

DISABILITY AND REHABILITATION RESEARCH COALITION

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MEMORANDUM

To: DRRC Members

From: Peter Thomas, Bobby Silverstein, and Joe Nahra

Date: January 24, 2020

Subject: DRRC Year in Review and Proposed Agenda for 2020

Executive Summary

We write to provide you with an update on the activities of the Disability and Rehabilitation Research Coalition (DRRC) in 2019. As we enter 2020, 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. We will review the initiatives outlined below and discuss our agenda for the upcoming year at the DRRC annual all-member meeting, to be held on January 28, 2020. For more details and to RSVP for the meeting, please contact Joe Nahra at Joseph.Nahra@PowersLaw.com.

The DRRC's size and strength as a representative coalition of organizations concerned with the state of disability, independent living, and rehabilitation research is readily apparent in its active and productive portfolio of issues. This year was no exception, as the DRRC engaged with policymakers, federal agencies, and the rehabilitation research community to advance its targeted agenda. The DRRC continues to see positive results in several of its initiatives, including:

- Advocacy in support of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and its research mission in disability, independent living, and rehabilitation.
- Engagement with key administration officials regarding NIDILRR's Long-Range Plan and the Interagency Committee on Disability Research (ICDR) government-wide strategic plan.
- Monitoring of and reporting on the Fiscal Year 2020 federal appropriations process and funding of DRRC priorities.
- Providing feedback on research priorities and strategic planning relating to disability, independent living, and rehabilitation with key programs at the National Institutes of Health.
- Continued national presence and activity through comment letters, direct agency engagement, and participation in national forums on issues related to disability, independent living, and rehabilitation research.

Summary Recommendation: *The DRRC Steering Committee strongly recommends that all DRRC member organizations commit to funding the coalition in 2020 at the same levels as 2019.*

2019 Review: Initiatives and Engagement on Behalf of the DRRC

Throughout 2019, the DRRC engaged in a number of activities to advance rehabilitation, independent living, and disability research on multiple fronts. The following provides a summary of those initiatives and engagements conducted on behalf of the DRRC and its members.

1. Advocacy in support of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and its research mission

NIDILRR Appropriations FY 2020

In 2018, DRRC engaged in a comprehensive advocacy campaign to support NIDILRR and urge Congressional appropriations committees to reject a Presidential budget proposal to move and consolidate NIDILRR to the National Institutes of Health (NIH). These efforts were ultimately successful, as Congress did not move and consolidate NIDILRR and in fact included language in the Fiscal Year (FY) 2019 appropriations bill report indicating that the Committees did not agree with this proposal.

In 2019, DRRC made a concerted effort to increase the funding levels for NIDILRR, as outlined in our 2019 Policy and Advocacy Priorities. In order to capitalize on our successes in 2018, we implemented an advocacy campaign targeted around NIDILRR for the FY 2020 appropriations cycle. Over the course of the year, representatives from the DRRC Steering Committee held several meetings with key bipartisan leadership in the House and Senate responsible for appropriations, outlining our request to increase funding for NIDILRR for FY 2020. Additionally, we conducted a messaging campaign including historical funding charts and budget justifications for our request to targeted House offices to garner support for the proposed increase included in the Senate's subcommittee draft appropriations bill, which increased NIDILRR's funding by \$3 million. The [final government funding bill](#), signed into law on December 20, 2019, included this \$3 million increase for a total of \$111,870,000 in FY 2020. Of the \$3 million, \$1 million was directed to assistive technology and \$2 million was marked for continued investment in research focused on independent living, addressing the disabled aging populations, and targeting rural, frontier, and tribal communities.

Meeting with Former NIDILRR Director

In June, representatives from the DRRC Steering Committee met with the then-Director of NIDILRR, Jim Whitehead, and senior NIDILRR staff including Phil Beatty, the Director of the Office of Research Sciences. Also in attendance was Mary Lazare, the Principal Deputy Administrator for the Administration for Community Living (ACL), which houses NIDILRR. The group discussed the DRRC's role in supporting NIDILRR (and holding the Institute accountable), NIDILRR's relationship to and opportunities to partner with other offices within the Department of Health and Human Services (HHS), and the ongoing work of the Interagency Committee on Disability Research (ICDR). Unfortunately, soon after our meeting, Jim resigned as NIDILRR Director. The position has not yet been filled, but the DRRC will continue to monitor any new developments and engage with Kristi Hill, Acting Director, and Phil Beatty, Director of the Office of Research Sciences, with whom DRRC has met several times in the past.

NIDILRR Long Range Plan

In January, NIDILRR released its [2018-2023 Long Range Plan](#) (LRP), presenting a comprehensive agenda to advance the work being done by NIDILRR grantees and others in applied disability, independent living, and rehabilitation research and development. The DRRC submitted detailed comments regarding the draft LRP in March 2017, and distributed a DRRC memo outlining the major provisions and highlights of the final plan in February 2019.

Proposed Next Steps for 2020

DRRC should continue working with NIDILRR leadership to promote applied disability, independent living, and rehabilitation research. We will monitor all developments regarding the search for a new permanent director of the Institute and work to ensure continuity with the important work being conducted by NIDILRR. In 2020, we will continue to advocate for increased funding for NIDILRR's operations in the FY 2021 appropriations cycle. We will also work to further involve NIDILRR in the activities of the Centers for Medicare & Medicaid Services, especially regarding the role of NIDILRR's data stores and disability and rehabilitation science expertise in impacting the Medicare and Medicaid programs.

2. Fiscal Year 2020 Appropriations

In 2019, DRRC advocated for report language and appropriate funding levels in the FY 2020 House and Senate Appropriations bills. In the resulting bills and committee reports, several DRRC priorities were addressed by committee report language, and several priorities were level-funded or received increased funding for FY 2020. 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.

As in previous years, the DRRC provided members with real-time updates on the progression of the FY 2020 appropriations process, and disseminated materials detailing the decisions made in the final government funding package. These included a formal memo summarizing the major provisions of the legislation, a searchable index and catalog of relevant report language, and our updated appropriations chart tracking funding for DRRC priority programs over time and displaying the current funding numbers, as well as the year-over-year increases from FY 2019 to FY 2020.

Proposed Next Steps for 2020

In 2020, DRRC anticipates continuing to advocate with the House and Senate Appropriations Committees for report language and funding requests in the FY 2021 appropriations bills, 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. Additionally, we will engage in an effort to clarify the formula-based funding for the National Center of Medical Rehabilitation Research through the National Institute of Child Health and Human Development to ensure adequate resources are directed towards the Center's mission.

3. Advocacy before the National Institutes of Health

Meetings with NIH Leadership

Following the passage of bipartisan legislation to enhance and better coordinate medical rehabilitation research at NIH, the DRRC has been actively following and helping to shape the implementation of that legislation. To that end, the DRRC has conducted an effort to convene in-person meetings with NIH officials leading the Institutes that conduct disability and rehabilitation research at NIH. In previous years, the DRRC met with senior leadership at the National Institute of Child Health and Human Development (NICHD) including the leadership of the National Center on Medical Rehabilitation Research (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); and the Office of the NIH Director.

On October 30, 2019, the DRRC convened three on-campus meetings with NIH officials and representatives of DRRC Steering Committee organizations to discuss federal medical rehabilitation and disability research. The DRRC group met with:

- [Dr. Jill Heemskerk](#), Deputy Director of the National Institute of Biomedical Imaging and Bioengineering (NIBIB), and her senior program staff.
- [Dr. Robert Carter](#), Acting Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); and his senior program staff; including Dr. Chuck Washabaugh, who co-leads the Trans-NIH Medical Rehabilitation Coordinating Committee.
- [Dr. Alison Cernich](#), Deputy Director of NICHD; Dr. Theresa Cruz, Acting Director of NCMRR; and their senior program staff.

Overall, the October meetings with NIH helped highlight the importance of rehabilitation research at NIH to multiple Institute leaders and grow the relationship between the DRRC and NIH. The meetings stressed the importance of enhanced coordination and elevation of medical rehabilitation research at NIH.

NCMRR Director Search

In September 2019, Dr. Alison Cernich was [promoted](#) from the Director of NCMRR to the Deputy Director of NICHD. The DRRC sent a congratulatory letter to Dr. Cernich expressing our appreciation for her work in promoting rehabilitation science at NIH and outlining major accomplishments during her tenure with the Center. We also presented recommendations for the search for a new permanent director during our October meeting. While NIH's search process is not formally involving external stakeholders (as would be our preference), Dr. Cernich has assured us that the search committee is working to select a new director in a timely fashion who will be an effective and committed leader of rehabilitation research at NIH.

Additionally, representatives from the DRRC attended the May and December 2019 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 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 2019, rehabilitation research across NIH topped \$680 million. We provided updates on the two meetings to the DRRC membership on our monthly all-member calls.

Participation in NIH Strategic Planning Processes

In 2019, the DRRC took advantage of several opportunities to weigh in on the direction of NIH research on disability and rehabilitation by submitting formal comments on various strategic planning processes within NIH.

In February, the DRRC submitted comments on the draft strategic plan for NICHD, focusing on the role of NCMRR (which is housed within NICHD) in fostering the development of the scientific knowledge needed to enhance health, productivity, independence, and quality of life for people of all ages with disabilities. NICHD's draft plan included six main research themes, and DRRC's comments specifically included recommendations regarding understanding early human development, identifying sensitive time periods to optimize health interventions, improving health during the transition from adolescence to adulthood, and ensuring safe and effective therapeutics and devices. NICHD released its [final strategic plan](#) in September.

In June, the NIH, NCMRR, and the Medical Rehabilitation Coordinating Committee began the process of reviewing the NIH Research Plan on Rehabilitation, last updated in 2016. The NIH is statutorily required to update the Research Plan every five years, and therefore solicited public comment on the themes and research priorities that should be maintained, revised, and added in the next version, due to be released in 2021. DRRC submitted comments expressing our hope that the updated plan will maintain and expand the 2016 plan's support for high-quality rehabilitation research across the various ICs, and specifically recommended an understanding of rehabilitation research that is cross-cutting, multi-disciplinary, and focused on:

- Understanding the mechanisms of disability;
- Restoring and improving functional capacity in individuals undergoing rehabilitation; and
- Maintaining and preventing deterioration of functional skills while enhancing quality of life for people with disabilities.

In November, the National Institute of Neurological Disorders and Stroke (NINDS), one of the largest funders of rehabilitation research at NIH, announced the beginning of an institute-wide strategic planning process. NINDS invited stakeholders to provide input on broad strategic goals developed by the Institute as they formulate a draft strategic plan. DRRC submitted comments on several of these goals, mirroring many of the themes presented in our comments on the NIH Rehabilitation Research Plan. Additionally, we encouraged NINDS to prioritize outreach and collaboration with other Institutes at NIH as well as other agencies within the federal government to develop impactful research on rehabilitation and disability.

Proposed Next Steps for 2020

DRRC should continue working with NIH leaders to promote rehabilitation science, and follow up on visits from past years. Among those next steps, DRRC is proposing to conduct several related activities:

1. Follow up with those senior NIH leaders with whom DRRC has already engaged.
2. Meet with additional NIH leaders at Institutes and Centers relevant to the DRRC's mission, including the National Institute of Mental Health and the National Institute of Minority Health and Health Disparities to discuss the role of rehabilitation science at those ICs.
3. Draft comments and participate in NIBIB's strategic planning public comment process to ensure rehabilitation science is elevated within the Institute. Comments are likely to be solicited in mid-2020.
4. Continue to monitor any developments regarding the appointment of a new permanent director for NCMRR and engage with new personnel to ensure a continued and strong relationship between the DRRC and the Center.
5. Collaborate with NCMRR to highlight advancements in disability, independent living, and rehabilitation research through participation in the NIH Rehabilitation Research 2020 conference in October and efforts to recognize NCMRR's 30th anniversary.

4. Interagency Committee on Disability Research (ICDR)

In 2019, DRRC continued to advocate for ICDR to release and implement a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research. A [final plan](#) was released in April. DRRC's efforts included meeting with NIDILRR Director Jim Whitehead to discuss ICDR, among other topics.

The ICDR was established to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs – including programs related to assistive technology research and research that incorporates the principles of universal design. Given this purpose, DRRC has been closely engaged with the ICDR's efforts. In 2016, DRRC commented on a draft version of the strategic plan for FY 2017-2020, though the final plan was not released until midway through 2019. DRRC representatives also met with staff at ACL assigned to NIDILRR and ICDR in 2017 to advocate for completion of next steps for the plan.

The final plan was eventually released in April 2019, though the DRRC maintained some concerns about the final version, including, primarily, the disclaimer that the plan did not “represent the positions or policies of the ICDR or the Federal Government.” These concerns, as well as questions about the timeline and process for implementation of the plan, were discussed during our June meeting with the NIDILRR Director. Additionally, we expressed our support for the mission of the plan and our hope that the federal agency representatives who sit on the ICDR would commit to enacting the strategic goals and objectives outlined within the plan. In July, the DRRC sent a letter to HHS Secretary Alex Azar requesting a meeting to discuss implementation of the strategic plan, specifically requesting that the Secretary make clear that the chair of the ICDR (traditionally designated to be the NIDILRR director) carries the weight of the Secretary's office.

Proposed Next Steps for 2020

With the position of the NIDILRR Director still vacant, we maintain our concerns about the apparent lack of effort to fully implement the government-wide strategic plan. In 2020, we will continue to advocate with ICDR and ACL, specifically by meeting with ACL Deputy Administrator Mary Lazare and other staff, to encourage commitment to the plan and carrying out the objectives of improving interagency coordination and collaboration, promoting ongoing stakeholder input, and developing a government-wide inventory of disability, independent living, and rehabilitation research.