

# DISABILITY AND REHABILITATION RESEARCH COALITION

1501 M STREET, N.W. SUITE 700 WASHINGTON, D.C. 20005

September 30, 2016

## OVERVIEW NATIONAL INSTITUTES OF HEALTH RESEARCH PLAN ON REHABILITATION—MOVING THE FIELD FORWARD

On September 14, 2016, the National Institutes of Health (NIH) released its “[\*Research Plan on Rehabilitation—Moving the Field Forward\*](#).” The Plan was developed by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development and the NIH Medical Rehabilitation Coordinating Committee. The original plan developed by NIH, “*Research Plan for the National Center for Medical Rehabilitation Research*,” was published in 1993.

Below is an overview of the Research Plan, including the following sections:

- Introduction
- The Need for Rehabilitation Research
- NIH’s Investment in Rehabilitation Research
- Current Medical Rehabilitation Research Activities
- Opportunities, Needs, and Priorities
- Coordination With Other Federal Agencies

This overview paraphrases key statements included in the Research Plan.

### Introduction

In 1990, The National Center for Medical Rehabilitation Research (NCMRR) was established in the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) as part of Public Law 101-613, National Institutes of Health Amendments of 1990. The establishing legislation requires NIH to develop a comprehensive research plan for rehabilitation.

- In 1993, NCMRR published its first research plan for rehabilitation. Since then significant progress has occurred in the rehabilitation research field.
- 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 how NCMRR and NIH could further catalyze and support rehabilitation research across the agency.
- 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 5-year Research Plan is built on the progress made over the past two decades. The Research Plan represents an integrated and comprehensive vision from stakeholders across NIH.

The Research 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.

For purposes of the 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.

### **The Need for Rehabilitation Research**

According to the Census Bureau, approximately 56.7 million Americans have a disability—1 in 5 individuals. 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 may also suffer. 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 and Current Research Activities**

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. Rehabilitation is also well-represented in the NIH intramural research portfolio, with researchers both at the NIH Clinical Center and in the intramural programs of the Independent Centers (ICs).

### **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:

- 1) **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. The goal of rehabilitation is to optimize function and promote health and wellness through participant-engaged, data-driven, individualized care. Objectives include increasing the quality of evidence for rehabilitation interventions across the lifespan through increased focus on the design, dose, intensity, timing, mechanisms, and specified targets and outcomes of these interventions; addressing symptoms and secondary conditions associated with disability; and investigating the nature of health disparities and their impact on the implementation and effectiveness of rehabilitation interventions.

- 2) **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 support. The interplay of individuals and their contexts is a key priority area for NIH. Objectives include: developing self-management strategies; examining challenges and benefits experienced by caregivers; and examining the impact of sociodemographic influences on rehabilitation intervention outcomes.
- 3) **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. Objectives include advances in telehealth and the use of assistive technologies; providing an evidence base for device development, manufacturing, and implementation; and supporting research to better define new and innovative metrics and outcomes of interest in the use of various technologies in rehabilitation.
- 4) **Research Design and Methodology.** Evidence-based approaches are essential for individuals with disabilities. There is a need for new methods, strategies, and approaches to address challenges such as generating consistent clinical data from heterogeneous conditions. Emphasis must be placed on knowledge translation and data sharing and transdisciplinary research must be encouraged. Objectives include: conducting both efficacy and effectiveness trials, including but not limited to randomized clinical trials, but also adaptive and pragmatic trials and trials using other innovative designs; encouraging clinical translational research and dissemination and implementation research; and identifying, measuring, and comparing the costs and consequences of rehabilitation assessment, delivery, and monitoring approaches, interventions, devices, and technologies.
- 5) **Translational Science.** There is a need to advance understanding of the fundamental biological, physiological, and behavioral mechanisms that underlie disease and body-system level response to injury. Basic understanding of the effects of interventions is also needed. Precision medicine is an emerging approach for disease treatment and prevention, but it has not been widely applied to rehabilitation medicine. Objectives include encouraging approaches that exploit the biological and physiological adaptations associated with rehabilitation strategies in the clinical setting and determining the effectiveness of integrative, multimodal interventions that focus on defining the optimal combination and “dosing” of individual interventions to improve and possibly accelerate recovering from injury or disease.
- 6) **Building Research Capacity and Infrastructure.** Research capacity includes: researchers; research culture, environment, and infrastructure; funding; partnerships; and metrics. NIH will continue to find novel and innovative ways to build capacity for rehabilitation science. Objectives include: increasing the use of and coordination among the centers that make up the Medical Rehabilitation Research Infrastructure Network; reviewing and enhancing training programs; identifying methods to encourage knowledge translation to promote clinical competence; and providing a strategy for recruiting individuals with disabilities into the field of rehabilitation research.

**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.