

## SPECIAL COMMUNICATION

# National Institutes of Health Research Plan on Rehabilitation



## NIH Medical Rehabilitation Coordinating Committee

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### Abstract

One in five Americans experiences disability that affects their daily function because of impairments in mobility, 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. The plan was developed with input from multiple Institutes and Centers within the NIH, the National Advisory Board for Medical Rehabilitation Research, 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. The 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.

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Between 53 and 57 million Americans—about 1 in 5—have a disability of some kind.<sup>1,2</sup> 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, AARP estimates that the United States is home to approximately 43.5 million caregivers.<sup>3</sup> Clearly, given the percent 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. The National Institutes of Health (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. Since the publication of that document, the 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 (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 entire agency. One of the BRP's recommendations was to "develop a research plan that includes a trans-NIH strategic plan to tackle rehabilitation problems." 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,

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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 their 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 their 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 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: ([https://www.nichd.nih.gov/publications/pubs/Documents/NIH\\_ResearchPlan\\_Rehabilitation.pdf](https://www.nichd.nih.gov/publications/pubs/Documents/NIH_ResearchPlan_Rehabilitation.pdf)).<sup>4</sup>

## A: Rehabilitation across the lifespan

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 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 of 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 (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.

## 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.

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