DISABILITY AND REHABILITATION RESEARCH COALITION
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June 8, 2018

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

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

RE: FY 2019 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 2019 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.

DRRC recommends that the FY 2019 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] 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.

1. **National Institutes of Health (NIH):** Build upon the funding increases approved for the NIH in the FY 2018 omnibus appropriations legislation, and adopt funding increases comparable to those included in the FY 2018 Omnibus Appropriations legislation. Such funding increases help support medical rehabilitation research conducted across the various NIH Institutes and Centers, including the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the Institute in which the National Center for Medical Rehabilitation Research (NCMRR) is housed. Include report language to enhance the stature, visibility, and coordination of medical rehabilitation research across the NIH. Also, include report language to encourage NIH to support research on nonpharmacological interventions for pain.
2. **National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at the Administration for Community Living (ACL):** Increase funding for the NIDILRR to $119 million from $104,970,000 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. Include report language to recognize 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), and to reject the Administration's FY 2019 Budget proposal to decrease funding for NIDILRR and transfer and consolidate NIDILRR within the NIH.
3. **Traumatic Brain Injury (TBI) State Grant Program at ACL.** Increase funding for TBI State Grant Programs by $2 million in FY 2019.
4. **Centers for Disease Control and Prevention (CDC).** Reject the significant reductions in funding for FY 2019 proposed by the Administration for CDC and instead continue to 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.
5. **The Agency for Healthcare Research and Quality (AHRQ).** Reject efforts to decrease funding and transfer AHRQ to the 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).** Include funding for the completion of a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research to avoid duplication and identify gaps. Such funds should be designated from the Office of the Secretary of HHS. Include report language recommending that the ICDR issue a final government-wide strategic plan that is consistent with the goals and objectives of Title II of the Rehab Act, as amended.
7. **Substance Abuse and Mental Health Services Administration (SAMHSA).** DRRC recommends that the report accompanying the Senate's bill specify at least $7.828 million for Practice Improvement and Training programs within the total provided for Mental Health Programs of Regional and National Significance. Also, the DRRC recommends the Committee continue to recognize the critical need for programs such as

Rehabilitation Research and Training Centers (RRTCs), which advance the current knowledge base of the mental health delivery system by supporting evaluation studies, training, technical assistance, and knowledge translation activities that help adults with serious mental health illness achieve their life goals.

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:

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. We strongly oppose cuts proposed by the Administration's FY 2019 budget to critical research programs, which are essential for individuals with disabilities an our nation's efforts to enable people with disabilities to maximize their health and function, employment, and independence.

MEDICAL REHABILITATION RESEARCH AT NIH

Ask:

DRRC recommends that the Committee build upon the funding increases approved for the NIH in the FY 2018 omnibus appropriations legislation and adopt funding increases comparable to those included in the FY 2018 Omnibus Appropriations legislation. Such funding increases help support medical rehabilitation research conducted across the various NIH Institutes and Centers, including the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the Institute in which the National Center for Medical Rehabilitation Research (NCMRR) is housed.

DRRC also recommends that the report accompanying the FY 2019 Labor, HHS, Education, and Related Agencies bill support research on nonpharmacological interventions to address pain. In light of the ongoing national opioid epidemic, such interventions, including rehabilitative care such as physical therapy, occupational therapy, and others, can provide proven alternatives to opioids for treatments of acute and chronic pain.

DRRC also recommends that the report accompanying the FY 2019 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 NIH's ongoing efforts to ensure medical rehabilitation research is coordinated across NIH, and encourages senior leadership at NIH Institutes and Centers to become more involved in such coordination through the Medical Rehabilitation Coordinating Committee at NIH. Additionally, the Committee encourages NIH to incorporate the definition of medical rehabilitation research contained within Section 2040 to ensure consistent tracking of rehabilitation research across NIH. Additionally, the Committee encourages NIH Institutes and Centers engaged in rehabilitation and disability research to issue Program Announcements (PAs) and/or Requests for Application (RFAs) that signal to researchers priority areas of interest for investigator-initiated research. The Committee is most focused on research that addresses the wide range of needs identified by the National Center for Medical Rehabilitation Research (NCMRR) through the NIH Research Plan on Rehabilitation. Finally, the Committee encourages the NIH to support research on nonpharmacological interventions, including rehabilitative and habilitative care such as physical and occupational therapy, for the treatment of acute and chronic pain conditions."

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 2018.

In FY 2018, NICHD received an appropriation of $1,452,006,000. The Administration's FY 2019 budget proposes to reduce NICHD's appropriation to $1,340,000,000, a decrease of $112,006,000. Under a policy adopted by the Director of NICHD, NCMRR receives 6.5 percent of the NICHD's extramural research budget. The FY 2019 budget proposed by the Administration would result in a reduction in funding of more than $7 million for NCMRR. DRRC strongly supports meaningful funding increases, comparable to increases included in FY 2018 enacted levels, for this vital Institute.

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 a 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.

The ongoing opioid crisis in the United States reflects the unintended consequences of a nationwide effort to help individuals control their pain. The health care system has, since the

mid-1990s, employed an approach to pain management that focuses on the pharmacological masking of pain, rather than treating the actual cause(s) of the pain when its source can be identified. This strategy has resulted in a dramatic increase in opioid prescribing, causing widespread opioid misuse and addiction. It also has led, in the last few years, to a growing realization that current strategies for managing pain have to change—that opioid-centric solutions for dealing with pain—which, at best, mask patients' physical problems and delay or impede recovery and, at worst, may prove to be dangerous or even deadly. Moving forward, the health care system must reexamine its approach to pain, including how causal factors are identified, what tools or measures are used to quantify its impact, and how the approach to treatment is aligned with the patient's goals and values.

Nonpharmacological interventions, including rehabilitative and habilitative care such as physical and occupational therapy, have been shown to be highly effective for the treatment of acute and chronic pain conditions. Recent recommendations by the US Centers for Disease Control and Prevention (CDC) in its "Guideline for Prescribing Opioids for Chronic Pain" state that "Non-pharmacologic therapy and non-opioid pharmacologic therapy are preferred for chronic pain." The report expands on this thought, suggesting that "many non-pharmacologic therapies, including physical therapy…can ameliorate chronic pain." The DRRC is encouraged by these findings, and encourages the Committee to urge the NIH to support research on nonpharmacological interventions for pain.

NATIONAL INSTITUTE ON DISABILITY, INDEPENDENT LIVING, AND REHABILITATION RESEARCH (NIDILRR) AT THE ADMINISTRATION FOR COMMUNITY LIVING (ACL)

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 $104,970,000 for FY 2018. NIDILRR's pre-sequestration funding level was $108,599,000. The Administration has requested $95,000,000, a decrease of $9,970,000 from the FY 2018 Omnibus Appropriations Act and a decrease of $13,599,000 from the FY 2013 pre-sequestration level. Our requested 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 at NIDILRR that remain unfunded.

DRRC also recommends that the report accompanying the FY 2019 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. The Committee does not support the Administration's FY 2019 proposal to move NDIILRR to the National Institutes of Health (NIH), which would be detrimental to the critical, complementary, and unique mission and work of NIDILRR."

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 $103,970,000 until this year, when the FY 2018 Omnibus provided a $1 million increase for a total of $104,970,000. The Administration's FY 2019 budget request for NIDILRR is $95,000,000, a decrease of $9,970,000 for the FY 2018 Omnibus Appropriation Act, and a decrease of $13,599,000 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.

TRAUMATIC BRAIN INJURY (TBI) STATE GRANT PROGRAM AT ACL

Ask:

DRRC urges the Committee to include a $2 million increase for FY 2019 for TBI State Grant Programs at ACL.

Justification

The TBI State Partnership Grant Program provides funding to help states increase access to services and supports for individuals with TBI throughout the lifetime. This grant program is one component of the federal TBI Program, along with Protection & Advocacy, which is expected to:

- Help states expand and improve state and local capability so individuals with TBI and their families have better access to comprehensive and coordinated services.
- Generate support from local and private sources for sustainability of funded projects after federal support terminates. This is done through state legislative, regulatory, or policy changes that promote the integration of TBI-related services into state service delivery systems.
- Encourage systems change activities so that individual states can 1) evaluate their current structures and policies and 2) improve their systems as needed to better meet the needs of individuals with TBI and their families.

Between 1997 and 2013, 48 states, two territories, and the District of Columbia received at least one state agency grant. As of October 2016, 19 states receive funding for SPGs.

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, proposed by the Administration.

With respect to the National Center for Chronic Disease Prevention and Health Promotions, DRRC recommends the Committee include reasonable funding increases compared to those included in the FY 2018 Omnibus Appropriations legislation.

With respect to the Center on Birth Defects and Developmental Disabilities, DRRC recommends $152,610,000 for FY 2019, with the additional funding 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 2018 Omnibus was $140,560,000.

With respect to the National Center for Injury Prevention and Control, DRRC recommends maintaining funding for the National Injury Center's Unintentional Injury Division's Elderly Falls Prevention Program ($2.050 million). DRRC recommends the Committee increase funding for Injury Control Research Centers (currently funded at $9 million in FY 2018). 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. The Senate FY 2018 Appropriations report language offered support for such a surveillance system, stating, "The Committee is aware of the promising progress CDC has made in creating a comprehensive survey instrument which the agency will be piloting in the coming months to prepare for a national survey in the future. The Committee supports CDC's work in this area and urges the agency to increase its efforts." DRRC appreciates this language and supports additional funding and language in support of these efforts in FY 2019.

With respect to the National Center on Health Statistics, DRRC recommends the same funding levels included in the FY 2018 Omnibus Appropriations legislation.

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 2018 Omnibus was $1,162,896,000. The Administration's FY 2019 proposed budget for the Center is $939,250,000, a reduction of $223,646,000. DRRC strongly opposes any funding decreases to these programs, and reiterates our recommendation that the Committee include reasonable funding increases.

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 factors, 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 2018 Omnibus was $140,560,000. The Administration's FY 2019 budget for the Center is $110,000,000, a decrease of $30,560,000, or 22 percent. Our request is for $152,610,000 for FY 2019, with the additional amount 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 2018 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 2019 budget proposals 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 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 2018 Omnibus was $648,559,000. According to the FY 2018 Omnibus Appropriations Act report language, this funding level, which represents a significant total dollar increase over FY 2017's funding level ($286,059,000), is due to the inclusion of over $400 million to be directed to opioid-related programs, effectively serving as a decrease to the

overall levels for the Center compared to FY 2017. The Administration's FY 2018 budget for the Center is $266,000,000, a decrease of $382,259,000, 59 percent of the budget for the Center.

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 2019 request of $155,000,000 for health statistics is about $5 million below the FY 2018 enacted level.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

Ask:

DRRC urges the Committee to reject the proposal in the Administration's FY 2019 Budget proposal to decrease funding for AHRQ and transfer and consolidate the functions performed by AHRQ to NIH. Congress included a $10 million increase for AHRQ in FY 2018; DRRC supports inclusion of a similar increase in FY 2019.

DRRC also recommends that the report accompanying the FY 2019 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 2018 Omnibus Appropriations Act included approximately $334 million for AHRQ. The FY 2019 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 levels. 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 medial 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. 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 2020 a 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.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

Ask:

DRRC recommends that the report accompanying the bill specify at least $7.828 million for Practice Improvement and Training programs within the total provided for Mental Health Programs of Regional and National Significance. Currently, Practice Improvement and Training is funded at $7.828 million, and the Administration has requested $7.828 million for FY 2019, level funding the program.

DRRC also recommends that the report accompanying the FY 2019 Labor, HHS, Education, and Related Agencies bill include the following language:

> "Under Practice Improvement and Training programs, the Committee continues to recognizes the critical need for programs such as Rehabilitation Research and Training Centers (RRTCs), which advance the current knowledge base of the mental health delivery system by supporting evaluation, training, technical assistance, and knowledge translation activities that help adults with serious mental health conditions achieve their life goals."

Justification:

The Practice Improvement and Training programs address the need for disseminating key information, such as evidence-based mental health practices, to the mental health delivery system through activities including those conducted by Rehabilitation Research and Training Centers (RRTCs). RRTCs seek to advance the current knowledge base by supporting evaluation, training, technical assistance, and knowledge translation activities that help adults with serious mental health conditions achieve their life goals. The RRTCs are funded in partnership with the Administration for Community Living's National Institute on Disability, Independent Living, and Rehabilitation Research. Currently, there are two RRTCs focused on adults, funded for up to five years within this program area. The first program, RRTC on Improving Employment Outcomes for Persons with Mental Illness, is conducting evaluation studies, as well as providing training, technical assistance and knowledge translation for stakeholders (e.g. providers, administrators, employers, families, people with mental health conditions, educators), on using existing and new employment interventions to improve employment outcomes as a pathway to recovery. The second program, the RRTC on Center Self-Directed Recovery and Integrated Health Care, is currently conducting evaluation studies and providing training, technical assistance, and dissemination to develop, adapt, and enhance self-directed models of medical, mental health, and nonmedical services designed to improve health, recovery and employment outcomes for individuals with serious mental health conditions.

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CONTACTS

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On behalf of the members of the Disability and Rehabilitation Research Coalition, thank you for providing us with the opportunity to share our comments.

Sincerely,

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Principal, Powers Law

DRRC Members

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 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
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
Rehabilitation Engineering and Assistive Technology Society of North America
United Spinal Association