



MEMORANDUM

To: DRRC Members

From: Peter Thomas, Bobby Silverstein, and Joe Nahra

Date: February 1, 2021

Subject: DRRC 2020 Year in Review and Proposed Agenda for 2021

Executive Summary

We write to provide you with an update on the activities of the Disability and Rehabilitation Research Coalition (DRRC) in 2020. As we enter 2021, 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 **Tuesday, February 2 at 12:30pm ET**. For more details and to RSVP for the meeting, please contact Joe Nahra at Joseph.Nahra@PowersLaw.com or Emily Goodwin at Emily.Goodwin@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. Despite the uncertainty and upheaval of the COVID-19 pandemic, DRRC had a productive year in 2020, engaging with policymakers, federal agencies, and the rehabilitation research community to advance our preexisting priorities as well as key issues relating to the pandemic. The DRRC continues to see positive results in several of its initiatives, including:

- Advocacy regarding disability, independent living, and rehabilitation research relating to the COVID-19 pandemic, including data collection and targeted research for key populations.
- Providing feedback on research priorities and strategic planning relating to disability, independent living, and rehabilitation with key programs at the National Institutes of Health (NIH).
- 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.
- Monitoring of and reporting on the Fiscal Year (FY) 2021 federal appropriations process and funding of DRRC priorities.

- 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.

2020 Review: Initiatives and Engagement on Behalf of the DRRC

Throughout 2020, 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 regarding disability, independent living, and rehabilitation research relating to the COVID-19 pandemic

Disability Status Data Collection

In the initial stages of the legislative and regulatory response to the pandemic, Congress and the Administration advanced specific efforts to coordinate and enhance the collection of data around COVID-19 infections, testing, diagnoses, and treatment. Initial legislation referenced the importance of disaggregating data by demographic characteristics, but often did not consistently identify disability status as a key characteristic to monitor.

In April, Senator Elizabeth Warren (D-MA) and Reps. Ayanna Pressley (D-MA), Robin Kelly (D-IL), Karen Bass (D-CA) and Barbara Lee (D-CA) introduced the Equitable Data Collection and Disclosure on COVID-19 Act, which would require the Department of Health and Human Services (HHS) to collect and report racial and other demographic data, including disability status, on COVID-19 testing, treatment, and fatality rates. The DRRC, in consultation with experts from other stakeholder organizations, offered redline edits to ensure that disability was emphasized throughout the legislation. Later that month, Congress passed the Paycheck Protection Program and Health Care Enhancement Act, which included a provision requiring the Department of Health and Human Services (HHS) to produce a report on COVID-19 testing and diagnoses by “race, ethnicity, age, sex, geographic region, and other relevant factors.”

After significant advocacy and engagement by the DRRC and its partners, Sens. Warren and Bob Casey (D-PA) and Reps. Pressley and Jim Langevin (D-RI) issued a letter to HHS Secretary Azar formally requesting that disability status be collected as a mandated variable detailed in the report. The DRRC followed this letter with a separate, detailed letter supporting the request and outlining the observed and disparate impact of the pandemic on people with disabilities, underscoring the importance of robust disability data. The DRRC continued to pressure Congress and the Administration to collect this critical data, providing edits to the legislative text of the Democrats’ Heroes Act and including these requests in letters to Capitol Hill and the White House.

Including Disability and Rehabilitation in the Federal Pandemic Research Agenda

The federal government also began mobilizing its research infrastructure to build knowledge about the novel coronavirus. While the initial course of research was focused on identifying the

mechanics of the virus itself and beginning development of vaccines and treatment, it soon became clear that significant additional efforts were needed to understand and develop a response to the impacts of the pandemic on specific populations, as well as the impacts of social distancing, quarantine protocols, and the economic shutdown. The DRRC collected feedback from nearly all organizational members to understand a broad range of research questions specifically impacting the disability community regarding the pandemic.

The DRRC reviewed the feedback and organized the research topics into four key themes: ensuring inclusion of people with disabilities in existing COVID-19 research, disability-specific COVID-19 research, rehabilitation interventions for COVID-19 treatment and recovery, and the immediate impacts of the pandemic on people with disabilities. The DRRC drafted a detailed letter to key policymakers, including Congressional leaders and the leadership of HHS, NIH, the Centers for Disease Control and Prevention (CDC), and the Administration for Community Living (ACL). DRRC subsequently conducted meetings with key congressional offices to discuss these priorities and how the pandemic should impact federal research funding for the coming Fiscal Year.

In September, NIH, through the National Center for Medical Rehabilitation Research (NCMRR), issued a Notice of Special Interest (NOSI) for “Research on Rehabilitation Needs Associated with the COVID-19 Pandemic”. NOSIs indicate specific areas in which NIH seeks to encourage research applications. The NOSI focused on many of the same themes that were raised in the DRRC letter and incorporated the same or similar language in outlining potential topics of interest. DRRC continues to encourage its members and other stakeholders in the field to submit applications to conduct critical COVID-19 research impacting people with disabilities.

Proposed Next Steps for 2021

The DRRC should continue working with Congress and the incoming Biden Administration (beginning with the Steering Committee’s meeting with the Transition Team on January 12, 2021) to ensure that the federal response to the pandemic includes targeted research on the disparate impact of COVID-19 on people with disabilities, including “ripple effects” on access to services, health, and independent function not directly resulting from COVID-19 infection. As the Biden Administration conducts its first budgeting process, and as federal research agencies develop their strategic plans for the ongoing COVID-19 response, we will continue to advocate for consideration of the disability population.

2. 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 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.

Due to the COVID-19 pandemic, we did not schedule in-person meetings with NIH staff. In 2020. However, DRRC remained closely engaged with NIH staff, especially NCMRR leadership, regarding priorities for the disability and rehabilitation research community throughout the year. As noted above, the DRRC particularly focused on ensuring that NIH leadership, as well as other key agency staff, understood the importance of federal investment into COVID-19 research on disability, independent living, and rehabilitation.

Additionally, representatives from the DRRC attended the virtual May and December 2020 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 2020, rehabilitation research across NIH topped **\$720 million**. We provided updates on the two meetings to the DRRC membership on our monthly all-member calls and via email.

Participation in NIH Strategic Planning Processes

In 2020, 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 April, DRRC submitted comments on the draft framework for the NIH-Wide Strategic Plan for FY 2021-2025. DRRC's comments urged the agency to prioritize disability research across all the Institutes and Centers and to build on the last few year's significant progress in coordinating rehabilitation research throughout the federal government. Additionally, DRRC recommended that the Strategic Plan include a focus on improving research infrastructure, develop and adequately fund training programs for researchers with disabilities, and adopt the community engagement requirements used by NIDILRR and the Patient-Centered Outcomes Research Institute (PCORI) to ensure the participation of people with disabilities and their caregivers in NIH-funded research. DRRC will continue to utilize any future opportunities to comment on the plan before it is finalized in 2021.

In November, DRRC submitted comments on the proposed objectives for the NIH Rehabilitation Research Plan, last updated in 2016. NIH is statutorily required to update the Research Plan every five years, and therefore solicited public comment on the proposed objectives after a prior call for feedback in June 2019. DRRC's comments expressed our hope that NIH will continue to prioritize disability and rehabilitation research on the impact of the COVID-19 pandemic in the final plan, scheduled to be released in 2021, as the ripple effects on the disability community in particular will be felt long after the public health emergency has passed. Our comments also

recommended that NIH emphasize research on enhancing patient-centered rehabilitation care across the lifespan, increase the focus on developing and standardizing patient-reported outcomes measures, and examine the effectiveness of tele-rehabilitation and other innovative care delivery models.

Proposed Next Steps for 2021

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 (likely via virtual meetings).
3. Continue to engage with new personnel at NCMRR to ensure a continued and strong relationship between the DRRC and the Center.
4. Participate in future public comment opportunities to weigh in on the direction of NIH-wide and Institute-specific strategic planning processes.

3. Advocacy in support of NIDILRR and its research mission

In 2020, the DRRC continued its concerted efforts to increase the funding levels for NIDILRR, as outlined in our 2020 Policy and Advocacy Priorities. In order to capitalize on our successes in 2019, we implemented an advocacy campaign targeted around NIDILRR for the FY 2021 appropriations cycle. Over the course of the year, representatives from the DRRC Steering Committee held several virtual meetings with key bipartisan leadership in the House and Senate responsible for appropriations, outlining our request to increase funding for NIDILRR for FY 2021. Prior to the onset of the pandemic, DRRC had requested an increase of \$3 million (for a total FY 2021 funding level of just under \$115 million), engaging with key offices including Sens. Patty Murray (D-WA), Roy Blunt (R-MO), Bob Casey (D-PA), and Tammy Duckworth (D-IL) and Reps. Rosa DeLauro (D-CT), Tom Cole (R-OK), James Langevin (D-RI), and Don Young (R-AK). DRRC's efforts also led to the submission of a formal letter from the co-chairs of the Bipartisan Disabilities Caucus (Reps. Langevin and Young) to the leadership of the relevant subcommittee supporting this request.

As the wide-ranging impact of the COVID-19 pandemic on the disability population became clear, the DRRC recognized a need for additional funding for NIDILRR to conduct its critical applied research. Working especially with NARRTC, which drafted a position paper outlining the need for enhanced NIDILRR research, the DRRC advocated for an additional \$5-10 million increase for NIDILRR in FY 2021, for a total NIDILRR budget of \$120-125 million. The DRRC also requested specific language in the appropriations report emphasizing the importance of including disability and rehabilitation in the COVID-19 research agenda. We circulated letters to key congressional and appropriations committee leaders and met with several offices to underscore the importance of this request.

The final omnibus bill, signed into law on December 27, 2020, included a \$1 million increase for NIDILRR, for a total of \$112,970,000 in FY 2021.

Proposed Next Steps for 2021

The DRRC should continue working with current and future 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 2021, we will continue to advocate for increased funding for NIDILRR’s operations in the FY 2022 appropriations cycle.

4. Fiscal Year 2021 Appropriations

In 2020, the DRRC advocated for report language and appropriate funding levels in the FY 2021 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. In the resulting omnibus bill and committee reports, several priorities were level-funded or received increased funding for FY 2021.

As in previous years, the DRRC provided members with real-time updates on the progression of the FY 2021 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 2020 to FY 2021.

Proposed Next Steps for 2021

In 2021, the DRRC anticipates continuing to advocate with the House and Senate Appropriations Committees for report language and funding requests in the FY 2022 appropriations bills, and with the incoming 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.

5. Development of the DRRC Website

As discussed during our 2020 annual meeting, DRRC staff worked to increase the coalition’s online presence by developing a website for information about the coalition and our work. The new website will serve as a resource for current members as well as external stakeholders to learn more about the DRRC, including our advocacy archives going back several years. DRRC’s analyses of the annual appropriations process are also available in the “members only” section of the website. As DRRC continues to grow, we will publish additional information and resources on the website and identify new opportunities to publicize our work and grow the coalition’s profile. In conjunction with the launch of the new website, we also unveiled an updated DRRC

logo, which will be used to standardize the look and feel of DRRC documents (and can be found at the top of this memo).

The DRRC website is available at www.drcc-coalition.org, and the members only section can be accessed by inputting the password “**drccaccess**” when prompted. DRRC members are encouraged to review the website and send staff any feedback or suggestions to improve our online presence.

Conclusion

Though the impact of the COVID-19 pandemic significantly shifted many of our top priorities this year, the DRRC nevertheless carried 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 2021 and hope that the DRRC member organizations will continue to participate in the coalition at the same levels as 2020 to support this important work to benefit the populations we serve.

We encourage all DRRC members to join us (virtually) for the 2021 DRRC Annual Meeting, scheduled for Tuesday, February 2 from 12:30 – 2pm ET via Zoom. We will discuss our work in 2020 and discuss how to build on our successes and establish new priorities in 2021. All current members should have received a calendar invite with the dial-in information; if you have any questions regarding the annual meeting, please contact Joe Nahra at Joseph.Nahra@PowersLaw.com or Emily Goodwin at Emily.Goodwin@PowersLaw.com.