

MEMORANDUM

To: DRRC Members

From: Peter Thomas, Bobby Silverstein, and Leif Brierley

Date: December 6, 2018

Re: DRRC Year in Review and Proposed Agenda for 2019

Executive Summary

We write to provide you with an update on the Disability and Rehabilitation Research Coalition (DRRC). As we approach the end of 2018, we want to provide a summary of 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 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.
- Implementation of legislation to enhance the stature, visibility, and coordination of medical rehabilitation research at the National Institutes of Health (NIH).
- Monitoring of and reporting on the FY2019 federal appropriations process and funding of DRRC priorities.
- Advocacy with the Centers for Disease Control and Prevention (CDC) regarding disability and health issues at CDC.
- Engagement with key NIDILRR officials regarding NIDILRR's Long-Range Plan and the Interagency on Committee on Disability Research (ICDR) Government-Wide Strategic Plan.
- 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 2019 at the same levels as 2018.*

2018 Review: Initiatives and Engagements on Behalf of the DRRC

Throughout 2018, 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 in disability, independent living, and rehabilitation.

Throughout 2019, 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 NIH. DRRC's efforts in 2019 included:

- DRRC held meetings with the new Director of NIDILRR, Dr. Bob Jaeger, to learn more about his vision, goals, and objectives for NIDILRR.
- DRRC held meetings with key Congressional staff, intended to highlight to those staffers the importance and significance of NIDILRR, with the explicit message that Congress reject the recent proposal by the Trump Administration to move NDIILRR to the National Institutes of Health (NIH), which our coalition believes would be detrimental to the mission and work of NIDILRR.
- DRRC drafted multiple comprehensive letters addressed to House and Senate appropriators urging them to reject the Trump Administration's proposal, highlighting the importance of NIDILRR and its research products to people with disabilities.
 - These efforts were ultimately successful, as Congress did not move and consolidate NIDILRR, and Congressional appropriators included language in the reports accompanying the FY 2019 Labor, HHS, and Education appropriations bill indicating that the Committees do not agree with the proposal to move NIDILRR. NIDILRR also received a \$4 million funding increase for research related to assistive technology in FY 2019.
- DRRC convened a series of activities in conjunction with the NIDILRR 40th Anniversary celebration in October 2018, including:
 - DRRC worked with Congressional staff (Senate HELP Committee) to draft and introduce a statement in the Congressional Record in support of NIDILRR.
 - DRRC held a happy hour for all NIDILRR 40th anniversary event attendees that was widely attended and well-received
 - DRRC continued its advocacy and work with Dr. Bob Jaeger and engaged with him personally on multiple issues related to the 40th Anniversary event.

In 2019, DRRC should consider continuing to build off of the advocacy work conducted in 2018 and make a concerted effort to increase the funding levels for NIDILRR. While the FY 2019 budget included a \$4 million increase for NIDILRR targeted toward assistive technology research, the Institute remains funded below levels it would have attained prior to sequestration. NIDILRR has strong support and now has recognition from multiple key Congressional committees, and in its 40th year, would be well-served with an increase in funding for research that provides the translational and impactful benefits that NIDILRR research has. DRRC Should

consider implementing an advocacy campaign around NIDILRR beginning in early 2019 to capitalize on the FY 2020 appropriations cycle.

2. Implementation of Legislation to Improve the Stature, Visibility, and Coordination of Medical Rehabilitation Research at the NIH

Following the passage of bipartisan legislation to enhance and better coordinate medical rehabilitation research at the NIH, the DRRC has been actively following and helping shape the implementation of that legislation. To that end, the DRRC has convened four in person meetings with NIH officials at the NIH campus in Bethesda, MD, with researcher representatives from DRRC member organizations participating in those meetings on DRRC's behalf. The meetings, convened in the spring and fall of both 2017 and 2018, have yielded valuable insights into the state of medical rehabilitation research at the NIH, and have helped raise awareness of the new law and the importance of medical rehabilitation research with key NIH officials. Going forward, DRRC has a significant role to play in continuing its advocacy with NIH officials to ensure that the law is fully implemented and that ultimately, the stature, visibility, and coordination of medical rehabilitation research at the NIH is raised.

Most prominently, the DRRC has convened four on-campus meetings with senior NIH officials to discuss the implementation of the law at several NIH Institutes and Centers, and the coordination of the law's provisions with the NIH Office of the Director.

- On Tuesday, May 23, 2018, representatives of several DRRC member organizations and Powers Law staff met with NIH officials at the NIH campus. The DRRC group met with Dr. James Battey Jr., the Director of the National Institute on Deafness and Communication Disorders (NIDCD), and his senior program staff; and Dr. Ann O'Mara, a senior research leader at the National Cancer Institute (NCI) who serves on the Trans-NIH Rehabilitation Research Coordinating Committee, and her colleague Dr. Paul Jacobsen.
- On October 23, 2018, the DRRC group met with Alison Cernich, Ph.D., Director of the National Center for Medical Rehabilitation Research (NCMRR), and Lisa Kaeser, JD, Director, Office of Legislation and Public Policy, National Institute on Child Health and Human Development (NICHD); Ann Cashion, PhD, RN, FAAN, Acting Director of the National Institute of Nursing Research (NINR) and Scientific Director of the NINR Division of Intramural Research, and her senior program staff; David Shurtleff, Ph.D., Acting Director of the National Center for Complementary and Integrative Health (NCCIH), and his senior program staff.

Overall, the spring and fall meetings with NIH helped highlight the importance of rehabilitation research at the NIH to multiple Institute leaders. The meetings stressed the importance of enhanced coordination and elevation of medical rehabilitation research at the NIH, which from these meetings, did not appear to be fully realized as of yet. In 2019, DRRC may need to ensure a common understanding of the definition of medical rehabilitation research, as defined in the statute, is used across all NIH Institutes. DRRC will have a continued role to play in ensuring the

law is fully and appropriately executed, and that the stature, visibility, and coordination of medical rehabilitation research are elevated as the law envisions.

Proposed Next Steps for 2019

DRRC should continue working with NIH Institute and Center leaders to promote rehabilitation science, and follow up on visits from both 2017 and 2018. 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. Draft comments on NICHD's Strategic Plan and participate in NICHD's strategic planning process to ensure rehabilitation science is elevated within the Institute. Comments are due in January/February 2019.
3. Draft comments and participate in NCMRR's Rehabilitation Research Plan public comment process. Comments are likely to be solicited in late 2019.

3. FY 2018 Appropriations

In 2018, DRRC advocated for report language and appropriate funding levels in the Fiscal Year (FY) 2018 House and Senate Appropriations bills. In the resulting bills and committee reports, several DRRC priorities were addressed by the committee report language, and several priorities were level funded. Report language provides important non-binding guidance on the Congressional intent for the provisions it describes, essentially describing how Congress intends for federal agencies to spend appropriated funds.

Proposed Next Steps for 2018

In 2019, DRRC anticipates continuing to advocate with the House and Senate Appropriations Committees for report language and funding requests in the FY 2019 appropriations bills, consistent with previous efforts.

4. CDC Advocacy

In 2019, DRRC is proposing to engage with leaders at the Centers for Disease Control and Prevention (CDC) to ensure that the health of individuals with disabilities is always considered in the CDC's work.

In 2010, CDC appointed Dr. Vince Campbell to serve as the agency's Chief Disability and Health Officer and formed the Disability and Health Work Group. The Work Group, under Dr. Campbell's leadership made substantial progress ensuring that attention was given to disability-related issues throughout CDC's Centers and program areas, including:

- Recognizing disability as a key determinant in national surveys and other surveillance systems, and public health programs;
- Addressing health disparities among persons with disabilities;
- Enhancing health promotion and prevention and access to health care for people with disabilities under the Affordable Care Act;

- Fostering knowledge translation and communication efforts to bring persons with disabilities reliable information on a variety of public health topics;
- Developing new disability research initiatives through partnerships across CDC Centers and other federal agencies; and
- Developing public and private partnerships to support and advance disability issues.

When Dr. Campbell recently retired, a position was filled, but not with direct reporting to the CDC Director. This created a significant void in leadership on disability-related issues at CDC.

To address that void, in 2017, DRRC advocated for the inclusion of report language in the FY 2017 Senate Appropriations Committee report that addressed that need. Specifically, DRRC advocated for the inclusion of the following language regarding interagency leadership, coordination, and collaboration:

“The Committee encourages CDC to re-appoint a Chief Disability and Health Officer and re-establish the Disability and Health Work Group to provide leadership, coordination, and collaboration among Centers in order to expand and improve efforts to enhance the health of individuals with disabilities.”

The resulting Committee report included that exact report language. DRRC now proposes to follow up on the Committee’s language and work with CDC to see that the language is acted upon appropriately.

Proposed Next Steps for 2019

DRRC proposes to engage with the appropriate leaders at the CDC to help with the implementation of the Committee’s report language. The DRRC will arrange meetings with key officials and work in tandem with the research community to address these next steps.

5. Interagency Committee on Disability Research (ICDR)

In 2018, DRRC continued to advocate for ICDR to release a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research. DRRC’s efforts included meeting with NIDILRR Director Bob Jaeger to discuss ICDR, among other topics. DRRC also followed up on its comments, submitted in fall 2016, on the Draft Government Wide Strategic Plan FY 2017-2020 Prepared for ICDR, and discussed those comments with Dr. Jaeger in person multiple times.

Background

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, the ICDR released a draft government wide strategic plan for FY 2017-2020 prepared for the ICDR. DRRC submitted detailed comments on the draft, stating in comments submitted October 26, 2016:

The draft document presented for public comment provides comprehensive background information that can be used by the ICDR member agencies in formulating a strategic plan that derives organically from each agency's research domain, mission, and authority, and addresses specifically all of the requirements specified in the statute. We look forward to working with ICDR and its member federal agencies to take maximum advantage of the tremendous opportunity afforded by the creation of this government wide strategic plan.

Since the close of the commenting period, ICDR has not released an updated draft or other related documents. 2017 was a transition year for ICDR, as the advent of the Trump Administration also meant the ICDR experienced a change in leadership.

DRRC representatives met with ACL staff in 2017, discussing ICDR and other priorities. In meetings with the Principal Deputy Administrator of ACL, Mary Lazare, and other senior staff assigned to NIDILRR and ICDR, DRRC staff discussed the draft strategic plan and advocated for the completion of next steps.

Proposed Next Steps for 2019

In 2019, DRRC proposes to monitor closely for the government-wide strategic plan, which serves a valuable government-wide coordinating function in disability, independent living, and rehabilitation research. DRRC will continue to engage with Dr. Jaeger and look for opportunities to influence the final product.

6. NIDILRR Long-Range Plan 2018-2023

In March of 2017, DRRC submitted comments on the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Draft Long-Range Plan for 2018-2023. The draft long-range plan was formulated as a draft guide for NIDILRR's work in disability, independent living, and rehabilitation research. Overall, DRRC expressed support for the provisions of the draft plan. In addition to expressing overall support of the plan in the comments, DRRC made recommendations in several sections of the draft. Since the release of the draft plan, NIDILRR has not announced plans to release a final version of the plan. NIDILRR's new Director, Dr. Jaeger, has confirmed that the plan is currently working its way through the HHS clearance process, and a final plan is expected in the near term.

Background

DRRC generally provided comments in support of the plan, encouraging its release in final form. DRRC did include some recommendations in its comments. Specifically, DRRC made recommendations in the draft section on "health and function." DRRC expressed support for the approach to addressing the health and function needs of people with disabilities outlined in the draft, but made two additional recommendations that the approach include research related to:

- Comparative effectiveness research that could inform post-acute/rehabilitation policymakers.
- Transitions of care, particularly from acute to post-acute or across post-acute care settings. Preventative wellness and adaptive fitness programs.

DRRC also recommended that the NIDILRR long-range plan incorporate language indicating that NIDILRR will seek to build better relationships with the Centers for Medicare and Medicaid Services (CMS), so as to potentially better inform Medicare and Medicaid policy on related issues. The DRRC also recommended that the NIDILRR long-range plan incorporate language indicating that NIDILRR will seek to build better relationships with the Centers for Disease Control and Prevention (CDC), and in particular the National Center on Birth Defects and Developmental Disabilities (NCBDDD).

DRRC also recommended greater investment in employment-related projects including the tracking of employment statistics, the investigation of psychiatric disabilities, the study and development of interventions for youths and young adults with disabilities, the fielding of surveys on employer practices, the development of a model of return on investment for vocational programs, and the examination of possible employment disincentives.

Proposed Next Steps for 2019

In 2019, DRRC will continue to engage with NIDILRR and ACL staff. ACL is the parent organization to NIDILRR. Such engagement with the two agencies would be valuable and serve to encourage the release of the finalized long-range plan, which helps guide future directions of NIDILRR and advance the vital work being done in applied disability, independent living, and rehabilitation research and development. DRRC proposes to set up meetings with the appropriate political appointees and senior staff at ACL and NIDILRR to fulfill these advocacy goals.