

# DISABILITY AND REHABILITATION RESEARCH COALITION

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

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**VIA E-MAIL** [Jyoung@foxkiser.com](mailto:Jyoung@foxkiser.com)

Dear Jonathan Young:

Knowing of President Obama's commitment to enabling and empowering individuals with disabilities to live and function as independently as possible in the mainstream of American society, the Disability and Rehabilitation Research Coalition ("DRRC") is pleased to share with you and your colleagues at the Campaign our recommendations for improving the lives of Americans with disabilities by enhancing the federal commitment to disability and rehabilitation research.

DRRC is a coalition of national non-profit organizations committed to improving the science of rehabilitation and disability. The DRRC seeks to maximize the return on the federal investment in disability and rehabilitation research with the goal of improving the ability of Americans with disabilities to live and function as independently as possible.

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 the Candidate support the development and implementation of a comprehensive disability and rehabilitation research agenda that will:

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

## **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 the Candidate support the following policies:

- 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.

## **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 the Candidate support the increase of visibility of federal disability and rehabilitation research within relevant federal agencies. Specifically, DRRC recommends that the Candidate support the following policies:

- Consistent with the recommendations of a Blue-Ribbon Panel established by the Director of NIH (2012), 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).
- Enhance the stature and visibility of and support for the National Institute on Disability and Rehabilitation Research (NIDRR) in the Department of Education.
- Enhance support for disability and rehabilitation research at the Centers for Disease Control and Prevention (CDC) by elevating the position of Chief Disability and Health Officer, expanding and improving the functioning of the Disability and Health Work Group, and oppose budget consolidation for disability initiatives, particularly initiatives funded through the *National Center on Birth Defects and Developmental Disabilities (NCBDDD)*.
- Examine the role of the VA/DoD disability and rehabilitation research programs and enhance the interaction between these programs and civilian research capacity.

## **Increase Support for Research and Development, Including 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 the Candidate 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 the Candidate 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 the Candidate 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.

### **Invest in 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 is not alone in this respect. The Institute of Medicine has recommended significant investments in disability and rehabilitation research as well. DRRC recommends that the Candidate support significant investments for the various federal agencies supporting and conducting disability and rehabilitation research.

If you have any questions please call or email Peter Thomas or Bobby Silverstein.

Sincerely,

American Academy of Orthotists & Prosthetists  
American Academy of Physical Medicine & Rehabilitation  
American Association of People with Disabilities  
American Association of Spinal Cord Injury Nurses  
American Association of Spinal Cord Injury Psychologists and Social Workers  
American Association on Health and Disability  
American Congress of Rehabilitation Medicine  
American Hospital Association  
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  
ARA Institute  
Arthritis Foundation  
Association of Academic Physiatrists

Association of Rehabilitation Nurses  
Brain Injury Association of America  
Christopher and Dana Reeve Foundation  
Disability Rights Education and Defense Fund  
Federation for American Hospitals  
National Association for the Advancement Orthotics & 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  
National Multiple Sclerosis Society  
Paralyzed Veterans of America  
RESNA  
United Spinal Association

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