



Submitted Electronically

October 11, 2024

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

**RE: DRRC Response to Request for Information (RFI): NICHD Strategic Plan for 2025–2029
(NOT-HD-24-028)**

Dear Director Bianchi:

The Disability & Rehabilitation Research Coalition (DRRC) appreciates the opportunity to provide comments on the Eunice Kennedy Shriver National Institute of Child Health and Human Development's (NICHD) Request for Information for the NICHD Strategic Plan. We comment below on selective aspects of the plan document.

The DRRC is a coalition of 25 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. Since DRRC's inception in 2008, we have been a strong supporter of NICHD and, particularly, the National Center for Medical Rehabilitation Research (NCMRR).

Maximizing Investment in Disability and Rehabilitation Research

We would like to emphasize the importance of NCMRR's mission to foster the development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of people of all ages with physical disabilities. 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 continuing our work with you to achieve major advances for people with injuries, illnesses, disabilities and chronic conditions in the future.

The DRRC believes that NICHD's strategic plan should prioritize the continued expansion and coordination of rehabilitation research, particularly given the growing number of Americans living with disabilities. Rehabilitation science is essential to improving the health and independence of individuals across the lifespan. We recommend that NICHD continue to support robust research programs focused on enhancing rehabilitation methodologies and technologies, which have the potential to transform patient outcomes and quality of life for individuals with both congenital and acquired disabilities.

Research Goal #4: Recommendation to Addressing the Transition Years for Children with Disabilities

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 healthcare model, a lifetime of knowledge of the developmental pathway of a particular child's condition can be essentially lost. Another issue is the services available for the pediatric population that are not available for adult populations. Consistency in services is particularly important for children and adults with chronic conditions that require more wrap around care. This impacts all aspects of life of a young adult with a disability, including health care, functional status, independent living, education, employment, community integration, and social interaction.

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. Addressing this issue will further support NICHD's goal of improving the long-term health outcomes and independence of individuals with disabilities.

Cross-Cutting Themes: Recommendation to Add People with Disabilities to Health Disparities

We urge the inclusion of people with disabilities as a recognized population experiencing health disparities in alignment with the decision by the National Institute on Minority Health and Health Disparities (NIMHD) to designate people with disabilities as a health disparities population. People with disabilities still encounter significant barriers to accessing equitable healthcare and face systemic biases that exacerbate health disparities. Including this population

in the cross-cutting themes discussed in the strategic plan will reinforce NICHD's commitment to addressing inequities that impact millions of Americans.

We encourage NICHD to ensure that research programs are inclusive of diverse populations, particularly those with disabilities. We believe that there should be an emphasis on research that addresses health disparities experienced by individuals with disabilities, including the intersection of disability with other social determinants of health such as race, socioeconomic status, and geographic location. This is particularly important in the context of NICHD's leadership in pediatric, maternal, and family health, as disability-related health inequities tend to begin early in life.

Cross-Cutting Themes: Recommendation to Add Promoting Research Training for People with Disabilities

We believe NICHD's cross-cutting theme of research training should include a concerted effort to actively recruit and encourage the participation of researchers with disabilities. People with disabilities bring unique perspectives that can drive innovation and enhance the relevancy and impact of research. However, individuals with disabilities are underrepresented in the biomedical and rehabilitation research workforce. We encourage NICHD to develop programs and initiatives that not only support their inclusion but also provide mentorship, resources, and accessible environments that empower individuals with disabilities to thrive as researchers. Actively fostering diversity in the research community will lead to more comprehensive and inclusive science that better reflects the needs of the population it aims to serve.

Cross-Cutting Themes: Recommendation to Add Combatting Ableism

Furthermore, we recommend that NICHD actively address ableism as part of these cross-cutting themes. We are pleased to see the investment in research on ableism in medicine and the recent announcement of \$30 million in funding to study the impact of ableism on outcomes for pregnant and postpartum individuals. Ableism, or inherent bias against people with disabilities, not only influences societal attitudes but also permeates throughout healthcare systems, research, and policy. A focused effort to combat ableism in research design, healthcare delivery, and workforce development will help dismantle systemic barriers and contribute to more equitable health outcomes.

We applaud the progress of NICHD and NCMRR and believe the research conducted 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. We look forward to continued collaboration with NICHD and other stakeholders in ensuring that individuals with disabilities receive the research and care that can maximize their potential and well-being.

Thank you for your attention to this matter and for your ongoing leadership in advancing health and disability research. For any questions, please contact DRRC Co-Coordinator Peter Thomas at Peter.Thomas@PowersLaw.com or Natalie Keller at Natalie.Keller@PowersLaw.com.

Sincerely,

The Undersigned Members of the Disability & Rehabilitation Research Coalition

American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine and Rehabilitation
American Association on Health & Disability*
American Congress of Rehabilitation Medicine
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association*
American Physical Therapy Association*
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National Neurotrauma Society
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****DRRC Steering Committee Member***