



November 24, 2023

SUBMITTED ELECTRONICALLY

Monica Bertagnolli, M.D.
Director
National Institutes of Health
1 Center Drive
Bethesda, MD 20892

Re: DRRC Comments on the Proposed Update to the NIH Mission Statement

Dear Dr. Bertagnolli:

The undersigned members of the Disability & Rehabilitation Research Coalition (DRRC) greatly appreciate the opportunity to provide comments on the proposed update to the National Institutes of Health (NIH) mission statement.

The DRRC is a coalition of 26 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 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.

The DRRC believes that the NIH must address systemic and structural factors that contribute to the exclusion of people with disabilities both in the scientific workforce and with respect to clinical research participation through an agency-wide culture shift. The DRRC enthusiastically applauds NIH's efforts to implement this culture shift in a variety of ways, including the endorsement of the landmark recommendations from the Advisory Committee to the Director (ACD) Working Group on Diversity, Subgroup on Individuals with Disabilities, December 2022 report, new Notices of Funding Opportunities (NOFOs) for research into ableism and health disparities, and the recent designation of people with disabilities as a distinct health disparities population.

We are also pleased that NIH is prioritizing disability inclusion by proposing a new NIH mission statement that reflects this cultural shift and hope this action propels future changes throughout NIH's Institutes and Centers. The NIH's current mission statement is "to seek fundamental knowledge about the nature and behavior of living systems **and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.**" The proposed revision eliminates the phrase "reduce illness and disability" which stems from a medical model of disability and can perpetuate an ableist view of disability as a disease or condition to cure.

The proposed revised mission statement would read “to seek fundamental knowledge about the nature and behavior of living systems and **to apply that knowledge to optimize health and prevent or reduce illness for all people.**”

We strongly support the removal of “reduce [...] disability” from the mission statement as one step in NIH’s larger cultural shift to promote inclusivity in part by combating ableist language and beliefs. It is important to recognize that, in the large and diverse population of people with disabilities, many find identity and pride in their disability. The mission statement of the world’s largest biomedical research funding agency should not undermine the disability community’s right to claim their identity rather than reducing “disability” to a medical term describing a condition to be cured. This recognition and removal of ableist language will help NIH in its objectives to cultivate a diverse workforce, forge partnerships with diverse stakeholders, and focus on research that addresses the needs of underserved populations in pursuit of optimizing health, reducing illness, and reducing health disparities.

While strongly endorsing NIH’s proposed removal of the phrase “reduce illness and disability” from its current mission statement, the DRRC believes that NIH must continue its vital emphasis on rehabilitation and disability research as a component of optimizing health. In fact, if one key concept is missing from the revised mission statement, it would be inclusion of research to maximize function. An individual can be considered perfectly healthy by medical metrics and still lack the ability to perform daily activities and function independently due to disability. This is the reason why the President’s Commission on Consumer Protection and Quality in the Healthcare Industry debated and agreed on the following statement in their seminal final report entitled “Quality First: Better Health Care for All Americans,” issued on March 12, 1998:

“The purpose of the health care system must be to continuously reduce the impact and burden of illness, injury and disability, and to improve the *health and functioning* of the people of the United States.” [Emphasis added]

Despite ableist language involving the “burden of disability” in this report, the report establishes that the purpose of the health care system is to improve *health and functioning* of the people of the United States. For instance, a person who loses a lower limb in an accident may be perfectly healthy from a medical standpoint, but may have significant functional limitations if not provided with appropriate prosthetic limb care. In this manner, the concept of function is critical to the disability population and should be considered for inclusion in the revised NIH mission statement as a central aim of scientific research. We suggest NIH consider language focused on pursuing scientific advancements that improve the ability of people with disabilities to live and work in our society. We suggest the following language to reflect that outlook: “...and to apply that knowledge **to optimize health and function, and prevent or reduce illness for all people.**” Many of our member organizations support adding this language to the mission statement as both a strategic and symbolic effort to ensure priority setting at NIH includes a focus on people with disabilities.

Additionally, an even more representative mission statement would include language that captures the broader purpose of research not only for people with disabilities but all human beings. NIH may also wish to consider including the following language in its revised mission statement: “...and to apply that

knowledge **to optimize health and function, and prevent or reduce illness for all people in the pursuit of improving quality of life, independent living, and participation in the community.**" This phrase would serve to promote a fundamentally people-focused mission for NIH that includes individuals with disabilities.

We greatly appreciate your consideration of our comments and NIH's ongoing efforts to advance disability inclusion across NIH's Institutes and Centers and the entire scientific workforce. We look forward to continuing to engage with NIH as the agency addresses implementation of other recommendations and offer any support that we can provide. Our member organizations strongly support the mission statement change as an essential step forward for the entire scientific community. Should you have any further questions regarding this letter, please contact DRRC Co-Coordinator at Peter.Thomas@PowersLaw.com or Natalie.Keller@PowersLaw.com or by calling 202-466-6550.

Sincerely,

The Undersigned Members of DRRC

American Academy of Orthotists & Prosthetists

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*

National Association for the Advancement Orthotics & Prosthetics

Rehabilitation Engineering and Assistive Technology Society of North America

Spina Bifida Association

United Spinal Association

Indicates DRRC Coalition Steering Committee Member*