

DISABILITY AND REHABILITATION RESEARCH COALITION

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June 29, 2017

The Honorable Roy Blunt, Chairman
Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education
260 Russell Senate Office Building Washington, DC 20510

The Honorable Patty Murray, Ranking Member
Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education
154 Russell Senate Office Building Washington, D.C. 20510

The Honorable Tom Cole, Chairman
House Appropriations Subcommittee on Labor, Health and Human Services, and Education
2368-B Rayburn House Office Building Washington, DC 20515

The Honorable Rosa DeLauro, Ranking Member
House Appropriations Subcommittee on Labor, Health and Human Services, and Education
1016 Longworth House Office Building Washington, DC 20515

RE: FY 2018 Appropriations and Suggested Report Language for Disability, Independent Living, and Rehabilitation Research Priorities

Dear Chairman Blunt and Ranking Member Murray:

In the course of your deliberations relating to the FY 2018 appropriations bill for Labor, Health and Human Services, Education and Related Agencies, the Disability and Rehabilitation Research Coalition (“DRRC”)¹ urges you to recognize the significant return on investment that is a direct result of Congress’ support for disability, independent living, and rehabilitation research (including development, capacity building, and knowledge translation) across a number of federal agencies in keeping with each agency’s mission and in a coordinated fashion to prevent or minimize the impact of injuries and disability-related conditions on the ability of individuals with disabilities to live as independently as possible and be contributing members of society. The distinct but complementary research performed by the various agencies is essential to guide policies and payment systems with regard to, among other things, effective methodologies, accommodations, and environmental modifications, which often change over the lifespan of an individual.

¹ The DRRC is a coalition of national non-profit organizations committed to improving the science of disability, independent living, and rehabilitation. The DRRC seeks to maximize the return on the federal investment in disability, independent living, and rehabilitation research and development with the goal of improving the ability of Americans with disabilities and chronic conditions to live and function as independently as possible and to contribute to the health and economic well-being of our nation.

DRRC recommends that the FY 2018 Labor, HHS, Education, and Related Agencies appropriation bill provide necessary and sufficient funding for the various federal agencies supporting and conducting disability, independent living, and rehabilitation research to address the current and future needs for individuals with disabilities and society. We also recommend that the report accompanying the bill include language recognizing the critical importance of disability, independent living, and rehabilitation research. Below is a summary of our recommendations:

1. **National Institutes of Health (NIH).** Reject the significant reductions in funding for FY 2018 proposed by the Administration for NIH, including the reductions for the National Institute of Child Health and Human Development (NICHD), the Institute in which the National Center for Medical Rehabilitation Research (NCMRR) is housed. Adopt funding increases comparable to those included in the FY 2017 Omnibus Appropriations legislation. Include report language to enhance the stature, visibility, and coordination of medical rehabilitation research at the NIH, through meaningful efforts by the Director and others, adoption of a Research Plan, and submission of an annual progress report.
2. **National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR):** Increase funding for the NIDILRR to \$119 million to support research and development, capacity building, and knowledge translation in the life domains of employment, participation and community integration, and health and function as well as disability demographics and assistive technology and the ADA National Network.
3. **Centers for Disease Control and Prevention (CDC).** Reject the significant reductions in funding for FY 2018 proposed by the Administration for CDC and instead provide reasonable increases in funding for disability and rehabilitation research initiatives at CDC in general and restore and/or retain critical disability-related initiatives supported by the various Centers. DRRC also recommends the inclusion of **report language** supporting the reappointment of a Chief Disability and Health Officer and the re-establishment of a Disability and Health Work Group.
5. **The Agency for Healthcare Research and Quality (AHRQ).** Reject efforts to move AHRQ to the new Institute for Research on Safety and Quality at NIH. Reject funding decreases for FY 2018 proposed by the Administration for research supported by AHRQ, which is transferred to the new Institute at NIH. Include report language ensuring that research supported by AHRQ addresses the needs of individuals with disabilities and chronic conditions.
6. **Interagency Committee on Disability Research (ICDR).** Reaffirm Congress' support for the development of a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research to avoid duplication and identify gaps.

Set out below is a more in-depth articulation of our requests and justification for these recommendations regarding each of disability-related research initiatives within program operating components in the Department of Health and Human Services, including:

- National Institutes of Health [pages 5-6]
- National Institute on Disability, Independent Living, and Rehabilitation Research [pages 7-9]
- Centers for Disease Control and Prevention [pages 10-13]
- The Agency for Healthcare Research and Quality [pages 14-16]
- Interagency Committee on Disability Research [page 17]

IN-DEPTH REQUESTS AND JUSTIFICATIONS

BACKGROUND

Demographic trends over the next two decades indicate a substantial increase in the number of people with injuries, illnesses, disabilities, and chronic conditions resulting from trauma, developmental disability, war-related injuries, the effects of chronic illness, and an increasingly aging population. Disability, independent living, and rehabilitation research can and must play a critical role in enabling and empowering individuals with disabilities to live the American dream, consistent with the goals of federal disability policy articulated in the Americans with Disabilities Act (ADA)—equality of opportunity, full participation, independent living, and economic self-sufficiency.

- Disability, independent living, and rehabilitation research provide the evidence-bases to maximize health and function, employment, independent living, and overall quality of life for people with injuries, illnesses, disabilities and chronic conditions across the lifespan.
- Research identifies appropriate outcomes and demonstrates the efficacy of various interventions, services and supports, treatments, and devices.
- Translational research transforms research results into improvements in the home, employment setting, and community-based level.
- Research leads to appropriate policies that maximize the return on investment of our financial commitments while improving individuals' independence, economic self-sufficiency, quality of life, and the status of our overall economy.

DRRC believes that investments in disability, independent living, 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, employment, and independent living of people with disabilities translates into increased tax revenues and less dependency costs over time. In short, disability and rehabilitation research has a high return on investment.

Unfortunately, disability, independent living, and rehabilitation research is currently underfunded, considering the magnitude of the current need and the future projected impact of disability on individuals, families, and American society. If Congress were to adopt the cuts for these research programs proposed by the Administration in its FY 2018 Budget, it would be

devastating for individuals with disabilities and our nation's efforts to enable people with disabilities to maximize their health and function, employment, and independent living.

MEDICAL REHABILITATION RESEARCH AT NIH

Ask:

DRRC recommends that the Committee reject the significant proposed cuts to NIH, in general, and the National Institute of Child Health and Human Development (NICHD), in particular, included in the FY 2018 Budget proposed by the Trump Administration. DRRC recommends that the Committee include funding increases comparable to those included in the FY 2017 Omnibus Appropriations legislation.

DRRC also recommends that the report accompanying the FY 2018 Labor, HHS, Education, and Related Agencies bill include the following language:

“The Committee encourages NIH to fully implement Section 2040 of the 21st Century Cures Act to enhance the stature, visibility, and coordination of medical rehabilitation research conducted at NIH. The Committee is encouraged by the release of NIH’s new Rehabilitation Research Plan and looks forward to reviewing NIH’s first annual progress report and is encouraged by NIH’s ongoing efforts to ensure that reporting of rehabilitation research is consistent with the definition of “rehabilitation research” included in the legislation.”

Justification.

Medical rehabilitation research at NIH is currently conducted at the National Center for Medical Rehabilitation Research (NCMRR) (housed within the National Institute of Child Health and Human Development) and almost all of the other independent institutes and centers at NIH. According to NIH, institutes and centers conduct and support approximately \$500 million in medical rehabilitation research annually, approximately \$70 million of which was supported by NCMRR in FY 2017.

In FY 2017, NICHD received an appropriation of \$1,380,295,000. The Administration’s FY 2018 budget proposes to reduce NICHD’s appropriation to \$1,032,029,000, a decrease of \$348,266,000. Under a policy adopted by the Director of NICHD, NCMRR receives 6.5 percent of the NICHD’s extramural research budget. The FY 2018 budget proposed by the Administration would result in a reduction in funding of more than \$17 million for NCMRR.

In an effort to understand the scope and breadth of medical rehabilitation research being conducted and supported by the NIH, in 2011 the Director of NIH and the Director of NICHD formed a Blue Ribbon Panel on Medical Rehabilitation Research which issued a comprehensive report in 2012.

The panel concluded that medical rehabilitation research is not thriving at NIH and that reforms are needed to assist people with injuries, illnesses, disabilities and chronic conditions in maximizing their health and their ability to function, live independently, and return to work if possible. The report also found that all aspects of medical rehabilitation research at the NIH must increase, including basic science and efficacy trials. The 2012 report additionally found that

“There is a critical need to substantially increase ALL aspects of rehabilitation research across the continuum of translational research and the WHO-ICF framework to meet the growing rehabilitation needs of the American people.”

Consistent with these important findings from the Blue Ribbon Panel’s report, on December 7, 2016, Congress passed bipartisan legislation to enhance the stature and visibility of and better coordinate medical rehabilitation research at NIH as part of the landmark 21st Century Cures Act. Section 2040 of the legislation:

- Focuses on creating greater links within NIH to help coordinate rehabilitation research across Institutes and Centers to streamline rehabilitation research priorities and maximize the current federal investment in this area of research;
- Involves the Office of the NIH Director in coordination activities, raising the stature of rehabilitation science across the NIH’s 27 Institutes and Centers;
- Calls for a Rehabilitation Research Plan to be updated every 5 years following a scientific conference or workshop. The existing research plan has not been updated since 1993; and
- Provides for an annual progress report; ties funding of medical rehabilitation research projects to the Research Plan, and includes a definition of medical rehabilitation research to ensure consistent tracking of rehabilitation research across NIH.

NATIONAL INSTITUTE ON DISABILITY, INDEPENDENT LIVING, AND REHABILITATION RESEARCH (NIDILRR)

Ask:

DRRC recommends that the Committee appropriate \$119 million for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). Currently, NIDILRR is funded at \$103,970,000. NIDILRR's pre-sequestration funding level was \$108,599,000. The Administration has requested \$95,127,000, a decrease of \$8,843,000 from the FY 2017 Omnibus Appropriations Act and a decrease of \$13,472,000 from the FY 2013 pre-sequestration level. The funding increase is justified given the decrease in funding from the pre-sequestration level, the years of level funding at the post-sequestration level, and the critical research and development initiatives that remain unfunded.

DRRC also recommends that the report accompanying the FY 2018 Labor, HHS, Education, and Related Agencies bill include the following language:

“The Committee recognizes the successful transition of NIDILRR from the Department of Education to the Administration for Community Living (ACL) within the Department of Health and Human Services (HHS). NIDILRR supports critical research and development in the interrelated domains of health and function, employment, participation and community living and cross-cutting research and development activities, including: technology for access and function; disability statistics research; and the ADA National Network. The Committee strongly supports these activities as germane to the mission of NIDILRR to contribute new knowledge in the area of participation of individuals with disabilities of all ages, in the home, community, schools and the workplace. Also, the Committee supports a continued focus on knowledge translation and ensuring that the practical implications of research outcomes are put in a timely manner, into a form that is usable by individuals with disabilities, their families, their communities and the general public in order to both make a difference in the lives of individuals with disabilities and to inform the public about the research activities it supports.”

Justification:

According to the National Research Council of the National Academies of Science in a report entitled, *Review of Disability and Rehabilitation Research: NIDRR Grantmaking Processes and Products*, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) [added independent living to the name in 2014 by Section 433 of the Workforce Innovation and Opportunity Act] is the principal, flagship federal agency supporting applied research, development, and training to improve the lives of individuals with disabilities. NIDILRR, originally established in 1978, plays a unique role in that it invests in research that is tied more closely to longer-term outcomes, such as independence, community participation, and employment. NIDILRR's five outcome domains are: employment, participation and community living, health and function, technology for access and function, and disability demographics.

In FY 2015, NIDILRR was transferred from the Department of Education to the Administration for Community Living in the Department of Health and Human Services following the enactment of the Workforce Innovation and Opportunity Act of 2014.

NIDILRR's mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDILRR'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.

NIDILRR 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, NIDILRR's ability to fulfill its mission has been severely hampered by the lack of adequate funding. NIDILRR's FY 2013 pre-sequestration level of funding was \$108,599,000. Its funding level post sequestration has been level at \$103,970. The Administration's FY 2018 budget request for NIDILRR is \$95,127,000, a decrease of \$8,843,000 for the FY 2017 Omnibus Appropriation Act, and a decrease of \$13,472,000 from the pre-sequestration level.

Additional funding for NIDILRR would expand and improve:

- Research and development in general, including expanding the field-initiated research program that offers significant opportunity to expand knowledge and create a basis for more advanced research; improving the advanced research portfolio (which supports multi-site research, especially with its model systems program for traumatic brain injury (TBI), spinal cord injury (SCI) and burn); improving the infrastructure for outcome-based research by funding the development of more specific measures and outcomes of particular relevance to people with disabilities;
- Capacity building (addressing the insufficient numbers of adequately prepared rehabilitation researchers), including the development of models of interdisciplinary collaboration; predoctoral training in rehabilitation research; and advanced training for post-doctoral research.
- Knowledge translation, including taking the findings from rigorous and relevant research and effectively translating them in measurable ways into usable practices and training provided to practitioners, funneling promising practices from the field back into the research agenda and developing models and testing strategies to conduct these processes in the most efficient and effective ways.
- Knowledge and consultation to entities that have a duty to implement the Americans with Disabilities Act (ADA).

Currently NIDILRR is drafting a Long-Range Plan for 2018-2023. The draft reaffirms NIDILRR's commitment to improve outcomes of people with disabilities in the three inter-related domains of: 1) Health and Function; 2) Employment; and 3) Community Living and Participation. In addition, the draft long-range plan continues to focus on cross-cutting research and development activities, including: 1) Technology for Access and Function; 2) Disability Statistics Research; and 3) the ADA National Network.

Furthermore, the draft long-range plan continues to focus on activities that promote the quality and use of NIDILRR-sponsored research and development, including capacity-building grants and activities to ensure the field has well-trained research personnel. Finally, the draft long-range plan focuses on knowledge translation to ensure that new knowledge and products gained through the course of research and development ultimately improve the lives of people with disabilities and further their participation in society.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC).

Ask:

DRRC strongly urges the Committee to include reasonable increases in funding and reject the significant reductions in the budgets for the CDC, in general, and the National Center for Chronic Disease Prevention and Health Promotions, the National Center on Birth Defects and Developmental Disabilities, the National Center for Injury Prevention and Control, and the National Center for Health Statistics, in particular.

With respect to the National Center for Chronic Disease Prevention and Health Promotions, DRRC recommends the Committee include the same funding increases included in the FY 2017 Omnibus Appropriations legislation.

With respect to the Center on Birth Defects and Developmental Disabilities, DRRC recommends \$152,610,000 for FY 2018, with the additional \$15 million representing the amount needed to sustain the Zika response, which was initiated in FY 2016 while maintaining the core work of the Center. Funding for the Center in the FY 2017 Omnibus was \$137,560,000.

With respect to the National Center for Injury Prevention and Control, DRRC recommends restoring funding for the National Injury Center's Unintentional Injury Division's Elderly Falls Prevention Program (\$2 million) and the Injury Control Research Centers (\$9 million). In addition, we recommend continued funding for the National Injury Center's TBI program (\$6.7 million) in a separate line item to continue its work on brain injury management in children, pediatric guidelines to assist in proper diagnosis and management of mild TBIs, and to continue support for sports-related concussion initiatives. We also support \$5 million to pilot a new National Concussion Surveillance System to accurately determine how many Americans (children and adults) get a concussion each year, and determine what caused the injury.

With respect to the National Center on Health Statistics, DRRC recommends the same funding increases included in the FY 2017 Omnibus Appropriations legislation.

DRRC also recommends that the report include the following language regarding interagency leadership, coordination, and collaboration:

“The Committee encourages CDC to re-appoint a Chief Disability and Health Officer and re-establish the Disability and Health Work Group to provide leadership, coordination, and collaboration among Centers in order to expand and improve efforts to enhance the health of individuals with disabilities.”

Justification

CDC supports several critical initiatives that promote the health and well-being of persons with disabilities, including initiatives adopted by:

- National Center for Chronic Disease Prevention and Health Promotion,

- National Center on Birth Defects and Developmental Disabilities,
- National Center for Injury Prevention and Control, and
- National Center for Health Statistics.

The National Center for Chronic Disease Prevention leads our nation’s efforts to prevent and control chronic diseases and associated risk factors by: supporting public health response at all levels by implementing chronic disease prevention interventions; monitoring chronic diseases, conditions, and risk factors to track national trends and evaluate interventions; conducting and translating public health research and evaluation to enhance the uptake of effective public health strategies; providing national leadership and technical assistance to build the evidence for effective prevention programs; communicating to partners and the general public about chronic disease burden, risks, and prevention opportunities; and informing sound public health policies that effectively combat chronic diseases and associated risk factors.

Funding for the Center in the FY 2017 Omnibus was \$1,115,596,000. The Administration’s FY 2018 proposed budget for the Center is \$952,000,000, a reduction of \$163,596,000.

The National Center on Birth Defects and Developmental Disabilities is a Center at CDC that focuses on those that are especially vulnerable to health risks – babies, children, people with blood disorders and children and adults with disabilities. NCBDDD is the only place that takes a public health approach to birth defects, developmental conditions, and disability. It does not duplicate work from other agencies. NCBDDD focuses on four key areas:

Saving Babies through Birth Defects Prevention and Research. 1 in 33 babies are born with birth defects. NCBDDD improves *Birth Defects* and *Congenital Heart Defects* surveillance, research, and prevention; *Infant Health* protection, such as *Fetal Alcohol Syndrome Disorder* (FASD); prevention of *Zika virus*, early detection and intervention systems to identify *deaf and hard of hearing* infants.

Helping Children Live to the Fullest by Understanding Developmental Disabilities. Even more children are being diagnosed with developmental disabilities – *Autism Spectrum Disorder* (ASD) now affects 1 in 68 children in the U.S. NCBDDD provides essential data on developmental disabilities, such as ASD, search for risk facts, and develop resources to help identify children with developmental disabilities as early as possible. NCBDDD also improves the lives of those living with *Attention Deficit and Hyperactivity Disorder*, *Tourette Syndrome*, and other *Child Mental, Behavioral, and Developmental Disorders*. The *Legacy for Children* program within the Disability and Health portfolio saves \$16 million in lifetime health care costs among children served within this behavioral problem population.

Protecting People and Preventing Complications of Blood Disorders. Blood disorders affect millions of Americans each year. *Hemophilia A* affects about 400 babies each year, with about 20,000 people living with hemophilia in the US. All races and ethnic groups are affected. *Sickle cell disease* affects about 100,000 Americans, who often have less access to comprehensive team care. This leads to over \$475 million in hospitalizations. NCBDDD reduces

the public health burden of blood disorders by contributing to a better understanding of these disorders and their complications; developing, implementing and evaluating prevention programs

Improving the Health of People with Disabilities. Americans living with disabilities are the largest minority in the country (57 million). NCBDDD reduces health disparities and the severity of additional conditions that may occur as a result of having a disability. NCBDDD improves the health of people living with life-long disabilities such as *Fragile X*, *Spina Bifida*, *Tourette Syndrome*, and *Muscular Dystrophy*. Targeted health promotion programs, like *Living Well with a Disability*, have been shown to save nearly \$1,000 per person in annual healthcare costs.

Funding for the Center in the FY 2017 Omnibus was \$137,560,000. The Administration's FY 2018 budget for the Center is \$100,000,000, a decrease of \$37,560,000. Our request is for \$152,610,000 for FY 2018, with the additional \$15 million representing the amount needed to sustain the Zika response, which was initiated in FY 2016 while maintaining the core work of the Center. This modest increase over FY 2017 enacted levels would provide adequate funding for NCBDDD and represents a sound public investment that will continue to prevent birth defects and developmental disabilities and help people with disabilities and blood disorders live the healthiest life possible.

More specifically, DRRC opposes the FY 2018 budget requests to eliminate funding for some cancer activities, Racial and Ethnic Approaches to Community Health (REACH), Prevention Research Centers, Epilepsy, Hospitals Promoting Breastfeeding, the National Lupus Patient Registry, Million Hearts, National Early Child Care Collaboratives, and Health Promotion activities.

The Administration proposes a new 5-year chronic disease prevention and health promotion Block Grant, *America's Health* focuses on the leading chronic disease challenges specific to each State, which could include preventing and better managing heart disease and diabetes—two of the most common and costly chronic diseases—as well as arthritis, the leading cause of disability in the United States. For FY 2018, CDC requests \$500,000,000 for the *America's Health* Block Grant, all from the Prevention and Public Health Fund (PPHF).

The National Center for Injury Prevention and Control (NCIPC) is the nation's leading authority on violence and injury prevention. NCIPC is committed to saving lives, protecting people, and lowering the social and economic costs of violence and injuries. NCIPC collects data to identify problems and monitor progress, uses research to understand what works, and promotes evidence-based strategies to inform real-world solutions.

CDC's research and programs include efforts to prevent traumatic brain injury (TBI) and help people better recognize, respond, and recover if a TBI occurs. CDC provides training to coaches, families, and athletes on identifying and preventing TBIs. CDC supports state surveillance, evaluates solutions, identifies best practices for prevention, and works with healthcare providers to improve treatment of TBIs. CDC also is working to develop mild TBI (mTBI) clinical guidelines on the diagnosis and management of mTBI within the pediatric population to address the lack of clinical guidelines for healthcare providers on this issue. Further, CDC is piloting a

new National Concussion Surveillance System to determine accurately how many Americans (children and adults) get a concussion each year, and determine what caused the injury.

Funding for the Center in the FY 2017 Omnibus was \$286,059,000. The Administration's FY 2018 budget for the Center is \$216,000,000, a decrease of \$70,059,000.

The National Center for Health Statistics CDC's National Center for Health Statistics (NCHS) serves as the principal statistical agency designated by OMB to produce official health statistics for the nation. Federal health statistics provide critical information and evidence to shape policies, monitor programs, track progress, and measure change. A strong statistical system is critical to provide information that can answer important questions in public health and public policy. CDC's health statistics data provide critical information to support a robust portfolio of evidence informing a wide variety of program decisions in CDC, HHS, and in other federal agencies. CDC's FY 2018 request of \$155,000,000 for health statistics, including \$142,968,000 in PHS Evaluation Transfer, is more than \$5, million below the FY 2017 level.

Chief Disability and Health Officer, and Disability and Health Work Group. In 2010, CDC appointed Dr. Vince Campbell to serve as the agency's Chief Disability and Health Officer and formed the Disability and Health Work Group. The Work Group, under Dr. Campbell's leadership made substantial progress ensuring that attention was given to disability-related issues throughout CDC's Centers and program areas, including:

- Recognizing disability as a key determinant in national surveys and other surveillance systems, and public health programs;
- Addressing health disparities among persons with disabilities;
- Enhancing health promotion and prevention and access to health care for people with disabilities under the Affordable Care Act;
- 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.

When Dr. Campbell recently retired, his position was not filled. This created a significant void in leadership on disability-related issues at CDC.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

Ask:

DRRC urges the Committee to reject the proposal in the Administration's FY 2018 Budget to transfer the functions performed by AHRQ to NIH and reject the funding decreases for research from the level included in the FY 2017 Omnibus Appropriation legislation.

DRRC also recommends that the report accompanying the FY 2018 Labor, HHS, Education, and Related Agencies bill include the following language:

“The Committee encourages the Department of Health and Human Services, in conjunction with AHRQ, to make a substantial commitment to better support health services research generally, including 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. Health services research is not duplicative of the research portfolio at NIH and efforts to comingle these research programs are misguided. Health services research is critical to identifying the most effective treatments and improving our health care system's outcomes and return on investment.”

DRRC also recommends report language urging AHRQ to include in its research portfolio a focus on disabilities and chronic conditions.

“The Committee encourages AHRQ to include in its research portfolio a focus on disabilities and chronic conditions, including disability as a health disparity which results in disparate health outcomes for people with disabilities. We encourage AHRQ to use all three levels of evidence stratification and assessment recognized by the U.S. Preventive Services Task Force and recognize that the absence of randomized controlled trials does not equate to the absence of evidence. Similarly, the Committee encourages AHRQ to recognize that the inability to draw conclusions about the comparative effectiveness of a treatment does not mean the treatment is ineffective.”

Justification:

The FY 2017 Omnibus Appropriations Act included approximately \$334 million for AHRQ. The FY 2018 budget proposed by the Administration transfers functions performed by AHRQ to NIH, establishes a new institute within NIH known as the National Institute for Research on Safety and Quality (NIRSQ), and reduces the current funding level by approximately \$61 million. NIH and AHRQ have very different missions and conduct and support very different types of research. NIH is the federal government's premier basic science program focusing on biomedical research while AHRQ supports research that examines the impact of specific

healthcare systems and practices on outcomes and quality of care, as opposed to the development of new interventions. As such, its research is more closely aligned with healthcare policy issues than fundamental medical science. More specifically, AHRQ focuses on health services research designed to improve the quality and safety of health care services. AHRQ's unique focus on quality improvement and primary care helps both consumers and health care professionals, to receive and deliver the best health services, respectively. Combining these disparate research programs into one entity would ignore these significant differences, including mission focus and peer review systems, and would be a major mismatch. We strongly support an independent, well supported Agency for Healthcare Research and Quality.

With health care reform's emphasis on quality of care instead of quantity, AHRQ's role in quality improvement is vitally important. Improving the quality of health care will improve the nation's overall health, while putting pressure to health care organizations to deliver high-quality services efficiently.

AHRQ is one of the few research funding agencies that examines cost-effectiveness as well as efficacy of interventions. We know that costs of health care significantly influence patients' decisions, so it is important to preserve AHRQ's role and provide critical information to patients and their families.

Throughout the disability and rehabilitation fields, efficacy research must be enhanced and made a priority. AHRQ is well-suited to assist in achieving this goal. 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 relative 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.

At the same time, it is critical to recognize the criteria developed by the U.S. Preventive Services Task Force for evidence stratification and assessment in ranking treatment effectiveness. DRRC supports the use of the criteria below, including Level II and Level III studies to inform treatment guidelines:

Level I: Evidence obtained from at least one properly designed randomized controlled trial (RCT).

Level II-1: Evidence obtained from well-designed controlled trials without randomization.

Level II-2: Evidence obtained from well-designed cohort or case-control analytic studies, preferably from more than one center or research group.

Level II-3: Evidence obtained from multiple time series with or without the intervention. Dramatic results in uncontrolled trials might also be regarded as this type of evidence.

Level III: Opinions of respected authorities, based on clinical experience, descriptive studies, or reports of expert committees.

DRRC also understands the intent of comparative effectiveness research (CER) is to inform practitioners and patients of the relative risks and benefits of options when making treatment decisions. CER research helps patients and providers understand which treatment options is best, and can help maximize health outcomes and minimize risks and harms. When one considers the many conditions in rehabilitation medicine across the lifespan, we need more CER, not less, in order to “do the right thing, to the right patient, at the right time” (AHRQ, 2003). CER is not intended as a tool for denying patients access to needed care based on best practices, and in fact, the use of evidence-based medicine for such purposes is specifically denounced in state laws as well as the Affordable Care Act. Accordingly, it is important to recognize that the absence of an RCT does not equate to the absence of evidence. Given the nature of rehabilitation science, payers and other policymakers should be focused on the best available evidence, not Level I evidence alone. Similarly, the inability to draw conclusions about the comparative effectiveness of a treatment does not mean the treatment is ineffective.

COMPREHENSIVE GOVERNMENT-WIDE STRATEGIC PLAN

Ask:

DRRC recommends that the report accompanying the FY 2018 Labor, HHS, Education, and Related Agencies bill include the following language:

“The Committee expects the Interagency Committee on Disability Research will submit to this Committee by no later than January 2019a copy of the comprehensive, government wide strategic plan for disability, independent living, and rehabilitation research mandated by Section 203(c) of the Rehabilitation Act, as added by Section 434 of the Work Incentives Improvement Act. The plan must include, at a minimum, all of the information prescribed in the legislation. The plan will identify areas of duplication and overlap and gaps in research by recommending strategies for improving the coordination and collaboration among agencies. The Committee expects that the Secretary of HHS will fund this endeavor from funds designated for his or her Office and may seek support from the various agencies conducting disability, independent living, and disability research throughout the federal government, including those listed in Section 203(a) of the Rehabilitation Act.”

Justification:

Section 434 of the Work Incentives Improvement Act (WIOA), which added Section 203(c) to Title II of the Rehabilitation Act, directs the Interagency Committee on Rehabilitation Research (ICDR) to develop a “comprehensive government wide strategic plan for disability, independent living, and rehabilitation research.” The strategic plan must include, at a minimum: measurable goals and objectives; existing resources each agency will devote to carrying out the plan; timetables for completing projects outlined in the plan; and assignment of responsible individuals and agencies for carrying out the research activities.

In addition the strategic plan must include research priorities and recommendations; a description of how funds from each agency will be combined, as appropriate, for projects administered among Federal agencies, and how such funds will be administered; the development and ongoing maintenance of a searchable government wide inventory of disability, independent living, and rehabilitation research for trend and data analysis across federal agencies; guiding principles, policies, and procedures, consistent with the best research practices available, for conducting and administering disability, independent living, and rehabilitation research across federal agencies; and a summary of underemphasized and duplicative areas of research.

The strategic plan must be submitted to the President and applicable committees.

Section 203(a) of the Rehabilitation Act, as amended, specifies the agencies and departments that compose the ICDR.

CONTACTS

Thank you again for providing us with the opportunity to share our comments. If you have any questions, please contact Bobby Silverstein (email: Bobby.Silverstein@powerslaw.com; phone: 202.466.6550); Peter Thomas (email: Peter.Thomas@powerslaw.com; phone: 202.466.6550); or Leif Brierley (email: Leif.Brierley@powerslaw.com; phone: 202.466.6550)

Sincerely,

Academy of Spinal Cord Injury Professionals
American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine & Rehabilitation
American Association on Health and Disability
American Congress of Rehabilitation Medicine
American Foundation for the Blind
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
Amputee Coalition of America
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Association of University Centers on Disabilities
Brain Injury Association of America
Child Neurology Society
Christopher and Dana Reeve Foundation
National Association for the Advancement Orthotics & Prosthetics
National Association of Rehabilitation Research Training Centers
National Association of State Head Injury Administrators
National Multiple Sclerosis Society
Paralyzed Veterans of America
RESNA
United Spinal Association