



May 22, 2008

Donna Nangle
U.S. Department of Education
400 Maryland Avenue, S.W., Room 6029
Potomac Center Plaza
Washington, D.C. 20202-2700

RE: Input Regarding NIDRR's Long-Range Plan for Fiscal Years 2010-2014

Dear Ms. Nangle:

The purpose of this letter is to provide input on behalf of the Brain Injury Association of America to the Assistant Secretary for Special Education and Rehabilitative Services regarding the National Institute on Disability and Rehabilitation Research's (NIDRR's) long-range plan (LRP) for fiscal years 2010-2014.

Set out below is a brief review of the historical and policy context of NIDRR. This discussion lays the foundation for specific recommendations regarding the content and direction of NIDRR's new LRP, including the mission, Logic Model, goals, outcomes, focus, operational performance measures, and research agenda.

In addition, this letter identifies and recommends specific research topics highlighted by the Brain Injury Association of America as being consistent with NIDRR's mission.

HISTORICAL AND POLICY CONTEXT

Historically, Congress established NIDRR to serve as the Nation's "flagship" federal agency on rehabilitation and disability research and as such to maintain a broad portfolio of research designed 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 [Section 200 of the Rehabilitation Act of 1973, as amended]. Since 1978 and most recently in its long-range plan for Fiscal Years 2005-2009, NIDRR has recognized that its mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

NIDRR also has recognized the substantive focus of its investment activities is Research and Development applied to maximizing the participation of people with disabilities. More specifically, research and development activities are centered on the three major life domains of interest to NIDRR:

- **Employment,**
- **Participation and community living, and**
- **Health and function.** [71 *Federal Register* at page 8173]

The U.S. Department of Education's *Strategic Plan for Fiscal Years 2007-12* reaffirms the Department's obligations to fulfill its congressional mandate to "continue to support and monitor research leading to the development of interventions that support **health and physical function, participation and integration into the community, and employment of individuals with disabilities.** [Page 31, emphasis added]

Congress expects NIDRR to lead the way in learning about new and better strategies to improve health and function, employment, and community integration of people with disabilities, if we are to achieve the promises of the Americans with Disabilities Act. Research supported by NIDRR must continue to focus on improving the implementation of employment-related activities supported by OSERS, including RSA. Similarly, Congress directed NIDRR to serve as the lead agency supporting medical rehabilitation research that enhances the health and function of people with disabilities i.e., research designed to enhance treatments that allow persons with traumatic brain injury, spinal cord injury, and other impairments to more fully participate in activities of daily living and be part of society.

Historically, NIDRR has recognized the continuing need for medical rehabilitation research to improve function and for health status research to improve overall health and wellness of persons with disabilities. NIDRR also has recognized that there are many instances in which meaningful improvements in health and function may not translate directly into changes in vocational outcomes.

Based on our understanding of congressional intent, as reflected in our review of NIDRR's historical and policy context, we have developed a set of principles to help guide the development of our input regarding the content of NIDRR's new LRP.

NIDRR's new LRP should:

- Reflect NIDRR's history and policy designating NIDRR as the lead federal agency on rehabilitation and disability research and NIDRR's need to maintain a broad portfolio of research;
- Embrace the breadth and depth of critical domains impacting the lives of persons with disabilities (employment, participation and community living, and health and function);
- Build on NIDRR's current LRP;
- Include a Logic Model to help select those research activities to be supported that are most likely to lead to intermediate and long-term outcomes of interest;
- Build on the strong history of research accomplishments in all critical life domains; and

- Insist on the use of management strategies, including high-quality peer review, that result in support of rigorous research that is of utility to stakeholders.

MISSION

Consistent with Title II of the Rehabilitation Act, we recommend that NIDRR's new LRP include the following mission statement:

“The mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.”

LOGIC MODEL

We recommend that NIDRR's new LRP incorporate the Logic Model for planning for research outcomes that is set out in the current LRP. NIDRR's new LRP should recognize that significant gaps exist in knowledge, skills, policy, and practice and system capacity that prevent people with disabilities from having equal access to opportunities for employment, participation and community living, and health and function.

The substantive focus of NIDRR's investment activity should be centered on the three major life domains of interest to NIDRR—**employment, participation and community living, and health and function**. In addition, the Logic Model should include two additional domains—technology for access and function and disability demographics.

With respect to **employment**, for many people with disabilities, employment that is challenging, fulfilling, and adequately compensated is the ultimate rehabilitation outcome. Employment shapes the lives of individuals with disabilities who are interested in and qualified for workforce participation. At the individual and systems level success should be measured in terms of acquisition, improvement, and enhancement of skills, productivity, earnings, job retention and advancement and benefits. NIDRR should advance employment-related innovations that contribute to success at work and subsequent improvements in quality of life in education, home, and community.

With respect to **participation and community living**, NIDRR should focus on the extent to which people with disabilities are participating in the community in a manner that is meaningful to them and support research into programs and services that expand the scope of participation of people with disabilities, especially those with the most severe disabilities. NIDRR should sponsor research to improve knowledge of individual and societal level factors that may serve as barriers to, or facilitators of, participation among all people with disabilities. Research may include evaluation of specific participation-promoting programs, interventions and products, as well as development of methods, measures, and theories to enhance scientific rigor of these evaluations.

With respect to **health and function**, research on maximizing health and function among people with disabilities is critical to the achievement of NIDRR's mission and the associated higher-order goals of employment and community participation. Functional ability reflects the complex interaction between individuals and the environments in which they live. In conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

GOALS

The LRP should identify strategic goals that communicate NIDRR's main themes and directions. The goals should reflect NIDRR's mission and align with the targeted outcomes arenas depicted in the Logic Model. Thus, we recommend that NIDRR's new LRP include the following four goals:

- **Research and Development (R & D)**—Advance knowledge about disability and rehabilitation through research and development.
- **Capacity Building (C-B)**—Increase the capacity of individual (particularly those with disabilities) and institutions to conduct high-quality disability and rehabilitation research and development.
- **Knowledge Translation (KT)**—Increase the use of research and development knowledge to improve policy, practice, behavior and systems related to disability and rehabilitation.
- **Management**—continuously improve NIDRR outcomes through effective management, monitoring and use of program data.

OUTCOMES

Long-term outcomes arenas. NIDRR's long-term outcomes should focus on eliminating disparities between people with and without disabilities in employment, participation and community living, and health and function. These long-term outcomes should serve as critical anchor points guiding all strategic planning and research management efforts.

Short-term outcomes arenas. Within the logic model, there should be four short-term outcome arenas corresponding to NIDRR's investments in four functional arenas. These functional arenas are R&D, C-B, KT, and management corresponding to NIDRR's four strategic goals. R&D should be further divided to reflect three stages of knowledge development—(1) discoveries; (2) new or improved theories, measures, or methods; or (3) interventions, products, devices, and environmental adaptations.

FOCUS

At the heart of NIDRR's mission should be supporting research to improve the lives of people with disabilities. We recommend that NIDRR's new LRP focus attention on the major life domains as set out in the Logic Model. Improving **employment** outcomes should be a major concern of NIDRR as should be improving the functioning of OSERS' programs related to

employment, including vocational rehabilitation and programs related to the education of transition-age youth with disabilities. Similarly, improving **participation and community living** outcomes (including maximizing choices for persons with disabilities as they select their dwellings, transportation, and life activities) should be a major concern of NIDRR. Furthermore, improving **health and function** outcomes should be a major focus of NIDRR research as advances in this domain are the foundation for attaining outcomes related to employment and participation and community living.

OPERATIONAL PERFORMANCE MEASURES

The future research agenda for NIDRR should rest on the long-term outcomes depicted in the Logic Model, which call for eliminating disparities in employment, participation and community living, and healthcare between people with disabilities and the general population. However, because achieving this desired end-result requires changes in the overall condition of people with disabilities that go beyond the reach of the Institute's mission, it is necessary to articulate an additional set of more operational performance measures with respect to employment, participation and community living, and health and function.

RESEARCH AGENDA

The research agenda must reflect the critical life domains of individuals with disabilities—employment, participation and community living, and health and function.

When it comes to all three life domains, greater attention must be given to youth under the age of 16, particularly when it comes to research regarding traumatic brain injury (TBI). The primary emphasis of funding has historically been directed towards the needs of adults with TBI, as the TBI Model System program only addresses individuals with TBI ages 16 and older. The research conducted by the TBI Model Systems has moved the best practice model for rehabilitation of adults forward and has raised the standard of care for rehabilitation management and community integration. Yet, children are not simply little adults. While information arising from adult TBI research can be useful in treating children, injury to the maturing brain creates unique challenges not seen in adult populations which must be studied, monitored and treated episodically over the growth and development of a child with brain injury maturing to adulthood.

Regarding the domains of employment, as well as participation and community living, it is vitally important that more attention is given to the role of education in providing the building blocks for successful employment outcomes. For example, research is needed regarding what types of educational supports for children with TBI best facilitate the development of knowledge and skills necessary to achieving successful adult employment. Similarly, regarding the domain of participation and community living, without proper research attention to the development of social, behavioral and cognitive skills in children with TBI, the risks of isolation and community non-participation substantially increase. Right now, it is striking that an agency which falls under the Department of Education rarely mentions education and schools as priority research settings.

Regarding the health and function domain, as stated above, maximizing health and function of people with disabilities is critical to the achievement of NIDRR's mission. Functional ability reflects the complex interaction between individuals and the environment in which they live. Accordingly, NIDRR should conceptualize and examine issues of health and function at the individual and systems levels.

At the systems level, NIDRR-supported research should focus on the structure, organization, and delivery of health care and medical rehabilitation services. At the systems level, NIDRR also should study access to healthcare and rehabilitative services, and the complex delivery systems used for those services. Individual level research should focus on the development and testing of new interventions that improve functional and health outcomes for individuals. In conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

Specifically, the health and function agenda at the individual level should fund research that supports the development and evaluation of new interventions, products, devices, and environmental adaptations aimed at improving the health status and functional abilities of people with a wide range of disabling conditions.

With regard to TBI, the Brain Injury Association of America recommends funding research on the efficacy of cognitive rehabilitation as cognitive functioning is critical to employment, participation in community living, and health maintenance. Additionally, the Brain Injury Association of America recommends funding research related to issues of medication compliance in individuals with brain injury as this is an important, but all too often neglected, pragmatic issue impacting many individuals with cognitive impairment. Further, the Brain Injury Association of America suggests the further research be funded on the psychological needs of brain injury survivors as well as their caregivers.

Many of the health and function interventions described above will address the needs of people who are aging with disability, with particular emphasis on minimizing secondary disabilities. NIDRR should also fund research that leads to the development of the next generation of valid and reliable measures of health and functional status among people with disabilities.

At the Systems level, NIDRR should fund research that will generate new knowledge about the systematic causes and consequences of substandard access to rehabilitation, healthcare, and mental health care services for people with a wide range of disabling conditions. This research will identify and evaluate the effectiveness of specific service delivery approaches and reimbursement models aimed at minimizing physical, social, and economic barriers to the full spectrum of health, mental health, and rehabilitation services that are need by people with disabilities. In addition, research is needed to support the development of evidenced based practice methods that are consistent with rehabilitation treatment practices that currently exist in the field and with the rehabilitation research methods used to develop new assessments and interventions.

Overall Agenda—NIDRR’s research agenda in the area of health and function should be designed to:

- Increase the number of validated new or improved methods for assessing function and health status;
- Increase the number of interventions, products, and devices demonstrated to be efficacious in improving health and function outcomes in targeted disability populations; and
- Increase understanding of the underlying structures and processes that facilitate or impede equitable access to rehabilitation and physical and mental healthcare by people with disabilities.

If you have any questions, please feel free to contact Laura Schiebelhut, BIAA’s Director of Government Affairs, at (703) 584-8637 or by email to lschiebelhut@biausa.org.

Sincerely,



Susan H. Connors, President/CEO
Brain Injury Association of America