

### MEMORANDUM

To: DRRC

From: Bobby Silverstein and Peter Thomas

Date: February 6, 2019

Re: Highlights of the NIDILRR 2018-2023 Long Range Plan

In January 2019, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) released its 2018-2023 Long Range Plan (LRP). The NIDILRR 2018-2023 LRP presents a comprehensive, well-crafted agenda that will advance the vital work being done by grantees and others in applied disability, independent living, and rehabilitation research and development. The LRP emphasizes consumer relevance and scientific rigor. The LRP will enable NIDILRR to further its mission of enhancing the ability of people with disabilities to achieve inclusion and integration into society.

Set out below are some highlights from the LRP, including:

- Role and location of NIDILRR in the Administration for Community Living
- Overarching factors influencing the research agenda
- Outcome domains
- Cross-cutting research activities
- Stages of research and development
- Activities that promote the quality and use of sponsored research

#### ROLE AND LOCATION OF NIDILRR IN ACL

The NIDILRR 2018-2023 LRP reaffirms the unique role NIDILRR plays and the appropriateness of the 2014 congressional decision to transfer the Agency from the Office of Special Education and Rehabilitative Services within the Department of Education to the Administration for Community Living (ACL) within the Department of Health and Human Services.

- "While NIDILRR is one of several Federal agencies conducting research on behalf of people with disabilities, it is unique in conducting applied research." [page 5]
- "The context of NIDILRR's work in the area of health and function includes its historic role as the principal Federal funder of disability and rehabilitation research." [page 10]
- "NIDILRR's addition brought research capacity and competency to a strong policy, program, and services organization. NIDILRR has established collaborations within ACL



on topics such as traumatic brain injury and remains committed to exploring collaborative opportunities with Federal and state partners." [page 4]

- "During the next five years, NIDILRR plans to carry out a research agenda that ... [takes] advantage of the expertise of our colleagues in ACL..." [page 6]
- "NIDILRR's move to ACL has created opportunities for new or expanded research...ACL provides improved access to service delivery programs that can serve as sites for testing new research-based interventions." [page 10]
- "The Plan...recognizes NIDILRR's place within and the importance of partnership and collaboration with other Federal agencies as well as other stakeholders, with the understanding that research outcomes are increasingly needed to help refine national policy in support of those individual aspirations." [page 22]

#### OVERARCHING FACTORS IMPACTING RESEARCH AGENDA

Consistent with the 2018-2023 LRP, NIDILRR plans to carry out a research agenda that includes three important factors:

- Building on current investments;
- Taking advantage of colleagues in ACL; and
- Conducting research on health policy issues to inform the national agenda. [page 6]

It is also NIDILRR's expectation that projects that receive NIDILRR funding will involve people with disabilities in research activities. This input is essential to ensure that the knowledge and products are useful in addressing real issues faced by people with disabilities. [page 6; see also page 21]

#### **OUTCOME DOMAINS**

The LRP reaffirms longstanding focus on improving outcomes for people with disabilities in the three inter-related domains of:

- Community living and participation
- Health and function
- Employment

The LRP recognizes that while these three domains contain equally important and rich areas of research investment opportunity. The domain of community living and participation is the ultimate outcome of all of NIDILRR's research, development, capacity building, and knowledge translation grants.

• NIDILRR sponsors research on health care and rehabilitation not just to improve health and functional abilities, but because improved health and function allows people with disabilities to be more active and engaged in their communities and families.



• NIDILRR sponsors research on employment not just to generate new knowledge that can be used to close the large employment gap between those with and without disabilities, but because employment provides income and the financial means for people with disabilities to have real choices about how they engage and participate in their communities. [page 7]

## Community Living and Participation Domain [pages 7-9]

Given NIDILRR's prior investments and the ongoing U.S. aim of expanding home and community-based long term services and supports (LTSS) for people with disabilities, the areas of potential investment include:

- Community living and participation measurement;
- Transportation access;
- Family caregivers;
- Community access; and
- Accessible homes.

## Health and Function Domain [pages 9-11]

The LRP recognizes that maximizing the health and function of people with disabilities is critical to their general well-being and their fulfillment of personal aspirations in areas such as employment and community participation. [page 9]

The demographic realities regarding the growth of the population of people with disabilities requires the development of new and improved rehabilitation strategies and refinements of policies, programs, practices, and technologies that recue functional limitations and improve health outcomes. [page 9]

NIDILRR anticipates continuing to fund research related to rehabilitation interventions and access to rehabilitation and other health care services by people with disabilities. Areas of potential investment include [pages 10-11]:

- Aging with and into disability;
- Development of interventions that improve health and function (investments toward evidence-based interventions to promote health and functional outcomes will take place in NIDILRR's long-standing Model Systems programs as well as other programs and grant mechanisms);
- Implementation of existing evidence-based practices; and
- Policy impacts on access to health care services and outcomes.

## Employment Domain [pages 11-13]



NIDILRR's research agenda in the employment domain involves building on its current investments and moving them along the series of research stages with the goal of impacting employment outcomes for people with disabilities. Possible areas of research include:

- Disability employment statistics;
- People with psychiatric disabilities;
- Employment disincentives;
- Young adults;
- Employer practices; and
- Return on investment.

#### **CROSS-CUTTING RESEARCH ACTIVITIES**

In addition to the three domains of community living and participation, health and function, and employment, the LRP also reinforces the need for investment in three areas that support outcomes across these domains [page 1]:

- Technology for access and function
- Disability statistics and demographic research
- Nationwide network of technical assistance, training, and research centers to support implementation of the Americans with Disabilities Act (ADA)

#### Technology for access and function

NIDILRR recognizes four key technology research topics that include [page 14]:

- Rehabilitation technologies that restore, maintain, or slow the decline of function among people with disabilities;
- Assistive technologies that address activity and participation difficulties encountered by people with disabilities by augmenting, compensating for the loss of, or restoring function to improve performance;
- Service technologies that facilitate the provision of rehabilitation, assistive technology, training, and other interventions; and
- Systems technologies that provide improved access to and use of critical infrastructures used by people with disabilities and others in the general public.

Examples include: advanced human computer interfaces, personalized exo-prostheses, exo-skeletons that augment muscle function or compensate for the loss of structure and/or function, advanced wheelchair seating and positioning, rehabilitative and assistive robotics, and advanced sensory technologies. [page 15]



NIDILRR also anticipates continuing research of information and communication technologies, the built environment, and public transportation systems. [page 15]

#### Disability Statistics and Demographic Research

Valid and reliable demographic data serve as a foundation to the broader mission of NIDILRR and help provide an evidence-based platform for all agencies in the disability field. High-quality demographic data contribute to NIDILRR's mission and support research in the following ways [page 16]:

- Policy decisions;
- Demographics;
- Prevalence and context;
- Service delivery; and
- Current and emerging needs.

NIDILRR's research agenda for disability statistics and demographics includes [page 17]:

- Uniform disability identifiers;
- Adoption of the ACS six-question sequence of disability identifiers;
- Data mining;
- Policy research;
- Methodological quality; and
- Usage of measures.

Nationwide network of technical assistance, training, and research centers to support implementation of the ADA

NIDILRR intends to continue its support of the technical assistance, training, research, and data collection activities conducted by the ADA National Network. It will also explore ways to expand the impact of the Network to new audiences by fostering innovation in practices that aim to improve community participation and by creating greater linkages with other ACL, Health and Human Services (HHS) and Federal programs and constituencies. [page 18]

#### STAGES OF RESEARCH AND DEVELOPMENT

NIDILRR continues to promote concepts of "stages" of research and development. These stages include exploration and discovery, intervention development, intervention efficacy, and scale-up evaluation. Through the implementation of this stages framework, NIDILRR emphasizes that all of the research it sponsors in these stages leads to new knowledge that can be used to create and implement interventions that improve the lives of people with disabilities. Similarly, the development work that NIDILRR sponsors at the proof of concept, proof of product, and proof of adoption stages leads to products that are used to improve the lives of people with disabilities.



NIDILRR values and funds research at each of these stages because it is essential to derive interventions and develop products systematically and methodically based on scientifically sound foundations and concepts. [page 18]

# ACTIVITIES THAT PROMOTE THE QUALITY AND USE OF SPONSORED RESEARCH

Activities that promote the quality and use of NIDILRR-sponsored research, including capacity building and knowledge translation, will continue under the LRP. [page 2]

## Capacity Building

There is an ongoing need for capacity-building grants and activities to help ensure that the field of disability, independent living, and rehabilitation research has well-trained research personnel as well as tools and methods to support high-quality research activities that result in new knowledge and products. [page 20] NIDILRR intends to continue its capacity-building activities. [page 20-21]

## **Knowledge Translation**

NIDILRR believes that for knowledge translation to be successful, new knowledge or products must [page 21]:

- Address real issues faced by people with disabilities;
- Offer helpful information or solutions related to those issues;
- Be presented in ways that make it accessible to and feasible for the intended users; and
- Be disseminated or distributed effectively.

To maximize the relevance, feasibility, usability, and reach of the new knowledge or products, it is crucial that researchers involve people with disabilities and other stakeholders. [page 21]

NIDILRR intends to continue its efforts to help ensure that knowledge and products generated by NIDILRR grantees are used to improve the lives of people with disabilities [page 21-22]:

- Expansion;
- Strategic initiative support;
- Business process;
- Partnerships;
- Awareness and promotion; and
- Public access.

#### DRRC RECOMMENDATION



Powers' analysis of the NIDILRR Long Range Plan concludes that the draft version is a comprehensive vision of the agency's goals and priorities which are ultimately focused on positively impacting the individuals the agency was intended to serve: people with disabilities. It maintains consistency between traditional NIDILRR priorities and future activities, building on the success of its programs, domains, and areas of interest in the context of integration into its relatively new home in the Administration for Community Living. Powers recommends that DRRC strongly support this draft Long Range Plan in its submission of comments and seeks additional viewpoints from DRRC members to incorporate into its response to NIDILRR's call for public comment.