

Disability and Rehabilitation Research Coalition

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Summary of Recommendations to Develop and Implement a Comprehensive Disability and Rehabilitation Research Agenda in America

SUMMARY RECOMMENDATIONS SUBMITTED TO CONGRESS

**ON BEHALF OF THE FOLLOWING MEMBERS OF THE
DISABILITY AND REHABILITATION RESEARCH COALITION (“DRRC”):**

**American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association of Spinal Cord Injury Psychologists and Social Workers
American Congress of Rehabilitation Medicine
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Therapeutic Recreation Association
Amputee Coalition of America
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Brain Injury Association of America
Christopher and Dana Reeve Foundation
National Association for the Advancement of Orthotics and Prosthetics
National Association of Rehabilitation Research Training Centers
National Association of State Head Injury Administrators
National Council on Independent Living
National Spinal Cord Injury Association
United Spinal Association**

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SUMMARY RECOMMENDATIONS TO DEVELOP AND IMPLEMENT A COMPREHENSIVE DISABILITY AND RESEARCH AGENDA IN AMERICA

Introduction. DRRC believes that disability and rehabilitation research plays a critical role in enabling and empowering individuals with disabilities to live the American dream, consistent with the notion that disability, like race and gender, is a natural part of the human experience and the goals of federal disability policy articulated in the American with Disabilities Act (ADA)—equality of opportunity, full participation, independent living and economic self-sufficiency.

Significant disability and rehabilitation research, including translational research, is necessary to develop new and more effective approaches to test and evaluate the costs and benefits of current services, supports, treatments, and devices and to use these findings to affect future programs and maximize benefits to costs. Therefore, DRRC recommends that Congress support the development and implementation of a comprehensive disability and rehabilitation research agenda* that will:

- Increase federal funding for disability and rehabilitation research;
- Enhance the visibility and recognition of disability and rehabilitation research across the federal agencies responsible for supporting this research;
- Improve the coordination, cooperation, and collaboration among federal agencies in supporting disability and rehabilitation research; and
- Increase support for efficacy research, research capacity, and knowledge translation pertaining to disability and rehabilitation research.

Increase Funding for disability and rehabilitation research. DRRC believes that disability and rehabilitation research programs have been chronically underfunded for many years, especially considering the magnitude of the current and future veterans and civilians' need for rehabilitation and disability-related services, supports, treatments, and devices. DRRC recommends that Congress support significant increases in funding for the various federal agencies supporting and conducting disability and rehabilitation research.

Enhance the visibility and recognition of disability and rehabilitation research in federal agencies. DRRC believes that disability and rehabilitation research has limited visibility within federal agencies. In fact, for most federal agencies it is extremely challenging to even identify the level and extent of disability research being supported. DRRC recommends that Congress support the increase of visibility of federal disability and rehabilitation research within relevant federal agencies. Specifically, DRRC recommends that Congress support the following policies:

- Elevate to independent status the National Center for Medical Rehabilitation Research (NCMRR) within the National Institute of Health (NIH). Currently, NCMRR is housed within the National Institute of Child Health and Human Development (NICHD).

* For a detailed review of the findings and conclusions on which these recommendations are based, see the accompanying analysis entitled *Comprehensive Recommendations for Improving the Lives of Individuals with Disabilities by Enhancing the Federal Commitment to Disability and Rehabilitation Research*.

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- Solidify what has been longstanding practice at NIDRR by recognizing the health and function domain of disability and rehabilitation research in addition to the domains of employment and community participation. In the alternative, Congress may want to consider moving the health and function responsibilities to another relevant agency where this portfolio can flourish.
- Create an Office of Disability and Health at the Centers for Disease Control and Prevention (CDC).
- Examine the role of the VA/DoD disability and rehabilitation research programs and enhance the interaction between these programs and civilian research capacity.

Improve the coordination, cooperation, and collaboration among federal agencies in supporting disability and rehabilitation research. DRRC recognizes the limited success of current efforts to coordinate disability and rehabilitation research among federal agencies. DRRC recommends that Congress support the following policies:

- Expand and improve the authority of the Interagency Committee on Disability Research (ICDR) to coordinate research among federal agencies;
- Develop a comprehensive government-wide strategic plan for disability and rehabilitation research;
- Support a disability and rehabilitation research agenda-setting summit; and
- Develop a government-wide data base of disability and rehabilitation research.

Increase Support for Efficacy Research, Research Capacity, and Knowledge Translation.

- **Efficacy Research.** DRRC is concerned that in light of the heavy reliance of health care payors on research-based evidence of efficacy of practice, insufficient efficacy research may negatively impact the provision of high-quality, technologically advanced rehabilitation services, supports, treatments, and devices. DRRC recommends that Congress endorse expanded support for efficacy studies documenting the benefit (including cost-benefit) of rehabilitation services, supports, treatments, and devices, including support for large scale randomized clinical trials (where appropriate).
- **Research Capacity.** DRRC believes that in the area of disability and rehabilitation research, there are significant insufficiencies in research capacity, including a small number of adequately prepared researchers; lack of sufficient models and venues for interdisciplinary and collaborative research; and lack of research infrastructure, particularly for complex clinical research. DRRC recommends that Congress support steps to enhance research capacity in the field of disability and rehabilitation research.
- **Knowledge Translation.** DRRC believes that translating research findings into practice is critical. DRRC recommends that Congress support additional funding and focus to enhance knowledge translation so that research is more widely and efficiently translated into practice for the benefit of individuals with disabilities.