

# National Institutes of Health Research Plan on Rehabilitation

## National Institutes of Health Medical Rehabilitation Coordinating Committee

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One in 5 Americans experiences disability that affects their daily function because of impairments in mobility, impairments in cognitive function, sensory impairment, or communication impairment. The need for rehabilitation strategies to optimize function and reduce disability is a clear priority for research to address this public health challenge. The National Institutes of Health (NIH) recently published a Research Plan on Rehabilitation that provides a set of priorities to guide the field over the next 5 years (Eunice Kennedy Shriver National Institute of Child Health and Human Development [NICHD] & NIH Medical Rehabilitation Coordinating Committee [MRCC], 2016). The plan was developed with input from multiple institutes and centers within the NIH, the National Advisory Board for Medical Rehabilitation Research (NABMRR), and the public. This article provides an overview of the need for this research plan, an outline of its development, and a listing of six priority areas for research. NIH is committed to working with all stakeholder communities engaged in rehabilitation research to track progress made on these priorities and to work to advance the science of medical rehabilitation.

Between 53 and 57 million Americans—about 1 in 5—have a disability of some kind (Brault, 2012; Courtney-Long et al., 2015). Thirty-three million of these 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. The range of disabilities, whether in mobility, cognition, sensory impairment, or communication, represents a significant public health challenge. In addition, disability also affects those who support or care for people with

disabilities. Based on a 2015 study, the AARP Public Policy Institute and the National Alliance for Caregiving (2015) estimates that the United States is home to approximately 43.5 million caregivers. Clearly, given the percentage of the population affected by these challenges, identifying effective means to promote optimal function and reduce disability is a priority for research.

The extent of disability in the United States and its widespread public health impact requires a response aimed at improving function, activity, and participation for people with disabilities and their families. NIH initiated this response in 1990, after the passage of a law that created the National Center for Medical Rehabilitation Research (NCMRR). The Center published a rehabilitation research plan in 1993 that guided the development of this scientific field in its nascent stages (NICHD, NIH, & U.S. Department of Health and Human Services, 1993). Since the publication of that document, NIH has invested in building capacity in the field through the funding of research grants and infrastructure networks in rehabilitation, training new scientists, and supporting small businesses developing solutions.

In 2012, the director of NIH convened a Blue Ribbon Panel 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 entire agency. One of the panel's recommendations was to "develop a research plan that includes a trans-NIH strategic plan to tackle rehabilitation problems" (NICHD & NIH MRCC, 2016, p. 8). In 2015, NCMRR, the NIH MRCC, and NABMRR initiated an update to the 1993 plan. The new plan, presented here, is built upon progress made over the past two decades, especially an increased capacity to embark on new research efforts that address remaining and new challenges in the field.

The primary aims of rehabilitation research at NIH are to improve rehabilitation and habilitation outcomes 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 quality of life. Despite incredible progress in rehabilitation research over the past 20 years, new directions and challenges are apparent and underlie the need for new priorities to drive rehabilitation science.

The plan presented below represents an integrated and comprehensive vision from stakeholders across NIH. Because of the breadth of the conditions, diseases, and approaches addressed by participating NIH institutes and centers (ICs), each of the ICs supports rehabilitation research in its respective mission areas. 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. What follows are the six priority research areas that NIH will support as goals for development in the rehabilitation research arena. The full plan is available online and contains more detail about the development of the plan, the rationale behind the priority areas, and examples of research relevant to the priority areas (NICHD & NIH MRCC, 2016).

## A. Rehabilitation Across the Lifespan

1. Increase the quality of evidence for rehabilitation interventions in populations of people with disabilities across the lifespan (pediatric, adult, and geriatric) 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 transition (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 the life course.

## B. Community and Family

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 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 adherence and assistance with in-facility or home-based care or in setting treatment goals to optimize outcomes.

## C. Technology Use and Development

1. Advance the use of telehealth in rehabilitation assessment, delivery, and adherence monitoring.
2. Advance the use of assistive technologies, 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.

## D. Research Design and Methodology

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.

## E. Translational Science

1. 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 after injury or disease.

## F. Building Research Capacity and Infrastructure

1. Increase the use of and coordination among the centers that make up the Medical Rehabilitation Research Network (NICHD, 2015).
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).

## Discussion

NIH works to advance science to optimize functioning, reduce disability, and promote health and wellness. NIH invests in the training of rehabilitation researchers, supports the development of new rehabilitation techniques and interventions, establishes research networks, enables data sharing, and develops new assistive technologies and mobility devices to help individuals regain function. NIH funds have also led to better understanding of the basic biology of disabilities and contributed to the funding of studies to evaluate rehabilitation outcomes.

Although a great deal has already been accomplished, there is 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 provides for efficient leveraging of federal resources and allows findings to be more quickly shared and used.

The plan presented here builds on past accomplishments and establishes priorities in medical rehabilitation research for the next 5 yr. Engaging individuals with

disabilities in the research process will continue to be a priority. NIH looks forward to working with all the stakeholder communities involved in rehabilitation research to track progress on these newly established priorities and advance the science of rehabilitation in partnership with them. ▲

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