

MEMORANDUM

**To: DRRC Members**

**From: Peter Thomas, Bobby Silverstein, and Leif Brierley**

**Date: December 13, 2017**

**Re: DRRC Year in Review and Proposed Agenda for 2018**

**Executive Summary**

We write to provide you with an update on the Disability and Rehabilitation Research Coalition (DRRC). As we approach the end of 2017, 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:

- Implementation of legislation to enhance the stature, visibility, and coordination of medical rehabilitation research at the National Institutes of Health (NIH);
- Inclusion of report language in FY 2018 Congressional Appropriations committee reports on DRRC priorities addressing research in disability, independent living, and rehabilitation.
- Engagement with officials at the Interagency Committee on Disability Research (ICDR) and submission of comments regarding the release of ICDR's government-wide strategic plan on disability, independent living, and rehabilitation research.
- Support for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Draft Long-Range Plan for 2018-2023.
- Advocacy with the Centers for Disease Control and Prevention (CDC) regarding disability and health issues at CDC.
- Submission of position statements on legislative efforts in health care reform.
- 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 2018 at the same levels as 2017.*

## **2017 Review: Initiatives and Engagements on Behalf of the DRRC**

Throughout 2017, 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. 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 two 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, 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.

#### ***Background***

In December 2016, Congress passed bipartisan legislation to enhance and better coordinate medical rehabilitation research at the National Institutes of Health (NIH) as part of the landmark 21st Century Cures Act (PL 114-255). President Barack Obama signed the legislation into law on December 13, 2016. The rehabilitation research legislation, S.800/H.R. 1631, the Enhancing the Stature and Visibility of Medical Rehabilitation Research at the NIH Act, was included in Section 2040 of the Cures Act. Introduced in the House by Congressmen Gregg Harper (R-MS) and James Langevin (D-RI) and in the Senate by Senators Mark Kirk (R-IL) and Michael Bennet (D-CO), the bipartisan, bicameral legislation was fully supported by NIH officials, rehabilitation research organizations, clinical associations and disability and consumer groups. Overall, the legislation builds upon the conclusions and recommendations of an NIH Blue Ribbon Panel on Medical Rehabilitation Research, which issued a comprehensive report in January 2013.

DRRC members and staff led the effort to ensure the passage of S.800/H.R. 1631 by hosting a series of Hill visits with staff representing Members of Congress on the Senate Health, Labor, Pensions, and Education (HELP) committee and the House Committee on Energy and Commerce. DRRC members and staff were instrumental in ensuring the bill was included in the final version of the 21<sup>st</sup> Century Cures Act.

#### ***2017 Activities***

Since passage, DRRC has played an active role in the law's implementation. The DRRC has worked closely with NIH officials, convened meetings on the NIH's campus, and worked to ensure that medical rehabilitation research is enhanced at the NIH broadly. The DRRC maintains

close working relationships with key NIH senior staff, and has worked with those officials to coordinate efforts to address medical rehabilitation research.

Most prominently, the DRRC has convened two 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 2017, representatives of several DRRC member organizations and Powers Law staff met with NIH officials at the NIH campus to discuss federal medical rehabilitation and disability research and the implementation of S. 800 which was incorporated into the 21st Century Cures Act. The DRRC group met with Dr. Diana Bianchi, Director of the National Institute of Child Health and Human Development (NICHD), Dr. Alison Cernich, Director of the National Center for Medical Rehabilitation Research (NCMRR), and Dr. James Anderson, Director of the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) within the Office of the Director.

In all three meetings, the DRRC representatives described the history of DRRC efforts with NIH to date and the importance of medical rehabilitation and disability research, using illustrations of existing and emerging research topics. The group also sought feedback and input from the NIH staff on specific NIH research developments as well as the implementation of Section 2040 of the 21st Century Cures Act. Below is a brief summary of takeaways and discussion topics from the meetings.

1. Dr. Anderson indicated a willingness to support better awareness of rehabilitation research across the NIH Institutes and Centers and presented several ways to do so directly.
2. NCMRR is undertaking a vast research grant portfolio analysis to better understand the extramural rehabilitation research that the NIH funds.
3. Dr. Anderson broadly indicated that his office is looking to develop more metrics to better understand how research is conducted, the outcomes it produces, and ways for it to improve.

Similarly, on November 2, 2017, representatives of several DRRC member organizations and Powers staff met with National Institutes of Health (NIH) officials at the NIH campus to discuss federal medical rehabilitation and disability research and the implementation of recently-passed legislation, S. 800, which was incorporated into the 21<sup>st</sup> Century Cures Act. The DRRC group met with Dr. Walter Koroshetz, Director of the National Institute of Neurological Disorders and Stroke (NINDS), and his team, and Dr. Marie Bernard, Deputy Director of the National Institute on Aging (NIA), and her team.

This second series of meetings illuminated several important takeaways for the DRRC. Those takeaways include:

1. **Striking Differences in Perspective on Rehabilitation Research at NINDS vs. NIA.**  
Whereas NIA presented a holistic focus on function and functional outcomes as a key driver of its research priorities across several divisions, NINDS appeared more focused on disease-specific research areas and discovering the underlying neuromechanisms

behind those diseases, with little attention to their implications for rehabilitation and ultimately, function.

2. The Medical Rehabilitation Coordinating Committee at NIH is Meeting Regularly, But Needs More Attention from Senior Members of Institutes. Both Institutes mentioned their work with the MRCC, but knowledge of – and participation in - its activities appeared to have been delegated to mid-level staff, hampering the impact of the MRCC in influencing increased coordination at a whole-Institute level.

### ***Conclusions***

Overall, the spring and fall meetings with NIH drove home an impression of the importance of the recently-passed legislation, which is clearly still necessary and in various stages of implementation. Key points from the legislation include the 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 addition, a major focus will be to ensure a common understanding of the definition of medical rehabilitation research, as defined in the statute. 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 2018***

DRRC should continue visiting NIH Institute and Center leaders to promote rehabilitation science, and follow up on visits from 2017. 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. In particular, DRRC proposes to follow up with Dr. Anderson of DPCPSI to further engage him in the coordination efforts prescribed by the law. DRRC also proposes to draft resources for NINDS to ensure that the Institute is adopting the new interdisciplinary definition of medical rehabilitation research called for by the law, and engaging in coordinated, intra-institute efforts to advance medical rehabilitation research.
2. Engage with additional senior leaders of key NIH Institutes and Centers to drive the full implementation of the new law. DRRC is proposing to convene at least two more rounds of visits with senior NIH officials at the Bethesda campus in 2018.

## **2. FY 2018 Appropriations**

In 2017, 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. Several sections of the Senate committee report included language that addressed DRRC priorities, including language on medical rehabilitation research, the Centers for Disease Control and Prevention (CDC) and its Chief Disability and Health Officer, Practice Improvement and Training Centers, and the National Institute on

Disability, Independent Living, and Rehabilitation Research (NIDILRR). In 2018, DRRC anticipates continuing to advocate with the House and Senate Appropriations Committees for report language and funding requests in the FY 2019 appropriations bills.

## ***Background***

In summer 2017, DRRC submitted written comments to House and Senate Appropriations Committee members and staff. The House letter was sent in June 2017 and the Senate letter was sent in August 2017. DRRC held meetings with Senate Appropriations Committee majority and minority staff, advocating for several DRRC priorities, in August.

Specifically, the DRRC recommended that the FY 2018 Labor, HHS, Education, and Related Agencies appropriation bill provide necessary and sufficient funding for the various federal agencies supporting and conducting disability, independent living, and rehabilitation research to address the current and future needs for individuals with disabilities and society. DRRC also recommended that the report accompanying the bill include language recognizing the critical importance of disability, independent living, and rehabilitation research. Below is a summary of our recommendations:

The resulting Senate FY 2018 Appropriations bill included report language that addressed several DRRC priorities. That language included:

- Report language to the NIH encouraging the NIH “to fully implement Section 2040 of the 21<sup>st</sup> Century Cures Act to enhance the stature, visibility, and coordination of medical rehabilitation research conducted at NIH. The Committee is encouraged by the release of NIH’s new Rehabilitation Research Plan, looks forward to reviewing its first annual progress report, and is encouraged by its ongoing efforts to ensure that reporting of rehabilitation research is consistent with the definition of “rehabilitation research” included in the legislation.”
- Report language to the CDC encouraging the 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.”
- Report language to SAMHSA recognizing “the critical need for programs such as Rehabilitation Research and Training Centers, which advance the current knowledge base of the mental health delivery system by supporting evaluation, training, technical assistance, and knowledge translation activities that help adults with serious mental health conditions achieve their life goals.”
- Report language to the Administration for Community Living (ACL) recognizing NIDILRR and the significant opportunities it has to address healthcare costs and to improve quality of life for older adult and disabled populations.

## ***Proposed Next Steps for 2018***

In 2018, 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.

### **3. Interagency Committee on Disability Research (ICDR)**

In 2017, 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 the submission of appropriations report language to the House and Senate Appropriations Committees and in person follow up with Administration on Community Living (ACL) political appointees and senior staff regarding that strategic plan. DRRC also followed up on its comments, submitted in fall 2016, on the Draft Government Wide Strategic Plan FY 2017-2020 Prepared for ICDR.

#### ***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 2018***

In 2018, DRRC proposes to work closely with ICDR to advance the government-wide strategic plan, which serves a valuable government-wide coordinating function in disability, independent living, and rehabilitation research. To do so, DRRC proposes setting meetings with ACL and ICDR political appointees and senior staff.

## 4. NIDILRR Long-Range Plan 2018-2023

On March 20, 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. Additionally, NIDILRR is currently awaiting the appointment of a Director.

### *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 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 2018*

In 2018, DRRC proposes to engage with NIDILRR and ACL staff. ACL is the parent organization to NIDILRR, and ACL recently had a new administrator appointed. Meetings 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.

## 5. CDC Advocacy

In 2018, 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.

### *Background*

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 2018***

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.

## **6. Health Care Reform**

Since early this year, the President and Congressional Republicans have repeatedly attempted to repeal and replace the Affordable Care Act. The DRRC opposed efforts to repeal and replace the ACA because the American Health Care Act and every version of the Better Care Reconciliation Act undermined access to rehabilitative services and devices for Americans with disabilities. The Better Care Reconciliation (BCRA), the Senate version of the repeal and replace bill that passed the House, was introduced in the Senate in June. The BCRA would cut and cap Medicaid coverage and undermine patient protections established by the Affordable Care Act, including requirements for insurers to cover a defined package of essential health benefits (EHBs), which include rehabilitative services and devices. On July 21, the DRRC sent a letter to Senate Majority Leader Mitch McConnell (R-KY) and Minority Leader Chuck Schumer expressing concerns that the BCRA would limit access to rehabilitation services and devices for Americans with disabilities. Efforts to pass the BCRA collapsed at the end of July, when Senate Republicans failed to secure a simple majority to pass the legislation.

In September, Senate Republicans renewed their efforts to repeal and replace the ACA with the Graham-Cassidy bill. Graham-Cassidy also imposed cuts and caps on the Medicaid program and eroded the essential health benefits (EHB) requirement and other patient protections established by the ACA. On September 25, DRRC again sent a letter to the Senate Minority and Majority Leaders urging them to oppose the Graham-Cassidy bill. On September 26, Majority Mitch McConnell announced the Senate would not vote on the Graham-Cassidy bill after three Republican Senators, Susan Collins (R-ME), Rand Paul (R-KY), and John McCain (R-AZ), came out against the bill.

## ***Proposed Next Steps for 2018***

DRRC proposes to continue engaging with policymakers on relevant national issues impacting access to rehabilitative and habilitative care. DRRC will continue to monitor the health care reform debate and will propose and draft statements on the coalition's position should the need arise.