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Response to the NIH NCMRR RFI for the Research Plan on Rehabilitation

June 11, 2019

The [North American Spinal Cord Injury Consortium \(NASCI\)](http://www.nasciconsortium.org) is a community of 124 organizations and individuals representing an estimated 100,000 people living with SCI in North America. We operate by bringing together like-minded organizations, individuals, and groups to improve research, care, cure, and policies impacting people living with SCI, their families, and community.

Based upon review of the 2015 Rehabilitation Research (RR) Strategic Plan, our community perceives that the field of rehabilitative research has advanced, but little has translated to clinical practice or the community setting. Of the 6 research areas list as primary goals in the research plan, the following four appear to have limited representation in the funding portfolio:

**B: COMMUNITY AND FAMILY**

- Determine the ways in which individuals with disabilities can partner with caregivers and care providers as active members of the rehabilitation team, either in promotion of adherence and assistance with in-facility or home-based care or in setting treatment goals to optimize outcomes.

**C: TECHNOLOGY USE AND DEVELOPMENT**

- Provide an evidence base for device development, manufacturing, and implementation for individuals with disabilities, including methods to incorporate needs and preferences of users.

**D: RESEARCH DESIGN AND METHODOLOGY**

- Encourage clinical translational research and dissemination and implementation research to enhance reach and application of evidence-based approaches.
- Identify, measure, and compare the costs and consequences of rehabilitation assessment, delivery, and monitoring approaches, interventions, devices, and technologies using health economics methods, including cost analysis, economic evaluation, decision and transmission modeling, and regulatory impact analysis.

**F: BUILDING RESEARCH CAPACITY AND INFRASTRUCTURE**

- Identify methods to encourage knowledge translation to promote clinical competence based on evidence-informed treatment.
- Provide a strategy for recruiting individuals with disabilities into the field of rehabilitation research.

An emerging area of science that we believe will impact the research plan is the inclusion of persons with lived experience throughout the research process based on the framework of Integrated Knowledge Translation. Including persons with lived experience on grant reviews, in programmatic



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decisions, as partners in networks and training will produce more impactful and meaningful rehabilitation research.

We are looking forward to the next phase of the strategic plan and are willing to support and collaborate on this critical matter.

Sincerely,

The North American Spinal Cord Injury Consortium Executive Council

Kim Anderson, President (Case Western Reserve University)

John Chernesky, Vice-President (Rick Hansen Institute)

Barry Munro, Treasurer (Canadian/American Spinal Research Organization)

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