

# DISABILITY AND REHABILITATION RESEARCH COALITION

1501 M STREET, N.W. SUITE 700 WASHINGTON, D.C. 20005

**March 20, 2017**

**DRRC Comments RE:  
The National Institute on Disability, Independent Living, and Rehabilitation Research  
(NIDILRR) Draft Long-Range Plan, 2018-2023**

The members of the Disability and Rehabilitation Research Coalition (DRRC) wish to express our appreciation for providing us and other stakeholders with an opportunity to submit comments regarding the NIDILRR Draft Long-Range Plan, 2018-2023.

The DRRC is a coalition of national non-profit organizations committed to improving the science of disability, independent living, and rehabilitation. The DRRC seeks to maximize the return on the federal investment in disability, independent living, and rehabilitation research and development with the goal of improving the ability of Americans with disabilities to live and function as independently as possible.

DRRC members recognize that demographic trends over the next two decades indicate a substantial increase in the number of people with injuries, illnesses, disabilities, and chronic conditions resulting from trauma, developmental disability, war-related injuries, the effects of chronic illness, and an increasingly aging population. Disability, independent living, and rehabilitation research and development can and must play a critical role in enabling and empowering individuals with disabilities to live the American dream. This is consistent with the notion that disability is a natural part of the human experience and aligns with the goals of federal disability policy articulated in the American with Disabilities Act (ADA)—equality of opportunity, full participation, independent living, and economic self-sufficiency.

Significant disability, independent living, and rehabilitation research and development continues to be necessary in order to improve care, and maximize function, independence, and quality of life for people with injuries, illnesses, disabilities and chronic conditions across the lifespan. Research and development can help identify optimal outcomes and demonstrate the efficacy (or non-efficacy) of various interventions, services and supports, treatments, and devices. Translational research can help transform research results into improvements in care at the home and community-based level. This, in turn, leads to appropriate policies that maximize the return on investment of our financial commitments while improving individuals' quality of life and economic self-sufficiency and the status of our overall economy.

With the advent of a new administration at the federal government level, the DRRC believes that the draft long-range plan seizes upon a window of opportunity to advance the development and implementation of a comprehensive research and development agenda for disability, independent living, and rehabilitation research at NIDILRR that is aimed at the ultimate goal, shared by

NIDILRR, of enhancing the ability of people with disabilities to achieve their maximum desired participation in the community, with full access to all societal and life activities.

In fact, the new administration has a broader opportunity to use the expertise of NIDILRR and the role that its Director has played in the past as the Secretary's designee as head of the Interagency Committee on Disability Research (ICDR) to take a fresh look at rehabilitation, disability and independent living research across all federal agencies that conduct and support this research. Demographic changes will continue to increase pressure on federal health care programs for decades to come and research in this area is the most promising way to both improve quality and outcomes while targeting resources to most efficiently serving the needs of people with injuries, illnesses, disabilities and chronic conditions. We urge NIDILRR, as part of the development of this 5-year plan, to think big, to reassess where we are as a country on these critical issues from a broad perspective and within an all-inclusive context, and design a long-range plan that sets the building blocks for great strides in rehabilitation science over the coming decades.

NIDILRR's draft long-range plan for the period of 2018-2023 appropriately captures the current state of people living with disabilities in the United States and projects a comprehensive research and development agenda aimed at addressing the challenges facing people with disabilities. The draft long-range plan aims to improve outcomes of people with disabilities in the three inter-related domains of:

- 1) Health and Function;
- 2) Employment; and
- 3) Community Living and Participation.

In addition, the draft long-range plan continues to focus on cross-cutting research and development activities, including:

- 1) Technology for Access and Function;
- 2) Disability Statistics Research; and
- 3) the ADA National Network.

Furthermore, the draft long-range plan continues to focus on activities that promote the quality and use of NIDILRR-sponsored research and development, including capacity-building grants and activities to ensure the field has well-trained research personnel. Finally, the draft long-range plan focuses on knowledge translation to ensure that new knowledge and products gained through the course of research and development ultimately improve the lives of people with disabilities and further their participation in society. DRRC strongly supports the draft long-range plan and this structure.

The following text describes our comments on the specific sections of the draft long-range plan and the specific reasons we support them.

## **INTRODUCTION AND BACKGROUND**

The Introduction to the draft long-range report provides a comprehensive overview of the plan, its necessity, and history. Across eight pages of text, the Introduction identifies the initial

formulation of the plan, the overarching principles guiding it, the process used to craft the research agenda, the mission of NIDILRR, the current state of people with disabilities in the U.S., the agency context for the plan, and the scope of the plan in context of related work in this field. The DRRC strongly supports this structure to outline the importance of this work.

The plan is formulated as a guide for NIDILRR's work in disability, independent living, and rehabilitation research and development that coincides well with the overall mission and overarching principles of NIDILRR. In particular, the draft long-range plan identifies two overarching principles that guide it and NIDILRR's work:

- 1) The enhancement and full access to all aspects of life for people with disabilities, and
- 2) The funding of rigorous research and development activities in this space.

The DRRC strongly supports these two principles, and supports their inclusion in the draft long-range plan.

In crafting the draft long-range plan, to solicit feedback and to better understand the experiences and perspectives of people with disabilities, the choices and care options that they and their families seek, the high expectations that people with disabilities rightfully have for their care, providers who serve them, caregivers and other support system members (both formal and informal), policymakers, and academic researchers, NIDILRR conducted listening sessions around the country and solicited written comments. Those sessions and comments resulted in the emergence of several key themes that align with the current literature, and also serve to guide the draft long-range plan. Those themes highlight the fact that people with disabilities of all ages want to live successfully in the community, with access to the tools and supports they need to lead productive and meaningful lives. The DRRC believes the findings of the listening sessions are consistent with the current challenges, experiences, and perspectives of people with disabilities, and supports the public process used to elucidate them.

The draft long-range plan then provides an overview of the state of people with disabilities in the U.S., calling attention to the barriers that often complicate the simple goal of leading a happy and productive life in the community of one's choosing. Regarding people with disabilities, the draft long-range plan highlights access to and maintenance of needed supports to navigate a complicated system; the importance of employment and the challenges of finding it; the importance of safe, accessible, affordable, and usable housing; the continuum of care in the health care system, far beyond the walls of a hospital; and the gateway that adequate transportation can provide to employment and fulfillment of basic needs for people with disabilities. The DRRC agrees that this overview of the state of people with disabilities captures – in abbreviated form – many of the challenges and solutions facing people with disabilities.

The Introduction then places NIDILRR's mission and scope of the plan in context of the related agencies and federal efforts in this field at large. The DRRC appreciates the recognition of the many federal partners engaged on issues of disability, independent living, and rehabilitation research and development contained in this report.

Finally, the Introduction concludes with the key accomplishments of NIDILRR grantees since the last long-range plan. Those accomplishments include more than 1,200 products, including peer-reviewed publications, intervention protocols, software, and databases to enhance the opportunities of people with disabilities. DRRC is grateful for the many contributions that NIDILRR-sponsored research and development has made to the lives of people with disabilities, and appreciates the inclusion of this important statistic in this report.

### **RESEARCH AND DEVELOPMENT AGENDA**

Next, the draft-long range plan describes NIDILRR's continued goal of improving outcomes of people with disabilities across the three inter-related domains of:

- 1) Health and Function,
- 2) Employment, and
- 3) Community Living and Participation.

Complementing these, the draft long-range plan specifically identifies NIDILRR's five-year goal of delivering on a research and development agenda that addresses three related, important factors: building on current investments that are underway in research and development; utilizing the expertise of NIDILRR's parent agency, ACL, to expand the scope of projects in aging, disability, and community living; and conducting research on issues of national importance in health policy. DRRC strongly supports this five year goal to address the three domains.

The draft long-range report then lays out the rationale for NIDILRR's continued investment in the three inter-related domains of 1) Health and Function, 2) Employment, and 3) Community Living and Participation. Each of the domains is profiled with a context for research and development, a list of accomplishments, and a research and development agenda provided for each. This structure allows for NIDILRR to concisely provide depth and support for their proposed five-year plan, and DRRC supports this approach.

### **Health and Function**

Regarding health and function, NIDILRR correctly indicates that individuals with disabilities are significantly more likely than individuals without disabilities to be in fair or poor health and to experience a wide variety of diseases and chronic conditions. Additionally, they are more susceptible to experiencing functional limitations that can impair access to employment and community participation. The draft long-range plan rightly points out that the increasing number of individuals with disabilities will require the development of new and improved rehabilitation strategies and practices to improve health and function, and which give patients more choices in their rehabilitation care.

NIDILRR has worked in tandem with many federal partners, who are rightfully mentioned in the draft long-range plan in the context of providing additional partnership opportunities going forward. DRRC strongly supports the collaboration that the draft long-range plan aspires to continuing.

NIDILRR has enjoyed many accomplishments in the realm of health and function, and several – including the formation of several important longitudinal databases around spinal cord injuries, the creation of evidence-based practices and interventions to improve outcomes, and the

conceptualization of models around health reform impacts on people with disabilities – are profiled.

The draft long-range report highlights several areas NIDILRR proposes to invest in related to health and function, including aging with and into disability, continued development of interventions that improve health and function outcomes, implementation of evidence-based practices, investigating policy impacts on impacts to health care services and outcomes, and integration of person-centered planning and services. The DRRC believes there is an urgent need for research that demonstrates the best practices for delivering the right services to the right people in the right place and at the right time.<sup>1</sup> DRRC supports this approach to addressing the health and function needs of people with disabilities in the draft long-range report. DRRC also recommends that this 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.

Additional research in these foundational programs will positively drive individuals' functional progress in health, employment and community and independent living.

Finally, the DRRC wishes to provide the following additional comment and recommendation to be included in the final long-range plan. In particular, the DRRC recommends 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. For example, Medicare Advantage plans often make enrollees' post-acute care placement decisions based on proprietary guidelines which direct inpatient rehabilitation facility (IRF) patients to lower-cost skilled nursing facilities (SNFs) or, for SNF patients, set a seven-day cap limit on the number of covered days, all under the guise of value-based care. But these placement decisions are very often against the clinical judgment of the patient's physicians. This is one example where NIDILRR's rehabilitation research on appropriate rehabilitation settings can inform and strengthen CMS' / MA oversight policies. The DRRC also recommends 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).

### **Employment**

Concerning employment, the draft long-range plan highlights the importance of employment for individuals with disabilities. In providing context, the plan identifies a mix of challenges and solutions recently provided to address issues that people with disabilities encounter regarding employment, including the Great Recession of 2007-2009, the Workforce Innovation and

---

<sup>1</sup> See Agency for Healthcare Research and Quality [AHRQ]. A Quick Look at Quality. 2003; <https://archive.ahrq.gov/consumer/qnt/qntqlook.htm>. Accessed March 10, 2017.

Opportunity Act (WIOA), legislation and executive action intended to improve employer practices, disincentives to employment, vocational rehabilitation programs, and collaboration among federal agencies. DRRC supports these contextual challenges and solutions facing individuals with disabilities regarding employment.

NIDILRR has funded many successful employment-related projects, with accomplishments 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. NIDILRR indicates in the draft long-range plan that it intends to continue building on its previous work in these areas in its proposed research and development agenda. These are helpful areas that the DRRC supports and areas in which the DRRC encourages more investment.

### **Community Living and Participation**

Finally, regarding community living and participation, the draft long-term plan presents this section as a key outcome of any investment in the overall field of disability, independent living, and rehabilitation research and development, and therefore sees this section as essential. That is to say, in the words of the draft, improved health and function allows people with disabilities to be more active and engaged in their communities and families. Citing the Rehabilitation Act, the draft long-range plan appropriately identifies NIDILRR's mandate to conduct research on this topic. The draft also cites the rising percentage of federal dollars being spent on community living, and the need to understand individual and system-level factors that can impact community living outcomes.

To that end, NIDILRR has sponsored research and development work on quality measures, home and community-based services, housing barriers, transportation access, public transportation, transportation technology, and environmental access for people with disabilities. In their proposed agenda, NIDILRR intends to build upon this base of research but also expand it to include measurements of community living and participation, access to transportation, the impact on family caregivers, community access, and the accessibility of homes. DRRC believes these are all worthy goals, and well thought out to meet the broad mandate that NIDILRR has from statute.

### **CROSS-CUTTING RESEARCH AND DEVELOPMENT ACTIVITIES**

Similar to the Research and Development Agenda section, this section of the draft long-range plan identifies and describes three areas that are truly cross-cutting in the field of disability, independent living, and rehabilitation research. They include:

- Technology for Access and Function;
- Disability Statistics Research; and
- Americans with Disabilities Act (ADA) Technical Assistance, Training, and Research.

### **Technology for Access and Function**

For Technology for Access and Function, NIDILRR outlines an approach that will address four technology domains, including rehabilitation, assistive, service, and system technologies. Through this framework, and while recognizing the rapidly developing technology field and its promise for individuals with disabilities, NIDILRR describes its future research and developments efforts in this space as building on the accomplishments of its prior grantees in those four domains. The draft long-range plan proposes to tackle emerging opportunities in technology over the next five years, supporting initiatives such as universal design and usability, and products and services that improve medical and functional outcomes for individuals with disabilities. DRRC strongly supports this section of the draft long-range plan.

### **Disability Statistics Research**

Regarding Disability Statistics Research, the draft long-range plan aptly recognizes the importance and utility of data on disabilities and incorporates them into its goals. Of course, disability statistics support all aspects of research and development; however, by harnessing data effectively, NIDILRR argues it is possible to generate new information that can be used by a whole host of cross-disciplinary groups and individuals to tackle today's disability, independent living, and rehabilitation challenges. Therefore, the draft long-range plan proposes to build on its accomplishments – such as the inclusion of questions on disability in major national surveys, the production of common data elements, and the development of a National Center on Disability Statistics – by increasing capacity within the field to generate new insights. Specifically, NIDILRR proposes to do this by supporting work on uniform disability identifiers, data mining, policy research, methodological quality, and usage of measures. DRRC strongly supports this proposal.

### **ADA Technical Assistance, Training, and Research**

Finally, regarding ADA Technical Assistance, Training, and Research, the draft long-range plan highlights the ADA National Network, a network of ten regional centers that NIDILRR runs to provide technical assistance, training, and information dissemination about the ADA. The draft plan highlights the Network's impact, but also the ongoing need for the provision of its services. DRRC strongly supports the work of the network and its continued need.

### **NEW KNOWLEDGE**

The draft long-range plan also highlights NIDILRR's continued commitment to funding projects that lead to new knowledge that can be used to create and implement interventions that improve the lives of people with disabilities. DRRC strongly supports the NIDILRR's commitment to promoting all stages of research and development, and encourages NIDILRR to retain this important section in the final long-range report.

### **BUILDING CAPACITY**

Additionally, the draft long-range plan describes NIDILRR's continued investment in the field of disability, independent living, and rehabilitation research to ensure that well-trained research personnel are engaged. The draft plan highlights a number of areas that NIDILRR funds, including the Research Fellowship Program (Switzer) and the Advanced Rehabilitation Research Training (ARRT) program; the Rehabilitation Research and Training Centers (RRTCs) and

Rehabilitation Engineering Research Centers (RERCs); and the Section 21 Program for minority-serving institutions. NIDILRR proposes to continue supporting those programs and areas. NIDILRR has had and can continue to have an important impact on rehabilitation research capacity. In addition to mechanisms for training individual researchers and formally designated training centers, however, NIDILRR should recognize the model system programs and its investment in development of research tools as important ways of generating enduring research infrastructure. DRRC is strongly supportive of this goal.

### **KNOWLEDGE TRANSLATION**

Finally, the draft long-range plan highlights the importance of Knowledge Translation, which NIDILRR describes as the multidimensional, active process of ensuring that new knowledge and products gained through the course of research and development ultimately improves the lives of people with disabilities. The draft plan briefly describes the various components in ensuring that Knowledge Translation occurs, highlighting the role of people with disabilities and other stakeholders in all components. Knowledge Translation is embedded into NIDILRR's grant making operations, making this practical component of research an institutionalized component of NIDILRR's support for the field. In its proposal, NIDILRR proposes to expand Knowledge Translation in new areas, better build it into business processes, strengthen existing partnerships with stakeholders, increase awareness of NIDILRR-funded products and knowledge, and increase public access to products and data. NIDILRR should be commended for its continued commitment to a sophisticated notion of knowledge translation. This reflects the reality that active processes are needed to make research outcomes useful to stakeholders, and that there is no simple one-to-one correspondence between a single study's outcomes and applicable knowledge, implied by earlier models of "dissemination." DRRC strongly supports Knowledge Translation and firmly supports the inclusion of this section in the final long-range plan.

### **CONCLUSIONS**

Overall, the NIDILRR draft long-range plan for the period 2018-2023 provides a comprehensive, appropriate, and well-crafted vision and plan of execution to advance scientific research and development in the field of disability, independent living, and rehabilitation at NIDILRR. The undersigned organizations of the DRRC strongly support the approach taken in the draft, and urge NIDILRR to fully incorporate the draft plan with attention to our comments on the draft.

Thank you again for providing us with the opportunity to share our comments. If you have any questions, please contact Bobby Silverstein (email: [Bobby.Silverstein@powerslaw.com](mailto:Bobby.Silverstein@powerslaw.com); phone: 202.466.6550); Peter Thomas (email: [Peter.Thomas@powerslaw.com](mailto:Peter.Thomas@powerslaw.com); phone: 202.466.6550); or Leif Brierley (email: [Leif.Brierley@powerslaw.com](mailto:Leif.Brierley@powerslaw.com); phone: 202.466.6550)

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition (DRRC):

Academy of Spinal Cord Injury Professionals  
American Academy of Orthotists & Prosthetists  
(continued on page 9)

American Academy of Physical Medicine & Rehabilitation  
American Association on Health and Disability  
American Congress of Rehabilitation Medicine  
American Foundation for the Blind  
American Medical Rehabilitation Providers Association  
American Music Therapy Association  
American Occupational Therapy Association  
American Physical Therapy Association  
American Therapeutic Recreation Association  
Amputee Coalition of America  
Association of Academic Physiatrists  
Association of Rehabilitation Nurses  
Association of University Centers on Disabilities  
Brain Injury Association of America  
Child Neurology Society  
Christopher and Dana Reeve Foundation  
National Association for the Advancement Orthotics & Prosthetics  
National Association of Rehabilitation Research Training Centers  
National Multiple Sclerosis Society  
Paralyzed Veterans of America  
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)  
United Spinal Association