



April 9, 2024

Monica Bertagnolli, M.D.
Director, National Institutes of Health (NIH)
9000 Rockville Pike
Bethesda, Maryland 20892

CC: Tara Schwetz, Ph.D.
Director, NIH Division of Program Coordination, Planning, and Strategic Initiatives

RE: Meeting Request and Support for WGD-SID Recommendations

Dear Director Bertagnolli,

The Disability and Rehabilitation Research Coalition (DRRC) Steering Committee would like to schedule a meeting with you to discuss the implementation of the recommendations of the Working Group on Diversity's Subgroup on Individuals with Disabilities ("WGD-SID Recommendations"). These recommendations were unanimously endorsed by the Advisory Committee to the NIH Director (ACD) on December 9, 2022. Several have already been adopted, including the official designation of people with disabilities as an NIH health disparity population on September 26, 2023, but other critical actions, including the creation of a Disability Research Office (DRO), have not yet occurred. We want to help.

The DRRC, formed in 2008, includes 24 national research, clinical, and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. We seek to maximize the return on the federal research investment to improve the ability of Americans with disabilities to live and function as independently as possible following an injury, illness, disability, or chronic condition.

In 2010, DRRC leaders began to meet periodically with NIH Director Francis Collins and NICHD Director Duane Alexander to discuss medical rehabilitation research efforts at the NIH. 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.

In 2016, Senate Bill 800, the *Enhancing the Stature and Visibility of Medical Rehabilitation Research at the NIH Act* was enacted, and DRRC leadership worked with NIH to implement its provisions. As a result, the NIH now boasts over \$900 million in rehabilitation and disability research across the 29 institutes and centers. The DRRC has continued to lobby aggressively for increased funding for the NIH and related federal research agencies like the National Institute on

Disability, Independent Living and Rehabilitation Research (NIDILRR) and the Centers for Disease Control (CDC).

During the pandemic, the disability community, including DRRC member organizations, was horrified by the disproportionate morbidity and mortality impacts of COVID-19. After the election of President Biden, we worked tirelessly with the new Administration and a broad array of disability research and advocacy organizations to recognize and begin to address the enormous health and healthcare disparities experienced by Americans with disabilities. We were encouraged when the ACD Working Group on Diversity established its Subgroup on Individuals with Disability. While we were not part of their confidential deliberations, we coordinated messaging on potential NIH reforms and their impacts with stakeholders in the disability research community.

We enthusiastically supported the ACD-endorsed WGD-SID recommendations and stand ready to assist with their implementation. Establishing a dedicated Disability Research Office (DRO), housed within the Office of the NIH Director, appears to be the logical next step for this implementation process. Such an office would serve as a critical hub for advancing disability and rehabilitation research, coordinating disability-related research and activities across the NIH Institutes, Centers, and Offices, and ensuring meaningful input from the disability community on NIH programs and policies. The new DRO would amplify the NIH's public health impact, contribute to improved health outcomes for millions of Americans with disabilities, and advance the pace of biomedical research beyond what is currently possible.

We understand that a new DRO will require new federal funding, particularly given the size and diversity of the disabled population in the US (advocates often cite the United Nations' definition of people with disabilities as "the world's largest minority group" to highlight the ubiquitous role of disablement across the life course). Like the Office of Research on Women's Health, it may require new federal legislation to adequately fund the DRO, and we are willing to work with a bipartisan group of Congressional disability allies and the White House on this issue. We are also eager to discuss the administrative requirements for this action with the Division of Program Coordination, Planning and Strategic Initiatives, which is why we have copied Director Schwetz on this letter.

We look forward to continuing to engage with NIH as the agency addresses implementation of these recommendations. Our member organizations strongly support the recommendations as an essential step forward for the entire scientific community. If you have any questions, or if the DRRC can provide any assistance to you and your colleagues, please do not hesitate to contact Peter Thomas and Natalie Keller, DRRC Co-Coordinators, at Peter.Thomas@PowersLaw.com and Natalie.Keller@PowersLaw.com, or call 202-349-4251.

Sincerely,

The Undersigned Members of DRRC

American Academy of Physical Medicine and Rehabilitation
American Association on Health & 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
Association of Academic Physiatrists*
Association of University Centers on Disabilities
Brain Injury Association of America*
Christopher & Dana Reeve Foundation
National Association for the Advancement Orthotics & Prosthetics
National Association of Rehabilitation Research and Training Centers*
Rehabilitation Engineering and Assistive Technology Society of North America
Spina Bifida Association
United Spinal Association

**** DRRC Steering Committee Member***