

# DISABILITY AND REHABILITATION RESEARCH COALITION

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June 24, 2011

The Honorable Tom Harkin, Chair  
Subcommittee on Labor, Health and  
Human Services, Education, and  
Related Agencies  
Committee on Appropriations  
United States Senate  
731 Hart Senate Office Building  
Washington, DC 20510

The Honorable Richard C. Shelby, Ranking  
Subcommittee on Labor, Health and  
Human Services, Education and  
Related Agencies  
Committee on Appropriations  
United States Senate  
304 Russell Senate Office Building  
Washington, DC 20510

## **RE: FY 2012 Appropriations for Disability and Rehabilitation Research Priorities**

Dear Chair Harkin and Ranking Member Shelby:

Knowing of your commitment to enabling and empowering individuals with disabilities to live, function, and work in the mainstream of American society, the undersigned members of the Disability and Rehabilitation Research Coalition (“DRRC”)<sup>1</sup> urge you to consider including in the FY 2012 appropriations bill for Labor, Health and Human Services, Education and Related Agencies significant increased investment in disability and rehabilitation research (including capacity building and knowledge translation) across a number of federal agencies. DRRC is fully cognizant of the fiscal issues affecting our country. We believe that investments in disability and rehabilitation research today will not only enhance the quality of life of persons with disabilities, including veterans with disabilities, but will also result in significant mid-term and long-term savings to the federal government in regards to reduced reliance on social security programs, Medicaid and Medicare, and programs serving individuals with significant disabilities, including education, job training, housing, and veterans programs. Maximizing the functional capacity of people with disabilities translates into higher rates of employment of this population, increased tax revenues, and less dependency costs over time. In short, disability and rehabilitation research has a high return on investment.

Recent Institute of Medicine (IOM) studies on disability concluded that disability and rehabilitation research programs across federal agencies have been **chronically underfunded** for many years, especially considering the magnitude of the need for rehabilitation and disability services. Funding for rehabilitation and disability research is not in line with the current, and particularly, the future projected impact of disability on individuals, families, and American society. For example, *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*, the 1997 IOM report on disability bluntly stated that the combined federal research effort was not adequate to address the needs of people with disabilities and that more funding would be required to expand research to meet these needs. According to *The Future of Disability in America* (the 2007 IOM report on disability), despite modest increases in funding, the situation essentially remains the same today.

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<sup>1</sup> DRRC is a coalition of 30 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 and chronic conditions to contribute to the health and economic well-being of our nation.

As part of the FY 2012 Labor/HHS/Education/Related Agencies appropriations bill, we urge you to support significant increases for various agencies within the federal government conducting disability and rehabilitation research, capacity building, and/or knowledge translation of that research, including:

- **Funding** for the **Interagency Committee on Disability Research (ICDR)** to support the conduct of a disability and rehabilitation research summit and the development of a comprehensive government-wide strategic plan for disability and rehabilitation research, including capacity building and knowledge translation.
- **Report language** encouraging a greater recognition of, support for, and focus on disability and rehabilitation research at **NIH** through meaningful efforts by the Director and others.
- Increases in funding for the **National Institute on Disability and Rehabilitation Research (NIIDRR)** to support research and development, capacity building, and knowledge translation in the key life domains of employment, participation and community integration, and health and function as well as disability demographics and assistive technology.
- Increases in funding for disability and rehabilitation research initiatives at **CDC** and **report language** strongly supporting the disability-related programs under **CDC** and opposing budget consolidation efforts.
- **Report language** directing **the Centers for Medicare & Medicaid Services (CMS)**, in conjunction with **the Agency for Healthcare Research and Quality (AHRQ)**, **DHHS** to conduct research to develop unambiguous functional and medical appropriateness standards that will make it possible for patients to be admitted to the proper rehabilitation care setting.
- Increases in funding for **SAMHSA** which would include demonstration projects to identify effective services to better serve persons with co-occurring or other functional disorders. Also, the inclusion of **report language** urging **SAMHSA** to continue funding the development of new interventions, tools, services, evaluation projects, and science to practice techniques for individuals with behavioral health conditions/psychiatric disabilities and co-occurring or functional disorders, and those who serve or support them.

## **SPECIFIC APPROPRIATION REQUESTS**

Set out below is a more in depth justification for our specific recommendations.

### **1. Comprehensive Government-Wide Strategic Plan**

The DRRC strongly urges the inclusion of **\$1.5 million** for the Interagency Committee on Disability Research (ICDR) to conduct a disability and rehabilitation research summit and support the development of a comprehensive government-wide strategic plan for disability and rehabilitation research, including knowledge translation. ICDR was established by Congress (Section 203 of the Rehabilitation Act) to promote the coordination and cooperation among federal departments and agencies conducting disability and rehabilitation research. The strategic plan should include, but not be limited to, consideration of recommendations by the Institute of Medicine (IOM) in its various reports on disability and recommendations by the 2005 Rehabilitation Medicine Summit: building research capacity; establishing a government-wide database on disability and rehabilitation research; conducting efficacy research; supporting knowledge translation; addressing the interaction between disability and rehabilitation research conducted by the VA and DoD and civilian initiatives; and building our nation's disability and rehabilitation research capacity.

## **2. Medical Rehabilitation at NIH**

DRRC believes that NIH needs to take concrete steps to enhance and increase collaboration and support for medical rehabilitation and disability research at the National Center for Medical Rehabilitation Research (NCMRR) (currently housed within the National Institute of Child Health and Human Development) and across NIH. Consistent with two recent reports by the Institute of Medicine, DRRC continues to believe that this goal can best be achieved by elevating NCMRR to a freestanding Institute or Center within NIH. There is a need for a high profile entity within NIH that has medical rehabilitation and disability research as its primary mission and that appropriately occupies an organizational level that reflects this primary mission. There is a concomitant need for enhanced stature, emphasis, and leadership at NIH relating to medical rehabilitation and disability research in order to garner the attention of other institute and center directors and to coordinate and collaborate on rehabilitation science that cuts across the multiple institutes and centers. DRRC recommends the inclusion of the following **report language** accompanying the bill:

“The Committee recognizes that the science of human function, human activity and human enablement (which is the focus of medical rehabilitation research) is fundamentally different from the study of particular diseases and their prevention and cure. The Committee continues to believe that the Director should take meaningful administrative steps to work with the National Center for Medical Rehabilitation Research and other relevant NIH institutes and centers to emphasize medical rehabilitation research and enhance the collaboration and support for medical rehabilitation and disability research across the NIH. In order to better inform the Director and the Congress, the Committee supports efforts, through the appointment of a Blue Ribbon Panel, to complete a comprehensive landscape surveillance of the different agency’s research efforts to identify gaps in rehabilitation research and formally report the results to the Director and the Congress. The Blue Ribbon Panel should include NIH experts and outside rehabilitation scientists.”

## **3. National Institute on Disability and Rehabilitation Research (NIDRR)**

The DRRC urges **doubling of the funding for NIDRR over the next five years (\$20 million per year)** to support NIDRR’s mission-oriented agenda. This DRRC recommendation constitutes a dramatic increase in funding at a time when federal budget conditions are at their most difficult. But this recommendation reflects the high return on investment that DRRC believes will come with increases funding for rehabilitation and disability research.

Since Congress established NIDRR in 1978, it has served as the flagship federal agency on disability and rehabilitation research. NIDRR’s mission has been to explore the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities of all ages in the home, community, school and workplace. Thus, NIDRR’s mission includes exploring new and innovative strategies, interventions, and technologies to better achieve the promises of the Americans with Disabilities Act—equality of opportunity, full participation, independent living and economic self-sufficiency for individuals with disabilities. NIDRR carries out its mission by generating new knowledge through research and development in the major life domains of employment, participation and community integration, and health and function; promoting its effective use (knowledge translation), and building the capacity of institutions and individuals to conduct high quality research and development.

Unfortunately, NIDRR’s ability to fulfill its mission has been severely hampered by the lack of adequate funding—NIDRR’s funding has been virtually flat for many years now.

The doubling of funding for NIDRR over the next five years would support:

- Research and Development in General, including:
  - Expanding the field initiated research program which offers significant opportunity to expand knowledge and create a basis for more advanced research (a significant barrier to the growth of evidence-based rehabilitation practice is the limits on funding for testing hypotheses at an early stage of research development);
  - Improving the advanced research portfolio (which supports multi-site research, especially with its model systems program for TBI, SCI and burn) and expanding the advanced research portfolio to focus on other areas such as stroke, arthritis, and psychiatric disabilities;
  - Evaluating the capacity of the American health and post-acute care systems to meet the health, behavioral, functional, and rehabilitation need of individuals with disabilities; and
  - Improving the infrastructure for outcome-based research by funding the development of more specific measures and outcomes of particular relevance to people with disabilities. There is a need for increased support for development and testing of adequate instruments for measuring the effectiveness of specific medical rehabilitation interventions and their duration or setting, as well as measuring the effectiveness of specific psychiatric interventions and functional recovery. A major expansion of research is necessary to develop measurement approaches for disability that will assist in research regarding the outcomes of specific rehabilitation interventions and measuring the independence of the person with a disability in community living and the job environment.
- Research and Development in Particular, including:
  - Expanding medical and rehabilitation strategies (e.g., combination of technological, clinical, and community interventions) for people aging with and aging into disability (current research portfolio is very limited and thus does not adequately address the changing demographics described above);
  - Expanding and improving medical and rehabilitation strategies for infants and young persons with disabilities (congenital and well as acquired);
  - Better understanding about life-span/developmental issues as they differentially impact individuals with disabilities (e.g., are medications used to treat diverse medical and psychiatric conditions in individuals without chronic disabilities effective in treating individuals with disabilities?);
  - Better understanding how key life transitions (e.g., school to work and work to retirement) are impacted by disability;
  - Supporting rigorous research on employment, vocational rehabilitation, and other interventions to address the dismal employment rate of persons with disabilities;
  - Supporting research on the types of supports needed by individuals with disabilities to live in the community (rather than in institutions) and the use of social networks to decrease isolation and alienation;
  - Supporting research regarding the application of new technologies and communication modalities (e.g., Facebook) to the lives of persons with disabilities.
- Capacity building (addressing the insufficient numbers of adequately prepared rehabilitation researchers), including:
  - Supporting the development of models of interdisciplinary collaboration, which is critical given the diversity of people, interventions, and environments that are the subject of disability and rehabilitation research;

- Supporting the development of effective models of clinical research short of clinical trials as well as the infrastructure for the complex and demanding clinical research area;
- Supporting predoctoral training in rehabilitation research; and
- Expanding funding for advanced research training for post-doctoral training in rehabilitation research.
- Knowledge translation, including expanding support for taking the findings from rigorous and relevant research and effectively translating them into usable practices and training provided to practitioners as well as funneling promising practices from the field back into the research agenda. Additional support is needed across all of NIDRR's portfolio to facilitate the use of NIDRR research. There is also a need to support additional efforts to provide knowledge and consultation to entities that have a duty to implement the ADA.

DRRC also recommends the inclusion of the following report language:

“Given the severe injuries incurred in Iraq and Afghanistan by some members of the armed services, the Committee recognizes the need for research at NIDRR on long-term outcomes from catastrophic injuries such as traumatic brain injury, spinal cord injury and burns. The Model Systems programs funded by the National Institute on Disability and Rehabilitation Research are the only sources of longitudinal data on these conditions and the Committee encourages continued funding with the resources needed to assure further advancements in assessment and treatment and maintain current levels of productivity.”

#### **4. Centers for Disease Control and Prevention (CDC).**

DRRC believes a strong disability and health program at CDC is critical to promoting the health and well-being of persons with disabilities. DRRC supports the appointment by Dr. Frieden of a chief disability and health officer and the establishment of a disability and health group at CDC as a positive step forward. However, DRRC is gravely concerned with the reductions in funding for disability and rehabilitation-related programs and proposals to consolidate specific funding categories into a single budget line entitled, “Health and Development for People with Disabilities.”

Specifically, DRRC recommends that Congress provides at least **\$144 million** in FY 2012 to sustain the vital programs and activities funded by the **National Center on Birth Defects and Developmental Disabilities**. DRRC also recommends **\$65 million** be appropriated in FY 2012 and directed to CDC's **Division of Disability and Health Development** to maintain support for, among other things, research on risk factors and measures of health, functioning and disability. Continued funding for research will address knowledge gaps in promoting health of people with disabilities. In addition, we urge **\$20 million** be appropriated to the **Center for Injury Control and Prevention** to support tertiary prevention (i.e., rehabilitation) of conditions such as traumatic brain injury and spinal cord injury. Priorities for research include improved identification, assessment, and management of conditions; development and application of methods for calculating population-based estimates of the incidence, costs, and long-term consequences of conditions; identification of methods and strategies to ensure that individuals with specified conditions receive needed services; and the development and evaluations of the effectiveness of interventions.

DRRC recommends that the Committee include the following **report language**:

“The Committee is encouraged by the Director's decision to appoint a CDC chief disability and health officer and the establishment of a disability and health work group at CDC. The Committee encourages the work group and the key program operating components in CDC to

address the following key issues that address ongoing strategic efforts to support and strengthen public health research activities focused on people with disabilities: recognizing disability as a key determinant in national surveys and other surveillance systems and public health programs; addressing health disparities among people with disabilities; enhancing health promotion and prevention and access to health care for people with disabilities; fostering knowledge translation and communication efforts to bring persons with disabilities reliable information on a variety of public health topics; developing new disability research initiatives through partnerships across CDC Centers and other federal agencies; and developing public and private partnerships to support and advance disability issues.”

The Committee is greatly concerned, however, and has significant reservations about the budget consolidation that CDC has proposed for disability initiatives, particularly initiatives funded through the *National Center on Birth Defects and Developmental Disabilities (NCBDDD)*. The Committee believes that, as proposed, such a consolidation would jeopardize the progress that has been made on behalf of people with disabilities, as well as the partnerships that have developed. Therefore, the Committee cannot support the proposed budget consolidation in the FY 2012 appropriation. The Committee directs the CDC to report on the evaluation of the impact of any proposed changes to current programs and existing sub-lines for the 2013 appropriations process before implementing any such consolidation. CDC has not demonstrated, as evidenced by its consolidation Strategic Plan, that it has considered sufficiently the needs and essential elements of support for the included categories of individuals with disabilities. The Committee further directs that CDC, prior to budgeting for and executing a consolidation or change in support, complete and forward to Congress a disability community needs assessment that outlines the included categories of individuals’ needs, validates the value of such a consolidation, considers the input of the disability community’s partner groups, and establishes the basis for any proposed efficiencies and commonalities. Further, the Committee expects CDC to provide concurrently a statement that establishes in detail how existing support for this community will be impacted.

##### **5. Centers for Medicare & Medicaid Services (CMS) and Agency for Healthcare Research and Quality (AHRQ).**

Throughout the disability and rehabilitation fields, efficacy research must be enhanced and made a priority. Insufficient research is having a deleterious impact on the provision of quality, technologically-advanced rehabilitation services, supports, treatments, and devices. As all payers look to research-based evidence to assess the efficacy and medical necessity of various healthcare interventions, it is critical that the field of rehabilitation, which has a paucity of research evidence, not get left behind. There is a need for more efficacy research to prevent the lack of sufficient evidence on effectiveness from being misread as evidence of lack of effectiveness.

There is also a need for increased support for development and testing of adequate instruments for measuring the effectiveness of specific medical and psychiatric rehabilitation interventions and their duration or setting. In addition, there is a need for increased support for the development and testing of adequate instruments for the effectiveness of specific psychiatric interventions on the capacity of individuals for functional recovery. A major expansion of research is necessary to develop measurement approaches for disability that will assist in research regarding the outcomes of specific rehabilitation interventions and measuring the independence of the person with a disability in community living and the job environment.

We recommend the inclusion of **report language** urging CMS in conjunction with AHRQ to make a substantial commitment to better support efficacy studies designed to document the input and output of rehabilitation interventions concerning particular rehabilitation services, supports, treatments, and

technologies. For example, research needs to be funded (including large scale randomized clinical trials, \$2M-\$5M per trial) to develop unambiguous functional and medical appropriateness standards that will make it possible for patients to be admitted to the proper rehabilitation care setting without the need for federal enforcement authorities to retroactively review and deny coverage and payment to providers of care.

**6. Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.**

DRRC recognizes the important role that SAMHSA has played relative to many Americans with disabilities. This is reflected in the SAMHSA mission that espouses "A Life in the Community for Everyone." This vision is based on the premise that people of all ages, with or at risk for mental or substance use disorders should have the opportunity for a fulfilling life that includes a job/education, a home, and meaningful personal relationships with friends and family. SAMHSA's role within that vision is to provide national leadership to expand the availability of effective treatment and recovery services for persons with mental illnesses and/or alcohol and drug problems, as well as monitor ADA compliance within settings that fall under their purview.

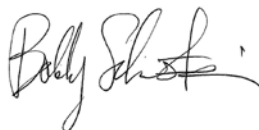
Emerging research indicates that persons with severe mental illness experience additional conditions that impact their ability to function within the community. These co-occurring or other functional disorders can include substance use disorder, hidden traumatic brain injury, chronic medical conditions, or other conditions. Rates of substance use disorders have been shown to be higher for persons with disabilities, yet access to treatment is limited or in some cases almost non-existent. Transitioning youth with disabilities often have no access to substance abuse prevention education, although drug use initiation has been shown to impact future school and vocational success.

DRRC recommends expanding funding for SAMHSA in order to better serve persons with co-occurring or other functional disorders. This should include expanded funding to address poly co-morbidity in CMHS, and co-occurring and other function disorders in CSAT and CSAP. Increased funding for SAMHSA would include **\$\$4 million** for CMHS for funding or co-funding of disability demonstration programs, **\$5 million** for joint funding with NIDRR of Rehabilitation Research and Training Centers in Adult and Children's Serious Mental Illnesses, **\$3 million** for CSAT to fund disability focused programs, and **\$3 million** for substance abuse prevention programs focused on youth with disabilities.

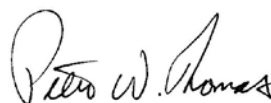
We recommend the inclusion of **report language** urging the agency to continue making a substantial commitment to funding the development of new interventions, tools, services, evaluation projects, and science to practice techniques for individuals with behavioral health conditions/psychiatric disabilities who have co-occurring or multiple disabilities, and those who serve or support them.

If you have any questions, please contact Bobby Silverstein or Peter Thomas at 202.466.6550. Bobby's email is [bobby.silverstein@ppsv.com](mailto:bobby.silverstein@ppsv.com) and Peter's email is [peter.thomas@ppsv.com](mailto:peter.thomas@ppsv.com).

Sincerely,



Robert Silverstein



Peter Thomas

# DISABILITY AND REHABILITATION RESEARCH COALITION

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

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