

DISABILITY AND REHABILITATION RESEARCH COALITION

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Submitted Via Email: NICHDStrategicPlan@nih.gov

Diana W. Bianchi, M.D.
Director
Eunice Kennedy Shriver National Institute
of Child Health and Human Development
31 Center Drive, Room 2A03, MSC 2425
Bethesda, MD 20892-2425

**RE: DRRC Response to Request for Information: NICHD Strategic Plan Fiscal Years
2020-2024**

Dear Director Bianchi,

On behalf of the Disability and Rehabilitation Research Coalition (“DRRC”), we appreciate the opportunity to provide comments on the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development’s (“NICHD”) Request for Information: NICHD Strategic Plan Fiscal Years 2020-2024.

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.

We would like to emphasize the importance of the National Center for Medical Rehabilitation Research (“NCMRR”) and its mission to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of people of all ages with physical disabilities. An important component of this includes the integration of nutritional guidance and exercise into rehabilitation efforts, as well as maximizing the outcomes of those twin pillars of health throughout a child’s development. While we recognize the NCMRR

represents only a portion of the NICHD's budget, the progress the NCMRR has made to date has presented incredible opportunities to enable people with disabilities and chronic conditions to live more functional and independent lives. We must also stress the major strides that have been made by NCMRR, NICHD, and the NIH overall over the past few years in the area of rehabilitation and disability research. We applaud your Institute's commitment to this vital area of research and look forward to continue working with you to achieve major advances for people with injuries, illnesses, disabilities and chronic conditions in the future.

Of the six main research themes that NICHD has developed for its strategic plan, DRRC would like to provide comments and suggestions on themes one, four, five, and six.

Research Theme #1: Understanding Early Human Development

The DRRC supports this theme and the goal of enhancing knowledge of genes and regulatory networks to gain a better understanding of what developmental factors contribute to birth defects and other congenital conditions on a cellular level. For millennia, disabilities have been a natural component of human development and the NICHD has played an important role in studying and understanding these disabling conditions. DRRC would like to emphasize the importance of this research to identify birth defects and congenital conditions at an early stage of human development, as well as the outside exposures and genetic risks that may cause them.

We recommend that the NICHD use data gathered from its research to develop prevention strategies to reduce, control, and modify contact with harmful outside exposures to help reduce the number of birth defects and lower the infant mortality rate. In addition, we would like to stress the importance of providing supportive services to both the child and the parent of a child born with a congenital condition at an early stage in the child's life to ensure the child is able to maximize his or her development and ability to function.

We believe this requires a research focus on early and ongoing intervention of habilitation services and devices to ensure the child is keeping pace with developmental stages. For instance, studies demonstrate the value of cochlear implantation (CI) to address the hearing needs of deaf children before the age of 18 months, and yet, many children with deafness do not receive CI until much later, if at all, for a variety of reasons.

Research Theme #4: Identifying Sensitive Time Periods to Optimize Health Interventions

DRRC supports the NICHD's goal of gaining a better understanding of the sensitive time period when prevention and treatment strategies will have the greatest impact on development and rehabilitation. The Department of Defense ("DOD") has been at the forefront of understanding this sensitive time period and has modified how they provide medical services on the battlefield to save more lives and achieve better long-term outcomes. Recognizing that trauma patients reaching advanced medical care sooner presents the best chance of surviving a traumatic injury, a former military surgeon coined the term "golden hour" to promote this urgency between injury and care. With this in mind, the DOD has been able to develop a system to maintain readiness to provide necessary trauma treatment within the first hour of a traumatic injury.

Many civilian trauma centers, particularly Level I trauma centers, strive to achieve similar processes and results, but there are lessons that can be learned from one system to another. For example, the military has been focusing on ways to have a better, more objective evaluation tool for a suspected mild brain injury. Identifying cases of a mild brain injury early and providing the proper education can be a crucial component to better recovery. All too often when an individual sustains a concussion and goes to the emergency department, that individual receives only a cursory evaluation. If serious trauma is ruled out, no education is provided about recovery from a mild brain injury. This education is vital to the recovery process, and this lack of awareness and education may lead to negative health outcomes.

The timeliness of medical rehabilitation is also a major factor in the achievement of successful outcomes. For many patients, rehabilitation should start in the surgical suite. For instance, a consultation by a prosthetist during a traumatic limb amputation to optimize the residual limb's ability to adapt to a prosthesis can have life-long implications on functional outcomes. Similarly, early intervention to address the needs of individuals with peripheral neuropathy and diabetes can prolong ambulation and delay—if not prevent—the need for amputation. Numerous examples could be cited with almost any major medical condition.

Timely medical rehabilitation at the appropriate intensity, scope, and duration is often a function of access to care, usually dictated by insurance coverage and other mechanisms to manage utilization of the health care system. For instance, the use of prior authorization, fail first techniques, insurance caps, exclusions of coverage and other limitations have a material impact on the timeliness and sufficiency of rehabilitation treatment. Studies to illuminate the harmful effects of these limitations on medical and function outcomes would help build an evidence base for reforms that could have a material impact on patient care in the future. We urge NICHD to incorporate into its research agenda real-life factors that impact the ability of individuals to access rehabilitation and habilitation care at the appropriate time, intensity and duration.

Research Theme #5: Improving Health During the Transition From Adolescence to Adulthood

The DRRC supports the goal of improving the transition from pediatric to adult care and gaining a better understanding of the impact it has on children with disabilities and other chronic conditions. The transition from pediatric to adult care can be very difficult for children and families of children with disabilities or complex or rare conditions, and if not executed seamlessly, these transitions may lead to negative health outcomes. For instance, when transitioning from a pediatrician to an adult care model, a lifetime of knowledge of the developmental pathway of a particular child's condition can be essentially lost. This transition can be traumatic for certain individuals to an extent that the transition itself may discourage continued active engagement with the health care system. Access to providers with specialized expertise to treat children entering the adult world can be difficult to identify and access. Therefore, we recommend that the NICHD gain a better understanding of the impact that transitioning from pediatric to adult care has on continuity of care. Additionally, we recommend the NICHD consider best practices for maintaining continuity of care during this transition period.

Research Theme #6: Ensuring Safe and Effective Therapeutics and Devices

Finally, the DRRC supports the research goal of developing, testing, and validating safe and effective therapeutics and devices for individuals with disabilities. Individuals with disabilities have unique needs and it is important to understand how these individuals interact with their assistive devices. It is important to ensure the safety and effectiveness of assistive devices for people with disabilities and chronic conditions, but it is also important to properly code these devices for purposes of third party coverage and reimbursement. There are currently a raft of safe and effective assistive devices that are simply inaccessible to individuals who need them due to a lack of proper coding, coverage and payment policies. Again, these real-life factors have a material impact on the ability of individuals to maximize their functional outcomes once they incur injuries, illnesses, disabilities and chronic conditions.

The health care system tends to view assistive devices and technologies as items, or widgets, instead of components of a patient's overall plan of care. For instance, it is incorrectly believed that many individuals living with different levels of paralysis and chronic conditions can sit in virtually any wheelchair. However, the appropriate wheelchair is critical for both health and safety reasons and may enable that individual to perform all aspects of daily living and prevent secondary conditions. The appropriate wheeled mobility device is an outgrowth of the individual's overall plan of care, including a therapy regimen, an exercise program, one's living environment, work status, and ability to interact with the community. Too often, research focuses on the widget itself and not the integration of the device with the clinical services and overall plan of care necessary to achieve maximal outcomes. We urge NICHD and NCMRR to view device research in this conceptual manner in the future. It is not the device itself, but rather how an individual interacts with that device that makes it most effective. We also recommend that NICHD consider not only the safety and effectiveness of therapeutics and devices for individuals with disabilities in the short term, but how these individuals adapt to and use these technologies over a longer period of time.

Thank you for the opportunity to comment on these four themes from the NICHD Strategic Plan and how important this research is to individuals with injuries, illnesses, disabilities and chronic conditions. We applaud the progress the NICHD and NCMRR has made on this important national research agenda, as well as the progress made NIH-wide, and believe the research conducted and supported by NIH in the area of rehabilitation, disability and independent living will continue to have a genuine and meaningful impact on the lives of people with disabilities.

If you have any questions, please contact Peter Thomas or Bobby Silverstein at (202) 466-6550 or by email at Peter.Thomas@ppsv.com and Bobby.Silverstein@ppsv.com.

Sincerely,

Disability and Rehabilitation Research Coalition

Steering Committee Members

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American Physical Therapy Association
Association of Academic Physiatrists
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