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Submitted Electronically

August 16, 2024

The Honorable Cathy McMorris Rodgers
Chair
Energy and Commerce Committee
U.S. House of Representatives
Washington, D.C. 20515

RE: DRRC Response to “Reforming the National Institutes of Health: Framework for Discussion”

Dear Chair McMorris Rodgers:

The Disability & Rehabilitation Research Coalition (DRRC), a coalition of national non-profit organizations committed to improving the science of medical rehabilitation, disability, and independent living, write to share our feedback on the recent framework for discussion to restructure the National Institutes of Health (NIH) and the establishment of a new institute dedicated to disability research.

The DRRC is a coalition of 25 national research, clinical, and consumer non-profit organizations committed to improving the science of disability, independent living, and rehabilitation. The DRRC seeks to maximize the return on the federal research investment in these areas with the goal of improving the ability of Americans with disabilities to live and function as independently as possible following an injury, illness, disability, or chronic condition.

Our coalition has long advocated for increased focus and resources on disability and rehabilitation research, and we are pleased to see a National Institute for Disability Related Research in the framework. The DRRC strongly advocated for the designation of people with disabilities as a “health disparities population” by the National Institute on Minority Health and Health Disparities (NIMHD) in September 2023 which allows NIH funding for projects focusing on disability health disparities and enhances participation of clinical researchers and participants with disabilities. We acknowledge and appreciate your recognition of the need for a freestanding institute in this critical area. Such an institute could significantly enhance the coordination and impact of research aimed at improving the lives of individuals with disabilities, including individuals with brain and spinal cord injuries, limb loss and limb difference,

neurological and musculoskeletal conditions, intellectual and developmental disabilities, and many other disabling conditions. Rehabilitation and disability research encompasses the whole person and includes numerous body systems. We recognize the proposal's intent to enhance these areas and thank you for your support for improved health outcomes for individuals with disabilities and chronic conditions.

Establishment of an NIH institute dedicated to rehabilitation and disability research has been a goal of the disability and rehabilitation research communities for decades. In 1990, the NIH Reauthorization Act¹ was enacted which created the National Center for Medical Rehabilitation Research (NCMRR) within the National Institute of Child Health and Human Development (NICHD). Because of the cross-cutting nature of rehabilitation and disability research, the legislation also created a Medical Rehabilitation Coordination Committee (MRCC) chaired by the NCMRR Director. To maximize the return on investment on rehabilitation science, Congress passed in 2016 the Enhancing the Stature and Visibility of Medical Rehabilitation Research at the NIH Act (S. 800).

In 2012, Dr. Collins initiated a Blue Ribbon Panel on Medical Rehabilitation Research to conduct a landscape survey of rehabilitation science. The resulting Blue Ribbon Panel Report led to several immediate policy changes at the NIH, and the DRRC began to shepherd new federal legislation required to implement additional recommendations. Presently, NIH invests over \$900 million annually in rehabilitation and disability research and, due to the cross-cutting nature of rehabilitation science, these dollars are spread across most of the 27 institutes and centers. Both the Office of the NIH Director's Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) and the MRCC play a role in coordinating rehabilitation science to maximize the return on investment.

Given our long-standing goal, our initial inclination is to support the creation of a free-standing NIH Institute on Disability Related Research. However, in examining the comprehensiveness of the proposed reorganization of NIH, the DRRC has concerns about the broader implications of a such a massive overhaul of the NIH structure to accommodate this new institute. Although we support the idea of establishing an institute focused on disability-related science, we are cautious about the potential costs and disruptions associated with such a major reorganization. It is essential to weigh the benefits of a dedicated institute against the possible drawbacks, unintended consequences, unresolved questions, and the impact on existing research programs and infrastructure. In short, DRRC would need to know far more detail about such a reorganization effort before we would lend our support to such a major initiative. Above all, we would not want a reorganization of this magnitude to divert NIH's attention for a multi-year period away from advances in basic and clinical science, particularly in the area of rehabilitation and disability research without a much clearer understanding of the benefits of this exercise.

¹ National Institutes of Health Revitalization Amendments of 1990, H.R. 5661, 101st Cong. (1990).

As a longtime supporter of and advocate for federal investment in rehabilitation and disability science, we believe it is crucial to highlight the expertise that currently exists within NIH, particularly in the National Center for Medical Rehabilitation Research (NCMRR) and broadly across the Department of Health and Human Services (HHS). We also wish to highlight the importance of maintaining a diverse ecosystem of funding and research support. Federal entities like the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the Administration for Community Living (ACL), the Centers for Disease Control and Prevention (CDC), the Veterans Administration, the Department of Defense, the National Science Foundation, and the Agency for Healthcare Research and Quality (AHRQ) each play vital roles in funding and supporting different aspects of rehabilitation and disability research. The government-wide rehabilitation and disability research agenda is coordinated by the Interagency Committee on Disability Research (ICDR), chaired by the Director of NIDILRR. The work of these agencies complements NIH's efforts and addresses unique aspects of health and disability that are not be fully captured under the NIH framework and its emphasis on basic and clinical science. This expertise should be preserved in any NIH restructuring efforts to ensure that existing strengths are not lost in the process.

Therefore, as a coalition, we are not convinced at this point that a total rewrite of NIH's structure is necessary to improve its functioning or to ensure the best return on investment for research funding, including funding the rehabilitation and disability research agenda. We advocate for thoughtful, evidence-based improvements where needed but caution against a wholesale reorganization that might detract from ongoing research efforts.

In light of these concerns, we recommend a more measured approach that includes thorough consultations with stakeholders, including researchers, clinicians, and individuals with disabilities, the ultimate beneficiaries of disability and rehabilitation research. The DRRC is committed to being a constructive partner in these discussions, aiming to maximize the impact of research on improving lives while maintaining a robust and effective research infrastructure. As discussions on this proposal continue, we remain committed to being a supportive partner and resource. We share the common goal of maximizing the impact of federal research dollars to bring meaningful improvements to people's lives, especially people with disabilities and chronic conditions. We look forward to working collaboratively with you and your colleagues to ensure that any changes made will enhance, rather than hinder, our shared mission.

Thank you for your attention to this matter and for your ongoing leadership in advancing health and disability research. Please contact DRRC Co-Coordinator Peter Thomas at Peter.Thomas@PowersLaw.com or Natalie Keller at Natalie.Keller@PowersLaw.com

Sincerely,

The Undersigned Members of the Disability & Rehabilitation Research Coalition