DISABILITY AND REHABILITATION RESEARCH COALITION
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Submitted Via Email

Alison N. Cernich, PhD, Director

National Center for Medical Rehabilitation Research (NCMRR)
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

National Institutes of Health

Bethesda, MD 20814

RE: DRRC Response to Request for Information: Research Plan on Rehabilitation

Dear Director Cernich:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to provide comments on the National Center for Medical Rehabilitation Research's *Request for Information: Research Plan on Rehabilitation*.

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.

As the National Center for Medical Rehabilitation Research (NCMRR), the National Institutes of Health (NIH), and the Medical Rehabilitation Coordinating Committee review the 2016 research plan, we hope that the updated plan will maintain and expand its support for high-quality rehabilitation research across the various Institutes and Centers. The plan should 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 3) maintaining and preventing deterioration of functional skills while enhancing quality of life for people with disabilities.

As the health care system in the United States continues to pursue truly value-based care, we hope that the research plan can include priorities aimed at expanding the translational impact of NIH rehabilitation research, with increased focus on efficacy studies, comparative effectiveness research, and new and innovative models of rehabilitation care 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. NIH's 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.

We have included specific responses to the questions posed by the RFI below.

1. The community's perception of progress towards achieving the priorities specified in the research plan.

There has been great progress at NIH since the enactment of the 21st Century Cures Act and Sec. 2040 of that legislation, which focuses on medical rehabilitation research. There is a renewed focus on rehabilitation research throughout NIH as well as strong new leadership at NCMRR and its parent agency, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). We believe that the disability and rehabilitation community has recognized a significant increase in the coordination and intensity of rehabilitation research and a high level of enthusiasm towards this area within NIH in recent years. We also appreciate the increased emphasis on responsive research, supported by the Cures Act, which helps people manage rather than attempt to cure their chronic illness or injury, slowing disease progression and identifying practical interventions that facilitate education, workforce, and community participation. This extends not only to NCMRR, but throughout the various Institutes and Centers under the NIH umbrella.

The rehabilitation research field has benefitted greatly from NIH's investments in rehabilitation training programs and research infrastructure networks, and we appreciate the progress NIH has catalyzed through the 2016 research plan and its efforts since publication. We are pleased with the engagement of the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) in the Trans-NIH Medical Rehabilitation Coordinating Committee, as well as the support from the Office of the Director for this essential, cross-cutting research area.

2. Potential priorities or areas of research to consider in the update of the research plan.

While the current iteration of the research plan has helped achieve significant progress and improvements in the rehabilitation research being conducted and supported throughout NIH, the 2016 plan priorities remain quite broad. The plan recognizes that the primary aims for rehabilitation research at NIH are "to improve rehabilitation research for individuals with disabilities and to gain knowledge about the underlying diseases that cause disability," and that the NCMRR's mission is "to reduce disability by conducting and supporting research and research training."

As the 2021 plan is being considered, the refreshed priorities should be inclusive of issues such as chronic care management, function and participation, and quality of life to extend the reach of NIH research into the daily lives of people living with long-term disabilities or conditions which require rehabilitation. We believe it is essential not to focus exclusively on the underlying causes of disability, but to include research goals addressing the challenges faced by the approximately

54 million Americans currently living with disability as well. Many in this population may benefit from increased emphasis on "low-tech, high-touch" health care and support services, which can and should be bolstered and expanded with functional and translational research efforts.

The current priorities cover a wide range of concepts that should be maintained, but the updated plan should include additional focus on the following areas as well as the existing priorities.

- **Orthotics and prosthetics.** The research plan and NCMRR should specifically and fully embrace research around orthotics and prosthetics (O&P). The O&P field is the only specific field of research cited explicitly in the authorizing statute for NCMRR, and the research plan should highlight this as a priority as well.

- **Adaptive fitness, exercise, and nutrition**. The research plan should 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 NIH's research efforts.

- **Community participation across the lifespan**. The research plan should address aspects of disability and chronic conditions that affect societal participation across the lifespan, including among those with disparities. Learning to manage disabling conditions could drastically reduce health care costs. Rehabilitation is a critical component of a more efficient health care system targeted not just to disease, but to outcomes of living.

- **Data science**. The plan should also link to the *NIH Strategic Plan for Data Science*. Work currently funded should be expanded to embrace data on outcomes information from sources such as Medicare IMPACT Act outcomes, the goals of the NIH All of Us program, and data from initiatives targeted towards improving general health and social determinants of health. Further, data from other new repositories and registries, such as the PT Outcomes Registry, should be considered as potential sources to illuminate rehabilitation effectiveness.

3. Current priorities that should be retained and continued.

As outlined above, we believe that NIH has been successful in carrying out the priorities in the current iteration of the research plan, and we appreciate the commitment and enthusiasm with which the ICs and their leadership have supported medical rehabilitation research. However, we do believe that more specific priorities should be highlighted as well as maintaining a focus on the broad, cross-cutting categories currently included in the research plan, and we outline these in our response to Question 5.

We propose the following refinements to the existing priorities to better address the goals of rehabilitation research within NIH:

- **Priority B** (Community and Family): The plan should acknowledge the significant time and opportunity costs faced by caregivers providing "informal assistance" to individuals with disabilities, even though these services are not reimbursed by insurance.
- **Priority C** (Technology Use and Development): The plan should prioritize research on access to assistive technologies as well as the development of the tools. Access to rehabilitative technologies is frequently restricted due to high costs and limited coverage by public or private insurance, and NIH should consider barriers to access as an essential part of rehabilitation technology research. Additionally, NIH funding should support real-world trials that test the utility of new technologies in the home and communities of people with disabilities, as well as the lab. Finally, NIH should prioritize research that also examines potential barriers to effective integration of the technology into users' daily lives.
- **Priority D** (Research Design and Methodology): The plan currently recognizes the need to develop new methods to generate usable, impactful data for people with disabilities. Randomized clinical trials may not always be practical or necessary to determine the efficacy of rehabilitation interventions, and they should not be privileged above other types of effective rehabilitation research methods.

4. Emerging areas of science that will impact the research plan on rehabilitation.

The research plan will benefit by anticipating two key developing areas: emerging biometric technology and an increased focus on inclusion and participatory research.

Current medical rehabilitation practices are increasingly augmented with biometric technologies (both clinical and commercial devices) that collect extensive research-relevant data. Such technologies include clinical biofeedback equipment and commercially available smartwatches, which can track heart rate, sleep, and other metrics. These devices can also support the development of cost-effective, evidence-based treatment modalities with prescriptions (i.e., specific frequencies, durations, and intensities of treatment for rehabilitation conditions) that are easily and readily available, as well as cost-effective. It will be important for NIH research to examine the possibilities of such technology to monitor both for patient adherence to treatment protocols and for additional biometric data. Such data is already being collected and monitored in many situations, but targeted research can refine the process and ensure that data is being effectively utilized to improve outcomes.

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. NIH and the updated research 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). Fundamentally, people with a disease, impairment, or functional limitation are the experts on living with specific disabilities and should be recognized as such. NCMRR led the way at 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 NIH

should include relevant stakeholders in research development, data collection, analysis and interpretation, and the dissemination and utilization of research findings.

Moreover, the NIH should 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.

5. Potential focus areas for concentrated work in medical rehabilitation research.

As stated in our response to Question 2, broad-based research in the disability and rehabilitation fields is certainly necessary, and should continue to be supported, but we believe there is a need to explore specific fields in greater depth. We have outlined some suggested areas for emphasis below:

- The **Limb Loss and Preservation Registry** project, recently funded by NIH and the Department of Defense, marks a significant development that will support and enhance the lives of individuals with limb loss and improve limb preservation. NIH should continue to support this effort and explore similar efforts in the area of paralysis. A paralysis registry would improve and focus efforts to improve health care and rehabilitation for individuals experiencing paralysis and to better address the secondary conditions associated with paralysis.

- The **Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative** is an important step forward for NIH. We suggest that the updated research plan 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. We specifically need to develop the knowledge base around dosing, pharmacological and therapeutic interventions, behavioral needs and interventions, and cognitive impairments within these populations.

- The research plan and NCMRR 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.

- NIH should consider (through the research plan) further opportunities to engage in research relating to **rehabilitative interventions** for urinary and fecal incontinence and sexual disorders, addressing pain for individuals with disabilities, investigating how

therapeutic modalities can help individuals across the lifespan with chronic conditions including diabetes, peripheral neuropathy, and women's health related to disability.

- In addition to supporting research on technology to facilitate compensatory activities that enhance living, NIH should support research that will help better understand how **environmental factors** may be addressed to prevent negative events (i.e., falls) or enable function and participation across society throughout the lifespan.

- **Cancer rehabilitation** is an area that significantly enhances survivors' quality of life and reduces healthcare utilization, but care is often delivered inconsistently, and should not be limited to only when patients have become disabled. NIH, and especially the National Cancer Institute, should 1) incentivize cooperative clinical trials to study rehabilitative interventions, 2) prioritize function-directed pain management interventions across the continuum of cancer, and 3) emphasize dissemination and implementation in this area.

Research on the underlying causes and reducing the incidence of disability is important, but so too is research focused on improving the lives of people with disabilities. In addition to condition-specific areas of research, the NIH plan should increase its emphasis on research impacting community inclusion for individuals with disabilities.

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Thank you for the opportunity to comment on the development of the updated NIH rehabilitation research plan. We look forward to continuing to engage with NIH as this plan takes shape, and we hope that our collective comments will help to guide the publication of the final plan in 2021. If you have any questions, please contact Peter Thomas or Bobby Silverstein at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com and Bobby.Silverstein@PowersLaw.com.

Sincerely,

DRRC Steering Committee Members

American Academy of Physical Medicine and Rehabilitation
American Congress of Rehabilitation Medicine
American Occupational Therapy Association
American Physical Therapy Association
Association of Academic Physiatrists
Brain Injury Association of America
National Association of Rehabilitation Research and Training Centers

DRRC Signatories

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