



DRRC Response to NINDS Draft Strategic Plan 2021-2026

(Submitted via [public comment webform](#) on March 15, 2021)

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to provide comments on the draft Strategic Plan for NINDS. 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. 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.

We appreciate the role of NINDS as one of, if not the largest, funder of rehabilitation research at NIH and the attention to stakeholder feedback reflected in this draft plan. To the extent that NINDS performs rehabilitation research, we urge the Institute to emphasize an understanding of rehabilitation science that is cross-cutting, multi-disciplinary, and focused on:

- 1) Understanding the multifaceted mechanisms and contextual factors underlying disability;
- 2) Restoring and improving capacity and independence in individuals with disabilities, functional impairments, injuries, illnesses, and chronic conditions; 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 and other populations facing health inequities.

While we understand that the plan by design does not directly address the COVID-19 pandemic, we encourage the Institute to continue to engage in critical research on the direct and indirect impacts of COVID-19, including the post-acute neurological sequelae, related long-term functional impairments, and resulting disability in COVID survivors, and to develop appropriate rehabilitation interventions for this potentially large population of newly disabled individuals. In addition, we urge NINDS to work with other Institutes and Centers at NIH to support research on the rehabilitation experiences and outcomes for individuals with clear rehabilitation needs (e.g., stroke, brain injury, etc.), but whose standard post-acute care processes were or still are derailed by COVID-related dominance of resources and services. We encourage NINDS to review our September 2020 letter to NIH regarding critical research areas at the intersection of COVID-19, rehabilitation, and disability, available at www.drcc-coalition.org.

Below, we offer comments on three themes within the draft strategic plan.

Biomarkers and Outcome Measures

We appreciate the growing role of and emphasis on biomarkers in disease treatment and the focus on the NINDS biomarkers program in the draft plan. Even so, the long-term and proximate causes for many

neurological disorders are not limited to genetics. Environmental and community factors, as well as genetic predisposition, are indispensable to fully comprehending the wide range of conditions under the umbrella of NINDS-sponsored research. In many cases, despite the expanded availability of genetic testing capabilities, biomarkers are not identified in individuals until after the onset of disease or condition. Further study of these biomarkers is useful for understanding the mechanisms of neurological events, but overreliance in this area may not contribute significantly to decreasing the prevalence of or preventing these conditions. Given the widespread focus throughout NIH and the federal government on understanding the impact of social determinants of health, we believe NINDS should encourage additional research into prevention and environmental medicine to address the needs of individuals currently or soon-to-be living with neurological conditions.

In addition, we urge NINDS to expand the discussion of outcome measures in the draft plan. The DRRC and the disability and rehabilitation communities have long championed the expanded use of functional outcome measures to best serve patients in need of rehabilitation. The scope of effective rehabilitation interventions should advance beyond a solely biological health focus and towards increasing the functional abilities (including participation in activities of daily living, community integration, and quality of life) of individuals receiving treatment.

The plan should work to ensure that generalizable outcome measures are utilized across NINDS-funded research, allowing both greater translational utility of research findings as well as expanding the ability for investigators outside of the most traditional NINDS-specific fields to engage in research under the aegis of the Institute. For example, many clinical rehabilitation providers and researchers prioritize time at home as a key functional outcome measure when assessing the effectiveness of rehabilitation. In clinical practice, it is understood that the patient should be involved in the discussions around treatment goals, and what functional outcomes are prioritized by the patient as well as the treating clinician. The final NINDS plan should reflect a similar patient-centered understanding of effective treatment and desired outcomes.

Diversity and Inclusion

It is essential that neuroscience research in the field of disability and rehabilitation should reflect the population which the research aims to serve. We agree with the draft plan's priority of enhancing the diversity and inclusiveness of the neuroscience research workforce. We note that the plan as drafted is broadly geared towards diversity of all underrepresented groups, as is the NINDS statement on Enhancing Diversity. We recognize the importance of viewing diversity through a broad lens to ensure this goal is met; however, we also encourage NINDS to include more specificity in the plan under this priority to ensure that the full breadth of diversity and intersectionality is addressed.

Diversity within the NINDS workforce, NINDS training and mentorship programs, and among NINDS grantees must include individuals with neurological conditions and disorders. Relatedly, neuroscience research, especially regarding disability and rehabilitation, should reflect the population which the research aims to serve. NINDS should work to develop and equitably fund pre-doctoral and post-doctoral training programs for researchers with disabilities and encourage grant applicants to disclose the disability status of team members. NINDS should ensure that mentorship programs supported by the Institute are inclusive of individuals with neurological conditions and other disabilities as well, both among the mentor and mentee populations. We also note that there are particularly high rates of disability within racial and ethnic minority populations – the intersection of health disparities should be

recognized as an overarching concept, rather than considering underserved populations as discrete groups.

The goal of increasing diversity should not end with the research workforce. We continue to urge NINDS to prioritize patient engagement, as noted in the plan, throughout NINDS research. Modern research practice recognizes the importance of breaking down the divisions between researchers and their subjects to create more equitable, generalizable, meaningful, and translatable research. As NINDS refines the section of the plan devoted to patient engagement, we again note the existence of robust community engagement requirements currently in use by the National Institute of Disability, Independent Living, and Rehabilitation Research and the Patient-Centered Outcomes Research Institute and encourage NINDS to consider adopting similar standards. We believe that many or most of the rehabilitation studies sponsored by NINDS should include relevant stakeholders in research development, data collection, analysis and interpretation, and the dissemination and utilization of research findings.

Quality of Life

The draft plan notes that one goal is to provide an “overarching strategic framework” to result in improvements in quality of life for people with neurological disorders. We urge NINDS to incorporate this critical concept more fully throughout the strategic plan. One area that is crucial for enhancing quality of life, but is largely absent from the strategic plan, is research involving adaptive fitness, exercise, the importance of standing to improve bodily functions, bone health, and nutrition. We believe that research investigating the utility of these basic but critical building blocks to good health, including neurological and cognitive health, is woefully lacking, yet important to the well-being of individuals with neurological conditions. Other crucial areas are functional cognition, how an individual utilizes and integrates their thinking and processing skills to accomplish everyday activities, and the ability to communicate. Finally, two areas often overlooked after neurological trauma are pain management and behavioral health disorders, both of which dramatically impact an individual’s quality of life and are commonly associated with neurological disorders and stroke.

To truly focus on quality of life, research should emphasize how a given treatment may enhance a person’s ability to participate in those activities that are most important to them within their community, including activities of daily living and social participation. We also recommend that the NINDS plan prioritize the consideration of multi-disciplinary studies and collaboration when appropriate, to increase the likelihood that innovative rehabilitation strategies will be translated to the largest number of individuals possible, including individuals with disabilities, illnesses, injuries, and chronic conditions.

Thank you again for the opportunity to comment on the draft plan. If you have any questions, please contact the DRRC coordinators by email at Peter.Thomas@PowersLaw.com, Bobby.Silverstein@PowersLaw.com, and Joseph.Nahra@PowersLaw.com.