

MEMORANDUM

To: DRRC Members

From: Peter Thomas and Joe Nahra, DRRC Coordinators

Date: December 14, 2022

Re: DRRC 2022 Year in Review and Proposed Agenda for 2023

Executive Summary

We write to provide you with an update on the activities of the Disability and Rehabilitation Research Coalition (DRRC) in 2022. As we enter 2023, we want to provide a summary of the efforts made on behalf of the DRRC and its member organizations over the past twelve months, and to provide you with a forecast of issues that the coalition may engage in over the coming year.

The DRRC's size and strength as a representative coalition of organizations concerned with the state of disability, independent living, and rehabilitation research. The strength of the coalition is readily apparent in its active and productive portfolio of issues. DRRC had another busy year in 2022, engaging with policymakers, federal agencies, and the research community to advance our preexisting priorities and other key issues as they arose.

This memorandum summarizes the DRRC's work across a number of top priorities in 2022 that were developed and affirmed in a vote by the DRRC membership early this year. We also highlight some of the Coalition's major successes this year and offer a preview of the suggested advocacy agenda for 2023. As in past years, the full DRRC membership will discuss and approve a full slate of policy priorities for the coming year at the upcoming Annual Meeting.

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. We encourage DRRC members to review this memo and consider any suggestions for continued or new policy priorities in 2023. We will discuss our work this year and our plans for next year at the upcoming DRRC Annual Meeting, **scheduled for Tuesday, February 7 from 1-3pm ET. The annual meeting will be held in-person at the Powers Law offices (1501 M Street NW, Washington, DC) with a hybrid virtual option available via Zoom.** The meeting is open to all DRRC members.

For more information about the Annual Meeting, please contact Joe Nahra at Joseph.Nahra@PowersLaw.com.

Key DRRC Successes in 2022

- Secured a \$3.5 million *increase in funding for NIDILRR* in the final FY 2022 omnibus package.
- Secured inclusion of report language in omnibus *supporting the ICDR* (verbatim as drafted by DRRC) as well as language encouraging NIH to examine health disparities faced by people with disabilities and to collect data on diversity of the biomedical research workforce, including disability status.
- Succeeded in convening a Working Group within NIMHD to explore designating people with disabilities as a *health disparity population*.
- Supported release of white paper 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*.
- Advanced comprehensive recommendations for COSWD to *implement its strategic plan from a disability perspective*.

2022 Review: Initiatives and Engagement on Behalf of DRRC

I. Designating People with Disabilities as a Health Disparities Population

In April, DRRC worked with our members and representatives of the National Council on Disability (NCD) to prepare a [detailed recommendation](#) for the National Institute on Minority Health and Health Disparities (NIMHD) to officially declare people with disabilities a health disparity population. NIMHD, in consultation with the Agency for Healthcare Research and Quality (AHRQ), has the authority to designate such populations if there is “a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.” Advancing this designation became a key priority for the Coalition in 2022, as it would better allow NIMHD and the entire National Institutes of Health (NIH) to conduct prioritized and focused research on the causes of disparities and methods to prevent, diagnose, and treat such disparities among people with disabilities.

DRRC included this recommendation in [written testimony](#) submitted for the record during the Ways & Means Health Subcommittee’s hearing in February on *Bridging Health Equity Gaps for People with Disabilities and Chronic Conditions*.

DRRC representatives met with the NIMHD Director in August to discuss our recommendation further and urge the Institute to act. We presented an overview of extensive clinical evidence detailing the disparities faced by people with disabilities, as well as recent Administration and Congressional actions recognizing the importance of health disparities research about people with disabilities. Soon after, the NIMHD Advisory Board announced the formation of a Working Group to explore the benefits of making this designation and to provide “general guidance and strategic direction” on opportunities to advance the science of disability disparities.

Proposed Next Steps for 2023

The DRRC should continue to advocate within NIH and with senior leadership at the Department of Health and Human Services (HHS) to promote the disparity population designation. DRRC should also advocate before Congress to build awareness and support for the designation and ensure that NIMHD has the political capital, and external encouragement, necessary to move forward.

II. Ensuring Inclusion of People with Disabilities in Diversity, Equity, Inclusion, and Accessibility Efforts at Federal Research Agencies

DRRC also greatly expanded its efforts in 2022 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.

In February, DRRC submitted comprehensive [comments](#) on the draft strategic plan for the Chief Office for Scientific Workforce Diversity (COSWD), intended to ensure that COSWD recognizes that its scope should and does include people with disabilities, particularly as NIH carries out the President's Executive Order on *Advancing Racial Equity and Support for Underserved Communities*. After the final plan was released, DRRC followed up with [specific recommendations](#) for implementing the plan through a disability lens, offering specific questions and suggestions for measuring NIH's disability inclusion efforts and advancing impactful, accountable, long-term policies to support people with disabilities in the scientific workforce. Representatives from the DRRC met with Dr. Marie Bernard, head of COSWD, and other senior leaders at NIH to discuss these recommendations in June. DRRC also submitted similar [recommendations](#) in response to the NIH-Wide Strategic Plan Framework on DEIA in April.

DRRC engaged informally with the NIH Advisory Committee to the Director (ACD) Working Group on Diversity, Disabilities Subgroup as they prepared a targeted 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. The report was presented to the full ACD in December and will be a major focus of disability inclusion efforts in the coming year.

Proposed Next Steps for 2023

The 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 2023, DRRC should advocate as an external stakeholder with NIH and beyond to implement the ACD's recommendations and advance additional strategies identified by the membership to further these critical goals.

III. Advocacy in Support of NIDILRR and its Research Mission

In 2022, DRRC continued its longstanding engagement with NIDILRR and maintained a close relationship with new director Dr. Anjali Forber-Pratt. DRRC coordinators kept in regular contact with Dr. Forber-Pratt to discuss key priorities and offer support for NIDILRR initiatives, including the early development of the next NIDILRR Long-Range Plan, which will cover Fiscal Years 2024 through 2028. In November, the DRRC submitted [initial feedback](#) on the plan, covering both the process for soliciting stakeholder input, NIDILRR's research and grantmaking processes, and important research subjects for inclusion in the next plan, including Long COVID, the intersection of disability and aging, and disability disparities.

DRRC also continued our concerted efforts to increase the funding levels for NIDILRR. Though the appropriations process this year was far removed from the normal cycles (with FY 2022 funding only being finalized in March and FY 2023 funding still unfinished), we maintained our advocacy for a significant NIDILRR increase to address the need for applied research related to the pandemic and key disability, independent living, and rehabilitation research themes. As a result of our advocacy in 2021 and early 2022, the final omnibus package for FY 2022 signed in March included a \$3.5 million increase for NIDILRR.

In April, DRRC submitted [comments](#) in support of a proposed rule change governing NIDILRR's peer review process. The changes sought to better enable greater workforce participation by researchers with disabilities among NIDILRR grantees by creating separate criteria for applicants' engagement of individuals with disabilities along with other underserved populations. NIDILRR finalized the proposed changes shortly thereafter.

We also continued to support the ICDR and work closely with Dr. Forber-Pratt to advance our mission of reinvigorating the Committee and raising its profile across the federal government. In addition to our NIDILRR funding requests, DRRC succeeded in getting report language, drafted verbatim by the Coalition, in the final FY 2022 omnibus package highlighting the importance of ICDR and its role in advancing interagency collaboration, particularly coordinating the collection of disability-specific data. The full language can be found [here](#).

Proposed Next Steps for 2023

The DRRC should continue working with current NIDILRR leadership to promote applied disability, independent living, and rehabilitation research and advocate externally in support of NIDILRR and its research mission. In 2023, DRRC's work will include:

1. Advocating for increased funding for NIDILRR's operations and grantmaking capabilities for the FY 2024 appropriations cycle.
2. Working with NIDILRR leadership to provide detailed input and help shape the next NIDILRR Long-Range Plan for Fiscal Years 2024-2028.
3. Continue engaging with NIDILRR leadership and officials in the Administration for Community Living (ACL) to reaffirm commitment to disability, independent living, and rehabilitation research.

Specifically regarding ICDR, DRRC will continue advocating for an expanded recognition of the role of ICDR and enhanced collaboration on disability research across federal agencies by:

1. Seeking dedicated funding to support ICDR's status as a standalone interagency committee and promoting the Committee's role as a convener of all federal agencies conducting disability, independent living, and rehabilitation research.
2. Advocating with ACL and the leadership of ICDR to promote the implementation of the government-wide strategic plan on disability, independent living, and rehabilitation research and encourage commitment to ICDR's mission.

IV. Advocacy Before the National Institutes of Health

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. In previous years, DRRC has met with senior leadership at the National Institute on Child Health and Human Development (NICHD), including the leadership of NCMRR; the National Institute on Deafness and Communication Disorders (NIDCD); the National Cancer Institute (NCI); the National Institute of Nursing Research (NINR); the National Center for Complementary and Integrative Health (NCCIH); the National Institute on Aging (NIA); the National Institute of Neurological Disorders and Stroke (NINDS); the National Institute of Biomedical Imaging and Bioengineering (NIBIB); the National Institute of Arthritis and Musculoskeletal Disorders (NIAMS); and the Office of the NIH Director.

As NIH and other federal agencies continue to grapple with policies for a return to in-person business, we purposely did not schedule in-person meetings this year with NIH officials. However, DRRC organized virtual meetings with key NIH offices, including with NCMRR, COSWD, and NIMHD. We were pleased to welcome individual researcher representatives from many different DRRC members to provide the "on the ground" perspective on the key issues facing the Coalition.

Additionally, representatives from the DRRC attended the virtual May and December 2022 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. In FY 2022, rehabilitation research across NIH ***topped \$820 million***. We also attended meetings of the NIH ACD and the ICDR. We provided updates on these meetings to the DRRC membership in writing and on our monthly all-member calls.

V. Fiscal Year 2023 Appropriations

In 2022, the DRRC advocated for report language and appropriate funding levels in the (still-unpassed) FY 2023 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 2022 omnibus package passed in March and we have continued to advocate for further victories in the forthcoming FY 2023 package.

As in previous years, the DRRC provided members with real-time updates on the progression of the FY 2023 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-passed 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 increases from FY 2022 to FY 2023.

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 2023

In 2023, the DRRC anticipates continuing to advocate with the House and Senate Appropriations Committees for report language and funding requests in the omnibus FY 2024 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

The DRRC continued to carry out a high level of advocacy in a number of different areas regarding the enhancement of disability, independent living, and rehabilitation research at the federal level. We expect another busy year in 2023 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.

We encourage all DRRC members to join us, virtually or in-person, for the 2022 DRRC Annual Meeting, scheduled for Tuesday, February 7. We will discuss our work in 2022 and how to build on our successes and establish new priorities in 2023. All current members should have received a calendar invite with the location and dial-in information for the meeting. If you have any questions regarding the Annual Meeting, please contact Joe Nahra at Joseph.Nahra@PowersLaw.com.