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Adam M. Politis  
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White House Office of Science and Technology Policy (OSTP)  
725 17<sup>th</sup> Steet, NW  
Washington, DC 20504

**Re: Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity; FR Doc. 2024-11838**

Dear Mr. Politis:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), a coalition dedicated to improving disability and rehabilitation research policy and funding, we thank you for the opportunity to provide input on the development of the Federal Evidence Agenda on Disability Equity at the May 28<sup>th</sup> Disability Data Equity Listening Session and with this written response. We appreciate the federal government’s significant efforts in recent years to invest in disability research, particularly at the National Institutes of Health (NIH) and the Administration for Community Living (ACL).

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.<sup>1</sup> 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 DRRC fully supports President Biden’s executive orders (EO) on equity, diversity, and inclusion, EO 13985 on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government and EO 14091 on Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. We applaud the recognition that the government’s goal in advancing equity is “to provide everyone with the opportunity to reach their full potential.” We also support the directive that “each agency must assess whether, and to what extent, its programs and policies perpetuate systemic barriers to opportunities and benefits for people of color and other underserved groups” which includes people with disabilities, and the assertion that “such assessments will better equip agencies to develop policies and programs that deliver resources and benefits equitably to all.” It is critical that people with disabilities are recognized as an underserved population facing health and

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<sup>1</sup> More information about DRRC and its members at <https://drcc-coalition.org/>

societal inequities, and that federal policy be cognizant of the disparities faced by the disability population and other underserved groups.

People with disabilities have always faced structural inequities in health, access to health care, employment, community participation, and numerous other aspects of society. These disparities are widely recognized by the federal government, stakeholder organizations, and the public. We are pleased that the Disability Data Interagency Working Group (DDIWG) is actively engaging the community in the development process for a Federal Evidence Agenda on Disability Equity as part of the implementation of the President's EOs.

We recognize that the federal government has made commendable strides in disability and rehabilitation research in recent years. The NIH, for example, has increased its funding for rehabilitation science and disability research to over \$900 million in fiscal year 2024, officially recognized people with disabilities as a health disparity population in September 2023, and released a Notice of Funding Opportunity (NOFO) to fund disability disparities research.<sup>2</sup>

Additionally, the ACL has established longitudinal databases through the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) for traumatic brain injury, spinal cord injury, and burns, alongside longitudinal data grants that center on the collection of data for services provided to people with intellectual and developmental disabilities (I/DD). Initiatives such as the Limb Loss and Preservation Registry (LLPR), initially a public-private partnership between the Department of Defense and NIH and now a freestanding nonprofit entity, exemplify the importance of collaborative efforts in data collection. These partnerships are crucial for enhancing data collection and improving the understanding of disability outcomes.

Despite these advancements, there remain disparities in access to medical rehabilitation that could be better understood through federal investment and data collection. Additionally, the federal government should invest in robust demographic data collection that includes disability status as discussed in more detail below.

### **Medical Rehabilitation Data Gaps**

*Dosing of Rehabilitation Therapies.* There is a need for in-depth research into the appropriate dosing of rehabilitation therapies post-illness or injury. Understanding the optimal amount and type of therapy required to maximize rehabilitation outcomes and facilitate a return to work is crucial. Current therapy caps restrict the duration and intensity of therapy, which may negatively impact patient outcomes. Investigating the outcomes of extended or unlimited medically necessary therapy could provide valuable insights to overall functional restoration and improved quality of life. Research should focus on the duration, frequency, and intensity of therapies required for different conditions, considering factors such as comorbidities and individual patient needs.

*Intensity and Sites of Care.* It is essential to determine which settings—inpatient rehabilitation hospitals and units (IRFs), long term acute care hospitals (LTCHs), skilled nursing facilities (SNFs), outpatient therapy, or home health care—are most effective for specific conditions and patient profiles. Research should focus on the intensity of care and the most appropriate sites for

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<sup>2</sup> See DRRC statement in support of NIH decision: <https://drcc-coalition.org/wp-content/uploads/2023/10/drcc-statement-on-nimhd-decision.pdf>

rehabilitation. This data will help tailor rehabilitation programs to meet individual needs, optimizing recovery and functional outcomes. Research should aim to match patients with the care settings that maximize their rehabilitation potential and appropriate management of their medical condition, considering both medical and functional factors.

*Long-Term Outcomes and Quality of Life.* Conduct longitudinal studies to assess the long-term outcomes of different rehabilitation strategies. This includes tracking quality of life, return to work, independent living, and active participation in community activities over time.

*Disparities in Access to Rehabilitation.* It is well known that access to rehabilitation is limited by payers through utilization management tools and other mechanisms that restrict the amount, duration, and scope of rehabilitation services for individuals with illnesses, injuries, and chronic conditions. Social determinants of health also impact access to rehabilitation. There is a need to investigate disparities in access to rehabilitation services based on factors such as race, socioeconomic status, and geographic location. Understanding these disparities can inform policies aimed at ensuring equitable access to rehabilitation for all individuals.

*Technological Innovations in Rehabilitation.* Evaluate the role of emerging technologies, assistive devices, durable medical equipment (DME), prosthetics and orthotics, robotic-assisted therapy, and tele-rehabilitation in improving rehabilitation outcomes. Research should focus on accessibility, effectiveness, and patient satisfaction with these technologies.

### **National Health Interview Survey and Disability Demographic Data Collection**

The last time the federal government conducted the National Health Interview Survey-Disability Survey (NHIS-D), collecting extensive data on sensory, mobility, and functional limitations, was in 1994 and 1995. This data is crucial for understanding disability, informing public health policies, and planning for disability services and support. A new survey, carried out by the National Center for Health Statistics, is urgently needed. Much of the current disability data still relies on this 30-year-old survey, underscoring the need for updated, comprehensive data to inform current and future policy decisions.

In addition to conducting a new NHIS-D data collection, the federal government needs to develop a plan for enhancing disability demographic data collection, including addressing current efforts at the U.S. Census Bureau to change the American Community Survey (ACS) questions on disability.<sup>3</sup> Demographic data collection is critical to advancing equity, not only to support traditional research endeavors, but to better identify and understand the disparities and inequities faced by people with disabilities and other underserved populations. Furthermore, accurate and comprehensive data, disaggregated by disability status and other demographic factors, allows policymakers and other stakeholders to more appropriately develop and evaluate policy solutions addressing the needs of people with disabilities.

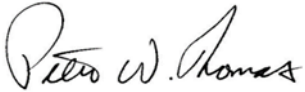
The DRRC appreciates OSTP's commitment to advancing disability equity through data-driven policies. We believe that the insights provided will significantly enhance the federal government's ability to understand and address disparities faced by individuals with disabilities, leading to better policy outcomes and a more inclusive society.

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<sup>3</sup> See DRRC letter to U.S. Census Bureau regarding ACS question change: <https://drcc-coalition.org/wp-content/uploads/2023/12/drcc-comment-letter-on-acs.pdf>

We greatly appreciate your consideration of our comments, and we look forward to continuing to engage with OSTP as you form the evidence agenda. Should you have any further questions regarding this letter, please contact DRRC Co-Coordiators at [Peter.Thomas@PowersLaw.com](mailto:Peter.Thomas@PowersLaw.com) or [Natalie.Keller@PowersLaw.com](mailto:Natalie.Keller@PowersLaw.com) or by calling 202-466-6550.

Sincerely,



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