DISABILITY AND REHABILITATION RESEARCH COALITION
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# DRRC Final Response to NINDS Strategic Planning

*(Submitted 11/1/19)*

**Goal 1: Be a model of excellence for supporting and performing paradigm-changing, innovative, and rigorous neuroscience research. (10,000 character limit)**

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to provide comments on the strategic planning process at the National Institute of Neurological Disorders and Stroke (NINDS). The DRRC is a coalition of more than 20 national research, clinical, and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. 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. The coalition plays a leadership role in coordinating the activities of stakeholders to increase and leverage federal resources devoted to research and development in the areas of rehabilitation, disability, and independent living.

We appreciate the role of NINDS as one of, if not the largest funders of rehabilitation research at the National Institutes of Health. We offer our perspective below on the role NINDS should continue to play in advancing disability, independent living, and rehabilitation science, and we hope that this will continue to be a critical element of NINDS' strategic plan for the next ten years. To the extent that NINDS performs rehabilitation research, we hope that the strategic plan will ensure an understanding of rehabilitation research that is cross-cutting, multi-disciplinary, and focused on 1) understanding the mechanisms of disability, 2) restoring and improving functional capacity in individuals undergoing rehabilitation and individuals with disabilities, and 3) maintaining and preventing the deterioration of functional skills while enhancing quality of life and supporting societal participation across the lifespan for people with disabilities, including for those with disparities.

As the health care system in the United States continues to pursue truly value-based care, we hope that NINDS' research efforts can include priorities aimed at expanding the translational impact of NINDS disability and rehabilitation research, with increased focus on efficacy studies, comparative effectiveness research, and new and innovative models of rehabilitation treatment in order to continue building the evidence base for rehabilitation services and devices and to optimize the impact of research and development on people with disabilities and functional impairments. To the extent possible, this should include a focus on sensitive, feasible, and practical measures of function, meaningful participation, and engagement. NINDS' current and future research on disability, especially effective interventions and outcomes, can and should help policymakers develop improved reimbursement policy for disability and rehabilitation, and in turn increase access for individuals with disabilities to evidence-based care.

With 1 in 5 Americans currently living with disability, and the aging population, a comprehensive understanding of disability and age is crucial to research across NIH, and especially within NINDS. The plan should prioritize funding research that will help develop a deeper understanding of rehabilitation's effects on disability and preserving brain health into old age to prevent cognitive and functional decline associated with brain-related conditions.

In addition to our comments about broad-based disability and rehabilitation research in the NINDS portfolio, we believe there is a need to explore specific fields in greater depth. The Brain Research through Advancing Innovative Technologies (BRAIN) Initiative is an important step forward for NINDS and NIH as a whole. We suggest that the updated NINDS strategic plan highlight and expand upon this initiative and focus on the opportunities for research advancement in the brain injury and stroke fields. More work is needed to develop best practices and pathways to effective care for treating, intervening, rehabilitating, and facilitating full participation for individuals with brain injury and stroke. More research is needed specifically around developing the knowledge base for dosing, pharmacological and therapeutic interventions, behavioral needs and interventions, and cognitive impairments within these populations.

Additionally, the strategic plan should promote research related to complementary approaches to rehabilitation, which can support a range of beneficial outcomes. For instance, the Department of Defense has recently funded research for the use of mobile games for neurocognitive assessment and treatment purposes. Specifically, the focus is to increase treatment compliance and engagement among soldiers using prescribed games, or recreation, as a treatment modality that is fun and engaging while also demonstrating high adherence rates. Additionally, mobile technologies can be used to collect data related to recreational and gaming interventions while supporting researchers and clinicians for diagnostic- and treatment-related goals.

In the spinal cord injury (SCI) area of research, NINDS must encourage research that provides improved care for SCI patients in the acute trauma setting so that individuals with SCI are transported to the appropriate rehabilitation facilities in order to increase access their maximum rehabilitation potential and functional mobility outcomes. Additionally, NINDS research should expand SCI education and SCI expertise throughout the rehabilitation continuum, and increase the application of assistive technologies to improve functional recovery for individuals with SCI. Specifically, we encourage NINDS to facilitate research efforts to: designate SCI Centers of Excellence to define standards of care; ensure that interdisciplinary and SCI-specific expertise be present in rehabilitation facilities with SCI programs across the country; support on-site SCI education, particularly in the areas of autonomic dysreflexia, bowel and bladder management programs, and skin care programs; support and enhance the critical role of the rehab continuum for the SCI and SCD community in outpatient and community programs; and collect rehabilitation outcomes and health economics data to compare outcomes across settings and review health costs across the rehabilitation continuum.

The NINDS strategic plan should also elevate research around adaptive fitness, exercise, and nutrition throughout the plan. Research investigating the utility of integrating these basic but critical building blocks to good health in rehabilitation is woefully lacking. For too long, research

gaps have only widened in studying the health outcomes that adaptive fitness, exercise, and nutrition can produce in rehabilitation programs when integrated into the treatment plan. This should be considered a priority throughout all of NINDS' and NIH's research efforts.

Finally, 21st century research practice increasingly recognizes the importance of breaking down the divisions between researchers and their subjects, in order to create more equitable and meaningful research. NINDS and the updated strategic plan should adopt the community engagement requirements used by the National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the Patient-Centered Outcomes Research Institute (PCORI) as it outlines its research priorities for years to come. Fundamentally, people with a disease, impairment, or functional limitation are the experts on living with specific disabilities or rehabilitation needs and should be recognized as such. The National Center for Medical Rehabilitation Research led the way at the NIH by including six out of eighteen NCMRR Advisory Board members as persons with disabilities. It is now time that many or most of the rehabilitation studies sponsored by NINDS (and NIH as a whole) should include relevant stakeholders in research development, data collection, analysis and interpretation, and the dissemination and utilization of research findings.

Overall, the impact of NINDS research on rehabilitation specifically has been significant, and we hope that the strategic plan will continue to prioritize this critical area. Specifically, it is important to emphasize research focused on neuro-recovery and function, as well as the specific areas outlined above. We also hope that the plan will consider certain areas of evolving science, including the delivery of treatment and rehabilitation in the home, the role of stem cells in neuroscience and the treatment of neurological disease, and the integration of biologic and functional phenotyping into recovery science. Lastly, we encourage the NINDS plan to establish a formal goal of studying rehabilitation as a component of most disease and injury-oriented programs.

**Goal 2: Be a model of excellence for funding and conducting neuroscience research training and career development programs and ensuring a vibrant, talented, and diverse neuroscience work force. (10,000 character limit)**

Neuroscience research in the field of disability and rehabilitation should reflect the population which the research aims to serve. As NINDS considers its research training funding and career development priorities, NINDS should work to develop and adequately fund pre-doctoral and post-doctoral training programs for researchers with disabilities (analogous to existing programs for racial and ethnic minorities), and encourage grant applicants to disclose the disability status of team members. Supporting disability research by researchers with disabilities will lead to more responsive research and dissemination strategies.

**Additional comments. (2,500 character limit)**

As NINDS continues to develop the strategic plan, we encourage the Institute to engage directly with external stakeholders and other experts to ensure a comprehensive plan that includes input from the entire neurological disorder and stroke community. Both within and outside of the

formal public comment process, NINDS should consult with physiatrists and other rehabilitation professionals (such as physical, occupational, and speech therapists; rehabilitation nurses; and rehabilitation psychologists), especially those who are leaders or have focused clinical expertise in neurorehabilitation, as well as consumer representatives, to provide a broad array of perspectives.

We appreciate that NINDS has gradually and successfully increased its support of clinical trials, but recognize that the Institute provides limited support of early-phase clinical research. We encourage the strategic plan to include an emphasis on expanding support in this area.

We also encourage NINDS to prioritize outreach and collaboration with other Institutes at NIH as well as other agencies within the federal government to develop impactful research. We specifically encourage additional outreach to federal-funded networks, such as those led by the Department of Defense and National Institute on Disability, Independent Living, and Rehabilitation Research, with long-standing phenotypic data sets to enhance the knowledge base around biologic predictors (such as biomarkers, imaging, and genetics) and their impact on long-term functional outcomes.

Thank you again for the opportunity to comment on the development of the updated NINDS strategic plan. We look forward to continuing to engage with NINDS as this plan takes shape, and we hope that our collective comments will help to guide the publication of the final plan and to emphasize the importance of disability and rehabilitation research under the NINDS umbrella. If you have any questions, please contact Peter Thomas or Bobby Silverstein at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com or Bobby.Silverstein@PowersLaw.com.