# National Institutes of Health (NIH) Research Plan on Rehabilitation

# MOVING THE FIELD FORWARD



# National Institutes of Health Research Plan on Rehabilitation

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U.S. Department of Health and Human Services National Institutes of Health Developed by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development and the NIH Medical Rehabilitation Coordinating Committee

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# **Executive Summary**

Millions of Americans have a disability so severe that they have difficulty with everyday tasks such as going to work or taking care of themselves. Some have been injured in accidents or war. Some were born with their disability. Some have developed disabilities over time.

Rehabilitation research explores the intricate biology of disabilities and looks for ways to help restore lost function and to help people with disabilities reach their full potential.

The National Center for Medical Rehabilitation Research (NCMRR) within the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development of the National Institutes of Health (NIH) coordinates federal medical rehabilitation research. NCMRR has led the effort to release the NIH Research Plan on Rehabilitation.

This 5-year plan lays out priorities in medical rehabilitation research; will guide NIH support for rehabilitation medicine; and will benefit individuals with temporary or chronic limitations in physical, cognitive, or sensory function that require rehabilitation.

The plan was submitted for public comment in October 2015. The National Advisory Board on Medical Rehabilitation Research (NABMRR) reviewed the public comments in December 2015, and the NABMRR provided a second review of the revised objectives in May 2016. The final public input was received through the Town Hall meeting held during the May 2016 conference "Rehabilitation Research at the NIH: Moving the Field Forward."

The plan addresses the following topics:

- The Need for Rehabilitation Research
- NIH's Investment in Rehabilitation Research
- Current Medical Rehabilitation Research Activities at NIH
- Opportunities, Needs, and Priorities
- Coordination with Other Federal Agencies

**The Need for Rehabilitation Research.** Disability casts a long shadow over the United States. According to the Centers for Disease Control and Prevention about 53 million people have a disability—1 in 5 Americans; estimates from the Census Bureau are relatively similar with estimates of disability, 56.7 million Americans. People with disabilities are more likely to have health problems, but they have a harder time getting to a health care provider. Meanwhile, more than 43 million people in the United States are caregivers to people with disabilities, and their health also may suffer.

**NIH's Investment in Rehabilitation Research.** Many more professionals are now entering the field of rehabilitation research, thanks in part to NIH investment in rehabilitation research training. NIH has also funded the development of new mobility devices, rehabilitation techniques and interventions, and studies of the body's self-repair mechanisms in hopes of better harnessing those mechanisms.

**Current Medical Rehabilitation Research Activities at NIH.** In fiscal year 2015, NIH awarded \$514 million to support rehabilitation research conducted by investigators in universities, nonprofit institutions, and small businesses. The funding has stimulated many advances, including in braincomputer interface systems. These systems can restore communication and control to people paralyzed or "locked in" by amyotrophic lateral sclerosis or other neuromuscular disorders.

**Opportunities, Needs, and Priorities.** Rehabilitation research runs wide and deep within NIH. Seventeen Institutes and Centers fund rehabilitation research. This research plan helps coordinate those efforts and focuses on six areas of rehabilitation research: rehabilitation across the lifespan, family and community, technology use and development, research design and methodology, translational science, and building research capacity and infrastructure.

**Coordination with Other Federal Agencies.** NIH also coordinates the funding of rehabilitation research with other federal agencies to ensure the best use of federal dollars. NIH coordinates with the National Institute on Disability, Independent Living, and Rehabilitation Research and the Department of Veterans Affairs, among others. These agencies attend regular meetings together, including meetings of the NABMRR and the Interagency Committee on Disability Research.

Much progress has occurred since NIH released its first rehabilitation research plan in 1993. We have more rehabilitation researchers because of funding given to training programs. We have new and more advanced mobility devices and a deeper understanding of how the body's repair mechanisms work, and we know better how to apply that understanding to improve outcomes.

This research plan provides a framework to continue that work and to give all individuals, whatever their abilities and disabilities, the chance to live to their full potential.

# Introduction

#### THE NEED FOR REHABILITATION RESEARCH

About 53 million to 57 million Americans—about 1 in 5, or 22.2 percent of adults—have a disability of some kind (<u>Courtney-Long et al., 2015</u>; <u>Brault, 2012</u>). About 33 million Americans have a disability that makes it difficult for them to carry out daily activities, ranging from attending school or work to daily physical care. Approximately 2.2 million people in the United States depend on a wheelchair for day-to-day tasks and mobility; additionally, 6.5 million people use a cane, a walker, or crutches. Cognitive disability is frequently cited as a disability, with 15.2 million Americans estimated to have difficulty with mental or emotional functioning (6 percent). Disabilities associated with sensory abilities are widespread. About 36 million American adults (17 percent) report having some degree of hearing loss; nearly one-half of adults ages 75 years and older have hearing loss. About 3.6 million Americans have visual impairment, and more than 1 million of them are legally blind. Nearly 7.5 million people in the United States have trouble using their voices, and between 6 million and 8 million people in the United States have some form of language impairment.

When setting national health priorities as part of the Healthy People 2020 initiative, the Department of Health and Human Services documented that individuals with disabilities are more likely to experience health disparities (Peacock et al., 2015). They are more likely to experience delays or difficulties in accessing health care, have fewer preventive tests or procedures (e.g., Pap tests or mammograms), spend less time on fitness activities, and have higher rates of tobacco use and obesity than the general population. Although the Agency for Healthcare Research and Quality (AHRQ) found a high rate of improvement in quality indicators for health care in those without disability over a 10-year period, only 20 percent to 35 percent of these quality indicators improved for individuals with activity limitations (AHRQ, 2015).

Disability affects not only those who experience these challenges firsthand but also those who support or care for people with disabilities. Based on a 2015 study, American Association of Retired Persons (AARP) estimates that the United States is home to approximately 43.5 million caregivers (<u>AARP, 2015</u>). Most caregivers are adults age 50 and older. People who provide care can experience emotional stress, poor health, decreased opportunity to work, financial strain, and decreased ability to participate in social or community roles.

The extent of disability in the United States and its widespread public health impact on those with disabilities and their families and communities requires a response aimed at improving function, activity, and participation for these people with disabilities. The primary aims of rehabilitation research at the National Institutes of Health (NIH) are to improve rehabilitation and habilitation approaches for individuals with disabilities and to gain knowledge about the underlying diseases that cause disability. For the purpose of this plan, rehabilitation research includes the study of mechanisms, interventions, and methods that improve, restore, or replace lost, underdeveloped, or deteriorating function for people with disabilities in the context of their environment. Function includes a person's use of body systems, ability to complete activities and participate in society, and satisfaction with their quality of life.

Rehabilitation research faces a number of challenges that have parallels in other areas of medicine. Those who could benefit from the research have limitations in transportation, mobility, finances, and access to information that can interfere with their participation in studies. These factors place significant limitations on researchers' ability to conduct appropriately powered studies. Outcome metrics rely on more subjective self-report and individual clinician measurement that can vary over time. Although evidence-based therapy is urgently needed, conducting a tightly controlled study can be difficult. Finding a well-matched comparison group for the treatment group poses significant challenges. Masking the treatment and control conditions, which is useful to ensure an impartial analysis of the results, can be problematic. Despite incredible progress over the past 20 years, new directions and challenges are apparent and underlie the need for new priorities to drive rehabilitation science.

#### NIH'S INVESTMENT IN REHABILITATION RESEARCH

The Americans with Disabilities Act and the subsequent Public Law 101-613, National Institutes of Health Amendments of 1990, provide for the establishment of the National Center for Medical Rehabilitation Research (NCMRR) in the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), part of NIH. NCMRR's mission is to reduce disability by conducting and supporting research and research training in medical rehabilitation. The establishing legislation requires NIH to develop a comprehensive research plan for rehabilitation that encompasses: (1) current medical rehabilitation research activities conducted or supported by the federal government; (2) opportunities and needs for additional research, and priorities for such research; (3) recommendations for the coordination of such research conducted or supported by NIH and other federal government agencies.

In 1993, NCMRR published its first research plan for rehabilitation, which guides development of and support for rehabilitation research at NIH. The 1993 research plan included a conceptual model of disability that incorporated scientific principles and social values. It used a systems approach to medical rehabilitation, with the individual at the center of the rehabilitation process. It encompassed personal background factors (organic, psychosocial, and environmental factors) and quality of life factors (survival, productivity, and social and work relationships) that influence the course and outcome of rehabilitation for individuals who require services at different points in their lives. Recognizing that rehabilitation research was an emerging science and that the research capacity was still relatively weak compared to other biomedical areas and disciplines, NIH suggested that research initiatives and funding opportunities to advance the science of medical rehabilitation were needed in seven general categories: mobility; behavioral adaptation; whole body system response; technical devices; measurement, assessment, and epidemiology; treatment evaluation; and training of research scientists.

Since NCMRR published the first research plan, significant progress has occurred in the rehabilitation research field. NIH's investment in rehabilitation training programs in multiple rehabilitation-focused disciplines has led to an increase in the number of people entering the field of rehabilitation research. Through NIH investment in research infrastructure networks, the field has gained access to consultation, training, education, and small pilot grant opportunities in fields as diverse as simulation research, neuromodulation, commercialization, analysis of publicly available data, and genomics and other individual markers of rehabilitation intervention and outcome. NIH supported the development of new

mobility devices, rehabilitation techniques and interventions, and studies of the underlying mechanisms that support plasticity and repair.

In 2012, the Director of NIH convened a Blue Ribbon Panel (BRP) on Medical Rehabilitation Research to assess the state of rehabilitation research at NIH and determine how NCMRR and NIH can catalyze and support rehabilitation research across the agency. To meet the growing rehabilitation needs of Americans with physical disabilities, the BRP made several recommendations for the field of rehabilitation research: (1) define rehabilitation research; (2) develop a research plan that includes a trans-NIH strategic plan to tackle rehabilitation problems; (3) increase the clinical and societal relevance of NIH's rehabilitation research by addressing the gaps in translational research and the World Health Organization's International Classification of Functioning, Disability, and Health framework; (4) substantially increase funding for all aspects of translational rehabilitation research; (5) continue to build research capacity; and (6) increase participation of persons with disabilities and public advocates in the development and implementation of all rehabilitation research.

In 2015, NCMRR, the NIH Medical Rehabilitation Coordinating Committee (MRCC), and the National Advisory Board on Medical Rehabilitation Research (NABMRR) initiated an update to the 1993 plan. The new plan, presented here, is built upon progress made over the past 2 decades, especially an increased capacity to take on new research efforts that address remaining and new challenges in the field. To update and inform the 2016 Research Plan on Rehabilitation, the NIH community looked first to the NABMRR to recommend current priority areas, to explore plans of action, and to formulate ways in which NIH could build capacity in the workforce and infrastructure that support rehabilitation research. Following this consultation, the MRCC worked to draft tangible priorities and objectives that are applicable across all of NIH and are consistent with the NIH mission: "to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability." The plan presented below represents an integrated and comprehensive vision from stakeholders across NIH. This plan will coordinate and guide NIH's support for programs to advance the science of rehabilitation medicine across the conditions, diseases, and syndromes that challenge individuals with disabilities, optimizing these individuals' ability to function, to address environmental barriers, and to ensure that personal factors are included in the rehabilitation intervention.

#### **CURRENT MEDICAL REHABILITATION RESEARCH ACTIVITIES AT NIH**

Rehabilitation research has grown rapidly as a result of better understanding of basic biological mechanisms; improved access to data related to rehabilitation care and outcomes; and new technological applications in medical diagnostics, imaging, bioinformatics, regenerative medicine, and assistive technology and mobility devices. Rehabilitation research has always included a wide range of medical disciplines. It now includes even more disciplines, demanding an integrative view of disability and expanding opportunities to enhance abilities, increase participation, and improve human health.

#### **Extramural Research**

In 2015, NIH committed \$514 million in grants and contracts to support extramural rehabilitation research and research training to individuals, institutions, organizations, and small businesses in the United States. The rehabilitation research portfolio at NIH is broad and reflects the NIH mission as well as the specific missions of the various Institutes and Centers (ICs). The portfolio encompasses the full range of biomedical, behavioral, and social sciences research from basic to applied. In addition to research supported by individual ICs, the NIH Common Fund, within the NIH Office of the Director, funds cross-cutting, trans-NIH scientific programs that are high-impact, transformative, and managed against defined milestones. This fund supports programs that align with rehabilitation research goals and allow for a strategic and nimble approach to address key roadblocks in biomedical research and capitalize on emerging opportunities.

#### Intramural Research

Rehabilitation is well-represented in the NIH intramural research portfolio, with researchers both at the NIH Clinical Center and in the intramural programs of the ICs. The portfolio of research within the intramural program ranges from the basic science of neuroplasticity, to outcome monitoring systems for care delivery, to intervention trials in multiple conditions including movement disorders, traumatic brain injury (TBI), pulmonary disease, and stroke. Development and refinement of methodology for use in rehabilitation science is also a key component of the intramural program with exploration of the use of new technologies for capturing physical function, use of neuroimaging to monitor the effects of interventions in the central nervous system, and novel approaches to data related to disability in the workplace.

The collaborative and interdisciplinary nature of the work funded by NIH is clearly demonstrated through the work supported. What follows is a list of recent examples of advances in rehabilitation science which, though not exhaustive, is illustrative of the breadth and depth of the work across the ICs.

#### **Examples of NIH-Supported Research**

Advances in developing brain-computer interface (BCI) systems: About 40 years ago, the National Institute of Neurological Disorders and Stroke (NINDS) pioneered the field of neural prostheses, such as cochlear implants. Today, NINDS, the National Institute of Biomedical Imaging and Bioengineering (NIBIB), the National Institute on Deafness and Other Communication Disorders (NIDCD), and NICHD work together to support this field. BCI systems can restore communication and control to people severely paralyzed or "locked in" by amyotrophic lateral sclerosis, brainstem stroke, cerebral palsy, or other neuromuscular disorders. Other potential applications include providing real-time information about brain states—such as changes in brain activity associated with the onset of a seizure—to therapeutic devices. Advancing BCI systems requires real-time monitoring and decoding of information from multiple brain systems simultaneously. NIH works with investigators to develop implantable sensors, decoding and control algorithms, and robotic interfaces. Investigators are now working to incorporate both transmission and receipt of information at the implant site. In a <u>recent study</u>, researchers found that it is possible to simultaneously gather and decode important information about a user from different brain systems in real time, and to evaluate the impact of concurrent activity in different brain systems on decoding performance (Gupta, et al., 2014). Another team of researchers supported by NIH and the Department of Veterans Affairs (VA) developed technology that detects brain signals and uses them to control assisted devices. This investigational system—called <u>BrainGate2</u>—turns brain signals into useful commands for external devices, such as desktop computers or other communication devices, powered wheelchairs, or prosthetic or robotic limbs; the system components can turn thought into action. Findings from a related study, which is supported by NICHD, NINDS, NIBIB, National Center for Advancing Translational Sciences (NCATS), and NIDCD, indicate that the interface provides repeatable, accurate, point-and-click control of a BCI to an individual for as long as 1,000 days after implantation of this sensor (<u>Simeral et al., 2011</u>).

**Refining prosthetics for individuals with amputation:** NIBIB, NICHD, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and NINDS are working to improve the design, fit, usability, and interface of prosthetic limbs for individuals with amputations. This work includes testing the feasibility of using implantable prosthesis devices made with a variety of materials in animal models to ensure reduction in infection and integration with remaining body systems (Farrell et al., 2014). Other developments are aimed at ensuring that the interfaces and control of prosthetics is intuitive, enhances the feedback from the device to the user, and can respond to changes in the environment. For example, researchers have developed a technology to enhance control of hand and arm prosthetics by using muscle signals that remain in a limb after amputation. Sensors implanted into the residual limb wirelessly transmit intramuscular electrical signals to external electronics that command prostheses to operate in a more natural way, including individual control of fingers. Researchers also are developing a novel sensory feedback system by placing sensors in a prosthetic hand that transmit signals wirelessly to the upper arm, where implanted electronics receive and process the signals, then deliver electrical stimulation to peripheral nerve fibers. This sensory feedback allows the amputee to both control and actually "feel" touch with the prosthetic hand (Pasquina et al., 2015). Finally, advances in powered prosthetic legs are benefiting from robotics research on two-legged autonomous robots, giving the user the ability to provide both the power and intelligence to stably respond to changes in terrain or other adjustments. This approach may improve mobility and quality of life for individuals after amputation and for those who survive stroke or spinal cord injury.

**Developing and implementing retinal prosthetics and training for individuals with low vision and blindness:** The National Eye Institute (NEI), NIBIB, and NICHD collaborate to fund novel retinal prostheses designed to restore vision or improve vision for patients who are blind from retinitis pigmentosa or age-related macular degeneration. In February 2013, the Food and Drug Administration approved the Argus II Retinal Prosthesis System, the first implanted device that allows patients with photoreceptor loss from advanced retinitis pigmentosa to regain ambulatory vision. Argus II, developed by Second Sight over the course of 15 years with support from the Department of Energy, the National Science Foundation (NSF), and NEI, uses miniature spectacle-mounted cameras coupled to electrodes to stimulate visual perception. NEI-supported researchers are developing a standardized rehabilitation curriculum for ultra-low vision, with separate tools to (1) train Argus II wearers to use their implants in daily life, (2) measure the effectiveness of prosthetic vision, and (3) develop instructional materials to allow researchers and rehabilitation specialists to use these tools. The heterogeneity of visual

impairment from low vision to blindness presents unique needs and strategies for rehabilitation. There are different degrees of vision loss, and different diseases cause qualitatively different visual impairment. In addition, vision loss is dynamic, and individuals often integrate other perceptual systems to compensate for lost vision. Thus, more than one rehabilitation strategy is needed for different types of vision loss at different stages. NEI research also is focusing on integrating perceptual learning approaches into effective therapies for individuals with impaired vision, including the use of computer games and virtual reality systems to train individuals to navigate the visual world.

*Aural rehabilitation technologies and strategies:* NIDCD-supported scientists are examining the scientific bases of aural rehabilitation and improving the provision of aural rehabilitation services to individuals with hearing loss. Aural rehabilitation refers to enhancing a person's perception of spoken communication, particularly through the auditory channel. It includes counseling individuals with hearing loss about the nature and effects of their hearing loss and about intervention options, and it involves training on how to use these interventions. Such interventions include hearing aids, cochlear implants, other augmentative and alternative communication devices (such as those that integrate communication information from vision and touch), and auditory training programs. NIDCD-supported scientists also are developing more effective interventions for the speech, voice, and language impairments often associated with stroke, cerebral palsy, autism, Alzheimer's disease, and other neurologic and neurodevelopmental disorders.

*Virtual typing by people with tetraplegia:* Several previous studies have demonstrated that paralyzed individuals can type through a computer using various BCIs. However, these devices are tiresome, burdensome, and unreliable, requiring frequent recalibration. A new study has combined three calibration methods that allow seamless typing and stable control. Using this method, two individuals with tetraplegia were able to compose long texts at their own paces, with no need for recalibration. This research is supported by NIDCD, NICHD, NINDS, the VA, and private groups.

*Electrical stimulation of the spinal cord to restore function:* People with paraplegia were able to move paralyzed muscles using a novel therapy involving electrical stimulation of the spinal cord. The patients flexed their toes, ankles, and knees while the stimulator was active. The movements were enhanced when combined with physical rehabilitation. The team developed its approach with support from NINDS (Angeli et al., 2014). Other research supported by NIBIB, NICHD, and NINDS used noninvasive transcutaneous stimulation and physical training to allow patients with complete motor paralysis to generate step-like movements (Gerasimenko et al., 2015). The patients also experienced improvements in blood pressure control, body temperature regulation, bladder control, and sexual function (Gad et al., 2014). The research leading to these advances is an extension of decades of NINDS investment in basic research on spinal cord injury.

**Exoskeletons.** NIH has broad funding in this area, and the interagency National Robotics Initiative continues to fund new projects. For example, wearable robots, such as powered braces for the lower extremities, can improve mobility for individuals with impaired strength and coordination due to aging, spinal cord injury, cerebral palsy, or stroke. However, methods for determining the optimal design of an assistive device for use within a specific patient population are lacking. NIBIB and NICHD are supporting

a project to create an experimental platform for an assistive ankle robot to be used in patients recovering from stroke. In addition, NIH is funding research to extend assisted physical therapy into the home by providing patients with a lightweight robotic exoskeleton that can be placed on an affected arm and provide the kind of therapeutic guidance found at a rehabilitation center (NIH RePort).

**Exploring strategies and therapeutic interventions for knee injuries:** A study of 900 people who had a torn anterior cruciate ligament (ACL) repaired surgically found that within 6 years of the surgery, 19 percent of patients underwent at least one additional operation on the knee that had been repaired, and 10 percent needed surgery on the other knee (Hettrich et al., 2013). NIAMS-funded investigators found that stitching a bioengineered sponge between the torn ends of an injured ACL allows blood to clot and collect around the damaged ligament, encouraging ACL healing. Animal studies showed that the bioengineered sponge healed ACL injuries as well as standard reconstruction surgery and was much less likely to lead to arthritis. In 2014, FDA approved safety testing of the sponge in 10 people with ACL injuries (Murray et al., 2013).

A multisite clinical trial of 351 participants indicates that many people with knee osteoarthritis and a meniscal tear may be able to avoid surgery and achieve comparable relief from physical therapy. After 6 months, people who were randomized to the physical therapy arm of the study and those who were randomized to the surgical arm experienced similar and substantial improvement in function and pain levels. However, 30 percent of patients assigned to physical therapy alone elected to undergo surgery within 6 months of enrolling in the study because their symptoms were not improving or were worsening. The people who remained in the physical therapy group through the end of the 12-month period continued to show improvements that were equivalent to the improvements in those who had surgery (Katz et al., 2013; Buchbinder, 2013).

Interventions for urinary and fecal incontinence and sexual disorders: The NIH Office of Research on Women's Health and NICHD have partnered to improve the clinical approach to rehabilitation for women with pelvic floor disorders, including the use of sacral neuromodulation as a treatment, through the Pelvic Floor Disorders Network. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) established the Symptoms of Lower Urinary Tract Dysfunction Research Network to improve the measurement of patient experiences with lower urinary tract symptoms, including incontinence. Valid measurements are critical for clinical trial design. A trial to compare different surgical procedures for stress incontinence in women was co-funded by NIDDK and NICHD. After 1 year and 5 years of follow-up, women in both arms of the trial had high satisfaction with their surgery (Richter et al., 2010; Kenton et al., 2015). A collaboration among NIDDK, the National Center for Complementary and Integrative Health (NCCIH), and the Office of Dietary Supplements, the Complementary and Alternative Medicine for Urinary Symptoms study tested whether a commonly used phytotherapy could relieve symptoms of lower urinary tract obstruction in men. The randomized, double-blind controlled trial found that saw palmetto extract was no more effective than placebo in reducing lower urinary tract symptoms (Barry et al., 2011). Fecal incontinence affects 8 percent to 15 percent of the population. A pilot study in NIDDK will test whether translumbar and transsacral magnetic stimulation will significantly improve fecal incontinence by enhancing anal muscle strength and improving stool perception.

Understanding the population of individuals with disabilities who receive rehabilitation services: Institutes including NICHD, the National Institute on Aging (NIA), and others invest in studies to better understand the population of individuals who have disability, the rehabilitation services they receive, and the outcomes of their care. The National Health and Aging Trends Study is designed to produce a nationally representative, longitudinal dataset appropriate for studying disability dynamics at older ages. The design incorporates both an overweighting of the oldest-old population (those who live beyond their life expectancy) and annual data collection. This allows investigators to track trends in disability over time rather than just prevalence, as in most national studies. In addition, NICHD funds the <u>Center for Large Data Research and Data Sharing in Rehabilitation</u> (formerly the Center for Large Data in Rehabilitation), which builds rehabilitation research capacity by increasing the quantity and quality of rehabilitation outcomes research using large administrative and research datasets. The Center also aims to enhance data sharing through the archiving of information from completed rehabilitation research studies. One of its recent studies examined rehabilitation readmission rates for patients with the six most common issues requiring rehabilitation care and included the reasons for readmission, geographic variations, and facility types.

*Investigating how weight-bearing exercise can help individuals with diabetes and peripheral neuropathy:* Diabetes affects more than 20 million people in the United States. Many who have diabetes also suffer from peripheral neuropathy, a condition caused by nerve damage. Peripheral neuropathy can cause weakness, numbness, and pain in the body, especially in the hands and feet, and people with the condition have a high risk of reduced mobility. <u>NIH-funded research</u> found that patients with diabetes and peripheral neuropathy who participated in weight-bearing exercise increased both the distance they could cover in a 6-minute test and their average daily steps. Those who participated in non-weight-bearing exercise showed improvement in their blood sugar control (<u>Mueller et al., 2013</u>). Other studies in NIDDK's portfolio assessing the role of exercise in nerve regeneration in people with diabetes and pre-diabetes found that exercise could increase skin nerve density, which is a measure of neuropathy (Singleton et al., 2014).

Addressing pain for individuals with disabilities: NIH continues to fund studies of non-pharmacologic methods of treating pain and of the mechanisms that underlie the effectiveness of these methods. For example, in a study examining the effect of acupuncture combined with traditional opioid management of acute pain following a surgical procedure for knee or hip replacement, acupuncture resulted in a significant reduction in the severity of pain compared with those who received only opioids. Other aspects of pain management, such as behavioral or learning factors related to pain, other non-pharmacologic approaches to pain management, and the neural signatures of pain and their relationship to patient self-report remain a high priority for NINDS, NCCIH, and other ICs.

*Improving self-management strategies and caregiver interactions:* Enabling optimal function, supporting self-management of chronic disease, and addressing the needs of caregivers is a focus of a number of ICs, including the National Institute of Nursing Research, NIA, and NCMRR. NIH supports work focused on how to optimize physical activity in older adults following traumatic injury with a specific focus on patient-level and environmental challenges. In addition to optimizing general activity, researchers have examined the patient- and facility-level characteristics of those who had better motor

function and higher rates of change in motor function from admission to discharge after receiving treatment for hip fractures. Finally, work to support caregivers includes development of a conceptual model of health-related quality of life in caregivers of individuals with TBI and in qualitative analysis of quality of life for these caregivers.

### **Opportunities, Needs, and Priorities**

As described above, NIH advances scientific knowledge about disabilities and rehabilitation while also providing vital support and focus for the field of medical rehabilitation. This work is routinely coordinated within NIH, and programs collaborate closely to ensure that NIH supports rehabilitation science in all areas that affect public health. The goals and objectives of the ICs that support medical rehabilitation were formulated by the MRCC, which includes representatives from the 17 ICs that fund rehabilitation research. These ICs have their own individual strategic plans and research agendas, which are aligned with legislative mandates related to specific diseases or body systems. The NIH Research Plan on Rehabilitation dovetails with the plans and agendas of the ICs. The coordination and collaboration between the ICs will enhance NIH's overarching work to promote innovative and integral science in medical rehabilitation. NIH will accomplish this coordination and collaboration not only through the extramural funding awarded to universities, academic health centers, small businesses, and other research institutions to support research and research training, but also through the intramural laboratories and Clinical Center on NIH's main campus in Bethesda, Maryland.

The following sections list the research areas as six primary goals (A to F).

Although a request was made during the period of public comment to include specific goals for individual conditions or populations of individuals with specific challenges, it is outside the scope of the current plan to address these individually. Due to the breadth of the conditions, diseases, and approaches addressed by participating NIH ICs, each of the ICs will support rehabilitation research in their respective mission areas.

#### A: REHABILITATION ACROSS THE LIFESPAN

The NIH rehabilitation research portfolio reflects the essential need for rehabilitation research for people with disabilities at all points during the lifespan. Models of rehabilitation may require different approaches, implementation strategies, or considerations given the developmental stage of the individual receiving the services, the extent of disability and comorbidities, and the social context and environmental challenges the individual faces. The individuals who benefit represent different racial and ethnic populations, socioeconomic levels, and gender identities, and live in diverse communities with different levels of access to rehabilitation services. The goal of rehabilitation is to optimize function and promote health and wellness through participant-engaged, data-driven, individualized care. The first research priority is to address the critical understudied issues in rehabilitation.

#### **Objectives**

- 1. Increase the quality of evidence for rehabilitation interventions in populations of people with disabilities across the lifespan (pediatrics, adult, and geriatrics) through increased focus on the design, dose, intensity, timing, mechanisms, and specified targets and outcomes of these interventions.
- 2. Through basic, translational, and clinical research, determine the methods by which lifestyle and wellness interventions can promote health and prevent and treat comorbidities in individuals with disabilities.
- 3. Address symptoms and secondary conditions associated with disability through the development, adaptation, or evaluation of interventions (e.g., pain, cognitive impairment, depression). Determine methods to address symptom burden and improve health-related quality of life.
- 4. Investigate the nature of health disparities and their impact on the implementation and effectiveness of rehabilitation interventions.
- 5. Identify and test care delivery models during periods of lifespan transitions (e.g., from home to school, from childhood to adolescence, from adolescence to adulthood, from adulthood to late life) that enable the highest level of benefit from health interventions.
- 6. Through longitudinal and population-based cohort studies, determine the natural history of conditions that cause disability and common secondary conditions that develop over time.

Examples of actions that will help meet these objectives include the following:

- Understand the impact of development, maturation, or decline of biological systems on disease course and rehabilitation interventions.
- Determine mechanisms by which rehabilitation affects recovery and repair at the molecular, cellular, organ, and system levels during critical time periods.
- Develop prognostic risk factors or biomarkers that aid in treatment selection for individuals with temporary or chronic disability.
- Evaluate the impact of age, sex, race/ethnicity, and other sociodemographic factors on the implementation and effectiveness of rehabilitation interventions.
- Address the gaps in knowledge particular to pediatric rehabilitation, including the effects of maturation and the impact of early intervention.
- Link studies of adaptive physical activity and exercise to functional outcomes in physical, emotional, social, community participation, and cognitive domains.
- Determine the impact of modifiable lifestyle and health behaviors (e.g., nutrition, physical activity, sleep) on rehabilitation outcomes of interest, prevention of secondary conditions, psychosocial functioning, and community participation.
- Leverage existing large data repositories and publicly available large datasets to examine the course of a disabling condition as well as its relationship to health care delivery and outcomes for individuals over the life course.
- Examine the effects of interventions at early life stages on later life outcomes through studies that include health economics.

#### **B: COMMUNITY AND FAMILY**

Each person with a disability lives within the context of a community that may include a family, a social group, or other supports. The interplay of individuals and their contexts is a key priority area for NIH. As the population ages, the degree of disability in the community will increase, as will the need for rehabilitation services to maintain function, rehabilitate chronic conditions that limit activity, and support caregivers and families who provide formal and informal assistance to individuals with disabilities.

#### **Objectives**

- 1. Develop self-management strategies that can be implemented in community settings to promote quality of life by helping individuals better understand and manage disabilities and achieve and maintain independence.
- 2. Examine the stressors, challenges, and benefits experienced by caregivers of individuals with disabilities, and examine the impact of these on the health of the caregiver and the care recipient.
- 3. Develop and test interventions that address stress and burden, and that maximize benefits and resilience in caregivers.
- 4. Examine the impact of sociodemographic influences on the outcomes of rehabilitation interventions.
- 5. Determine the ways in which individuals with disabilities can partner with caregivers and care providers as active members of the rehabilitation team, either in promotion of adherence and assistance with in-facility or home-based care or in setting treatment goals to optimize outcomes.

Examples of actions that will help meet these objectives include the following:

- Support collaborations between the person with disability, the caregiver, and the rehabilitation team.
- Examine community-based interventions for caregiver, family, and community support.
- Develop self-management interventions to improve long-term management of chronic conditions.

#### **C: TECHNOLOGY USE AND DEVELOPMENT**

Technology has played a significant role in research and clinical applications in rehabilitation science in the form of diagnostics, treatment devices, assistive devices and technology, orthotics, prosthetics, and other rehabilitation technologies geared to treatment delivery or self-management. Computational science has also played a significant role, providing advanced algorithms for device control, increased use of modeling and simulation, and approaches to analyzing big data. To best harness technology in the laboratory and treatment settings, NIH must promote interdisciplinary collaboration within the health disciplines and with colleagues in computer science, math, statistics, and engineering, and with the end-users of the technology.

#### **Objectives**

- 1. Advance the use of telehealth in rehabilitation assessment, delivery, and adherence monitoring.
- 2. Advance the use of assistive technologies (AT), noninvasive sensors, and mobile health (mHealth) approaches in rehabilitation science.
- 3. Provide an evidence base for device development, manufacturing, and implementation for individuals with disabilities, including methods to incorporate needs and preferences of users.
- 4. Support research to better define new and innovative metrics and outcomes of interest in the use of various technologies in rehabilitation.
- 5. Encourage the use of computational models for designing and developing new rehabilitation technologies and for evaluating their functional outcomes.
- 6. Support technology development that incorporates monitoring and remote access in the acquisition, analysis, and monitoring of data from individuals who are receiving care or continued support in their homes.

Examples of actions that will help meet these objectives include the following:

- Explore the potential of remote treatment delivery and monitoring for improving access to services, reducing health disparities, and improving short- and long-term outcomes for individuals with disabilities.
- Develop and test tools and new technologies to assist in the assessment, care, treatment, and monitoring of individuals with disabilities while incorporating appropriate measures for ensuring security and privacy.
- Examine telehealth and AT solutions to promote functioning and independence of individuals with disabilities.
- Enhance the effective use of AT or sensors in detecting secondary complications, monitoring adherence to rehabilitation therapies, providing outcome data, and developing other applications pertinent to rehabilitation medicine.
- Integrate AT, mHealth, and sensor-based approaches into monitoring and self-management of chronic conditions and determine best practices in providing information to providers and alert systems.
- Support the development and evolution of both invasive and noninvasive systems that assist individuals with disabilities, including hardware and software.
- Improve control mechanisms for devices and encourage intuitive design systems that respond to the changing needs and preferences of the user and to the user's environment.
- Examine the safety, effectiveness, and utility of noncommercial (e.g., nonprofit, open source) devices for individuals with disabilities.
- Support low-cost technology solutions to provide a broader reach to the user community.
- Integrate understanding and measurement of the human-technology interface. Evaluate whether a technology works as intended and meets the needs of the users for whom it is intended.
- Incorporate developmental and aging considerations into device or AT development to allow for flexibility of application.

#### **D: RESEARCH DESIGN AND METHODOLOGY**

Evidence-based approaches are essential for individuals with disabilities, and the results of recently completed large efficacy trials of rehabilitation approaches have demonstrated the need for new methods, strategies, and approaches to address challenges such as generating consistent clinical data from heterogeneous conditions. Emphasis must be placed on data sharing and knowledge translation. Finally, transdisciplinary research must be encouraged.

#### **Objectives**

- 1. Expand the evidence base for specific treatment interventions and approaches with an emphasis on validated protocols associated with improved outcomes for conditions that cut across populations of individuals with disabilities (e.g., spasticity, bowel and bladder control, sexual function, gait disturbance).
- 2. Conduct both efficacy and effectiveness trials, including not only randomized clinical trials, but also adaptive and pragmatic trials and trials using other innovative designs.
- 3. Examine the use of existing databases and registries as mechanisms for discovery.
- 4. Encourage clinical translational research and dissemination and implementation research to enhance reach and application of evidence-based approaches.
- 5. Improve characterization of environmental barriers and biological comorbidities that might impede rehabilitation adherence or efficacy of a rehabilitation intervention.
- 6. Identify and test models of rehabilitation that increase participation by older adults, women, ethnic minorities, and people of low socioeconomic status.
- 7. Identify, measure, and compare the costs and consequences of rehabilitation assessment, delivery, and monitoring approaches, interventions, devices, and technologies using health economics methods, including cost analysis, economic evaluation, decision and transmission modeling, and regulatory impact analysis.

Examples of actions that will help meet these objectives include the following:

- Develop and support the use of common metrics and standards to enable cross-validation or aggregation of studies and to identify gaps in measurement (e.g., quality metrics, measures of patient preference, specific functional impairments).
- Support FAIR (findable, accessible, interoperable, reusable) data standards and appropriate data-sharing efforts to enable aggregation of data and secondary analyses.

#### **E: TRANSLATIONAL SCIENCE**

NIH sponsors multiple programs to advance understanding of the fundamental biological, physiological, and behavioral mechanisms that underlie disease. For the purpose of rehabilitation research, this understanding would encompass genomic and other cell-based, process-level contributions to plasticity and adaptation; body system-level responses to injury; and methods by which people adapt to and accommodate for injury or illness at the cell, tissue, and system levels. Basic understanding of the effects of interventions, both in animal models and in humans, is also needed. Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in

genes, environment, and lifestyle. Although researchers have made some advances in precision medicine, the practice is not in use for most diseases or conditions, nor has it been widely applied for use in rehabilitation medicine.

#### **Objectives**

- Integrate cell-, tissue-, and model organism-based research to identify the principal physiological mechanisms and key interventional targets in the adaptive and maladaptive changes associated with disabling conditions.
- 2. Encourage approaches that exploit the biological and physiological adaptations associated with rehabilitation strategies in the clinical setting.
- 3. Advance the understanding of precision medicine approaches relevant to rehabilitation medicine.
- 4. Characterize biomarkers associated with specific injuries, illnesses, or disorders that are prognostic or guide prescription of rehabilitation interventions.
- 5. Determine the effectiveness of integrative, multimodal interventions that focus on defining the optimal combination and "dosing" of individual interventions to improve and possibly accelerate recovery following injury or disease.

Examples of actions that will help meet these objectives include the following:

- Identify the biological basis and intervention points of secondary processes that impede functional recovery at the cellular and tissue levels in chronic conditions.
- Expand research on mechanisms of action underlying rehabilitation interventions and integrate preclinical and modeling research to inform rehabilitation practice and trial design.
- Increase the use of regenerative rehabilitation techniques and therapies to optimize the functional outcomes of individuals with disabilities.
- Develop valid measures of functional change that expand understanding of the physiological actions of clinically driven therapies.
- Facilitate synergistic basic and clinical patient-oriented rehabilitation research by creating and supporting reverse translational, hypothesis-generating/testing human neuroscience research opportunities.
- Examine the underpinnings of plasticity, adaptation, and response to illness or injury or to rehabilitation intervention (e.g., biomarkers, -omics).

#### F: BUILDING RESEARCH CAPACITY AND INFRASTRUCTURE

The capacity of the rehabilitation research field is exponentially greater than it was when NCMRR was established in 1993. NIH has provided steadfast support to the rehabilitation science community, creating a research infrastructure network to provide training, consultation, and collaboration; funding training programs targeted to the development of basic scientists, physician scientists, allied health professionals, and engineers who focus on biomedical devices or rehabilitation; and providing courses at regional, national, and international conferences. As noted in the report from the 2005 Rehabilitation Medicine Summit on building research capacity (Frontera et al., 2005), capacity includes:

(1) researchers; (2) research culture, environment, and infrastructure; (3) funding; (4) partnerships; and (5) metrics. NIH is active in all five of these areas and will continue to find novel and innovative ways to build capacity for rehabilitation science.

#### **Objectives**

- Increase the use of and coordination among the centers that make up the <u>Medical</u> <u>Rehabilitation Research Infrastructure Network</u>.
- 2. Enhance the rehabilitation research community's use of and contribution to training programs, including predoctoral, postdoctoral, and continuing education for researchers with unique training needs or partnerships.
- 3. Review the current model for training in rehabilitation research and develop a strategy to increase the availability of training and partnerships between programs to provide it.
- 4. Evaluate the availability of funding opportunity announcements both from extramural sources and from the NIH Common Fund that include disability or rehabilitation targets, and determine gap areas or areas for enhancement that could spur cooperative funding strategies.
- 5. Identify methods to encourage knowledge translation to promote clinical competence based on evidence-informed treatment.
- 6. Promote interdisciplinary collaboration in rehabilitation research. Develop metrics that can be used to evaluate and encourage interdisciplinary science and that accurately reflect the contributions of scientists who work to drive rehabilitation research.
- 7. Provide a strategy for recruiting individuals with disabilities into the field of rehabilitation research; consider enhanced diversity supplements and partnerships with other federal agencies (e.g., National Science Foundation; National Institute on Disability, Independent Living, and Rehabilitation Research).

# **Coordination with Other Federal Agencies**

NIH recognizes that it is not the only federal agency invested in developing and funding research that addresses disability and rehabilitation and that supports training in the field. Through regular interactions with federal partners both at the NABMRR, where NIH's partners serve as ex officio members, and at the Interagency Committee on Disability Research, where NIH serves as an executive member, NIH is active in coordination and collaboration throughout the federal government. These interactions serve not only to help synergize efforts, but also to spur unique collaborations and opportunities for the rehabilitation research community as a whole. Although the following section includes several departments and agencies that are close partners in rehabilitation research, it does not fully encompass all of the federal entities with which NIH collaborates.

#### **DEPARTMENT OF DEFENSE (DOD)**

#### Joint Program Committee-8/Clinical and Rehabilitative Medicine Research Program (JPC-8/CDMRP)

JPC-8/CRMRP focuses on definitive and rehabilitative care innovations required to "reset" wounded warriors, in terms of both duty performance and quality of life. The program has multiple initiatives to achieve its goals, which include improving prosthetic function, enhancing self-regenerative capacity, improving limb and organ transplant success, creating full-functioning limbs and organs, repairing damaged eyes, treating visual dysfunction following injury, improving pain management, and enhancing rehabilitative care.

NIH's work with DoD includes serving on the JPC not only for the CDMRP, but also for programs in Military Operational Medicine and Combat Casualty Trauma; assisting with Capability-Based Assessments conducted by the Defense Health Agency to guide the DoD's research agenda and priorities; participating in joint program reviews and analysis of the DoD's rehabilitation medicine and TBI portfolios; and working with the U.S. Army Medical Materiel Development Agency on projects related to developing and commercializing pharmaceuticals and devices that benefit individuals with disabilities. There are multiple examples of collaboration. NIH joins VA and DoD in the Spinal Cord Injury Research Program vision-setting meeting, which works to ensure that the agencies' respective portfolios are aligned with their missions and to reduce funding overlap. There is also a cooperative agreement between NIH and the DoD to support regenerative medicine approaches to limp, craniofacial, burn, scarless wound, and genitourinary repair through the Armed Forces Institute of Regenerative Medicine.

#### Defense Advanced Research Projects Agency (DARPA)

NIH works closely with DARPA's Biological Technologies Office, especially through the following programs: Revolutionizing Prosthetics, Reliable Neural-Interface Technology (RE-NET); Hand Proprioception and Touch Interfaces (HAPTIX); Electrical Prescriptions (ElectRx); Neural Engineering System Design (NESD); Restoring Active Memory (RAM); Microphysiological Systems (MPS), and Warrior Web. The research areas cover several disciplines and seek to develop technologies and to enhance understanding of biological processes associated with quality of life and human performance, disease, and healing.

#### **DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)**

#### Agency for Healthcare Research and Quality (AHRQ)

AHRQ is a health services research agency within HHS that invests in reviewing evidence and research to understand how to make the health care system safer and to improve quality. AHRQ generates measures and data used to track and improve performance and evaluate progress of the U.S. health system. Its mission is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable and to work within HHS and with other partners to make sure that the evidence is understood and used. AHRQ also has a congressional mandate to conduct health research and disseminate research findings for persons with disabilities, who are included in the agency's focus on priority populations. AHRQ is a valued partner for NIH, especially for the provision of quality data

indicators, research reports and systematic reviews of available research in particular areas of health, and technology assessment.

#### Centers for Disease Control and Prevention (CDC)

CDC works to protect the United States from health, safety, and security threats, both foreign and domestic. CDC works with communities and citizens to counter diseases that are chronic or acute, are curable or preventable, and result from human error or deliberate attack. NIH routinely works with CDC to coordinate efforts related to health, disability, and injury prevention, especially efforts related to epidemiology of specific diseases and coordination of common data elements to improve reporting. NIH and CDC partner on initiatives related to TBI, including the development of CDC's pilot surveillance system for youth concussion, reports to Congress, and initiatives focusing on the standardization of data elements related to TBI. NIH and CDC also work closely to achieve the goals set out in the priorities related to the Disability and Health area of the Healthy People 2020 initiative to maximize inclusion and participation to improve health-related quality of life and well-being through initiatives such as implementation and tracking of the Patient Reported Outcomes Measurement Information System (PROMIS).

#### Food and Drug Administration (FDA)

NIH works in close partnership with the FDA to enable efficient and effective exchanges of information related to drugs and devices that apply to rehabilitation research. The Medical Devices Working Group, which includes, FDA, NIH, and other federal partners meet quarterly to discuss programs, initiatives, and partnerships that aid the development of medical devices, including rehabilitation devices and AT. NINDS established a Memorandum of Understanding (MOU) and a regularly meeting working group with the FDA Center for Devices and Radiological Health (CDRH). The MOU allows exchange of information and discussion of issues of common interest to the CDRH and NINDS missions, which includes devices that are relevant to paralyzed individuals. This MOU complements a longstanding MOU and working group between NINDS and the FDA Center for Biologics Evaluation and Research (CBER), which has been continuously active for more than a decade and has discussed issues of interest to paralyzed individuals in the realm of stem cells, gene therapy, and other biologics. DARPA, NIH, VA, and DoD have worked collaboratively to pilot the Innovation Pathway Initiative, a program that gives priority review to breakthrough medical devices. This program worked closely with all the agencies to conduct a pilot review of a direct brain-control upper extremity prosthetic, the DARPA Arm.

#### National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

Newly located within the Administration for Community Living, NIDILRR is a federal government agency that sponsors grantees to generate new disability and rehabilitation knowledge and promote its use and adoption. NIDILRR encompasses a broad range of investigator-initiated research, centers, model systems, and training programs, including the Disability and Rehabilitation Research Projects program, Rehabilitation Research and Training Centers program, Rehabilitation Engineering Research Centers program, Mary E. Switzer Fellowships program, Field-Initiated Projects program, and Small Business Innovation Research program.

NIH's coordination with NIDILRR is focused in three primary areas: (1) representation on and work with the Interagency Committee on Disability Research, chaired by NIDILRR; (2) collaboration with NIDILRR's model systems programs to develop and implement common data elements, sharing data from these systems with NIH researchers, and using the infrastructure sustained by NIDILRR to encourage intervention and treatment studies; and (3) service as reviewers for NIDILRR's programmatic review panels.

#### **NATIONAL SCIENCE FOUNDATION (NSF)**

NSF and NIH have enjoyed a fruitful partnership through a variety of collaborative funding opportunities. NIH's ability to work with a network of researchers with specialization in engineering, computer science, data science, computational neuroscience, and a host of other skills has augmented the strategies that NIH scientists use to address disability and rehabilitation. For example, the <u>National Robotics Initiative</u> (<u>NRI</u>) promotes co-robots for a variety of applications, including rehabilitation. The NIH component of the NRI is especially interested in promoting assistive medical robotics for home care and long-term personalized care; robotic wellness/health promotion and maintenance; robotic behavioral therapy; robotic aids for mobility, manipulation, communication, and cognition and for vision for non-sighted persons; and assistive robotics to eliminate health disparities across populations. Other programs through which NIH partners with NSF include the Cyber-Physical Systems program, the Collaborative Research in Computational Neurosciences program, and the Smart and Connected Health program.

#### **DEPARTMENT OF VETERANS AFFAIRS (VA)**

The VA Rehabilitation Research & Development Service (RR&D) supports preclinical, clinical, and applied rehabilitation research with strong implications for clinical translation to Veterans. Study areas supported by RR&D include injuries, disorders, and diseases with potential to cause long-term impairment or disability; rehabilitation interventions, techniques, and devices designed to maximize motor, sensory, and psychological recovery; and endpoints that include functional outcomes. Portfolio areas include Spinal Cord Injury and Neuropathic Pain, Regenerative Medicine, Traumatic Brain Injury and Stroke, Musculoskeletal/Orthopedic Rehabilitation, Sensory Systems/Communication Disorders, Psychological Health and Social Reintegration, Rehabilitation Engineering and Prosthetics/Orthotics, and Aging and Neurodegenerative Disease.

Recognizing that VA RR&D is an intramural program focused on research and its benefits to the veteran population, NIH contributes to VA strategic planning, programmatic review, and areas of research of mutual interest. NIH and VA have partnered to develop specific technologies in parallel that benefit not only Veterans but the public at large, including advanced prosthetic devices and control systems; BCI technologies; tissue regeneration; retinal prosthetics; wheelchairs and mobility devices; and a variety of specific rehabilitation techniques and approaches for spasticity, contractures, pain, and a host of other conditions.

# Conclusion

Millions of Americans have a disability—some so severe that they cannot work or live independently. As the population ages, the degree of disability in the community will increase, as will the need for rehabilitation services.

This rehabilitation research plan outlines how federal dollars have helped optimize the functioning of disabled individuals and helped promote their health and wellness. NIH has used these dollars to train rehabilitation researchers, support the development of new rehabilitation techniques and interventions, establish research networks, enable data sharing, and develop new assistive technologies and mobility devices to help individuals regain function. These funds have also led to better understanding of the basic biology of disabilities and better understanding of how to use large amounts of data to evaluate rehabilitation outcomes.

Although much has already been accomplished, there is much more to do. The medical rehabilitation field spans many types of disability and involves professionals from an array of disciplines. Seventeen NIH ICs actively support rehabilitation research. NCMRR coordinates these efforts across NIH and with other federal agencies. This coordination prevents duplication of efforts, provides for efficient leveraging of federal resources, and allows findings to be more quickly shared and built upon.

This plan builds on past accomplishments and lays out future priorities in medical rehabilitation research. The plan, which will guide NIH support for rehabilitation medicine for the next 5 years, was constructed with extensive input from all stakeholders, including those with disabilities and their advocates. Engaging individuals with disabilities in the research process will continue to be a priority.

The plan notes that technological advances must continue to be harnessed so that individuals with disabilities can be as healthy and live as independently as possible. This includes the use of telehealth, mobile health, smart home, prosthetics, and other technologies.

Evidence-based approaches are essential for rehabilitation research. Some recently completed large efficacy trials of rehabilitation approaches have demonstrated the need for new methods to generate standardized clinical data from heterogeneous conditions. There will be continued emphasis on data standardization, knowledge sharing, and transdisciplinary research.

The plan calls for the continuation of programs to understand the basic biological, physiological, and behavioral mechanisms that underlie disability.

Precision medicine is an emerging approach for disease treatment and prevention and will be encouraged as an approach to rehabilitation medicine. Health disparities that exist among different populations will also be considered. NIH will continue to build research capacity and infrastructure by increasing coordination among the centers that make up the Medical Rehabilitation Research Infrastructure Network, developing metrics that can be used to evaluate and encourage interdisciplinary science, and providing a strategy for recruiting individuals with disabilities into the field of rehabilitation research.

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# **Appendix B: Participating Institutes and Centers**

#### **NIH INSTITUTES**

National Cancer Institute (NCI) National Eye Institute (NEI) National Heart, Lung, and Blood Institute (NHLBI) National Institute on Aging (NIA) National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) National Institute of Biomedical Imaging and Bioengineering (NIBIB) *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) National Institute on Deafness and Other Communication Disorders (NIDCD) National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) National Institute of Mental Health (NIMH) National Institute of Neurological Disorders and Stroke (NINDS) National Institute of Nursing Research (NINR)

#### **NIH CENTERS**

NIH Clinical Center (CC) Center for Scientific Review (CSR) National Center for Advancing Translational Sciences (NCATS) National Center for Complementary and Integrative Health (NCCIH) Office of the Director, Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) Office of Behavioral and Social Sciences Research (OBSSR) Office of Disease Prevention (ODP) Office of Dietary Supplements (ODS) Office of Research on Women's Health (ORWH)