



November 21, 2022

Dr. Anjali Forber-Pratt

Director

National Institute on Disability, Independent Living, and Rehabilitation Research

330 C St. SW

Washington, DC 20201

ELECTRONIC SUBMISSION VIA [NIDILRRFuture@neweditions.net](mailto:NIDILRRFuture@neweditions.net)

**Re: Disability and Rehabilitation Research Coalition Preliminary Input on  
NIDILRR Long-Range Plan 2024-2028**

Dear Director Forber-Pratt:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to provide preliminary input on the development of the National Institute on Disability, Independent Living, and Rehabilitation Research's (NIDILRR) next Long-Range Plan for 2024-2028. DRRC strongly supports NIDILRR and its mission, and we look forward to continuing a close relationship with you, your colleagues, and the rest of the federal disability, independent living, and rehabilitation research community over the next five years and beyond.

The DRRC is a coalition of 26 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. The DRRC and many of its members were pleased to be able to provide verbal comments during NIDILRR's recent listening sessions, and we offer additional comments here.

**Process for Developing NIDILRR's Next Long-Range Plan**

We applaud NIDILRR for taking an early approach to stakeholder engagement during the development of the next Long-Range Plan. While we offer some initial comments on the forthcoming Plan here, we encourage NIDILRR to continue soliciting stakeholder input throughout the development process. In particular, as NIDILRR staff prepare a draft Plan, we strongly encourage the Institute to publish the draft for stakeholder comment. This should be provided with a sufficient timeframe for substantive response (at least 60-90 days) and with sufficient time between the close of the comment period and the due date for the final Plan. NIDILRR should be open to making substantive changes in response to feedback on the draft

Plan, allowing the final Plan to reflect the viewpoint of the Institute and the disability, independent living, and rehabilitation research community.

### **Areas for Research Focus**

While we recognize that the Long-Range Plan necessarily focuses on high-level concepts and themes across the Institute's entire research portfolio, we wish to highlight a few key areas for additional research focus that we believe will maintain their importance over the length of the next five years. We encourage NIDILRR to invest in targeted research in these areas and encourage submissions from the field to explore these critical issues.

#### *Long COVID/Impact of COVID on PWDs*

As the Biden Administration prepares to transition away from the COVID-19 public health emergency (PHE), it is essential that federal research agencies do not put aside their research into the impact of COVID, not only the direct biomechanical investigation of the virus but also the broader impact on the entire population. NIDILRR is well-positioned to fund critical research into the pandemic's impact on people with disabilities and chronic conditions, including the increased barriers to accessing health care and social services, loss of employment, social isolation, and other disparate impacts on people with disabilities. Additionally, as the world continues to grapple with the impacts of Long COVID, NIDILRR should explore all avenues to support research into the needs of this newly disabled population. As NIDILRR creates the next Long-Range Plan, we encourage the Institute to collaborate with other federal partners, including the recently established Office of Long COVID Research and Practice within the Department of Health and Human Services, to identify the areas in which NIDILRR can most productively contribute to the federal research agenda in this area.

#### *Disability & Aging*

We encourage NIDILRR to explore opportunities to focus more deeply on the intersection of disability and aging. While the disability population and the aging population are not the same, there is significant overlap between these groups and yet there continues to be a major imbalance between the amount of federal funding and emphasis focused on aging research and that focused on disability research. NIDILRR has the opportunity to help bridge this gap and encourage more collaboration and alignment across federal research in these areas, including by working to translate research results from the aging population to benefit those with disabilities and to partner with other agencies to fund more research related to older adults with disabilities.

#### *Disability Disparities in Health and Health Care*

As the issue of health disparities continues to be a major focus across the Administration, and particularly while the National Institute on Minority Health and Health Disparities (NIMHD) continues its exploration of making a formal health disparity designation for people with disabilities, we encourage NIDILRR to prioritize research into addressing the numerous disparities faced by people with disabilities. A large body of research clearly demonstrates that disability disparities are not limited to health but occur across all social determinants of health, including employment, education, housing, health care, rehabilitation, and disability support

services. NIDILRR should fund and support that systematically examines the role of ableism in creating and perpetuating these disparities and the ways in which ableism intersects with racism, sexism, ageism, homophobia, and transphobia to compound the disadvantages experienced by Americans with disabilities.

### **NIDILRR's Research and Grant Processes**

#### *Administrative Supplements*

We recommend that NIDILRR explore opportunities to further support and encourage applications by researchers with disabilities through the Long-Range Plan, building on the work the Institute is already conducting. NIDILRR should explore avenues to offer administrative supplements, such as those provided by NIH, to currently funded grants and future applications. For example, NIH's Research Supplement to Promote Diversity is available to investigators on projects that need additional support for disability accommodations. Offering a similar supplement as an Institute-wide process could significantly help grantees avoid having to partition their budget to accommodate the needs of members of the research team during the application process. Additionally, current projects may need such supplements if staff members change or if researchers develop needs for new accommodations during the course of an already-funded grant project.

#### *Community-Based Participatory Research*

We encourage NIDILRR to prioritize efforts to expand and further incentivize community-based participatory research under the NIDILRR umbrella in the next Long-Range Plan. We greatly appreciate the efforts NIDILRR has already taken to advance this goal, including the recent changes to NIDILRR's peer review criteria finalized earlier this year. NIDILRR can and often does provide an example to other federal research agencies that can adopt more inclusive community engagement practices and disseminating this model to other federal partners should be a priority within the Long-Range Plan.

### **NIDILRR and the Interagency Committee on Disability Research**

As the DRRC has shared many times before, we strongly support the missions of both NIDILRR and the Interagency Committee on Disability Research (ICDR) but maintain our longstanding position that these should be viewed as separate entities, though working in the same sector towards similar goals. The DRRC has and will continue to advocate with policymakers in Congress to more formally separate the two entities by providing a dedicated budget line to ICDR, to avoid the perception that ICDR activities are a sub-project of NIDILRR rather than a true interagency leader. We greatly appreciate the work that NIDILRR leadership and staff provide to the ICDR's activities and hope to continue supporting both entities without one coming at the expense of the other.

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Thank you again for your consideration of these comments, and we look forward to providing additional input as the Institute continues its development and drafting of the next Long-Range Plan. If the DRRC can be of any assistance during this process, please do not hesitate to contact the DRRC coordinators at 202-466-6550 or by email at [Peter.Thomas@PowersLaw.com](mailto:Peter.Thomas@PowersLaw.com) and [Joseph.Nahra@PowersLaw.com](mailto:Joseph.Nahra@PowersLaw.com).

Sincerely,

**The Undersigned Members of the DRRC**

***American Academy of Physical Medicine and Rehabilitation\****

American Association on Health and Disability

American Congress of Rehabilitation Medicine

American Medical Rehabilitation Providers Association

***American Occupational Therapy Association\****

***American Physical Therapy Association\****

American Therapeutic Recreation Association

***Association of Academic Physiatrists\****

Association of Rehabilitation Nurses

***Brain Injury Association of America\****

Christopher & Dana Reeve Foundation

***National Association of Rehabilitation Research and Training Centers\****

National Association of State Head Injury Administrators

Rehabilitation Engineering and Assistive Technology Society of North America

United Spinal Association

***\* DRRC Steering Committee Member***