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SPECIAL COMMUNICATION

Rehabilitation Research at the National Institutes of Health: Moving the Field Forward (Executive Summary)

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Approximately 53 million Americans live with a disability. For decades, the National Institutes of Health (NIH) has been conducting and supporting research to discover new ways to minimize disability and enhance the quality of life of people with disabilities. After the passage of the American With Disabilities Act, the NIH established the National Center for Medical Rehabilitation Research with the goal of developing and implementing a rehabilitation research agenda. Currently, a total of 17 institutes and centers at NIH invest more than $500 million per year in rehabilitation research. Recently, the director of NIH, Dr Francis Collins, appointed a Blue Ribbon Panel to evaluate the status of rehabilitation research across institutes and centers. As a follow-up to the work of that panel, NIH recently organized a conference under the title "Rehabilitation Research at NIH: Moving the Field Forward." This report is a summary of the discussions and proposals that will help guide rehabilitation research at NIH in the near future.

The conference took place at the NIH Campus on May 25 and 26, 2016. It was cosponsored by The Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Biomedical Imaging and Bioengineering, the National Institute of Neurological Diseases and Stroke, the National Institute of Nursing Research, the National Institute on Deafness and other Communication Disorders, the National Center for Complementary and Integrative Health, and the Office of Disease Prevention. The main objectives of the Conference were to (1) discuss the current NIH portfolio in rehabilitation research, (2) highlight advances in rehabilitation research supported by NIH, and (3) provide an opportunity for scientists and the general public to comment on gaps in knowledge,

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opportunities for training, and infrastructure needs. The program included a total of 13 expert panels, four remarks by NIH leaders, a consumer keynote, a town hall, a poster session, and the use of social media to disseminate information in real time. The following is a summary of the discussion and the subheadings correspond to the title of the expert panels.

Rehabilitation across the lifespan

(Moderator: Alan Jette, PhD, Boston University; Panelists: Andrea Cheville, MD, Mayo Clinic; Jonathan Bean, MD, Boston University; Shari Wade, PhD, Cincinnati Children's Hospital Medical Center)

The theme of this session was moving rehabilitation interventions from a traditional "one-and-done" isolated model of care to one where rehabilitation interventions are integrated into the mainstream of health care. The speakers addressed integrated care approaches in cancer care, primary care, and pediatric rehabilitation.

Barriers to integrating function-directed care into the comprehensive management of progressive diseases, particularly those with a heavy treatment burden, were identified. Cancer was used an exemplar of the simultaneously dynamic and insidious nature of disablement in chronic illness. Collaborative care approaches, including telecare, validated for pain and depression management, was considered a promising means to proactively and patient-centrically address cancer-related disablement. Current research in cancer rehabilitation suggests that challenges revolve around issues such as patient selection and timing, when and how to intervene, limitations of linear impairment-to-disability models (with multiple mild impairments the norm), and competition with disease-modifying therapies. Although functional limitations are prevalent (seen in 65% of all cancer patients), rehabilitation intervention remains underused. In contrast to ischemic and traumatic injuries, rehabilitation interventions in patients with cancer are less prescriptive, more negotiable, and subject to patient preferences. Current care delivery overwhelmingly emphasizes primary disease management.

Another presentation focused on limitations with mobility tasks, such as walking, rising from a chair, or climbing stairs, as a signal condition identifying older adult primary care patients at an increased risk for disability, morbidity, and death. It was discussed how rehabilitative care can play a critical role with older adult primary care patients by developing integrated care paradigms between primary and rehabilitative care providers focused on prevention of mobility decline among older adults. Prevention of adverse health outcomes represents a new conceptual role for rehabilitative care. Research priorities include determining the optimal content and design of preventative rehabilitative care; the potential benefits for patients, families, and health care organizations; and the cost/benefit of such approaches to care.

Traumatic brain injury (TBI) was used as a case example to discuss the need for further research on ways to integrate pediatric rehabilitation into the broader framework of child development. TBI is currently viewed as a discrete event with time-limited consequences while evidence from the TBI Model Systems suggests lifelong physical and cognitive consequences. Long-term pediatric studies are lacking, but existing evidence suggests long-term effects on educational attainment and vocational and social success. However, after the post—acute recovery phase, children with TBI receive little ongoing rehabilitation. TBI-related problems that emerge with shifting developmental demands may go unrecognized or be inaccurately characterized. Families and schools constitute powerful contexts for ongoing rehabilitation and later habilitation. How families function and interact with the child exerts a powerful influence on the recovery trajectory. Interventions need to be developmentally tailored and address the current developmental and neural context. Challenges remain in framing rehabilitation/habilitation as an ongoing process with tune-ups at various developmental stages rather than a one and done model. A better understanding of adult outcome metrics (e.g., education and employment) and long-term burden (disability and life quality) is needed. To reduce heterogeneity and improve prediction, research is needed to better categorize the initial injury/insult along with better understanding of effects on neurodevelopment and how this relates to long-term functional outcomes. Multicenter consortiums are urgently needed to support larger-scale outcome studies and provide an infrastructure to link school and medical data as well as study interventions and management practices more efficiently.

Technology in rehabilitation: From cutaneous to implanted

(Moderator: Ranu Jung, PhD, Florida International University; Panelists: Leigh Hochberg, MD, PhD, Harvard University; Reggie Edgerton, PhD, University of California, Los Angeles; Joseph Rizzo, MD, Harvard University; Mario Svirsky, PhD, New York University)

Innovation and advances in engineering and computing are having a ubiquitous impact on health and well-being. The purpose of this panel was to discuss the challenges and opportunities for developing technologies that interface with the nervous system at an appropriate level, are user-centric and responsive to the ability of the user and their life-span, and could provide new neuroscience insights to inform rehabilitation science. The panel also discussed the importance of having appropriate assessment methodologies and comprehensive engagement with regulatory, industry, and clinical partners. The moderator and panelists brought to the discussion their experience as neuroscientists, biomedical engineers, and clinical practitioner, some with personal experience of moving neurotechnology from the laboratory to human studies. Using examples from engineering of cochlear and visual prosthetic devices, brain, spinal cord, and peripheral nerve interfaces, they discussed the role of technology in scientific discovery and recovery and restoration of missing or lost function.

The overall span of the technology that can influence rehabilitation is broad: from assistive devices, rehabilitation robotics and implanted neuroprostheses to augmented connectivity between people and devices, use of virtual reality environments for training, and use of mobile health and telehealth platforms for deployment of rehabilitative therapies. The panel discussions focused on implanted neuroprostheses. Advances in neurotechnology will allow us to better access information about the living system at multiple scales, from cellular to behavioral. Improved understanding of the endogenous activity patterns of neural activity could help guide the design of neuroprostheses that can more precisely influence and modify the neural activity to initiate and sustain long-term beneficial neuroplasticity leading to repair or recovery. Design, development, and deployment of the neuroprostheses that form biohybrid systems with the living body has many challenges.

A major challenge in the deployment of neuroprostheses that effect recovery is to make the neuroprostheses adaptive and