

**MEMORANDUM**

**To: DRRC Members**

**From: Peter Thomas and Natalie Keller, DRRC Coordinators**

**Date: December 22, 2023**

**Re: DRRC 2023 Year in Review and Proposed Agenda for 2024**

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**Executive Summary**

As we begin 2024, we want to celebrate the accomplishments of 2023 and provide a summary of the efforts made on behalf of the Disability and Rehabilitation Research Coalition (DRRC) and its member organizations over the past twelve months. Additionally, we are providing you with a forecast of issues that the coalition may engage in over the coming year.

The DRRC is a unique coalition of organizations concerned with the state of disability, independent living, and rehabilitation research. The coalition's strength is readily apparent in its active, productive, and dynamic portfolio of issues. DRRC had a record year in 2023, engaging with policymakers, federal agencies, and the research community to advance our priorities and other key issues as they arose.

Further information on the DRRC's activities, as well as our advocacy archives, can be found on the DRRC's website at [www.drcc-coalition.org](http://www.drcc-coalition.org). We encourage DRRC members to review this memo and consider any suggestions for continued or new policy priorities in 2024. We will discuss our work this year and our plans for next year at the upcoming DRRC Annual Meeting on Thursday, February 8, 2024 from 12:00 – 2:00 PM (EST).

For more information about the Annual Meeting, please contact Natalie Keller at [Natalie.Keller@PowersLaw.com](mailto:Natalie.Keller@PowersLaw.com).

**DRRC Successes in 2023**

- Successfully secured the designation of people with disabilities as a distinct “health disparities population” by the National Institute of Minority Health and Health Disparities (NIMHD), applicable across the National Institutes of Health.
- Actively involved the disability community, fostering awareness and leading the policy debate about the proposed change of American Community Survey (ACS) questions on disability by the U.S. Census Bureau and submitted comments.

- Submitted recommendations to NIH for a new mission statement inclusive of people with disabilities and led discussions in the disability community regarding the mission statement change.
- Sent letter to Acting National Institutes of Health (NIH) Director Lawrence Tabak in support of the December report from NIH Advisory Committee to the Director Subgroup on People with Disabilities advancing key recommendations to support the inclusion of people with disabilities in the scientific workforce
- Submitted comment letter on the landmark HHS Section 504 proposed rule updating regulations prohibiting discrimination on the basis of disability
- Advocated for full funding of disability and rehabilitation research programs to the Senate Committee on Appropriations
- Sent a letter of support to the Limb Loss & Preservation Registry
- Met with multiple NIH Institute Directors and their staff to discuss the status of rehabilitation and disability science across NIH.
- Met with the NIDILRR Director and worked informally on key DRRC priorities with this agency.

## **2023 Review: Initiatives and Engagement on Behalf of DRRC**

### **I. Designating People with Disabilities as a Health Disparities Population**

On September 26, 2023, Dr. Eliseo Perez-Stable, M.D., Director of the National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health (NIH), designated people with disabilities as a distinct “health disparities population.” This decision was a stunning reversal of NIMHD’s expected approach after receipt of a contrary recommendation from its Advisory Council and represents a major success by the disability community in addressing health inequities for people with disabilities.

The need to recognize people with disabilities as a distinct health disparity population is well-established in the clinical literature and has been a long-standing goal of DRRC and the disability community. The COVID-19 experience highlighted the need for the federal government to make this formal designation. Since April 2022, the DRRC has written five letters to NIH urging NIMHD to designate people with disabilities as a health disparities population, most recently on August 2, 2023 ahead of the recommendation from the NIMHD working group. Additionally, the DRRC met with NIMHD administrators on August 9, 2022 to advocate for the designation. A health disparities designation allows NIH funding for projects that include a focus on disability health disparities and enhances clinical research by incentivizing the recruitment of both researchers and clinical research participants with disabilities.

On September 1, 2023, the Advisory Council for the NIMHD recommended to *not* designate people with disabilities as a “health disparities population,” calling instead for additional research to better understand the impact of health disparities on this population. NIMHD is the lead institute on monitoring minority health and health disparities research for the NIH. The NIMHD director is responsible for designating a health disparity population in consultation with the director of the Agency for Healthcare Research and Quality (AHRQ). On September 6th, a

stakeholder letter was submitted to the U.S. Department of Health and Human Services (HHS) urging the Agency to reconsider the NIMHD recommendation to not consider people with disabilities as a health disparities population. The letter was written by longtime advocates for this designation, Jae Kennedy, Ph.D., Professor of Community and Behavioral Health at the Washington State University College of Medicine and DRRC Steering Committee member, and Bonnie Swenor, Ph.D., M.P.H., Director, The Johns Hopkins Disability Health Research Center, on behalf of the DRRC and the disability community. This letter garnered the support of 1,291 healthcare providers, researchers, caregivers, organizations, and people with disabilities. In addition, former Congressman Tony Coelho, Chairperson of the Partnership to Improve Patient Care (PIPC), also sent a similar companion letter the same day to HHS that was signed by 175 additional stakeholder individuals and organizations.

In response to both letters, Dr. Perez-Stable issued a public statement on September 18, 2023, which noted that a final report was forthcoming, and that the Council's recommendation was advisory only and no official decision had been made. Dr. Perez-Stable stated that he would make the final decision in consultation with the AHRQ director based on the analysis that was conducted by NIMHD, stakeholder input, and a review of the science and evidence once a final report was delivered.

As a result of this review, as well as the massive advocacy effort by disability advocates, on September 26, 2023, the NIH and Dr. Perez-Stable decided to designate people with disabilities as a distinct health disparity population in a rejection of the Advisory Council's recommendation to the director. In the NIH press release, Acting NIH Director Lawrence Tabak, D.D.S., Ph.D., addressed the groundswell of support from the disability community by stating, "To the disability community, we hear you and thank you for sharing your lived experiences with NIH."

In addition to the designation, the NIMHD also announced a Notice of Funding Opportunity (NOFO) focused on the intersection of disabilities, race and ethnicity, and socioeconomic status in persons with developmental and physical disabilities. See link:

<https://grants.nih.gov/grants/guide/pa-files/PA-23-309.html>. The overarching goals are to support innovative research that focuses on the health (e.g., conditions, outcomes, trajectories, etc.) and healthcare (e.g., modalities systemic or structural factors, access/barriers, service delivery, care quality, utilization, etc.) of persons living with disabilities and the intersections with race and ethnicity, and socioeconomic status.

The NIH press release is available here: <https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities>

The Washington Post also published an article on the decision, in which the DRRC's Peter Thomas, Jae Kennedy, and Bonnie Swenor are quoted, and that article is available here: <https://www.washingtonpost.com/wellness/2023/09/26/disability-groups-win-fight-be-included-health-equity-research/>

### ***Proposed Next Steps for 2024***

The DRRC should continue to advocate within NIH and with senior leadership at the NIH and Department of Health and Human Services (HHS) to ensure implementation of this landmark decision under the leadership of a new NIH Director.

## **II. New NIH Mission Statement and Ensuring Inclusion of People with Disabilities in Diversity, Equity, Inclusion, and Accessibility Efforts at Research Agencies**

DRRC also greatly expanded its efforts in 2023 to ensure that diversity, equity, inclusion, and accessibility (DEIA) efforts in NIH and throughout the scientific workforce appropriately include people with disabilities, specifically to better support researchers with disabilities.

DRRC submitted letters in support of the NIH Advisory Committee to the Director (ACD) Working Group on Diversity, Disabilities Subgroup report recommending strategies for enhancing disability data collection, advancing evidence-based practices for supporting individuals with disabilities, and ensuring inclusion of people with disabilities throughout the research enterprise. DRRC successfully advocated for the implementation of several of these recommendations including the designation of people with disabilities as a health disparities population, funding for studying health disparities, and a new NIH mission statement.

DRRC worked closely with leaders at NIH and disability community stakeholders to recommend a new mission statement for the NIH that removed ableist language while still advocating for investment and focus on rehabilitation and disability research.

### ***Proposed Next Steps for 2024***

DRRC should continue to advocate for more inclusive policies both within NIH and throughout the entire scientific workforce to support researchers with disabilities, advance disability data collection, and ensure that all DEIA efforts at federal research agencies appropriately consider the needs of individuals with disabilities. In 2024, DRRC should continue to advocate as an external stakeholder with NIH and beyond to implement more of the ACD's recommendations and advance additional strategies identified by the membership to further these critical goals.

### ***Meetings with NIH Leadership***

DRRC continues to actively engage with NIH leadership to implement legislation enacted in 2017 to enhance and better coordinate medical rehabilitation research at the agency. Each year, DRRC convenes direct meetings between representatives of the DRRC Steering Committee and senior NIH officials to discuss these efforts and the practice of disability, independent living, and rehabilitation research across all NIH Institutes and Centers. This year DRRC met with senior leadership at the National Institute on Child Health and Human Development (NICHD), including the leadership of NCMRR; the National Institute of Neurological Disorders and Stroke (NINDS); and the BRAIN Initiative.

Additionally, representatives from the DRRC attended the virtual May and December 2023 meetings of the National Advisory Board on Medical Rehabilitation Research (NABMRR), the body that advises the directors of NIH, NICHD, and NCMRR on matters and policies relating to

the NCMRR's programs. The meetings included updates about NIH activities in the field of rehabilitation research, planned activities for the coming year, and updated numbers describing rehabilitation research funding across the various Institutes and Centers.

### **III. Fiscal Year 2024 Appropriations**

In 2023, the DRRC advocated for report language and appropriate funding levels in the (still-unpassed) FY 2024 House and Senate appropriations bills. Report language provides important non-binding guidance on Congressional intent for the provisions it describes, essentially outlining how Congress intends for federal agencies to spend appropriated funds. Several of our key priorities were included in the FY 2023 omnibus package passed in December 2022 and we have continued to advocate for full funding of disability and rehabilitation research funding in the midst of a tumultuous appropriations process.

As in previous years, the DRRC provided members with real-time updates on the progression of the FY 2024 appropriations process and disseminated materials detailing the decisions made in the President's Budget and Congressional committees' appropriations work. These included written summaries of the major provisions of the budget and House and Senate L-HHS legislation, a searchable index and catalog of relevant language, and our updated appropriations chart tracking funding for DRRC priority programs over time and displaying the proposed funding numbers, as well as the year-over-year proposed increases from FY 2023 to FY 2024.

Our appropriations summaries can be found on the [DRRC website](#), available to DRRC members only. To access the appropriations page, enter the password "drrcaccess" when prompted.

#### ***Proposed Next Steps for 2024***

In 2024, the DRRC anticipates continuing to advocate with the House and Senate Appropriations Committees for report language and funding requests for the FY 2024 and 2025 appropriations bills, and with the Biden Administration as appropriate, consistent with previous efforts. We will work with DRRC members to develop and prioritize appropriate requests to achieve the Coalition's goals of advancing disability, independent living, and rehabilitation research.

#### **Conclusion**

In 2023, DRRC led the disability community in a number of different advocacy realms regarding the enhancement of disability, independent living, and rehabilitation research at the federal level including securing the health disparities designation at NIH and engaging organizations on the changes to the ACS disability questions. We expect another busy year in 2024 and hope that the DRRC member organizations will continue to participate actively in the coalition to support this important work to benefit the populations we serve.

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