whole body response to lost function; 4) assistive devices to replace or enhance function; 5) outcome measures, epidemiology and demography; and 6) treatment intervention effectiveness in restoring, improving or maintaining function. The NCMRR will also provide resources for training scientists in the field of medical rehabilitation research.

This research will include basic science studies related to the pathophysiologic mechanisms and processes underlying functional loss. Basic and clinical studies of impairments that reduce function are included in the science of medical rehabilitation. Fundamental knowledge of normal functional development, change in functional capacity during development, and alteration of functional abilities post-injury or disease are focal points of medical rehabilitation research. The individual's adaptive and maladaptive behavioral responses to an impairment and functional change are the subject of a wide variety of basic, clinical and applied studies. How persons with disabilities adjust to the demands of society (family, work, support systems, etc.) and to natural and human-made environmental barriers determines the success or failure of medical rehabilitation programs. Another important aspect of the rehabilitation process is the adjustments made by families to disability and how they meet the needs of the individual with a disability through effective use and development of social, medical, vocational and recreational support services.

These studies of assisted recovery from, or adaptation to, functional loss will be conducted by researchers from a wide variety of scientific disciplines including, but not limited to, specialists in physical medicine and rehabilitation, neurology, pediatrics, urology, orthopaedics, neurosurgery, plastic surgery, dermatology, nursing, nutrition, physical, occupational, recreational, music, and horticulture therapy, speech - language pathology, audiology, rehabilitation and neuropsychology, sociology, demography, epidemiology, biomedical engineering, biomechanical engineering, rehabilitation engineering, and by orthotists, prosthetists, communication specialists, social workers, and other health professionals.

In addition, the basic sciences contribute to understanding mechanisms and processes fundamental to recovering, restoring or maintaining function. These disciplines include, but are not limited to, genetics, molecular biology, neuroscience, physiological sciences and the physical sciences.

## Historical Perspective

This century has seen remarkable discoveries in the health sciences that have provided new techniques for prevention of disorders, elimination of some diseases, and improvements in acute treatment of injury. These advances have lengthened considerably the average lifespan of Americans with and without disabilities. Along with these advances, the need for health care in general, and rehabilitation in particular, has increased significantly. Many of these advances in the health sciences were based on research using a reductionistic approach. While such an approach has advantages for some conditions, reducing the study of disability to a single aspect of the multiple problems caused by an impairment disregards the phenomenon of the whole person operating within the environment.

Organized rehabilitation efforts began following World War I in response to a national commitment to return veterans with disabilities to active participation in society. The complex problems faced by these returning veterans required the attention and skills of people from many existing professions and provided the demand for the formation of new specialties. The coalescence of these professionals into treatment teams began after World War II with a new influx of returning veterans with disabilities. The emphasis of these treatment teams was directed toward improving the function of persons with disabilities. The value of this approach was exemplified by the successful rehabilitation of many Korean conflict and Vietnam War veterans. In addition to major wars that prompted the development of the field of rehabilitation, the polio epidemic of the 1940's and 50's provided the impetus for developing rehabilitation strategies for the problems faced by women and children with disabilities.

One of the earliest and most powerful contributions of rehabilitation to modern health care was the concept of the interdisciplinary approach to medical treatment. This integrated, team approach to medical problem-solving provided a new and effective approach for treating individuals with disabilities, solving their sometimes complex medical and psychosocial problems, and filling their needs in vocational, home and social settings.

The establishment of training programs, the development of specialists in rehabilitation (rather than depending on skills diffused through other specialties), and the growth in the number of trained rehabilitation practitioners have been significant advances. Many professions contribute to the rehabilitation process and have provided other notable contributions: continuous refinement of medical rehabilitation treatment programs for specific problems (such as paralysis, polio, post-polio, spina bifida and other birth anomalies, head or brain injury, stroke, amputation, osteoporosis, arthritis, cardiovascular disease); advances in the treatment of primary injury or illness and the treatment of secondary complications; and creation of educational programs to train individuals with injury or disease, as well as their family members, in self-care aspects of treatment.

Advances made in the past three decades in the medical emergency system, pharmacological interventions, and surgical techniques saved the lives of many children and adults who would otherwise have died as a result of their congenital anomalies, injury or disease. The integration of these individuals into the mainstream of societal activities has been a direct effect of improved rehabilitation treatments developed by the interdisciplinary teams. The independent living movement of the past two decades has provided informed consumers who are often full members of interdisciplinary treatment teams.

In many cases, improved medical rehabilitation treatment practices have shortened the time spent by people with disabilities in rehabilitation facilities. The reduction in financial costs to the individual, third party payers, and society has been substantial. Perhaps most importantly, these advances in treatment have also resulted in a highly improved quality-of-life for many individuals.

The rehabilitation community stands at the threshold of an era in which the tools of basic research may be employed to improve the functional abilities of people with disabilities. During the past decade remarkable progress has been made in understanding basic biological and molecular mechanisms fundamental to

understanding how the human organism develops. At the same time, dramatic advances in many areas of technology have created opportunities for developing a new generation of devices for improving the functions of people with disabilities. Substantial improvement in existing rehabilitative treatments and assistive devices is possible if the efforts of these scientific communities are directed towards improving the function of people with disabilities. These advances would be invaluable for the development of programs to implement the Americans with Disabilities Act and, more generally, to promote empowerment of individuals with disability in their efforts to lead healthy, independent and productive lives.

## The Scope of Disability

"I was considered broken. The staff was going to fix me. They would teach me words. Except when I spoke nobody believed me. Six weeks of not being believed created an abiding belief that I will never be believed again. The effects of not being believed, of not being treated as a thinking person, of not being considered a part of my own healing, last. At home I was able to construct a care program for myself with therapists who listened, people who asked me to describe for them what I was experiencing, people who respected my choices about which needs to work on when. I and every other head injured person who has constructed a new life, a dignified, fulfilled life know what it takes to heal. We know what is needed from our worlds so that our worlds encourage us, rather than teach us how to be cripples, or teach us there is no valuable place for us." (Written Correspondence)

Disability can result from a number of causes: a condition present at birth; traumatic injury at any age; limited or deteriorating function due to onset of illness or disease; reduced function due to aging-related conditions; or exacerbations of previously-existing conditions. Few American families do not experience the effects of disability firsthand. In fact, any person at anytime may acquire a disability that could last a lifetime. Some families have children who are born with cerebral palsy, spina bifida, mental retardation or without one or more limbs. Other families are distressed when a loved one is in an accident and incurs a disabling head or brain injury, spinal cord injury, or amputation of a limb. For some families, the term "disability" becomes reality when a primary income-earner has a severe heart attack at age 50, necessitating months of rehabilitation and altered lifestyles. For others, the concept of disability becomes clear when an aging parent has a stroke or breaks a hip.

Disability has always been a fact of life for society, but its significance to social and economic policies related to the provision of and access to medical and rehabilitation services has increased exponentially as the number of Americans with severe disabilities has increased. Today, between 35 and 43 million Americans have a disabling condition that limits one or more of their daily activities. Of these, more than 13 million require some or significant assistance with activities of daily living, and an additional 9.7 million are unable to carry on the major activities of someone their age. The annual cost to the nation of disability-related transfer payments and health care for people with disabilities is in excess of \$170 billion. (Andrew M. Pope and Alvin R. Tarlov, *Disability in America: Toward a National Agenda for Prevention*, National Academy Press, Washington, D.C., 1991.) Prevention of Disability

Prevention of disability can be considered as a two-tiered process. The first process is prevention of the bodily insult that results in impairment of function. Prevention efforts include legislation and public awareness campaigns to encourage seat belt or bicycle helmet use; research on behavioral, situational and environmental conditions conducive to childhood injury; and intervention strategies to encourage individuals to modify lifestyles or behaviors that pose risks to themselves or their unborn children. These interventions can include encouraging pregnant women not to smoke cigarettes or ingest alcohol; dissuading intravenous drug users from using dirty needles; and promoting low-fat, high fiber diets and regular, sensible exercise programs.

Each of these behaviors has implications for the prevention of disability. Many head injuries are the result of motorcyclists or bicycle riders not wearing a helmet. Eleven percent of very low birthweight infants, those at highest risk for developmental disabilities, are born to mothers who smoke cigarettes during pregnancy. Use of dirty needles facilitates the spread of hepatitis and HIV infection. Poor diet and a sedentary lifestyle are implicated in the development of heart disease and probably some forms of cancer.

The AIDS epidemic has produced a new group of people with disabilities who need increased support and income maintenance systems, adaptive technology, and rehabilitation methods to maximize remaining

functions and slow the process of deterioration. In the short term, prevention of AIDS rests upon education, use of "safe sex" behaviors, and elimination of contaminated needles.

Increasingly, a major cause of severe disability is injury from gunshot or knife wounds that occur during violent domestic fights or street crime. These types of severe injury are found most often in lower socioeconomic groups, but people from all socioeconomic levels are susceptible. Preventing the causes of violence-related injuries will be a difficult task involving improved societal efforts to educate and employ people who do not have adequate personal or financial resources. Eliminating or modifying these behaviors is beyond the scope of the NCMRR. However, many of the agencies represented on the Center's Board support and conduct research aimed at preventing these problems and conditions which daily add to the numbers of individuals with a disability.

The second tier of prevention is the reduction or elimination of health problems in those who are currently disabled. A growing minority population in the United States today is composed of people who have survived illness or injuries that were fatal in the recent past. For the first time in history, significant numbers of children with severe developmental disabilities are surviving well into adulthood. With these increases in life span, people with disabilities have begun to experience health problems and function losses that have no precedents. People who use braces or wheelchairs for long periods may experience shoulder and upper arm pain and functional loss. Many people who survived polio are losing muscle strength as they reach middle age. Research indicates, however, that many of the secondary complications and other health problems of people with disabilities can be prevented by timely and appropriate treatment and technological devices. Thus, the prevention of health problems and functional loss for this minority is fast becoming an important focus for medical rehabilitation.

### ***Epidemiology and Demography of Disability***

During the past 20 years a number of researchers have begun to study the demographics of disability. No single research effort fully addresses the population of Americans with disabilities, nor in most cases can data from one study be compared directly with the data from other studies. Across studies, the definitions of disability vary widely and depend upon the focus of the research. Comparisons of data from different sources need to be approached cautiously. Differing disabilities are more prevalent among specific age groups. Different impairments may reduce or limit one or more function. The severity and co-morbidity are important considerations in studying the epidemiology and demography of disability. The incidence and prevalence of disability increases significantly among older individuals. Children with disabilities have the potential to live the most years with a disability. All of these factors and more will affect categorical studies of the relative societal costs and benefits of functional losses associated with different disabilities. Nonetheless, available data, drawn from a variety of resources, provides the following overview of disability in the United States, categorized according to either the type of limitation or the disease or disorder causing the disability.

### ***Categories of Disability: Functional and Physical Limitations***

The primary data set containing information about the specific causes of disability is the National Health Interview Survey (NHIS), which identifies major causes of activity-related disability (Table 1). One analysis of spending for health care estimated that the 16 percent of the population with activity limitations accounted for \$63 billion in 1980, about 40 percent of all health care expenditures for that year. This figure does not include the significant portion of those people with disabilities due to traumatic brain injury.

Of the major causes of disability, approximately 93 percent involve one or more physical impairments. A committee of experts on disability was recently convened by the Institute of Medicine, at the request of the Centers for Disease Control (CDC) and the National Council on Disability (NCD), to develop a national agenda for the prevention of disabilities. In the Institute of Medicine's review of demographic information about people with disabilities, the Institute interpolated the NHIS data cited in Table 1 to develop the following groupings:



* Mobility limitations	38 percent
* Chronic diseases (respiratory, circulatory, cancer and diabetes)	32 percent
* Sensory limitations	8 percent
* Intellectual limitations (including mental retardation)	7 percent
* Other	15 percent

### ***Categories of Disability: Disease or Disorder***

Some of the better known or more frequently cited diseases or disorders causing disability may also be used as a basis for categorization.

### **Traumatic Injuries**

A major cause of disability is traumatic injury, which can result in traumatic brain injury (TBI), spinal cord injury (SCI), amputation, burn or disfigurement. Approximately 2.3 million Americans are hospitalized each year as the result of injuries, with an additional 54 million requiring outpatient medical care.

There are more than 150,000 new amputees each year. Each case requires individualized attention to the manufacture and fitting of optimal prosthetic devices, training in the use of the prostheses, and rehabilitation of the individual's concept of self-identity. For those amputees that cannot wear artificial limbs for a variety of reasons, proper rehabilitation enables them to perform the activities of daily life and to maximize their function.

Spinal cord injury affects about 250,000 Americans; 6,000 to 10,000 new cases occur each year. SCI affects not only motor and sensory functions, but also bowel, bladder and sexual functions. The annual costs associated with spinal cord injury exceed \$9 billion. Traumatic brain injury occurs in approximately 500,000 individuals each year. The major causes of TBI are motor vehicle accidents, falls, bicycling accidents and, increasingly, gunshot wounds. These injuries result in damage that requires extensive medical and rehabilitative treatment, produces permanent disabilities, and results in varying degrees of need for ongoing assistance. Estimates of the annual direct and indirect costs attributable to head injury alone range from \$25 to 36 billion. (M.E. Milner and K. Wagner, "The Economics of Brain Injury," Vol. 3, Neurotrauma, Butterworth, Boston, MA, 1989.)

### **Sensory Impairments**

Sensory impairments account for approximately 8 percent of all disabling conditions, with both visual and hearing impairments increasing with age. The rate of hearing impairments among the general population is 91 per 1,000 people; among people aged 65 and older, the rate increases to 315 per 1,000. Visual impairments occur at the rate of 35 per 1,000 in the general population; among Americans aged 65 and older, the rate is 91 per 1,000.

### **Stroke**

An estimated 500,000 Americans experience strokes each year, accounting for about half of all patients hospitalized for acute neurological conditions. About 30 percent die shortly after the stroke, making stroke the third leading cause of death. The great majority of individuals who have had a stroke survive. It is estimated that 2.1 million stroke-survivors are alive today. A significant proportion of these individuals require rehabilitation, and approximately one-third of all stroke survivors have permanent disabilities. The annual costs associated with stroke exceed \$25 billion.

## Multiple Sclerosis

Multiple sclerosis (MS), the most common demyelinating disease of the central nervous system, is estimated to affect between 250,000 and 500,000 individuals in the United States. MS affects young adults, who nevertheless have a near average life expectancy and thus may live with a disability for decades.

## Arthritis and Musculoskeletal Disorders

The economic consequences of these disorders exceed \$36 billion annually. Juvenile rheumatoid arthritis, osteoarthritis, osteoporosis, adult rheumatoid arthritis, and systemic lupus erythematosus are the most prevalent forms of musculoskeletal disorders. More than 37 million people in the United States have some form of arthritis. Osteoporosis results in 1.3 million bone fractures a year; 1 out of every 2 women are at risk of developing bone fractures caused by osteoporosis, and 90 percent of women age 75 or older have osteoporosis in their dorsolumbar spine.

## Acquired Immunodeficiency Syndrome

More than 200,000 persons have been diagnosed with acquired immunodeficiency syndrome (AIDS). The number of AIDS cases has risen steadily each year for the past 10 years and recently there has been an alarming increase in the number of women with AIDS. This disease results in progressive deterioration of multiple body systems, with annual costs of \$50,000-80,000 per patient. Newly developed anti-viral therapies have brought increased survival times to persons with AIDS, accompanied by dramatically increased needs for rehabilitation.

## Cardiovascular Disorders

Atherosclerosis, congestive heart failure, myocardial infarction and other cardiovascular conditions can limit functional capacity. More than 6 million people who have had a heart attack are alive today. The annual economic impact of these disorders exceeds \$50 billion.

## Cancer

About half of the 1 million Americans who will be diagnosed with cancer this year will be alive in 5 years. Although cancer treatment and therapy have improved significantly over the past 20 years, cancer treatment often results in functional deficits caused by segmental bone, joint or limb amputations or removal of a diseased organ. Therapy can also cause severe disfigurement. Cancer is the major cause of amputation in children. The annual economic impact from all cancers exceeds \$100 billion.

## Developmental Disabilities

The category "developmental disabilities" includes disabilities that manifest themselves during childhood (i.e., prior to age 22). Many children with developmental disabilities have mental retardation, learning disabilities or other cognitive impairments. Among the many causes of physical disabilities in children are cerebral palsy (2-4 per 1,000), spina bifida, muscular dystrophy and associated disorders, traumatic injury, congenital heart disease, visual or hearing impairment, juvenile diabetes, juvenile rheumatoid arthritis and cystic fibrosis. Physical impairments often coexist with mental retardation. Approximately \$1,406 is spent per year for health care for a child with a disability, compared with an average of \$487 per year for other children.

## Chronic Conditions

The increasing age of the U.S. population, and improved medical care leading to survival after onset of conditions that previously would have been fatal, have led to a concomitant increase in chronic disabilities.

In Chartbook on Disabilities in the United States,<sup>4</sup> Kraus and Stoddard report that almost 40 percent of people age 65 and older report activity limitations due to disability, and that almost 60 percent of all people over 65 have some functional limitations in physical activities. As might be expected, the incidence and severity of disability increase dramatically with age. Forty-five percent of people age 65-69 report functional limitations and 72.5 percent of people over age 75 have functional limitations. For some, functional limitations result in reduced activity levels and an increase in dependence upon others for assistance. People who have activity limitations are four times more likely to require hospitalization than those who have no limitations. An estimated 1.3 million adults over the age of 65 are so severely disabled that they live in nursing homes or other long-term care facilities.

## **Conceptual Model of the Rehabilitation Process**

"The NCMRR has the opportunity to emphasize theory and basic research. It is the chance to help to incorporate medical rehabilitation into the mainstream of medicine by developing a scientific basis for our procedures and practices. This does not mean that the psychosocial aspect should be de-emphasized. On the contrary, these two aspects are intimately related..." (Written Correspondence)

The National Center for Medical Rehabilitation Research has a unique mission as reflected in the conceptual model developed by the Advisory Board. This model, as presented in Figure 1, emphasizes the individual person and successful reintegration and functioning in the community as the central focus of the medical rehabilitation process and incorporates five primary components.

### ***Systems Approach***

The Advisory Board rejected the traditional linear view of the disabling process and the medical rehabilitation process and recommends that much debate, discussion, and thought are needed to understand the complexities involved for each individual undergoing rehabilitation. The bidirectional arrows in Figure 1 reflect the complexities, feedback loops, and integrating aspects of the process. Thus, the systems approach is an essential feature of medical rehabilitation research and, ultimately, all health care delivery.

### ***Personal Background Factors***

There are three categories of personal background factors that influence an individual's response to a given situation.

#### **Organic**

The organic factors are characteristics of one's body and constitution that influence the reaction to disability onset and daily function, such as endurance, strength, general health status, genetic and family predisposition to certain disorders, and numerous other aspects of physical function.

#### **Psychosocial**

Among the psychosocial factors which seem to influence outcome are style of coping with stress, will to live, self-reliance, motivation, problem-solving, judgment, locus of control, cultural and ethnic group, gender, social skills, belief system, and others.

#### **Environmental**

The environment in which one grew up and in which one lives also influences daily function and response to disability. These factors include, but are not limited to, income, family and interpersonal support, access to and payment for proper health care, availability of transportation and proper habilitation, availability of physical and behavioral assistance (if needed), access to appropriate educational, recreational, and vocational resources.

These personal factors combine to give uniqueness to the individual's response to the onset of impairment. They are, however, only one element affecting the ultimate functional level reached during a lifetime with disability. Any of these personal background factors may help or hinder the person's ability to adapt and live in the community at a satisfactory level of function.

## ***The Person and the Rehabilitation Process***

The individual is considered to be the primary focus of this model of the rehabilitation process. Each individual has important aspects of personality, life before disability, etc., which significantly impact on the process of rehabilitation. In addition, the health care environment and society as a whole affect the person and the rehabilitation process.

### ***Quality of Life***

The successful process of rehabilitation restores the individual to maximal functioning and provides a foundation for a fulfilling, productive life following rehabilitation.

### **Survival**

Survival issues include maintenance of health, prevention of unnecessary medical complications, capacity for mobility and control of the usual tasks of daily living.

### **Productivity**

The outcomes of the medical rehabilitation research process are strategies, products, and treatments which enhance the probability that people with disabilities will participate in society. Activities which give a sense of purpose and enjoyment to life must be possible; these may include employment, education, recreation, family, and community involvement. This participation should provide meaning and dignity to life so that people with disability have a reason to live, not merely to exist.

### **Social and Work Relationships**

The focus of medical rehabilitation research is the improvement of function of people with disabilities so that they can live satisfactory lives in their community. Function within this context encompasses not only physical performance, but emotional, and cognitive functioning as well. The ability to develop and maintain social relationships with family, friends, and co-workers is a fundamental skill. Ability to manage finances, personal and work life, and supervise personal attendants is critical to successful community life.

### ***Life Span Issues***

Concern for the developmental cycle of the individual with the disability is an essential feature of medical rehabilitation research since intervention strategies, life activities, and quality of life outcomes will vary according to age. Rehabilitation research should incorporate knowledge of the normal developmental stages when assessing interventions or outcomes in children with disabilities. In the last decade, evidence has accumulated that those who have lived a considerable portion of their young and adult lives with a major physical disability acquire additional impairments which seem to be the result of an accelerated aging process. Additional musculoskeletal and body systems problems may accumulate which potentially reduce function of the individual in the community. This appears to be other than the normal aging process and must be a focus for research.

The model provides for the growing awareness that the initial impairment may be complicated by succeeding impairments across the life span. Problems unique to growing up and aging with disabilities are seen as relevant to the rehabilitation process. The resulting variation in, or loss of function, across time are important considerations in building a conceptual model of rehabilitation.

### ***Summary of the Model***

The specific terminology and descriptions within the model may differ when applied to children, however, all aspects of the model are relevant to the younger segment of the population.

The model gives special emphasis to outcome measures that reflect not only physical function, but also such elements as social relationships, normal life activities, and community life. Furthermore, the quality of life during the performance of these life activities receives special attention. Lastly, the individual with a disability must be considered in the context of the entire life span.

## Terminology in Disability Classification

"First, we need to speak to each other; we need lateral communication within and among the scientific disciplines.... Second, science itself is non-disciplinary. Man devised the disciplines for the sake of convenience, but such a decision is an artifice contrary to the way nature behaves ....and "Third, science is a humanistic venture. It has been through history, and it must continue in this tradition. Fourth.... Fifth, science is inseparable from the society that nourishes it, and from which it, in turn, benefits. Therefore, we will actively pursue the societal and public-interest fallout of what we do." Leo Schubert, Professor of Chemistry, The American University

There have been several attempts to provide a classification system which adequately conveys the range of problems encompassed by the field of rehabilitation. The terminology used by the World Health Organization (WHO), the Nagi terminology incorporated into the Institute of Medicine (IOM) report, and the approach suggested by the Public Health Service Task Force are presented in Table 2.

The National Advisory Board of the NCMRR studied these approaches to classification very carefully and decided that none of these truly fit the conceptual model (see previous section) developed by the Board to describe the medical rehabilitation process. Consequently the Board decided to expand the classification approach presented in the IOM report, *Disability in America*, to include "Societal Limitation" as a legitimate and separate aspect of the functional problems of disability. Furthermore, the Board rejected a linear model of pathology, impairment, functional limitation, disability, and societal limitation since the progression is not always sequential or unidirectional (see Figure 2). Rather the Board recognized the reality of the complex feedback loop that integrates the whole person as an entity who must adjust to problems in many of these areas simultaneously (refer back to Figure 1).

Definitions and examples of the five domains of science relevant to rehabilitation research are provided in Table 3. It should be noted, however, that this classification system is integrally linked to the conceptual framework of the rehabilitation process. Rehabilitation depends upon a great breadth of medical and other sciences. Rehabilitation focuses upon the individual. Effective rehabilitation depends upon not only maximum restoration of functioning of affected organs and of the individual, but also upon the restoration of the individual's maximum functioning within society.

Thus, rehabilitation must address a broad spectrum of issues -- biological phenomena at the fundamental levels including tissue, cellular or molecular events; the impairment of an organ or body part, the functioning of organ systems; the individual's response to a reduction or loss of function; and the interactions of the individual with his or her physical, social and societal environment. This description is not for pigeon-holing closely related activities but to emphasize the diversity and breadth of activities essential for rehabilitation.

In everyday usage, such words and phrases as impairment, functional limitation, disability, and handicap (societal limitations) are often used interchangeably. However, these terms are often used with specific meanings and sometimes given conflicting definitions by different agencies and in different reports. One must be sensitive to the existence of these different usages and to the reality that these usages may not be precise.

### ***Pathophysiology***

"Three months in the hospital with so many doctors, nurses, therapists, aides and only one person explained to me and my family how my brain was injured. Without his explanation, I would have blamed myself for what I could not now do. I understood I was injured. My mistakes were not my fault... Nobody told me my brain was permanently changed." (Written Correspondence)

"Some research has been done into treatment. However, without knowing the cause of the new difficulties experienced by polio survivors, effective and beneficial treatment programs are more a matter of trial and error rather than regimens based on sound scientific data." (Written Correspondence)

In this Research Plan, pathophysiology is defined as the interruption of, or interference with, normal physiological and developmental processes or structures. The pathophysiological domain focuses on cellular structural or functional events subsequent to injury, disease, or genetic abnormality. Research in this domain would reveal the mechanisms essential to improving the recovery of cellular and tissue function post injury, for example. Investigations of pharmacological agents that alter synaptic transmission of neural impulses in persons with head injury, stroke, or Alzheimer's Disease are also examples of medical rehabilitation research in the domain of pathophysiology.

### ***Impairment***

"Secondly, we believe that greater emphasis should be placed on the study of optimal post-surgical rehabilitation techniques (e.g. following total hip and knee surgery for generative arthritis, pinning for hip fractures, tumor resection, and prosthetic replacement of limb segment defects)." (Written Correspondence)

Impairment is a loss or abnormality at the organ or organ system level of the body. Impairment may include cognitive, emotional, or physiological function, or anatomical structure, and include all losses or abnormalities, not just those attributable to the initial pathophysiology. Examples of medical rehabilitation science in the impairment domain are imaging studies beginning immediately after injury of the brain, spinal cord, heart, or other organs to determine the physical changes and the markers of recovery of function. Computer modeling of joint articulations subsequent to amputation or injury provide needed information for medical treatment options involving surgery, physical therapy or prosthetic/orthotic interventions. Studies that measure force, endurance, and efficiency of muscles are further examples.

### ***Functional Limitation***

"Pediatric physical therapists are commonly the persons that address these issues by implementing therapeutic procedures to assist the child to ambulate and/or provide the guidance for use of assistive devices or alternative means of mobility." (Written Correspondence)

Restriction or lack of ability to perform an action in the manner or within the range consistent with the purpose of an organ or organ system constitutes a functional limitation. Applying the findings from studies of pathophysiology and impairment to the functional limitations they engender is an area of need and promise for the field of medical rehabilitation research. Examination of different approaches to accomplishing tasks using remaining physical abilities, substituting actions previously used for performing another function, and replacing lost function through assistive devices, illustrate the scope of research on functional limitations. Functional neuromuscular stimulation of remaining muscles to improve walking, writing, or functional skills is also within this domain. Computer assisted design for individualized devices to improve (prosthetic leg) or replace (wheelchair) lost mobility would also be included.

### ***Disability***

"I may have to give up a job I love and take disability because of ever-increasing pain and weakness. Daily I become more and more aware that quality of life is just as important as life itself. And I am only one of many hard-working people who would rather contribute to society than drain its resources." (Written Correspondence)



A limitation in performing tasks, activities, and roles to levels expected within physical and social contexts is defined as disability. The study of people with disability as individuals who learn or relearn academic skills, activities of daily living, and societal roles is "disability" research. For example, studies of how individuals with disabilities establish and maintain support networks, change or maintain emotional stability pre- and post- injury, and attain and maintain or redefine recreational activities constitute research into the domain of disability. Thus, research in this domain focuses on the successful adaptations made by individuals with disabilities to learn common skills associated with living despite the impairment and functional limitations.

### ***Societal Limitations***

"I feel if Ronnie could have gotten long term rehabilitation he could have come alot farther but because he didn't have any insurance, a state medical card would only pay for four weeks of rehab in the beginning and 2 weeks each year thereafter. With a head injury from what I understand the first year is the most important in recovery. If our state had a program for long term rehabilitation then a head injury patient would have much better chances. Basically what I have to say is that its been four years since Ronnie was hurt and I'm not sure what can be done for him at this point but there are still so many unanswered questions. Some of these are: Why did he stop talking? How much could he have been able to do if rehab had been made available?" (Written Correspondence)

"We must create a world in which disability is understood and accepted as a normal part of the human experience. We envision a world in which disability is not simply a life long experience of loss and sadness but one which is interesting, exciting, challenging, and even joyous. Much of the pain of the disability experience is in the social exclusion and unnecessary and unwanted economic dependence that persons with disabilities are subjected to." (Written Correspondence)

Restrictions attributable to social policy or barriers (structural or attitudinal) which limit fulfillment of roles or deny access to services and opportunities associated with full participation in society are considered to be societal limitations in this report. In this domain, medical rehabilitation research examines the interactions and effectiveness of different rehabilitation interventions with the institutions in our society. For example, financial and attitudinal disincentives can reduce chances of employment for people with disabilities. Without some financial assistance to purchase an assistive device, have surgical repair, or learn an exercise regimen to restore lost function, immobile individuals are not able to get to the worksite. Cost benefit analyses may examine the payoff of providing an amputee with a prosthetic device to restore walking or purchasing a wheelchair for a paralyzed individual to use to wheel to the worksite, or obtaining a portable computer programmed to provide memory assistance for directions to the worksite for a person with a head injury. All of these examples directly or indirectly influence the ultimate utility of research results of the other four research domains.

## Issues in Medical Rehabilitation Research

The science of medical rehabilitation can be described as the study of mechanisms, modalities and devices that improve, restore or replace lost, underdeveloped or deteriorating function. The effects of disability and subsequent habilitation or rehabilitation differ as a function of the age of onset. Thus, the onset of disability during and after childhood are discussed separately in the following section of this Research Plan.

### ***Onset of Disability Early in Life***

"The tactics developed for solving logistic problems during childhood may not work once the individual reaches out for independence. These tactics may depend on arrangements unique to the home environment or the special skills and willingness of family. They may engender counterproductive co-dependencies and make the achievement of independence even more difficult."  
(Written Correspondence)

"Rehabilitation for children cannot focus exclusively on the short-term outcome of medically-oriented interventions, but must consider a long-term continuum of medical, educational, social, and vocational goals. Given these changes over time, the most appropriate measure of the effectiveness of rehabilitation with children will be its success in facilitating the repeated successful negotiation of developmental tasks throughout a long period of growth toward adulthood."  
(Written Correspondence)

In normal development, variability in onset and performance of physiological development and behavioral skills is a fundamental phenomenon (Figure 3, curves A, B and C). In an optimal environment, an individual's abilities can be developed to the maximum extent possible (Figure 3, curve A). With a restricted environment, development languishes (Figure 3, curve C).

There is a comparable variability for development of functions in individuals with disabilities whose disability onset occurred at or before birth (Figure 3 curves D, E, and F). With optimal habilitation (a rich variety of therapies and necessary technical devices), individuals who experienced an early onset of physical impairment (cerebral palsy, spina bifida, genetic abnormality, etc.) can reach levels of development (curve D) that approach or even exceed the general functional abilities of their nondisabled peers. With restricted habilitation (limited therapy and no technical devices), they may die at a younger age than their normally developing peers or may continue living with difficult and expensive problems (curve F).

The third set of curves (G, H and I in Figure 3) illustrate the effects of a disability that occurs during childhood. The initial decrease in function that follows disease or injury can be reversed with habilitation. Early intervention with optimal habilitation results in the shortest time taken by the child with a disability to reach the highest level of function (curve G). When habilitation efforts are delayed and minimal as a result of inadequate resources, then the outcome is a poor quality of life for the child with disability (curve I).

Each functional skill that is achieved by the developing individual with a disability provides a greater opportunity to attain self-fulfillment. Studies on restoring function must consider the moving target presented by the rapid and loosely sequenced development of function as children grow into young adults. Teaching a child with spina bifida how to manage bowel and bladder problems will differ from the techniques acceptable to a teenager or young adult. As medical habilitation research discovers the mechanisms underlying the causes of dysfunction and develops new treatments to enhance function, the gap between the functional abilities of normal individuals and individuals with disabilities should narrow. The research issues for habilitation of individuals with early onset disabilities focus on the most effective methods of improving function in the most economic way.

Individuals with disabilities may develop unique variations in the complex web of interrelated skills necessary to perform everyday functions. Study of those individuals with disabilities at the top of the range (curves D and G, Figure 3) can reveal the cellular events that predict successful recovery, changes associated with successful functioning, personal attributes associated with adjustment to disability, and differential societal limitations on optimally habilitated individuals with disabilities. Findings from these studies can lead to treatments that reduce impairments and prevent the development of secondary complications.

Developing recreational skills for a child with cerebral palsy who uses a wheelchair for mobility may require a different set of skills from those exhibited by able-bodied children. Studying the successful social skill development in individuals with cerebral palsy who use wheelchairs for mobility may be the best model for understanding intervention strategies that work with children who are disabled. Designing treatment interventions based on this knowledge translates the findings of medical rehabilitation research to health service professionals, individuals with disabilities, and their families.

### ***Onset of Disability after Childhood***

For those individuals whose disability is a result of an injury or disease occurring later in life, the science of medical rehabilitation has a somewhat different focus. Medical rehabilitation research is directed towards restoring lost or diminished functions within the context of each individual's previous performance levels. Although the onset of a disability may occur at anytime in adult life, three general patterns are illustrated in Figure 4. Each set of curves represents a hypothetical example of the effects of optimal, average or restricted rehabilitation for a person who has attained his or her adult level of function. The curves also illustrate the varying (nonlinear) change in functioning over time.

### **Traumatic Injury**

"My Rodney is alive and he wants to grow and learn and live and if he could get the right help it could but the way it is now, he is sitting in his home day in day out with just books and TV. I made my son fight to live when he wanted to give up. Now I wonder if I done the right thing!" (Written Correspondence by a Mother of a Traumatic Brain Injured Son)

"Each day my husband's life is a battle against infections, body sores, pain and depression." (Written Correspondence of the Wife of a Person with Spinal Cord Injury)

In the context of normal development variability in development results in adults with differing levels of functional abilities. Most spinal and head injuries occur just as individuals have attained their level of adult functioning. Optimal therapeutic intervention and device development may allow these individuals to return to a high level of function and quality of life (Figure 4, curve A).

### **Chronic and Reoccurring**

"Since MS is incurable and can take a fluctuating or progressive course, it has been assumed by many health professionals that rehabilitation has no value for people with MS because it has no "therapeutic effect;" .it is a mistake to assess rehabilitation only in these terms. Rehabilitation should be seen as offering two types of benefits: enhancement of function, and, equally important, prevention or slowing of deterioration." (Written Correspondence)

"A person with rheumatoid arthritis will have pain, swelling, and limited flexibility at times. But over time this person even with the best of care will probably lose an observable amount of motion and may have persistent pain." (Written Correspondence)

"...many common treatment recommendations in primary care tend to prolong symptom reports and activity limitations. Many patients complain that their needs are not addressed in their typical physician encounters for low back problems...a knowledge of the natural history of recovery, greater attention to the patient's psychosocial needs, better patient education, and...are needed."  
(Written Correspondence)

For many people with disabilities, functioning levels vary over time as the impairment to an organ or organ system changes. Multiple sclerosis, arthritis, and low back pain, for example, are often episodic (curves D, E and F). During periods of remission, people with these disabilities can function effectively with little assistance. Over time, the number of remissions may decrease and the interval between remissions lengthens. In addition, ability to function independently decreases over time.

## Aging Effects

"As you get older, you slow down physically, and you can't do as many things as you could when you were younger." For most of us who grew up with a disability, who couldn't do as much as our peers without disabilities, this warning was rather meaningless. Others with disabilities, who did listen to this warning certainly did not expect that the aging process would be accelerated. However, people with disabilities are experiencing unexpected declines in their energy and activity levels as they age. We are exhibiting signs of aging earlier than the people of our age without disabilities." (Written Correspondence)

"I have Post-Polio Syndrome. It is devastating to overcome a debilitating disease and after many years have it slowly, but surely, rob you of your independence."  
(Written Correspondence)

As people with disabilities age, they often face new challenges. The post-polio syndrome offers an example of some unique problems that can develop in aging process of people with disabilities (curves G, H and I). Some polio survivors have experienced muscle weakness and pain as they reach their fifth and sixth decades. In some cases their mobility has been severely restricted, resulting in a substantial decrease in the quality of their life.

## Change in Function

The loss of function in adults may be isolated to one area (e.g., mobility in amputees, short term memory in an individual after a stroke, emotional stability for some individuals with head injury, or ability to perform strenuous physical activities in individuals with back pain). In other cases, for example, spinal cord injury, the decrease in functioning is in the most fundamental of life activities (breathing, bowel and bladder control, reproductive capacity, and movement of limbs). Complex life activities (writing, speaking, working, creativity and self-actualization) may be diminished, left unchanged or even enhanced post-injury.

Research on the restoration of function in individuals with later onset of disability obviously makes use of the knowledge of normal functioning; for example, comparing the gait of an amputee with the gait profile of a non-amputee. Another approach in medical rehabilitation research is to compare functional capacities of individuals with disabilities to their own reference group: comparing the gait of the amputee with that of other amputees who developed gaits which meet their daily needs but may not emulate the appearance of a normal gait. The goals of these approaches may be quite different. In the first case, using normal gait as a basis, the goal may be to have the amputee appear to walk in a normal fashion to improve his or her self-image and gain acceptance in the larger community. The second approach might focus on reduced energy expenditure to provide more time and energy for other aspects of the individual's life. Treatment goals could be based on studies of amputees who have developed a functional gait. This optimal functional gait would be the basis of a model for developing a prosthetic device that allows maximal mobility, and used to develop a training method for the amputee to reach the greatest level of prosthesis utilization.

Maximal attainment of function through the rehabilitation process depends on the level of function achieved before the onset of the disability, the motivation of the individual during rehabilitation, and the interventions during rehabilitation that encourage individual growth in new interests, skills and problem solving techniques. Sir Ludwig Guttmann expresses this concept in the following passage:

"...it is obvious that the essence of rehabilitation of the severely physically handicapped... must lie in the restoring of mind and promoting their determination to utilize those talents which are already apparent and manifest, in addition to encouraging new talents by awakening and mobilizing those intellectual potentials which are still dormant. In this process, early education and training of the disabled child and teenager and retraining of the adult with mature brain are the indispensable essentials. Education and training should be the guiding principles in our work in rehabilitating the disabled of any age, to counteract from the start those adverse psychological effects which follow almost inevitably in the wake of severe disability --- namely, frustration, apathy and resignation. Only then can new and dormant talents of the disabled be mobilized to enable him/her to become once again a respected and useful member of the community." (Sir Ludwig Guttmann, *Spinal Cord Injuries: Comprehensive Management and Research*, Blackwell Scientific Publications, London, 1976, p. 677.)

## Future Directions for the Field of Medical Rehabilitation Research: Meeting the Challenge

As people with disabilities become the focal point of research, the scientific enterprise needs to turn its attention to the functioning of the whole person within our society. The goal of improving independent living for people with disabilities depends on the development of a science that recognizes that the whole is greater than the sum of the individual parts. Consequently, it is essential that the complex issues of adaptive human function be addressed by all rehabilitative sciences.

Fostering excellence in medical rehabilitation research will have long lasting effects on our society. When the rehabilitation process fails, the cost to society and to the person with a disability is immense. When the rehabilitation process is successful, it can result in people with disabilities accomplishing their life goals. These individuals can then contribute to society intellectually, emotionally and financially. Providing adequate resources for this endeavor, especially in a time of national economic hardship, would be laudatory and would mark a significant advance in this civilization.

The opportunities for improving medical rehabilitation research abound (see section on Research Initiatives and Opportunities for Medical Rehabilitation Research). Technological advances in biomaterials have far surpassed their application in the production of devices to improve mobility, sensation, communication and cognition. Empowerment of people with disabilities through new legislation (Americans with Disabilities Act) has opened new vistas for self-directed behavioral adaptations to disability that have been little researched. Noninvasive neuroimaging offers the promise of tracking the progress of recovery of function in people who have had a traumatic brain or spinal injury. Device development for improving cognitive skills has begun to make its way from computer programmers to the market place. Applying these state-of-the-art intelligence amplifiers to the needs of people with head injury or stroke provides a tremendous opportunity for rehabilitation scientists.

Computer assisted devices could be modified for use by the rehabilitation sciences for monitoring the treatment effectiveness of different types of interventions. Measurement of individual improvement in function and aggregating these changes for large groups of people with disabilities is fast becoming a possibility with the advent of new statistical tools and the accumulation of large data bases. In addition, interest in developing scientists whose primary training is in the conduct of research on the rehabilitation process is growing within many of the professions that have traditionally been the providers of rehabilitation services. The opportunity to develop doctoral level research scientists offers an exciting future for these professions.

Along with these opportunities, there are surmountable barriers to achieving the objective of improving the health, welfare and independence of people with disabilities. First, medical rehabilitation research has not had its own **focus and identity**. Efforts related to medical rehabilitation research are dispersed within the NIH and other agencies. Much of the research has an emphasis on cause and cure with less attention to functional limitations. This research has achieved tremendous success with regards to diseases and has benefited medical rehabilitation. These efforts need to continue in all these locations with greater support and attention to rehabilitation as it pertains to the disease or organ of interest. At the same time, the new NCMRR needs to provide a focus for rehabilitation specific research, and take the lead in helping the field to develop a research base; define the problems it will address; formulate solutions to functional problems; develop instruments to assess relationships among impairment, functional limitation and disability; interact beneficially with disease-oriented research; and apply rigorous scientific methods to analyze functional outcomes of differing treatments. To foster increased attention to medical rehabilitation, the Medical Rehabilitation Coordination Committee, established by P.L. 101-613, will encourage and coordinate rehabilitation related research activities of the NIH.

A second major barrier to improving medical rehabilitation research is **inadequate funding**. Although 98 percent of the American public indicated in a recent poll that they believe "everyone, including disabled people, should have an equal opportunity to participate in American society," the available funding for

medical rehabilitation research can only meet a fraction of the need. Given the large numbers of Americans with disabilities, the social and economic impact of disability, and the opportunities for improvement of function through research, a significantly greater effort to fund medical rehabilitation research is clearly justified.

A third barrier in the conduct of medical rehabilitation research is **the lack of measurement tools and systems** that can be used to assess the **effectiveness of treatment interventions**. Until a measurement system is developed that can integrate the findings of many different outcomes in the context of the whole person with a disability, scientific investigations in the field of medical rehabilitation will remain isolated snapshots of specific effects of a limited number of variables and how they affect one aspect of the life of a person with a disability. A method for assessing both the strengths and weaknesses of persons with disabilities is needed to provide a framework for making decisions on treatment interventions. Access to technical devices and therapies depends, to a large degree, on the ability to justify their effectiveness in building new skills and reducing dependency. The effectiveness of these devices and interventions needs to be placed in the context of the costs incurred in the provision of devices and services. Government, private insurance and individual consumers are becoming increasingly skeptical of claims that devices and therapies are effective and efficient in restoring, increasing, or preventing further loss of function.

A fourth barrier is a **paucity of both experienced and developing scientists** available to conduct the necessary research focused on the study of pathophysiology, impairment, function, disability and society and the relationships among them. As funds for training scientists and clinicians in subspecialty areas have diminished over the past decade, little room has been left for the development of a cohort of scientists with an interdisciplinary approach to research. Candidates for this interdisciplinary training can be drawn from many fields including, but not limited to, medicine, nursing, neurosciences, pharmacology, occupational therapy, physical therapy, speech - language pathology, audiology, prosthetics, orthotics, psychology, bioengineering, special education, communication, and social work. A new generation of scientists will be able to build on progress that has been made to date and to develop further strategies to deal with the consequences of disabling conditions.

### ***Training of Rehabilitation Scientists***

"We agree with the Board that research (training) opportunities are not sufficient to develop a core of research scientists who are capable of understanding the key problems in rehabilitation...there is a DESPERATE SHORTAGE of training opportunities." (Testimony Given at the Houston Field Hearing)

The support of training has been recognized by the Board and staff of the NCMRR to be a priority, and the first grants awarded by the Center were to support institutional training programs. During the next 5 years, the recently-funded NCMRR institutional training programs will begin to produce scientists trained to conduct research both within domains and across domains of science. Expansion of these training programs and the addition of career development, fellowship, and other programs should continue to be a major focus of the NCMRR's activities for the next decade. In addition to the initial emphasis on training physician researchers, the development of research personnel in nursing, psychology, physical therapy, occupational therapy, orthotics, prosthetics, bioengineering, biomechanics, and neurosciences is needed. By committing resources to training and career development, by the year 2000 the field of medical rehabilitation should have a significant number of scientists capable of conducting research at a level of excellence equal to that of any currently supported by the NIH.

### ***Centers of Excellence***

"Support for centers of excellence that incorporate the rehabilitation philosophy into their treatment armamentarium...that incorporate the various schools of thought into a comprehensive treatment program because treatment .. requires a team approach." (Testimony Given at the Houston Field Hearing)

An improved capacity to foster excellence in medical rehabilitation research in this country will depend upon selecting research programs and mechanisms for funding research that are planned to meet both current and future needs. The Board recognizes that considerable time and effort will be needed to build interdisciplinary research teams that focus on functional problems of individuals with disabilities. Building a research capacity for the field of medical rehabilitation science will involve developing a infrastructure that will attract established investigators from different fields of science, provide resources for existing investigators to improve and broaden their expertise and develop a new generation of scientists who are trained in the interdisciplinary approach to studying the rehabilitation process. This effort will include building laboratories and supporting interdisciplinary research teams that have the critical mass of personnel trained to work together to study the nonlinear, complex, multidomain, lifespan issues that characterize the rehabilitation process.

The NIH has often used interdisciplinary research centers to facilitate the development of new fields of science. The Board concurs with the recommendation made by in NIH Report of the Task Force on Medical Rehabilitation Research that a number of centers of excellence in medical rehabilitation science be established during this decade. Centers located in several geographic areas are recommended in the following areas.

## Mobility

"...research in functional mobility could greatly benefit from the application of core robotic technologies: actuation, sensing, control, programming, human/machine interface, and mechanism design." (Written Correspondence)

Centers of excellence should be developed for the purpose of increasing the functional mobility of individuals with disabilities. Mobility is a critical factor in maintaining an individual's health and independence. Devices and therapies designed to improve upper and lower body functional mobility would be the focus of multidisciplinary research projects at these centers.

## Behavioral Adaptation

"In rehab I was evaluated, dissected, tested, and judged by everyone on the staff. Nobody ever asked me how I experienced what they were doing." (Written Correspondence)

Behavioral adaptation research depends on the coordination of information from studies of a variety of individual responses to physical and/or psychological disability as well as to societal limitations. The development of individual profiles describing the course of functional loss and differential effectiveness of treatment interventions fundamental to recovery of function will be the primary purpose of another set of centers. Comparisons of individuals with disabilities to individuals with similar functional loss and to people without disability will be made within the same research environment.

## Whole Body Response

"...the support of the NCMRR will play a crucial role in focusing basic science research on relevant topics in medical rehabilitation. Remarkable advances in the biological sciences provide real hope that we can learn to heal the body from within...." (Written Correspondence)

The integration of the effects of disability on whole body response to pathophysiology or impairment requires the organized input of the findings of many research projects. Conducting cellular recovery or impairment research in the context of a research program committed to examining disability at multiple levels would be the main purpose of these centers of excellence. Researchers who study the relationships of pathophysiology and limitation to the restoration of functional abilities could investigate the effects of



cellular recovery on organs and organ systems not directly related to the injured cells. Studies of the combined effects may predict a decrease in overall function of the individual better than single system studies. In turn, this cross-domain approach may better explain the individual's response to functional loss.

## Assistive Technologies

"A credible scientific analysis of the properties of specific devices and techniques will require the availability of individuals skilled in material engineering, computer imaging and biomechanical testing." (Testimony Given at the Houston Field Hearing)

"We believe that this research base should include significant collaboration with engineers and computer scientists who can provide support for the application of robotics and automation technologies. In particular, research in functional mobility could greatly benefit from the application of core robotic technologies: actuation, sensing, control, programming, human/machine interface, and mechanism design." (Written Correspondence)

Centers of excellence should be established to focus on the development of assistive technologies for medical rehabilitation. These centers would develop technologies that enhance the functional abilities of children and adults with disabilities. The centers would provide a focal point for encouraging engineers, biological scientists, treatment oriented rehabilitation experts, and people with disabilities to work together in developing devices that are reliable, functional, and attractive. This network of centers should play a major role in the development, application, and evaluation of personal, environmental, and activities specific technologies that will enable children and adults with disabilities to perform daily living, vocational and, recreational activities.

## Measurement, Assessment and Epidemiology

"...suggestion is that the NCMRR designate as a priority goal the eventual diffusion of scientifically based outcome measures into rehabilitation practice." (Testimony Given at the Bethesda Field Hearing)

Several centers of excellence should focus on measurement and medical rehabilitation outcomes. These centers would develop new measurement tools, develop standardized research protocols, provide expertise for transformation of existing data bases, collect data, provide data tapes to individual investigators for analysis, and provide guidance to national surveys in item selection and inclusion of areas of special concern to medical rehabilitation. This network of centers should play a major role in the development of methods to assess differential treatment effectiveness and the effects of assistive devices on function.

## Treatment Effectiveness

"...outcome/effectiveness studies must include balanced input from representatives of the rehabilitation team and involvement of scientists from relevant disciplines as principal investigators and key project staff. Achievement of research objectives...will benefit from facilitating multisite, collaborative studies." (Testimony Given at the Bethesda Field Hearing)

Research centers should be developed to assess treatment effectiveness. These centers would conduct clinical trials of currently existing and frequently used rehabilitative therapies and devices. Optimal treatment interventions could be developed and tested on a variety of functional limitations that arise from distinctly different etiologies. Linkage of the effectiveness of treatments and devices should be established at the pathophysiological and functional limitation domains. The short and long term efficacy of treatments

could be evaluated at these centers. These centers of excellence should make advances in treatments and devices available to physicians, other health professionals, and individuals with disabilities.

## Information Transfer

"Focus should be placed on...development of improved information management techniques to improve the effectiveness, integration, and delivery of rehabilitation treatment in multiple settings..." (Testimony Given at the Bethesda Field Hearing)

"Standardized information regarding the cognitive demand associated with each device or technique would be extremely valuable for consumers and their families and clinicians." (Written Correspondence)

Scientists need to be able to transfer their findings on the effectiveness of therapies and devices to rehabilitation therapists and people with disabilities and their families. Currently this information is not being disseminated in a timely manner, so some people who need not be disabled are living with permanently disabling conditions. The centers would utilize the new capabilities of information science to compile relevant data more rapidly, to transform the data into meaningful messages, to present the information in a variety of forms accessible by people with motor and sensory impairments, and to study the effectiveness of the information provided. Such studies would address the questions: Was the information used and did the user improve function as a result of the new information?

## ***Coordination of Research***

"A comprehensive and coordinated effort of funding opportunities in rehabilitation...across multiple agencies would lead to the more effective utilization of scarce resources and more rapid dissemination of knowledge and training activities to professionals and families that is so desperately needed." (Written Correspondence)

The goal of improving the quality of the lives of people with disabilities will best be served by providing a variety of funding resources for scientists interested in addressing the problems faced by individuals with disabilities. The boundaries of what is considered as medical rehabilitation research are undergoing change, in part, as a result of the establishment of the NCMRR and the increased attention to the needs of people with disabilities stimulated by the enactment of the Americans with Disabilities Act. The broad mission statements of the Federal agencies provide multiple funding sources for scientists interested in conducting research on a variety of topics in the field of medical rehabilitation (see Appendix A).

An overlap of funding sources is not unusual or even deleterious to efficient and efficacious government support of the research enterprise. For example, the study of learning disabilities is funded by the Department of Education, Department of Justice, the National Institute of Mental Health, the National Institute of Child Health and Human Development, the National Institute on Deafness and Other Communicative Disorders, the National Institute of Neurological Diseases and Stroke, the National Eye Institute, and the National Science Foundation. Each agency has provided support for somewhat different aspects of learning disabilities that range from basic research on genetics to classroom teaching. Medical rehabilitation research covers a large array of topics, no single agency has or will fund every research project in rehabilitation.

While multiple funding sources for a broad area of science is an accepted government practice, duplicate funding for the same research project is not. The NCMRR will work together with all Federal agencies funding medical rehabilitation research to assure Congress and the Office of Management and Budget that no research project receives funds from two agencies for the same work. The coordination of existing research and development of new initiatives for medical rehabilitation will evolve as the research plans are written for future fiscal years.

The Advisory Board recognizes that cooperation among agencies with activities in the field of medical rehabilitation will take time to develop. This Research Plan for Medical Rehabilitation Research has provided a forum for representatives from 11 Federal agencies funding medical rehabilitation research to listen to non-Federal members of the Board, members of the consumer, service provider and scientific communities and to each other. The emergence of improving function of people with disabilities as a theme for the NCMRR has given the representatives from the Federal agencies an opportunity to review their programs from a different perspective. Building cooperative research ventures with function as a focus will develop as the Federal agencies make plans for their Fiscal Year annual budgets in 1993 and 1994. The Advisory Board encourages all Federal agencies that support medical rehabilitation research to cooperate in planning scientific workshops, conferences, announcements of resource availability, to co-sponsor funded research projects, to pool resources to create large national samples of infrequently observed disabilities, to share research protocols for clinical trials of rehabilitation treatments, and to exchange information on effective therapies and devices that improve the lives of people with disabilities (see section on Progress of the National Center for Medical Rehabilitation Research).

## **Research Initiatives and Opportunities for Medical Rehabilitation Research**

In the development of this Research Plan for Medical Rehabilitation Research, persons with disabilities, scientists, clinicians and engineers have combined forces to identify the most critical issues and problems that need research, development and dissemination to the client and provider communities. The NABMRR recommends that the NCMRR and other Federal agencies support research on restoring, replacing or enhancing the function of children and adults with disabilities.

The research opportunities suggested in the various categories may overlap. This reflects the complex interactions of factors that may influence the restoration, replacement or enhancement of single function and multiple functions. The opportunities suggested are broad in nature and are subject to change as guidance is received during the development of the Center.

### ***Underserved Populations of Persons with Disability***

"It is important to identify and treat problems at an early age with the hope of habilitating or rehabilitating children to a nearly normal or satisfactory level of functioning and to minimize the long term effects of disabling conditions."

(Written Correspondence)

"There is an urgent and immediate need for development of an appropriate model of rehabilitation that addresses woman's own unique role, physically, and needs, within the structure of her own environment." (Testimony Given at the Bethesda Field Hearing)

"The problems of the non-white persons with disabilities are indeed complex... In many cases access to health care facilities, community agencies, stores, schools and transportation can only be acquired through the use of extreme measures. In addition, language, cultural, and attitudinal barriers impede access to needed resources." (Testimony Given at the Bethesda Field hearing)

"For the last 38 years I've led a normal life after my initial recovery from polio. But now, in less than 2 years I'm using a cane, leg brace, and electric wheelchair." (Written Correspondence)

Clearly, the needs of children, women, minorities and individuals with disabilities who are facing unique problems related to aging must be given increased emphasis within each of the research categories, priorities and opportunities. New initiatives should target the problems unique to these populations.

### ***Research Initiatives and Opportunities***

The research initiatives and opportunities listed below do not reflect a scientific analysis of national need. They represent a consensus of the Board for the research initiatives that are feasible for the new Center to begin to develop. The research opportunities that follow the research priorities in each category are not listed in order by Board preference or need. These initiatives and opportunities reflect the advice received by the Board at three field hearings held to gain guidance from the public on the research plan for the NCMRR. The testimony given at these hearings provided a broad scope of need for rehabilitation research that will provide the basis for developing new initiatives by the NCMRR and will provide a variety of new opportunities for other agencies funding rehabilitation related research. Agencies represented on the NABMRR, as well as other organizations, are encouraged to sponsor initiatives and develop rehabilitation related research opportunities based on the findings of these field hearings and to coordinate their efforts with those of the NCMRR.

## Mobility

"Whether I will be able to walk in twenty years, or ten years, or even five years. Will I be able to pick up a book, or type a letter? Will I be able to lift to hold my grandchildren years from now? These are questions that disturb me now, and the only answers can come from research." (Written Correspondence)

"...we need to learn better ways of treating problems associated with weakness and mobility limitations...motor control and spasticity" (Testimony Given at the Bethesda, MD Field Hearing)

The Advisory Board recommends that sponsoring research aimed at improving functional mobility be a primary activity of NCMRR.

The ability to move the hands, arms, legs, and other parts of the body, is vital to the individual's health and independence in daily living. Locomotion, being able to get from one place to another, makes it possible for people to interact with others and with the environment, and to be productive members of society.

Of the 43 million Americans with disabilities, approximately 38 percent have mobility limitations; more than 2 million use wheelchairs for mobility. The number of amputations exceeds 100,000 each year, resulting in the need for prosthetic devices or wheelchairs. More than 200,000 individuals with spinal cord injury and resulting paralysis have major mobility limitations. Estimates of lifetime costs of spinal cord injury exceed \$1 million dollars per person, a significant portion of which is in acquiring mobility. Many individuals with mental retardation have mobility restrictions. Orthopaedic impairments and arthritis, the main causes of disability in the working age population, rank as the top two causes of activity limitation, affecting 9.2 million people. Each year 275,000 cases of hip fracture alone cost as much as \$11 billion. Most of these fractures are the result of osteoporosis, one of the most prevalent disorders of the bones and other skeletal support structures.

One third of the 500,000 individuals who have a stroke each year will have a permanent reduction or loss of mobility. Mobility restrictions occur in some of the 700,000 persons who are hospitalized annually with a myocardial infarction. Both cancer and its treatment can cause impairment, including amputation, that leads to loss of functional mobility. Chronic infections, pulmonary disorders, and endocrine dysfunction compromise strength and reduce mobility. Diabetes often results in amputations and other impairments affecting mobility. Disorders of balance and loss of vision afflict a large proportion of the population, particularly older people. Fear of falling from these disorders restricts these individuals from full mobility.

## Research Priorities for Improving Functional Mobility

1. Adapt innovations in rehabilitation engineering technology to new designs for prostheses, orthoses, braces, wheelchairs, and other devices for improving mobility. There is an urgent need to evaluate and determine whether such technology and devices can significantly reduce energy expenditure and fatigue, and increase mobility. Analysis of cost effectiveness must also be included in technology research.
2. Define the effects of physical and pharmacological interventions on central nervous system involvement in upper and lower limb movements that are important for daily living activities.
3. Analyze and compare outcome in terms of gait efficiency (heart rate, oxygen consumption, stability and postural control) after conservative or surgical treatments of patients with musculoskeletal abnormalities secondary to disease or traumatic injury, especially cerebral palsy, spina bifida, traumatic brain injury, total joint replacement and amputation.
4. Conduct biomechanics research to quantify complex physical tasks such as walking, stair-climbing, reaching, kneeling, etc. Detailed biomedical information may lead to the development of protective devices and posture control techniques to help the elderly prevent falls and other injury, and would be important for developing new intervention strategies for locomotion-impaired individuals

## Other Research Opportunities for Improving Functional Mobility

- Characterize the short- and long-term effects of sensory feedback, muscle stimulation, and biofeedback on locomotor capacity training. Gain a better understanding of the cellular, physiologic and biomechanical mechanisms that control walking and other movements.
- Develop more accurate and sensitive methods for quantifying slight to moderate functional impairments. Develop practical methods for the systematic evaluation of body position changes, balance maneuvers, and other determinants of mobility in order to quantify the degree of functional impairment in the performance of routine daily tasks.
- Study both the technological and the human factors affecting the prevention of secondary injury and accidents that might result from the use of manual and powered mobility devices.
- Develop feedback control of prosthetic and orthotic devices and environmental systems. Feedback may include sensory information, signals obtained from nerve or muscle, etc.
- Develop better human/machine interfaces to ensure a good match between the functional needs of the user and the capacities for the control and operation of robotic devices. In addition, control systems for rehabilitation robotics should have the capacity to "learn" from previous activities and to adapt to new situations.

## Behavioral Adaptation

"...successful rehabilitation also depends on how the program educates the family and society to adjust to reasonable needs of individuals with a disability, and on how well the physical and social environments are modified to ensure stable, optimal support systems." (Written Correspondence)

"Methods of dealing with motivational issues...Longitudinal studies of the fate of individuals who have gone through the stages of living with a disability, the problems encountered at different points in time and at different ages and how they are resolved." (Written Correspondence)

The Advisory Board recommends that NCMRR sponsor research on how people adjust to disabilities, and on how to facilitate the process of positive adjustment.

How people adjust to functional limitations affects their personal autonomy, as well as their ability to care for such personal needs as eating, elimination, and reproductive activities. Reducing dependence on the health care system for basic self care will improve the individual's quality of life and reduce the nation's health care costs.

Dependence on others for the performance of life activities basic to survival varies significantly in such areas as respirators to breathe, indwelling catheters to remove fluids, feeding tubes, electroejaculation for sperm recovery, and artificial insemination to become pregnant. Each of these activities requires a complex set of interactions within the individual's own self (personality, motivation, life activities, and goals) and the environment (personal care assistants, nursing care, occupational and physical therapy, physician care, and assistive devices). The individual must either develop personal skills to perform self-care or develop a support network of people to provide assistance with self care.

## Research Priorities for Improving Behavioral Adaptation

1. Identify and characterize the primary and secondary behavioral factors that influence adjustment to, and prevention of, the disabling process across the life span.
2. Identify factors that enable persons with disabilities to perform self-care or to create and manage support networks to provide assistance in activities of daily life. Identify special coping methods for disabilities with fluctuating and/or unpredictable symptomatology/expression.

3. Identify coping strategies and support mechanisms, including service provision and family education, that promote successful adjustment and community integration of both children and adults with disabilities.
4. Identify the factors that contribute to the successful long-term integration of persons with functional impairment into their families and communities.

### **Other Research Opportunities for Improving Behavioral Adaptation**

- Identify the strategies that contribute to optimal function, including psychological factors, social integration, and employment.
- Identify and characterize behavioral and psychological factors which influence a person's willingness to cooperate with prescribed treatment approaches. Develop strategies to encourage commitment to follow-up evaluation, by clinicians and individuals with disability, after formal rehabilitation services.
- Develop cognitive rehabilitation strategies and appropriate prosthetics to enhance the functional capabilities of individuals with cognitive loss secondary to illness or injury.
- Identify methods to enhance the functional capabilities of individuals who experience pain secondary to illness or injury.
- Identify the factors which facilitate full participation in usual life roles in those individuals with disfiguring conditions.
- Identify strategies to enhance the functional capabilities of individuals with impaired sexual function secondary to illness or injury and programs to promote maintenance of stable, loving relationships.
- Identify behavioral factors that contribute to overuse injuries, such as the musculoskeletal problems that occur in the shoulders of long-term wheelchair users or the orthopaedic problems in individuals with asymmetric gait.
- Seek means of modifying habits or behavior patterns that contribute to substance abuse by people with disabilities and the resulting complex physiological and psychological complications.

### **Whole Body System Response**

"Characterization of chronic pain in disabled individuals and the complex interplay of musculoskeletal and neurologic pain syndromes." (Testimony Given at the Houston, TX Field Hearing)

"We need to better understand how rehabilitation intervention can enhance the natural recovery mechanisms of spinal cord injury. We need to learn how to minimize the development of spasticity, autonomic dysreflexia, detrusor-sphincter dyssynergia, chronic pain, and post traumatic syringomyelia." (Testimony Given at the Seattle, WA Field Hearing)

"The work ... has emphasized the intrinsic ability of nerve fibers in the brain and spinal cord to regenerate through nerve grafts and to make contact with other nerve cells from which injury had separated them. such regenerative capacities will surely be exploited in the design of strategies to assist patients to recover from injuries to the brain and spinal cord." (Testimony Given at the Bethesda, MD Field Hearing)

The Advisory Board recommends that NCMRR sponsor research on the response of body systems to injury, disease or congenital disorder.

Disorders of one organ or organ system do not always impair only the function of that organ or system. A damaged system (eg. the central nervous system, CNS) can cause serious dysfunction in other organs (eg. the bladder) as well as in the whole organism. In turn, secondarily injured organs, and the functional limitations on the whole person, can have effects that exacerbate the original injury, as well as causing damage in still other organs.

The Advisory Board believes that the broad category "body systems" is useful in defining medical rehabilitation research for several reasons: 1) most medical text books are organized by body systems; 2) body systems provide a traditional reference approach in studying patient problems in medical rehabilitation; 3) organizations funding research on medical rehabilitation are organized to focus on organ or organ systems; and 4) other proposed organizational schemes based on physical impairments or symptoms are either not comprehensive or are inconvenient because there are too many categories.

The pathophysiologic bases of many of the causes of dysfunctions are receiving increased attention. Areas of great promise for preventing or ameliorating impairment due to dysfunction in the cellular domain include studies of mechanisms of neuronal function and recovery after injury, mechanisms of neuroplasticity, mechanisms of change in function subsequent to electrical stimulation of nervous and/or muscle tissues, and the fundamental nervous system mechanisms involved in skill acquisition and motor learning after injury. Rehabilitation research on the long term effects of treatment intervention will, in the future, be based on the improved understanding of the mechanisms of cellular recovery of function.

There is a need for research on restoration of function through surgery, replacement of an organ or organ system by prosthetic devices, supplementing function by electrical stimulation of remaining muscles or neural pathways, and reduction of spasticity through implantation of devices that provide timed release of pharmacological agents to block physiological events that inhibit function.

## **Research Priorities for Improving Whole Body System Response**

1. Elucidate and develop means to control the factors influencing neural regeneration, growth and organization after disease or trauma and develop clinical trials linking these factors to impairment, functional limitations and disability.
2. Characterize the upper and lower bowel dynamics and bladder and sphincter dysfunction that result from disease and injury to the central nervous system and from aging.
3. Describe the interactions of the neuromuscular and musculoskeletal systems and study movement biomechanics, to better guide the development of assistive devices and therapies.
4. Develop mechanisms to enhance human learning, cognition, and skill acquisition after brain damage.

## **Other Research Opportunities for Improving Whole Body System Response**

- Define and control the events that influence musculoskeletal sensory adaptation to impairment .
- Study the remaining organ functions and likely secondary complications after spinal cord injury, brain injury, stroke, or other conditions. Utilize this knowledge to influence pathology and decrease impairments, functional limitations, and disabilities.
- Determine the complex factors which influence demyelination, remyelination, and neurodegeneration and explore the impact of these pathologies on impairments and functional limitations
- Study the biochemical, biomechanical and electrophysiological mechanisms of pain following disease or injury. Identify and enhance the adaptive mechanisms which the human body develops in response to chronic pain.
- Increase research on the physiology, biomechanics and pathophysiology of swallowing, taste, smell and speech in order to improve interventions for dysfunctions produced by neural damage, cancer, cancer treatments, or other causes.

## **Assistive Technology**

"... new endoskeletal artificial limb componentry is being developed and needs to be further researched to proceed to a new generation of light, comfortable, highly functional long lasting artificial limbs and orthoses for servicing the



thousands and thousands of physically disabled persons requiring assistive aids." (Testimony at the Seattle, WA Field Hearing)

"Assessment for device selection entails not only assessment of an individual's abilities and needs but also of the characteristics of each candidate device, including motor and cognitive operational requirements. Techniques must be developed for measuring the cognitive demand of learning to operate the device, and the mental workload associated with operation of the device by an experienced user." (Testimony Give at the Seattle, WA Field Hearing)

NCMRR should capitalize on the past decade's advances in such fields as robotics, artificial intelligence, ergonomics, biomechanics and materials science to spur the development of improved assistive devices.

Opportunities exist for: improving the design, performance, and biocompatibility of materials used in assistive devices; providing customized fit and more lifelike operation of prostheses; developing adjustable and expandable prostheses that permit adjustment for growing children; designing and producing new types of orthoses and seating systems; and discovering more effective cosmetic restoration materials. Advances in functional neuromuscular stimulation (FNS) have moved out of the laboratory into clinical application, and needs study in controlled trials.

## **Research Priorities for Improving Assistive Technology**

1. Develop, apply and evaluate personal, environmental and activity- specific technologies that will enable people with a disability to perform activities of daily living including vocational and recreational activities.
2. Develop assistive technologies to replace or restore physiological functions including, but not limited to, bladder, bowel and sexual function.
3. Study the cost effectiveness of using assistive technologies and assistive technology delivery systems to enhance the functional abilities of people with disabilities.
4. Develop, apply and evaluate neural control prostheses and functional neuromuscular stimulation systems to enhance or replace lost function.

## **Other Research Opportunities for Improving Assistive Technology**

- Support the application of proven technologies to enhance the functional abilities of people with disabilities.
- Determine the effectiveness of service delivery models in both city and rural environments for the delivery of assistive technologies to people with disabilities.
- Support the development of information referral systems that will help people affected by disabilities and their families obtain assistive technology services.
- Investigate the prevention of secondary injuries to people with disabilities and define functional tolerances in the extremities, develop preventive therapies and improve assistive devices.
- Investigate factors related to acceptance and use of assistive devices including psychosocial and environmental predictors of user and societal acceptance. Evaluate consequences of long-term use of assistive technology.
- Support research and development to improve sensory feedback control, custom-fitting methods, suspension, cosmesis, manufacture and delivery of prosthetic and orthotic devices. Encourage progressive use of computer software and hardware in the design and manufacture of prosthetic devices.
- Focus research on biomaterials, on internal implants for muscle, ligament, tendon and joint replacement, and on the reconstruction of musculoskeletal systems when bone and soft tissue loss occurs.

- Compare the effectiveness of different communication devices for those with motor, sensory or cognitive impairment affecting communication.

## Measurement, Assessment and Epidemiology

"The absence of adequate measurement tools has had a significant negative impact on our understanding of the development of children with disabilities." (Testimony Given at the Bethesda, MD Field Hearing)

"Research on the recovery of function presents a number of particular methodological difficulties...the absence of scientifically validated rehabilitation methods and assessment methods." (Testimony Given at the Bethesda, MD Field Hearing)

"The methodologic issue that I believe deserves greater attention and funding priority is the assessment of routine daily functioning, with its physical, social, and emotional components." (Written Correspondence)

"Much of research that has been conducted has used small samples of a given population. Additionally, there are few adequately compiled national databases available..." (Written Correspondence)

The Advisory Board recommends that NCMRR support the development of improved measurement and assessment of impairment, functional limitation and disability. Measurement and assessment should be improved in each of the domains, and across domains, and all should be related to societal impact.

Epidemiology is important for the planning of social programs and in determining priorities for research and treatment efforts. NCMRR should help establish consistent national data bases such as trauma registries that will provide the necessary information.

In the pathophysiological domain, DNA sequencing, pharmacokinetics of neurotransmitters, and PET and MRI brain imaging are examples of measures that could be used to study sequelae of disease or injury from a functional perspective. In the assessment of impairment, tools have been developed to measure, for example, strength, endurance, energy expenditure, range of motion, muscle activity, sensory capacities and cognitive processing. Disability measurements include self-assessments, recording performance of activities of daily living, motivational and personality tests, communication abilities, and many other measures used to study individual adjustment to impairment and loss of functioning. The relationships between the functional capacity of individuals with disabilities and the actual performance of life activities needs research attention.

Measurements of the societal impact of disability are most often made using assessment tools developed to measure employment, health care services utilization, technological development, and other mega trends. However, the major national data bases define disability in ways that leave out information important to understanding disability over the lifespan. Other data bases do not collect data on, or explicitly exclude, people with disabilities from the testing samples.

## Research Priorities in Measurement, Assessment and Epidemiology

1. Measure the effects of rehabilitation interventions. It is necessary to determine efficacy and effectiveness of complex rehabilitation techniques. Well-tested 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.
2. Develop new and precise quantitative measures of impairment, functional limitation, disability and societal limitation, with particular emphasis on disability and societal limitation. Such measures could supplement more traditional techniques and would quantify the influences of environmental factors,

including assistive technology, on the total experience of disability, and on responses to rehabilitative interventions.

3. Develop core rehabilitation outcome measures. Key variables of human performance must be identified, especially those relating to outcomes of adaptation and environmental interaction. Disease or condition-specific supplementary measures should also be developed and evaluated to complement the core measures.
4. Develop standardized measures of 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. Some existing scales developed in other fields examine subjective well-being, but the sensitivity of such scales in rehabilitation requires exploration.

## **Other Research Opportunities in Measurement, Assessment and Epidemiology**

- Develop and apply standards for the design and evaluation of measures of rehabilitation outcomes. Standards should address validity, reliability, precision, sensitivity, and feasibility. 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. Success in this effort would serve as a foundation for measuring quality of life, a concept that is receiving increasing attention from health services researchers, policy makers, and third-party payers.
- Identify antecedent and comorbidity (risk) factors. Lifestyle factors such as smoking, substance abuse, or risk taking behaviors may contribute to or influence the disabling process.
- Develop epidemiological evidence of prevalence and incidence of impairment, functional limitation, disability, and societal limitation. A large-scale data set should be gathered to describe the distribution and correlates of pathophysiology, impairment, functional limitation, disability, and societal limitation within the population. Populations which require special consideration include members of racial and ethnic minority groups, adults with developmental disabilities, and individuals with AIDS, all of whom tend to have the greatest difficulty in gaining access to rehabilitation care.
- Develop and test theoretical models of the determinants and course of the disabling process. Investigate and develop theoretical models of a) the factors that influence the relationships among pathophysiology, impairment, functional limitation, disability, and societal limitation; b) relationships between disorders and interventions; and c) factors predictive of recovery and adaptation.
- Investigate patterns and models of care delivery. Studies of patterns of rehabilitation care delivery are needed to understand variations in rehabilitation outcomes. Information is needed on access, sources of payment, costs, location, type of facility, length of treatment, and involvement of service providers and attendants. Success in this effort would serve as a foundation for policy changes.

## **Treatment Effectiveness**

"Research is required to analyze existing techniques, standardize their terminology, empirically assess their validity, synthesize effective approaches that make use of the best available knowledge, and provide the justification required to rehabilitation consumers and practitioners." (Written Correspondence)

"One of the major problems in the area of treatment ...is the question of cost effectiveness. Many, if not most of the treatments are highly labor intensive, performed by a skilled professional person, and therefore very expensive. Many of these procedures or interventions are often not based on clear scientific evidence." (Testimony Given at the Seattle, WA Field Hearing)

"...we are concerned that outcome studies develop methodologies for quantifying domains outside of the traditional domains of motoric components of activities of daily living. Examples of such studies might be (a) theory &

metrics for defining quality of life; (b) indicators for outcomes of cognitive and behavioral dysfunctions; (c) rationally derived measures of satisfaction; i.e. simple satisfaction with services is an important indicator of outcome." (Written Correspondence)

The Advisory Board recommends that NCMRR initiate and coordinate studies of the effectiveness of medical rehabilitation interventions using where possible the assessment methods and tools described in the "Measurement, Assessment and Epidemiology" of this report. Epidemiologic data derived from the studies recommended in the previous section should be used to assess the cost effectiveness of societal programs and assistance.

Many types of rehabilitation therapy, both traditional and innovative, are administered without ever having been subjected to rigorous proof of efficacy. Similarly, there are few sound methods for evaluating the effectiveness of social programs designed to provide assistance to people with disabilities. Focus on research strategies and methods need to distinguish more effective from less effective treatments. To do effectiveness and cost-effectiveness research, one must: 1) descriptively measure important inputs, processes, and outcome systems, and use this knowledge to quantify improvement curves and the most important predictors of outcomes, and 2) use this knowledge to design (multi-site) controlled studies that tease out the effects of different rehabilitation programs from powerful exogenous confounders. The sequence must be planned and supported over several years to obtain better knowledge of effectiveness.

Factors meriting study in relation to the primary underlying disease or impairment include comorbidity, nutrition, psychological status (including cognitive impairment and depression), demography, smoking or substance abuse, access to buildings and transportation facilities, and the availability of health care services. Data collected on reduced function associated with impairments and disabilities should go beyond the customary activities of daily living to examine outcomes related to occupational and avocational activities, productivity, social interaction, and performance of societal roles.

## **Research Priorities in Treatment Effectiveness**

1. Study the development, prevention and amelioration of secondary conditions associated with disabilities, such as depression; memory loss; muscle atrophy; and bowel, bladder, and sexual dysfunction.
2. Conduct controlled clinical trials to establish and compare long- and short-term efficacy of treatments to reduce impairments, functional limitations, and disabilities.
3. Conduct outcome research on the effectiveness of interventions in early childhood in a wide variety of pathophysiological conditions that can lead to disability.
4. Study how interactions among biological, psychological, sociological, and environmental factors contribute to the onset and amelioration of impairments, functional limitations, disabilities, and secondary conditions.
5. Study the effects on children with disabilities, including physical and cognitive functioning, educational attainment, and transition to adult roles, of educationally-related services in the Nation's public schools.

## **Other Research Opportunities in Treatment Effectiveness**

- Conduct long-term studies of the changing nature of impairments, functional limitations, and disabilities across the lifespan.
- Identify factors that may modify the relationships among pathophysiology, impairments, functional limitations, disabilities and societal limitations.
- Investigate patterns and models of health care and their effects on outcomes of rehabilitation.
- Conduct longitudinal studies that track the progress of people with disabilities during rehabilitation and post-rehabilitation to assess family and community integration.

- Identify the factors that contribute to optimal educational, prevocational and career development programs for children, adolescents and adults with disabilities. Such programs should ultimately lead to self-sufficiency, independence, and employment in adulthood.
- Evaluate the efficacy of neuroimaging techniques for capturing the effects of therapeutic interventions on brain function in persons with neurologic conditions.

## Training Scientists for Medical Rehabilitation Research

"As a doctoral candidate in rehabilitation and an academic professional actively engaged in medical education at the ... College of Medicine, I am convinced that our medical students are severely lacking in education about disability-related issues." (Written Correspondence)

"Training of scientists, prepared to conduct research in brain injury rehabilitation through fellowships and other programs should be a major focus of NCMRR activities." (Testimony Given at the Houston, TX Field Hearing)

"The biggest behavioral trouble is with the so-called professionals that families of the handicapped are treated with an attitude of total brain handicapped and 2nd rate citizens. We need to get the so-called professionals to majorly adjust their attitudes of handicapped minds with these bodies and same barbaric belief that family is unable to understand because they are suppose to be handicapped too!" (Written Correspondence)

The Advisory Board recommends that the medical rehabilitation research training sponsored by the NCMRR be inclusive rather than restrictive in those scientific disciplines targeted for training. This approach to research training reflects the multidisciplinary nature of medical rehabilitation and the complexity of the research issues requiring study.

The Advisory Board commends NIH on the recently announced research training supplement that provides funds to train individuals with disabilities for careers in science and allows individuals who have their scientific careers interrupted by injury or disease to return to the field of research. The Advisory Board recommends that the NCMRR and other funding agencies take full advantage of this new funding mechanism.

Current research training opportunities are not sufficient to address the promise of the medical rehabilitation field nor to foster highly qualified researchers essential to building the knowledge base needed to develop effective interventions and services. Because the number of senior investigators in medical rehabilitation research is limited, younger individuals interested in entering the field often do not have role models or mentors to guide their efforts.

Involvement in the clinical applications of laboratory findings to problems associated with disability should be included in medical rehabilitation research training programs. The integration of bioengineering and medical treatments to restore, replace, or supplement remaining function will require new types of training programs that may cross traditional divisions of professional training. Providing a multidisciplinary training experience that leads to a doctoral degree in rehabilitation research for individuals in physical therapy, occupational therapy, psychology, engineering, and other health professions is important for a better understanding of those therapies currently used and for the development of new rehabilitation therapies.

## Research Priorities for Training Medical Rehabilitation Scientists

1. Emphasize the development and improvement of pre- and post-doctoral training programs for disciplines where there are few doctoral level scientists including but not limited to physical therapy,

occupational therapy, bioengineering, biomedical engineering, rehabilitation device (orthotic and prosthetic) engineering, rehabilitation nursing, and rehabilitation psychology.

2. Initiate postdoctoral training programs in medical rehabilitation research in basic, applied and clinical science.
3. Identify new research training programs and ways to expand existing programs in order to increase the number of new and established investigators and the diversity of research specialties represented in the field.
4. Support training for scientists who will develop and apply effectively a new generation of assistive technology for persons with disabilities.

## **Other Opportunities for Training Medical Rehabilitation Scientists**

- Support research training programs that offer opportunities to develop medical rehabilitation research careers at the high school, undergraduate and predoctoral level of training.
- Develop programs to attract successful mid-career scientists and clinicians from the scientific domains of pathophysiology, impairment, function, disability, and societal limitations and from the clinical specialties serving people with disabilities into further training that would direct their expertise to the multi-domain research characteristic of medical rehabilitation.
- Analyze personnel availability and needs relevant to medical rehabilitation research.
- Support the development of research training programs that emphasize the need to study functional limitations and disability as they relate to the needs of people with disabilities and the societal limitations that exist including but not limited to the training of scientists in areas of independent living and epidemiology, biostatisticians and demography of disability.
- Include people with disabilities in research training programs.

## **Support for Research Initiatives and Opportunities**

"...we strongly encourage an increased funding level for 1993 in order to fulfill the Center's tremendous promise to the field. Specifically, we believe that a budget of \$20 million is needed...." (Written Correspondence)

"...Society will advocate for a \$20 million appropriation for the center...."  
(Written Correspondence)

Developing a research program at the NCMRR that has a focus on function will require time, effort and additional resources. The priorities described in this Research Plan for Medical Rehabilitation Research range from specific to broad. Some can be accomplished through coordination of research efforts of other NIH institutes or centers and other Federal agencies with activities in medical rehabilitation. Other priorities and opportunities will need to be accomplished through the support of individual investigators working at existing universities and rehabilitation facilities. To attract these investigators to the field of medical rehabilitation, the NCMRR will need to have new or uncommitted funds available.

## **Progress of the National Center for Medical Rehabilitation Research**

In November 1990, President Bush signed Public Law 101-613 (see Appendix B) which established a National Center for Medical Rehabilitation Research (NCMRR) in the National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). This law also stipulated that a National Advisory Board to the NCMRR be created; this Board was established in Spring of 1991. The Board is comprised of 18 public members appointed by the Director of NIH and includes individuals with disability as well as rehabilitation practitioners and researchers. Several Federal agencies that support medical rehabilitation research hold membership on the Board in an ex officio status.

On May 9-10, 1991, the first meeting of the Advisory Board was held to begin implementation of this legislation. Four subsequent meetings have been held to review progress made by the Acting Director, Acting Deputy Director, and other NCMRR staff and to provide continued guidance for future activities. Several significant milestones have occurred, as detailed below.

During 1991 and the beginning of 1992, a major effort was expended on producing this Research Plan for Medical Rehabilitation Research. This process included defining disability-related terminology, identifying areas of research relevant to medical rehabilitation, clarifying particularly salient issues and concerns of the rehabilitation field, and beginning to prioritize research areas. A framework was developed to initiate clinical research for a model system of medical rehabilitation. Public forums were held in Houston, TX, Seattle, WA, and Bethesda, MD to permit public review and comment on the Research Plan. The comments and suggestions have been incorporated into this Research Plan for Medical Rehabilitation Research.

Members of the medical rehabilitation research community have consistently expressed a great need for programs to train rehabilitation specialists in the techniques and methods of rehabilitation research. Following a recommendation made in the Report of the Working Group on Medical Rehabilitation Research Training, NCMRR staff issued a request for applications for National Research Service Award Institutional Training Grants in medical rehabilitation research. The scientific community responded rapidly by submitting 18 applications. A scientific review group rated 13 of the applications as having significant and substantial merit. Seven applications received partial funding in September 1991 and the remaining six will be funded in Fiscal Year 1992.

In addition to the daily interactions with the scientific community, the NCMRR has undertaken a number of other activities to address issues of medical rehabilitation research. Requests for applications for research on prosthetic and orthotic devices, reproductive issues for individuals with physical disabilities, and bowel and bladder management for individuals with disabilities will be announced in 1992, and additional requests for applications are anticipated for 1993. Conferences on prosthetic and orthotic devices, improvement in medical diagnosis of musculoskeletal disorders, integration of measurement in medical rehabilitation, osteogenesis imperfecta, and rehabilitation of chronic pain will be sponsored by the NCMRR in 1992.

As the mission and goals of the NCMRR become more widely known to the research community, it is anticipated that scientists from many fields will make application for support of medical rehabilitation research using the variety of mechanisms available to them at the NIH (see Appendix C). A technical and scientific review group with medical rehabilitation expertise will be established on the basis of the volume of grant applications received from rehabilitation scientists and scientists from other fields interested in working on rehabilitation related problems.



## Research Coordination

As prescribed by the law, a Medical Rehabilitation Coordinating Committee was established to coordinate medical rehabilitation research by NIH and other Federal agencies. This committee will analyze currently funded NIH grants and contracts identified by the Institute or Center as being rehabilitation related research. These activities will be reviewed in light of the classification scheme presented in this Research Plan for Medical Rehabilitation Research. This review will provide important information to the Institutes and Centers as they plan programs for fiscal year 1994.

In addition to this coordination effort, Federal medical rehabilitation activities are being reviewed (see Appendix A) in order to support interdisciplinary research by more than one Federal agency. Several NIH Institutes and Centers and three other Federal agencies with rehabilitation activities have requested that the NCMRR consider funding grant applications that they received in fiscal year 1992. At the NIH these include, the National Institute on Aging, National Institute on Neurological Disease and Stroke, National Center for Nursing Research, and National Center for Research Resources, the National Institute on Deafness and other Communicative Disorders, and the National Eye Institute. Other Federal agencies requesting NCMRR consideration for funding grant applications are National Institute on Disability and Rehabilitation Research (NIDRR) of the Department of Education, Centers for Disease Control, National Aeronautics and Space Administration, the Social Security Administration, the National Institute for Occupational Safety and Health, and the Agency for Health Care Policy and Research.

The NCMRR of the NICHD and the NIDRR have agreed to work together (described in a memo of understanding) in sharing information on grant applications prior to funding, in keeping an open communication system between staff, reviewing future funding plans, and sharing workshop and conference responsibilities for scientific topics of interest to medical rehabilitation. The NIDRR will coordinate the rehabilitation related research efforts for all Federal agencies through the Interagency Committee on Disability Research. The NCMRR will be represented on this committee by its Director.

## **Appendix A<sup>3/4</sup> Medical Rehabilitation Research Activities of Federal Agencies**

Medical rehabilitation research is conducted or supported by a variety of Federal agencies. As part of its legislative mandate to identify these activities for this first Report and Research Plan of the NCMRR, each agency was asked to provide a brief description of the type of medical rehabilitation research or rehabilitation-related activity it supports. While the major activities are described, neither all agencies that fund medical rehabilitation research nor all projects at each agency are included. The funding estimates given in this report are approximations. During the next several years, the NCMRR will review and analyze medical rehabilitation research efforts throughout government to better identify the gaps in research, better define medical rehabilitation, and improve coordination of research. These activities will provide the NABMRR and the NCMRR with the necessary information to improve the reports on the coordination of medical rehabilitation research funded by Federal agencies.

### ***National Institutes of Health***

Many of the NIH research institutes support research related to rehabilitation. The manner in which medical rehabilitation research was defined varies in scope from narrow to broad and basic to applied, depending upon the nature of the research at the institute or agency. While these general descriptions provide a useful overview, it is the detailed descriptions of research projects that distinguish the apparently similar research areas among agencies from each other. Within the broad context of defining rehabilitation-related research, the NIH institutes report total expenditures for this research of \$138 million for 1992. This represents approximately 1 percent of the NIH total budget. While much of this research relates to the mission of the NCMRR, it is not a substitute for the type of research that will be developed within the NCMRR.

National Institute of Child Health and Human Development (NICHD)  
(\$14.7 million FY 1992 estimate NICHD total)  
(8.3 million FY 1992 estimate - NCMRR portion)

The National Institute of Child Health and Human Development (NICHD) conducts and supports research on the reproductive, developmental, and behavioral processes that determine the health of children, adults, families, and populations. Medical rehabilitation research at NICHD has proceeded in several directions; it has encompassed the physical and cognitive aspects as well as the social environment for improving and enhancing the abilities of persons with disabilities. Most of this research has focused on mental retardation, developmental disabilities and congenital anomalies.

The breadth and the magnitude of medical rehabilitation research will expand greatly with the establishment of the new National Center for Medical Rehabilitation Research (NCMRR) at NICHD, formed in 1991 through P.L. 101-163. NCMRR will conduct, foster, and support research on restoring, replacing or enhancing the functional capability of children and adults with disabilities resulting from an injury, disease, congenital disorder or natural aging process. Specific attention will be given to research on: functional problems associated with diminished mobility, body systems' response to lost function, adaptive behavior systems modifications to functional loss, treatment intervention effectiveness in restoring function, assistive devices that replace or enhance function, and outcome measurement systems that provide an integrative method for tracking functional change over time in many different domains. Since its inception, seven institutional training grants have been awarded and six additional grants will be awarded in FY 1992. These grants will provide training to scientists who will study behavioral and biomedical processes involved with rehabilitation.

National Institute on Aging (NIA)

(\$12.9 million FY 1992 estimate)

Physical frailty and fall-related injuries represent significant threats to older persons' functioning and quality of life. The Physical Function and Performance Program (PFP) of the NIA part of the NIH which recognizes the critical need to reduce the loss of functional capacity, promote independence, and prevent fall-related injuries. PFP is designed to support research studying the interactions among biomedical, environmental, biomechanical, functional capacity, and strength factors which both contribute to these problems and offer prospects for their solution.

Patients with functional impairments utilize a high level of health care resources. This adds to the already escalating costs of health care. Better understanding of those diseases and conditions which predispose patients to frailty will lead to appropriate targeting in research and treatment designed to reduce frailty's impact on society. Geriatric evaluation units use specific rehabilitative programs which have demonstrated significant strength gains which lead to functional independence - even amongst the oldest-old institutionalized volunteers. With proper research, improvements in functional capacity of our older population can be achieved while reducing health care needs and costs. Population projections indicate a dramatic increase in the number of oldest old - persons 85 and over. This group, the most frail and the most dependent, presents a tremendous public health challenge. In response, the NIA Geriatrics Program (GP) is supporting studies that present innovative methods of preventing and treating frailty. Preliminary results indicate that some interventions can help older community-dwelling people and nursing home residents achieve greater independence and improve their physical functioning. Indeed, researchers have demonstrated that specific exercise programs can improve strength, gait speed, and endurance - even in nursing home residents.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)  
(\$18.1 million FY 1992 estimate)

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

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

National Cancer Institute (NCI)  
(\$14.1 million FY 1992 estimate)

The NCI supports a national research program to investigate the biology, causes, prevention, diagnosis, treatment and control of cancer and the rehabilitation of the cancer patient. The goal of the National Cancer Institute's rehabilitation program is to conduct and support research necessary to restore or maintain the fullest physical, psychological, social, vocational, avocational, and educational potential for cancer patients. Much of this research is interdisciplinary and interlocked with the Institute's treatment and control research. Some rehabilitation research focuses on specific cancers. For example, research related to head and neck cancer includes activities to improve breathing, swallowing, and speaking following surgery and other treatment. Research related to bone cancer investigates limb-sparing techniques and the attachment of

prostheses. Areas of rehabilitation research common to many cancers include quality of life, management of pain, self-care, childhood and adult cancer survivors, nutrition, and the adequacy of and needs for service of cancer patients and their families.

Cancer rehabilitation emphasizes restoring, replacing, or enhancing function throughout the course of disease, from preclinical stages through diagnosis, treatment, and recovery (or periods when recovery is unlikely). Because disabilities and rehabilitation needs vary through the course of cancer, and effects of treatment may contribute to both short- and long-term disabilities rehabilitation is an integral part of cancer treatment and continuing care. The diversity of different malignancies, the spectrum of effective therapeutic approaches and their consequences, and the changing pattern of dysfunction and disability during the course of disease present special challenges in cancer rehabilitation.

NCI's information dissemination activities also address rehabilitation: about 10 percent of the calls to the Cancer Information Service are related to rehabilitation, and rehabilitation research is the focus of a monthly CANCERGRAM publication on rehabilitation and Supportive Care. Because of the growing number of cancer survivors, the need for rehabilitation research and application is increasing, and activity in this area is expected to grow in the future.

National Institute on Deafness and Other Communication Disorders (NIDCD)  
(\$19.3 million FY 1992 estimate)

The NIDCD is responsible for research and research training related to both normal and disordered hearing, balance, smell, taste, voice, speech and language. The NIDCD is concerned with the special biomedical and behavioral problems associated with people having communication impairments and disorders. Currently, 59 percent of the extramural dollars are in hearing, 3 percent in balance, 7 percent in smell, 8 percent in taste, 7 percent in voice, 7 percent in speech, and 9 percent in language.

The great portion of dollars are in studies to improve assistive devices such as hearing aids, cochlear implants, and tactile devices. A small percentage of the rehabilitative projects in the area of hearing focus on other means of assisting the deaf and hearing impaired person to function in the hearing world.

The NIDCD addresses rehabilitation and treatment of individuals with voice disorders. Studies focus on development of specific surgical, pharmacological, and behavioral techniques in the treatment of selected voice problems. Speech disorders research focuses on development of devices for the non-vocal child and adults, the use of computer-based speech training systems for speech-impaired children, as well as the development and determination of the efficacy behavioral treatments for stuttering and other speech disorders. Research on language disorders address development or refinement of behavioral, computer-based, and pharmacological treatments which may provide more effective means of re-establishing communications skills in individuals with aphasia. Researchers studying child language disorders are involved in the development of treatment protocols for children with language impairments, and identification of impaired children who warrant intervention and the optimal times for providing treatment.

National Institute of Dental Research (NIDR)  
(\$7.9 million FY 1992 estimate)

The NIDR supports research to restore the form and function of orofacial tissues damaged as a result of birth defects, disease, surgery, or trauma. Cleft lip and cleft palate are among the most common handicapping birth defects and NIDR research over the years has supported interdisciplinary biomedical and behavioral research to improve surgical repair, prevent ear infections and other complications, improve speech and breathing, and other oral functions, and enhance self-image and social interactions. Future plans call for clinical trials to determine the optimal timing and methods for surgical repair. Other developmental anomalies under study include the ectodermal dysplasias, and osteogenesis-, dentinogenesis- and amelogenesis imperfecta. Researchers are conducting a clinical trial to determine the effectiveness of dental implants in ectodermal dysplasia patients, including issues of patient satisfaction and quality of life. Other dental implant research is evaluating various implant materials, methods of placement, and the mechanisms involved in the integration of the implant in the bone. Research support is also in the study of pain and

dysfunction involving the temporomandibular joint. This research is aimed at improving the diagnosis, treatment, and prevention.

NIDR also conducts research on the methods of correcting serious malocclusions of the teeth, ways to prevent relapse following corrective jaw surgery, and studies of oral motor and sensory functions in denture wearers. Biomaterials research is aimed at developing improved prosthetic materials and colorants for use to replace soft tissue and teeth. The portfolio includes studies of ways to enhance wound healing, such as the use of bone growth factors and demineralized bone matrix to repair bone fracture and fill bony defects.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)  
(\$4.4 million FY 1992 estimate)

The NIDDK supports research related to medical rehabilitation in two main areas: behavioral or psychological research that involves intervention strategies and impaired functional maintenance in patients with chronic disorders. Behavioral or psychological research addresses problems arising from diabetes, obesity, or gastrointestinal disorders, including: the ability to perceive blood glucose levels; blood glucose response to psychological and hormonal stressors; application of information gained from laboratory studies of the variables that control food intake to the treatment of obesity; the microstructure of eating behavior; and physiological versus psychological causes of irritable bowel syndrome. Efforts to improve the function of patients with chronic disorders include: research on why erythropoiesis remains suppressed in most maintenance dialysis patients; development of an artificial pancreas, with the ultimate purpose of implanting it into diabetic patients whose own pancreatic functioning is severely reduced; and analysis and isolation of clinical problems involved in organ transplantation.

National Eye Institute (NEI)  
(\$2.6 million FY 1992 Estimate)

The NEI supports and conducts research aimed at improving the prevention, diagnosis, and treatment of diseases that affect the eye and vision. Eye diseases and blindness cost the Nation an estimated \$16 billion per year. More than 11 million people in the United States suffer from significant, uncorrectable, impairment of vision. About 3 million persons are unable to read ordinary newsprint even with the best possible optical correction, and nearly 1 million people are classified as being legally blind.

The NEI is a leading source of support for research on visual impairment and its rehabilitation. Primarily through its Extramural and Collaborative Program, the NEI supports studies aimed at developing tests for assessing visual function, identifying factors involved in visual task performance, and developing and evaluating visual aids.

A priority for NEI's support of low vision research is the development of a battery of visual function tests that measure the ability of people to perform tasks that are important in their everyday lives. Other research includes: studying the usefulness of laboratory and clinical tests in predicting performance on tasks; the development of a mathematical formula for computerized image enhancement that has the potential to provide elderly macular disease and cataract patients with a better quality of life by enabling them to see printed photos and television more clearly; the development of clinical methods that can differentiate those patients who are likely to benefit from spectacle-mounted telescopes for general mobility from those who are not; and the development of a variety of aids for patients with low vision.

National Heart, Lung, and Blood Institute (NHLBI)  
(\$17.9 million FY 1992 estimate)

The NHLBI provides leadership for a national research program in diseases of the heart, blood vessels, lungs, and blood and in the uses of blood and the management of blood resources.

Rehabilitation -- ameliorating impairment of those with chronic illness or other conditions, and preventing acute illness from resulting in chronic impairment -- is a very substantial fraction of the Institute's research and other activities. but the boundaries of the rehabilitation activities are hard to demarcate. For example,

some of the life style changes for improving the everyday quality of life of those with cardiovascular or pulmonary impairment are also warranted for preventing progression of diseases and for its primary prevention in those with no evidence for disease. In addition, most treatment for acute or chronic cardiovascular or pulmonary disease has rehabilitation as an essential component, whether it is a lifestyle, medical, surgical or other intervention.

For the purpose of this report, rehabilitation is considered as actions that (1) have functional, physiological and/or psychological goals of decreasing or compensating for impairment and (2) require the continued involvement of the patient over a period of time in activities or behaviors more complex than simply taking medication.

Cardiac and pulmonary rehabilitation are integral parts of cardiac and pulmonary disease management -- and of the research, training, demonstration and education portfolio of the NHLBI.

National Institute of Neurological Disorders and Stroke (NINDS)  
(\$14.4 million FY 1992 estimate)

Much of the NINDS basic and clinical research on head injury, spinal cord injury, stroke, developmental, demyelinating and neuromuscular disorders is directly relevant to rehabilitation efforts. The primary emphasis in neurorehabilitation research is on restitution of function, prevention of secondary injury, and improving the quality of life. Basic and applied research into biochemical and physiological processes of brain injury in stroke and trauma and other neurological disorders has entered an era of novel and promising possibilities for future exploration. New research possibilities for dealing with neurological diseases are now rapidly developing as a result of technological advances, including MRI, PET, and SPECT. A wide variety of disorders, can now be systematically and sequentially assessed at structural and metabolic levels using these technologies, an accomplishment that was previously impossible and is providing new knowledge useful in the care of the disabled population.

The neural prosthesis program has opened up neurological rehabilitation research in ways unimaginable in even very recent years. The 1990's have been declared the "Decade of the Brain", and the National Advisory Council of the NINDS has formulated an implementation plan to address areas within the neurosciences that are poised for breakthrough. Each of the areas identified in the plan has a component of interest to rehabilitation.

The NINDS has expanded existing research programs in the areas of head and spinal cord injury, stroke, Alzheimer's disease, and movement and developmental disorders in response to program announcements and requests for applications in these areas. In addition, NINDS plans to encourage increased research efforts in the areas of neurological motor control and post-polio syndrome through the release of program announcements.

National Center for Nursing Research (NCNR)  
(\$4.0 million FY 1992 Estimate)

The NCNR fosters, conducts, administers, and supports research and research training programs directed at promoting the growth and quality of research related to nursing and patient care and expanding the pool of experienced nurse researchers. The NCNR funds rehabilitation-related research in several areas such as cancer rehabilitation in patients receiving chemotherapy or radiation therapy, geriatric concerns with incontinence, and rehabilitation issues related to hospital discharge, recovery from hip fractures, and effects of exercise training on the cardiovascular and respiratory systems. Other rehabilitation-related research supported by NCNR focuses on the prevention and treatment of pressure sores with spinal cord injured patients and older persons. Additionally, one of NCNR's Specialized Centers is supporting research focused on characterizing depressive signs and symptoms experienced by stroke patients at different points in time throughout recovery. The other NCNR Specialized Center is supporting research focused on women's health issues including lifestyles of women recovering from drug usage.

The NCNR funds excellent rehabilitation-related research that will provide information that is clinically relevant, scientifically rigorous, and which will improve health care to individuals and their families. Continuing to build this strong scientific foundation to guide nursing practice during recovery and rehabilitation is an important goal of the NCNR.

National Center for Research Resources (NCRR)  
(\$8.6 million FY 1992 estimate)

The NCRR strengthens and enhance the research environments of institutions engaged in rehabilitation research by developing and supporting a variety of essential resources for both basic and clinical studies.

Current work in the field of biomedical technology focuses on numerical simulations of blood flow in artificial hearts, "neural network" software to model nerve cell firing in the hippocampus of the brain, and the growth of bone cells into the textured surfaces of newly implanted hip and dental prostheses. By providing researchers with appropriate animal models, the NCRR also supports studies of cochlear prostheses histopathology, small vessel prostheses, and the implantation of sound amplifiers.

The NCRR provides grants for institutions to purchase expensive research instruments that are shared by groups of investigators. These instruments are used to conduct, for example, molecular studies of nerve allografts, nerve repair, and synthetic materials for musculoskeletal replacement devices. NCRR also supports the purchase of computers to analyze data on hip fracture repair, quality of life after organ transplantation, and self-management after cardiac arrest. In addition, through flexible support for short-term research needs, the NCRR has sponsored a broad range of rehabilitation research, including studies on hepatic lobe implants, tendon and ligament prostheses, total knee arthroplasty, and intraocular lens implants.

NCRR's General Clinical Research Centers provide clinical research infrastructure to investigators conducting rehabilitation studies; topics include the use of programmable implantable medication systems (PIMS) in diabetes, total hip and knee replacement, disease status modification through diet and exercise, and cochlear prostheses and implants. In addition, the Research Centers in Minority Institutions (RCMI) Program has sponsored studies on glucose turnover in infants with cerebral injury, poor perinatal outcome in blacks, and mental stress in blacks with HIV.

Department of Rehabilitation Medicine (DRM)  
NIH Clinical Center

The DRM provides comprehensive rehabilitative services to NIH patients and supports and collaborates on research in the area of rehabilitation as it pertains to NIH patients and the problems that they confront while patients at NIH. The DRM within the NIH Clinical Center is engaged in a wide scope of restorative research activities. The focus of its research is in the areas of speech, physical and occupational therapy, physical medicine, and biomechanics. Among the current projects are prosthetic intervention, evaluation of chewing and swallowing, and gait analysis, and creating adaptations for children with osteogenesis imperfecta. The DRM is working collaboratively with the NCMRR on a number of conferences to stimulate the field of rehabilitation medicine.

Research conducted at DRM is a collaborative effort with the institutes. This effort is billed to individual institutes through the management fund formula. Consequently, the institute FY 1992 estimates include DRM costs.

### ***Other Federal Agencies***

Centers for Disease Control (CDC)  
(\$1.3 million FY 1992 estimate)

The CDC provides support of rehabilitation research in the areas of injury control and disability prevention. Within its National Center for Environmental Health and Injury Control (NCEHIC), the CDC coordinates research dealing with all aspects of injury control including prevention, acute care, and rehabilitation. Rehabilitation projects in the injury control program include consequences of mild head injuries, cost of rehabilitation care, rehabilitation following spinal cord injury, and rehabilitation following lower extremity fractures. The NCEHIC Disability Prevention Program has as one of its major interests the prevention of secondary conditions among persons with disabilities and will be awarding demonstrations and epidemiology projects related to prevention of secondary disabilities in late FY 1992. The CDC program emphasizes applied research and coordinates its activities with other Federal agencies.

National Institute on Disability and Rehabilitation Research (NIDRR)  
(\$32.7 million FY 1992 estimate)

The NIDRR within the Department of Education provides leadership and support for a national and international program of comprehensive and coordinated research on the rehabilitation of disabled individuals. NIDRR's medical rehabilitation research program places greater emphasis on functional aspects of disability than it does on etiology and basic science issues. The Institute's mission also encompasses the dissemination of information concerning developments in rehabilitation procedures, methods, and devices that can improve the lives of people of all ages with physical and mental handicaps. One of the most important aspects of research supported by the Institute is that it helps to assure the integration of disabled persons into independent community life. The results to be achieved by this mission include:

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

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

The Director of NIDRR is the chairman of the Interagency Committee on Disability Research (ICDR), a legislatively mandated committee established in 1978 to promote coordination and cooperation among Federal agencies conducting rehabilitation research. NIDRR also cooperates with and receives policy guidance from the National Council on Disability, a Presidentially appointed body of noted rehabilitation professional and consumer members.

Veteran's Administration (VA)  
(\$26.8 million FY 1992 estimate)

Medical & Prosthetic Research in the VA serves two major functions: 1) to attract, educate, and retain trained, research-oriented physicians at VA Medical Centers; and, 2) to advance the diagnosis and treatment of health problems prevalent among veteran patients by applying the findings of VA medical research studies throughout the hospital system. In addition to supporting medical research, the VA has two administratively separate programs that fund studies, Health Services Research and Development (HSR&D) and Rehabilitation Research and Development (Rehab R&D).

HSR&D investigates factors relating to the existing organization, delivery, costs, and outcomes of VA health care programs by supporting peer reviewed research in issues related to the improvement of the quality, efficiency, and cost-effectiveness of health care provided by the VA.



Rehab R&D support efforts which will maximize the abilities and functional independence of physically disabled veterans. This mission includes development and evaluation of devices for use by Veteran patients and concepts, techniques and technology to improve the care of disabled veterans. Rehab R&D supports the development and ultimate commercialization of improved artificial limbs; orthoses; mobility aids such as wheelchairs and automotive adaptive equipment; and sensory aids for hearing, visual and communication-impaired veterans. Three priority areas have been designated for new research and development efforts: prosthetics, amputation, and orthotics; spinal cord injury; and sensory, cognitive, and communication aids.

Special emphasis is placed on studies relating to physical fitness and the aging process. The program is committed to research and development of new techniques and devices which help elderly disabled veterans achieve their maximum potential and compensate for the effect of the aging process on their disability. Rehab R&D also supports development of new technologies, techniques or procedures which minimize or eliminate the excess disability suffered by patients with schizophrenia or dementia.

## Appendix B<sup>3/4</sup> Authorizing Legislation

Public Law 101-613---November 16, 1990

Public Law 101-613  
101st Congress

"National Institutes of Health Amendments of 1990."

"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.
- (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).

"(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 (here-after in this section referred to as the 'Coordinating Committee').

"(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 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').

"(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 interest 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."
- "(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.

## **Appendix C<sup>3/4</sup> Mechanisms Used by NCMRR for Supporting Medical Rehabilitation Research**

Assistance Mechanisms Currently Used  
By NICHD To Support Research and Training

### **F32 Postdoctoral Individual National Research Training Award**

To provide postdoctoral research training to individuals to broaden their scientific background and extend their potential for research in specified health-related areas.

NIH Guide for Grants and Contracts, Vol. 13, No. 1, January 1984 (Special Edition).

### **F33 National Research Service Awards for Senior Fellows**

To provide opportunities for experienced scientists to make major changes in the direction of research careers, to broaden scientific background, to acquire new research capabilities, to enlarge command of an allied research field, or to take time from regular professional responsibilities for the purpose of increasing capabilities to engage in health-related research.

NIH Guide to Grants and Contracts, Vol. 8, No. 11, August 13, 1979, revised announcement dated November 2, 1982.

### **K04 Modified Research Career Development Award**

To foster the development of young scientists with outstanding research potential for careers of independent research in the sciences related to health. The RCDA will provide up to \$50,000 for salary for full-time research and research-related activities. Fringe benefits will be provided in addition to salary. Support is for 5 years and is not renewable.

Policy Brochure and Instructions, October 15, 1987.

### **K08 Clinical Investigator Award**

Provide the opportunity for promising, clinically trained individuals with demonstrated aptitude for research to develop into independent biomedical investigators in several clinical areas relevant to maternal and child health and to the biology and medicine of reproduction (pediatrics, clinical nutrition, obstetrics and gynecology, reproductive biology, and andrology). It is planned that this award would provide a transition between fellowship or trainee experience and a career as an independent investigator. Salary support not to exceed \$50,000 will be provided. Fringe benefits will be provided in addition to salary. Up to \$10,000 may be requested for supplies, equipment, travel and tuition. Support is for 5 years and is not renewable or transferable.

NIH Guide for Grants and Contracts, Vol. 13, No. 8, June 29, 1984, NICHD Instructions for Preparing Applications, June 1, 1984.

### **K11 Physician Scientist Award**

Designed to encourage the individual with clinical training to develop research skills in a fundamental science. To help support the transition from clinical training status to that of a productive investigator able to compete successfully for NIH research support, the Physician Scientist Award will provide the opportunity for clinicians to develop into independent investigators, to obtain research experience under sponsorship of a basic research scientist and to initiate a research program.

Candidates must hold a health professional degree in the clinical sciences (M.D., D.D.S., D.V.M., D.O., or equivalent). This 5 year non-renewable award is divided into two distinct phases that are related to an individual's progress in becoming an independent investigator. Allowable costs include:

salary not to exceed \$50,000 plus fringe benefits for essentially full-time (75 - 100 percent) effort; up to 10 percent of the primary sponsor's salary and fringe benefits during Phase I; \$10,000 per year (increasing \$20,000 per year in Phase II) for research project requirements and related support, e.g., technical personnel, supplies, equipment, travel, medical insurance premiums and tuition; and indirect cost not to exceed 8 percent of total direct costs less tuition, fees and equipment.

NIH Guide for Grants and Contracts, Vol. 15, No. 3, February 28, 1986.

#### K12 Physician Scientist Award

To enable individuals with clinical training in obstetrics or pediatrics to undertake up to 5 years of special study in basic science with a supervised research experience. The two existing programs supported by the Institute are special initiatives, jointly sponsored and funded by the Institute and private sources. It is not anticipated that additional K12 institutional program awards will be made.

NIH Guide for Grants & Contracts, Vol. 13, No. 8, June 29, 1984.

#### P01 Research Program Projects

For the support of a broadly based, multidisciplinary, often long term research program which has a specific major objective or a basis theme.

NICHD Guidelines, July 1, 1988.

#### R01 Research Project Grants - (Traditional)

#### R13 Conference

To support international or national meetings, conferences and workshops.

Support of Scientific Meetings, Special Information and Instructions, October 1980

#### R29 The First Independent Research Support and Transition Award (FIRST)

To encourage new investigators (including those who have interrupted early promising research careers) in basic or clinical science disciplines to develop their research interest and capabilities in biomedical and behavioral research. To help bridge the transition from training status to established investigators. First award applications must request 5 years of research support with not less than 50 percent effort commitment by the P.I. The total direct costs requested must not exceed \$350,000 for the 5 year period; no more than \$100,000 may be requested in any 1 year. Technical support, supplies, publication costs, travel and equipment may be requested. The R29 is not renewable.

NIH Guide for Grants and Contracts, Vol. 16, No. 22, June 26, 1987.

#### R43 Small Business Innovation Research Grants (SBIR) - Phase I

To support projects, to establish the technical merit and feasibility of R&D ideas which may ultimately lead to a commercial product(s) or service(s). These awards may be made only to small businesses. Awards normally may not exceed \$50,000 (for both direct and indirect costs) for a period normally not to exceed 6 months.

Omnibus Solicitation annually.

#### R44 Small Business Innovation Research Grants (SBIR) - Phase II

To support in-depth development of R&D ideas whose feasibility has been established in Phase I and which are likely to result in commercial products or services. These awards may be made only to small businesses. Awards normally may not exceed \$500,000 (including both direct and indirect costs) for a period normally not to exceed 2 years. However, grants in larger dollar amounts and/or for longer periods of support may be made in cases where agency needs or research plans so require.

#### T32 Institutional National Research Service Award

To enable institutions to make to individuals selected by them, National Research Service Awards for pre-doctoral and postdoctoral research training in specified shortage areas. The NICHD has established a single receipt date for these applications, January 10 each year for a starting date of July 1 in the succeeding year.

NIH Guide for Grants and Contracts, Vol. 13, No. 1, January 1984 (Special Edition) and Vol. 17, No. 24, July 29, 1988.

**U01 Research Project (Cooperative Agreement)**

To support a discrete, specified, circumscribed project to be performed by the named investigator(s) in an area representing his specific interest and competencies. A cooperative agreement is an assistance mechanism used in lieu of a grant when substantial programmatic involvement is anticipated between NICHD and the recipient during performance of the activity.

**U10 Cooperative Clinical Research (Cooperative Agreement)**

To support clinical evaluation of various methods of therapy in specific disease areas. These are usually collaborative programs between sponsoring institutes and principal investigators, and usually conducted under a formal protocol. A cooperative agreement is an assistance mechanism used in lieu of a grant when substantial programmatic involvement is anticipated between NICHD and the recipient during performance of the activity.