

DRAFT APRIL 19, 2018

Disability and Rehabilitation Research Coalition

1501 M Street, N.W. Suite 700 Washington, D.C. 20005

April XX, 2018

The Honorable Lamar Alexander
Chairman
Senate Committee on Health, Education,
Labor, and Pensions (HELP)
U.S. Senate
Washington, DC 20510

The Honorable Virginia Foxx
Chairwoman
House Committee on Education and
the Workforce
U.S. House of Representatives
Washington, DC 20515

The Honorable Patty Murray
Ranking Member
Senate Committee on Health, Education,
Labor, and Pensions (HELP)
U.S. Senate
Washington, DC 20510

The Honorable Bobby Scott
Ranking Member
House Committee on Education and
the Workforce
U.S. House of Representatives
Washington, DC 20515

**Re: DRRC Opposition to Proposed Transfer of National Institute on Disability,
Independent Living, and Rehabilitation Research (NIDILRR) to the National
Institutes of Health (NIH)**

Dear Chairman Alexander, Ranking Member Murray, Chairman Foxx, and Ranking Member Scott,

The undersigned members of the Disability and Rehabilitation Research Coalition (DRRC) write this letter to express our strong **opposition** to the Administration's proposal in its FY 2019 Budget to transfer the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to the National Institutes of Health (NIH). The proposal would refute Congress's thoughtful, forward-thinking decision in 2014 to amend Title II of the Rehabilitation Act (Title IV of The Workforce Innovation and Opportunity Act (WIOA)) to transfer NIDILRR from the Department of Education (ED) to the Administration for Community Living (ACL) in the Department of Health and Human Services (HHS).

Transferring NIDILRR to NIH would undermine NIDILRR's mission and decimate the diverse portfolio of research, development, training, technical assistance and knowledge translation projects carried out each year by NIDILRR that improve the abilities of individuals with disabilities to perform activities of their choice in the community and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

Further, DRRC continues to support provisions in the 2014 amendments to the Rehabilitation Act and Section 2040 of the 21st Century Cures Act that mandate cooperation, coordination, and collaboration between NIDILRR and NIH (and other agencies carrying out disability, independent living, and rehabilitation research) and your directive in the Rehabilitation Act Amendments for the Interagency Committee on Disability Research (ICDR) to develop and implement a comprehensive, government-wide strategic plan on disability, independent living, and rehabilitation research.

DRRC supported the transfer of NIDILRR from ED to ACL and now opposes the re-transfer of NIDILRR to NIH for the following reasons:

- NIDILRR's and NIH's respective missions are distinct and complementary, not duplicative;
- The transfer of NIDILRR to NIH would decimate NIDILRR's diverse portfolio of research, development, training, technical assistance and knowledge translation initiatives carried out on behalf of people with disabilities;
- The proposed transfer would foreclose accomplishments of the type achieved in the past;
- ACL is the appropriate home for NIDILRR and NIDILRR is fully complementary to ACL's overall mission; and
- Efforts to enhance cooperation, coordination, and collaboration are best accomplished through interagency agreements and the development and implementation of a comprehensive, government-wide strategic plan.

1. NIDILRR's and NIH's Respective Missions Are Distinct and Complementary, Not Duplicative

The policies establishing NIDILRR, its mission, and research and other covered activities are prescribed in Title II of the Rehabilitation Act of 1973, as amended by Title IV of WIOA. The ACL website provides a succinct overview of NIDILRR's legislative mandate. According to the ACL, NIDILRR's mission is to "generate new knowledge and to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities."

ACL goes on to explain that "as the federal government's primary disability research agency, NIDILRR achieves this mission by:

- Providing for research, demonstration, training, technical assistance and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- Promoting the transfer of, use and adoption of rehabilitation technology for individuals with disabilities in a timely manner; and
- Ensuring the widespread distribution, in usable formats, of practical scientific and technological information."

Across NIDILRR's agenda, the central focus is on the whole person with a disability, whose ability to function and quality of life are dependent on the complex interactions among personal, societal, and environmental factors.

The ACL website also recognizes the *unique* (emphasis added) role played by NIDILRR and contrasts its role with that played by NIH and other agencies:

"NIDILRR plays a unique role in that its target population includes all disability types and all age groups. While other federal research entities fund prevention, cure, and acute rehabilitation research, NIDILRR also invests in rehabilitation research that is tied more closely to longer-term outcomes, such as independence, community participation, and employment."

NIH's mission is distinct from and complementary to, not duplicative of NIDILRR's mission. According to the NIH website, NIH's mission is to "seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. The goals of the agency are to:

- Foster fundamental creative discoveries, innovative research strategies, and their applications as a basis for ultimately protecting and improving health;
- Develop, maintain, and renew scientific human and physical resources that will ensure the Nation's capability to prevent disease;
- Expand the knowledge base in medical and associated sciences in order to enhance the Nation's economic well-being and ensure a continued high return on the public investment in research; and
- Exemplify and promote the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science."

2. The Transfer of NIDILRR To NIH Would Decimate Its Diverse Portfolio

The current initiatives supported by NIDILRR would be eliminated, decimated, or radically transformed if NIDILRR were to be moved to NIH.

NIH programs are designed to improve the health of the Nation by conducting and supporting research in:

- The causes, diagnosis, prevention, and cure of human diseases;
- The processes of human growth and development;
- The biological effects of environmental contaminants;
- The understanding of mental, addictive and physical disorders; and
- Directing programs for the collection, dissemination, and exchange of information in medicine and health, including the development and support of medical libraries and the training of medical librarians and other health information specialists.

At NIH, the National Center on Medical and Rehabilitation Research (NCMRR), which is housed in the Institute on Child Health and Human Development, supports research on the following topics: pathophysiology and management of chronically injured nervous and

musculoskeletal systems (including stroke, traumatic brain injury, spinal cord injury, and orthopedic conditions); repair and recovery of motor and cognitive function; functional plasticity, adaptation, and windows of opportunity for rehabilitative interventions; rehabilitative strategies involving pharmaceutical, stimulation, and neuroengineering approaches, exercise, motor training, and behavioral modifications; pediatric rehabilitation; secondary conditions associated with chronic disabilities; improved diagnosis, assessment, and outcome measures; and development of orthotics, prosthetics, and other assistive technologies and devices. Many other Institutes at NIH perform similar types of medical rehabilitation research.

In contrast, NIDILRR's grant programs are designed to explore new and innovative strategies, interventions, and technologies to better achieve the promises of the Americans with Disabilities Act (ADA)—equality of opportunity, full participation, independent living, and economic self-sufficiency. More specifically, NIDILRR's grant programs vary in purpose, scope, duration, and size; each is designed to address at least one of the following outcomes areas:

- Employment
- Community Living and Participation
- Health and Function
- Technology for Access and Function
- Equal Opportunity/Nondiscrimination
- Disability Demographics
- Knowledge Translation
- Capacity Building for Rehabilitation Research and Training

NIDILRR supports, among other things, Rehabilitation Research and Training Centers, Rehabilitation Engineering Research Centers, and Model Systems Program that provide coordinated systems of rehabilitation care and conduct research on recovery and long-term outcomes for spinal cord injury, traumatic brain injury, and burn injury. [See Appendix]

Further, NIDILRR supports:

- ADA National Network, which provides technical assistance, training, and information resources related to the ADA;
- AbleData, an information center hosting an extensive database of assistive technology products and resources to increase awareness of and access to assistive devices; and
- National Rehabilitation Information Center (NARIC), a research library and information center that promotes access to disability, independent living, and rehabilitation research information.

As part of the Model Systems, NIDILRR supports:

- The National Spinal Cord Injury Statistical Center, which supports and directs the collection, management, and analysis of the world's largest and longest spinal cord injury research database.

- Traumatic Brain Injury National Data and Statistics Center, which provides technical assistance, training, and methodological consultation to 16 TBIMS centers as they collect and analyze longitudinal data from people with TBI in their communities, and as they conduct research toward evidence-based TBI rehabilitation interventions.
- National Data and Statistical Center for the Burn Model Systems which increases the rigor and efficiency of scientific efforts to assess the experiences and outcomes of individuals with burn injuries.

Given the different orientations between NIH and NIDILRR, it is obvious that a transfer of NIDILRR to NIH would result in the elimination, decimation, or radical transformation of most, if not all, of the initiatives currently supported by NIDILRR.

3. The Proposed Transfer Would Radically Diminish, if Not Foreclose, Accomplishments of the Type Achieved by NIDILRR Grantees In The Past

The transfer of NIDILRR to NIH would diminish, if not foreclose the impacts achieved by NIDILRR and NIDILRR grantees in the past that foster equality of opportunity, full participation, independent living and economic self-sufficiency for individuals with disabilities. A small sample of accomplishments by NIDILRR and NIDILRR grantees include:

- Promulgation of a standard by the FCC to allow phone companies to support real-time text, developed with NIDILRR funding.
- Making computer, telecommunication, and web technologies accessible to people with disabilities.
- Studying and developing interventions that help youth and young adults with disabilities transition successfully to postsecondary education and the workplace.
- Synthesizing and conducting research to create a new field of psychiatric rehabilitation with a body of knowledge, a set of techniques and service models that is now a standard component of most mental health and rehabilitation systems around the world.
- Providing leadership on the National Quality Forum's committee on measuring quality of home and community-based services.
- Tracking employment statistics comparing people with and without disabilities.
- Analyzing national data and generated new knowledge (and created new products) to facilitate and promote access to housing and transportation.
- Developing a diabetes tool kit designed to help people with mental health disorders
- Supporting the first practice-based evidence study of TBI rehabilitation.
- Improving self-directed recovery and integrated health care.
- Designing, testing and deploying the world's first and only foldable manual wheelchair wheel called the [Morph Wheel](#), which is now winner of seven international awards.
- Contributing to the development and application of high-intensity, variable locomotor training which has been applied to hundreds of patients who have experienced stroke and spinal cord injury.
- Examining work disincentives and strategies to facilitate reduction in reliance on SSDI and SSI.

4. ACL Is The Appropriate Home For NIDILRR and NIDILRR Is Complementary to ACL's Overall Mission

After extensive research, discussion, deliberation, and negotiation, in 2014 Congress decided to amend Title II of the Rehabilitation Act of 1973 (Title IV of WIOA) to transfer NIDILRR from ED to the Administration for Community Living (ACL), HHS. ACL's mission is to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers. Created in 2012, ACL combined the Administration on Aging, the Office of Disability, and the Administration on Intellectual and Developmental Disabilities to create a single agency charged with developing policies and improving supports for older adults and people with disabilities.

The transfer of NIDILRR to ACL also brought research capacity and competency to a strong policy, program, and service organization. In addition, NIDILRR's move to ACL has created opportunities for new or expanded research and development, particularly in the area of aging with long-term disability. For example, the Senate Report accompanying the FY 2018 Labor/Health and Human Services/Education appropriations bill states that "the Committee encourages NIDILRR to continue to support research and activities that help older or disabled adults to maintain or improve functional capabilities and allow for independent living." Further, ACL provides improved access to service delivery programs that can serve as sites for testing new research-based interventions.

In sum, DRRC continues to support Congress' decision to move NIDILRR to ACL.

5. Efforts To Enhance Cooperation, Coordination, and Collaboration Are Best Accomplished With Interagency Agreements and A Comprehensive, Government-Wide Strategic Plan.

DRRC strongly believes that federal agencies which focus broadly on enhancing the quality of life of people with disabilities should avoid duplication and overlap and facilitate cooperation, coordination, and collaboration. Because NIDILRR initiatives are complementary to, not duplicative of, initiatives supported by NCMRR and other medical rehabilitation conducted by other Institutes at NIH, DRRC believes that Congress made the correct decisions in 2014 to move NIDILRR to ACL, not to NIH.

In 2014 when Congress amended the Rehabilitation Act (through enactment of WIOA) it decided to move NIDILRR to ACL, ensure cooperation and coordination between NIH and NIDILRR, and mandate the development of a comprehensive government wide strategic plan for disability, independent living, and rehabilitation research by the Interagency Committee on Rehabilitation Research.

More recently, in 2016 when Congress enacted Section 2040 of the 21st Century Cures Act (Pub. Law No. 114-255) to enhance the stature and visibility of medical rehabilitation research at NIH, it included provisions to increase coordination of rehabilitation research across various federal agencies including between NCMRR at NIH and NIDILRR.

The actual interactions between NIDILRR and NIH and other federal agencies have been positive, efficient, effective, and fruitful. Where appropriate, the expertise developed by NIDILRR grantees is informing and supporting research pursued by NIH grantees, and vice versa.

Conclusion

In conclusion, NIDILRR's current location in ACL is working. There is no reason to move NIDILRR to NIH. In fact, there are many reasons why such a move would adversely affect the equality of opportunity, full participation, independent living, and economic self-sufficiency of people with disabilities enhanced by the research, development, training, technical assistance, and knowledge translation supported by NIDILRR.

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DRRC is a coalition of national non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. DRRC seeks to maximize the return on the federal investment in this type of research and development with the goal of improving the ability of Americans with disabilities and chronic conditions to live and function as independently as possible and to contribute to the health and economic well-being of our nation.

Please feel welcome to contact the DRRC with any questions. You may contact DRRC's coalition coordinators at 202-466-6550 or via email by contacting Peter Thomas at Peter.Thomas@PowersLaw.com, Bobby Silverstein at Bobby.Silverstein@PowersLaw.com, or Leif Brierley at Leif.Brierley@PowersLaw.com.

Sincerely,

The undersigned members of the DRRC:

APPENDIX

NATIONAL INSTITUTE ON DISABILITY, INDEPENDENT LIVING, AND REHABILITATION RESEARCH ADMINISTRATION ON COMMUNITY LIVING WEBSITE

- [Disability and Rehabilitation Research Program \(DRRP\)](#) - This program funds knowledge translation, building capacity for minority research entities, individual research projects, and other work.
- [Rehabilitation Engineering Research Center Program \(RERC\)](#) - This program funds advanced engineering research and development of innovative technologies to solve rehabilitation problems or remove environmental barriers for people with disabilities.
- [Switzer Research Fellowship Program](#) - This program provides grants for individuals to perform research on rehabilitation, independent living, and other experiences of people with disabilities.
- [Field-Initiated Projects Program Rehabilitation Research \(FIP\)](#) - This program is investigator-initiated research with projects to generate new knowledge.
- [Model Systems Program](#) - These programs provide coordinated systems of rehabilitation care and conduct research on recovery and long-term outcomes for spinal cord injury, traumatic brain injury, and burn injury.
- [Advanced Rehabilitation Research and Training Program \(ARRT\)](#) - This program increases capacity for high-quality disability and rehabilitation research by supporting grants to institutions to provide advanced research training to individuals with doctorates or similar advanced degrees.
- [Rehabilitation Research and Training Center Program \(RRTC\)](#) - These programs conduct advanced research, training, and information sharing on topic areas for improving rehabilitation methodology and service delivery systems; improving health and function; and promoting employment, independent living, family support and economic and social self-sufficiency for people with disabilities.
- [Small Business Innovation Research Program \(SBIR\)](#) - This program supports development of new ideas and projects useful to people with disabilities through grants to small business firms with strong research capabilities in science, engineering, or educational technology.
- [Americans with Disabilities Act National Network](#) - This program funds 10 regional centers for providing information, training, and technical assistance to individuals, businesses, and agencies with rights and responsibilities under the Americans with Disabilities Act.