



National Association of State Head Injury Administrators

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**National Association of State Head Injury Administrators Comments  
RE: The National Institute on Disability, Independent Living, and Rehabilitation Research  
(NIDILRR) Draft Long-Range Plan, 2018-2023**

Submitted March 17, 2017

The National Association of State Head Injury Administrators (NASHIA) appreciates the opportunity to submit comments regarding the NIDILRR Draft Long Range Plan, 2018-2023, on behalf of our members who represent state agency programs administering an array of services and supports for individuals with traumatic brain injury (TBI) and their families. Our membership also is comprised of associate members representing other professionals, providers, consumer organizations, and individuals with brain injury and their families. NASHIA, a nonprofit organization, was organized by state employees initially for purposes of sharing information as states began developing service delivery within their states. Overtime, NASHIA has grown into an organization that provides assistance to state agencies in developing effective, efficient service delivery systems and into one which can represent states collectively with regard to federal policies and legislation. NASHIA offers a forum for states to learn about other state and national policy initiatives and for learning about best practices as demonstrated by research, expertise, and experiences.

States began in the 1980s developing services specifically to address the needs of individuals with TBI and their families through a combination of funding streams. These funding streams include state general revenue; dedicated funding, generally referred to as trust fund programs; Medicaid State Plan services; brain injury Medicaid Home and Community-Based Services (HCBS) waiver programs; Vocational Rehabilitation services; and other federal and state funded programs. TBI programs are housed in different state agencies across the country. As such, programs and services may be administered by the state health, mental health, education, Vocational Rehabilitation, intellectual/developmental disabilities and/or Medicaid agency. As a result, it is important for federal research programs conducting disability research to communicate their findings to the broad array of state agencies that may be involved in different aspects of TBI service delivery.

States have also been awarded grants through the Administration for Community Living (ACL) Federal TBI State Grant Program authorized by the TBI Act of 1996, as amended, to improve access to service delivery. States have addressed underserved and unserved populations, including victims of domestic violence, veterans and returning servicemembers with TBI, culturally diverse populations; individuals with co-occurring conditions, and adults and youth in criminal justice systems. Currently, 19 states receive grant funding to address targeted populations by providing screening, training to professionals/paraprofessionals, information & referral services and resource facilitation, also known as service coordination, to link individuals identified as having a TBI-related disability to services, supports and resources.

NASHIA strongly advocated for the Federal TBI State Grant Program to be housed in the ACL in order to coordinate resources with other disability programs across the lifespan, as well as to be in a better position to collaborate with NIDILRR regarding research which could help with community living for individuals with brain injury and their families.

It is with this background that NASHIA is responding to your draft plan as organized by the headings of the plan.

## **INTRODUCTION AND BACKGROUND**

As noted by those participating in your regional listening sessions, NASHIA is also concerned with state budget short falls and with the Administration's proposal to cut non-defense discretionary programs. State brain Injury programs, similar to programs offering services to individuals with other disabilities, are receiving less funding, while the number of individuals surviving a brain injury is increasing. Some states have implemented waiting lists for individuals seeking services and other states have cut their services as their revenues have declined. State Medicaid programs are also changing the way they deliver services and benefits, which has impacted brain injury HCBS waiver programs in some states.

State program administrators are needing tools to demonstrate that services and supports indeed are cost-effective and prevent unnecessary institutionalization/nursing home placement, out-of-state residential placement, homeless situations in absence of assistance, incarceration, family upheaval – all the dire consequences that can happen when services and supports are unavailable. Budget staff and policymakers are asking for evidence that there is a positive return on investment with regard to public funding. That is, are people returning to work, living independently, and contributing to society. Are services preventing more costly interventions and alternatives is the question that is being asked. We believe that NIDILRR is positioned to help states to respond to policymakers with those questions, as well as to provide guidance to families and individuals with brain injury seeking assistance.

While the issues identified in the opening introduction are intended to address the needs of individuals with all disabilities, we would be remiss if we didn't point out that housing, employment, and community services and supports for individuals with brain injury are significantly lacking, especially when compared to systems which have been designed for individuals with intellectual/developmental disabilities, mental health and physical disabilities. Less than half of the states administer a HCBS Medicaid waiver program, which vary considerably across the country with regard to the numbers served. Less than half of the states administer state funded or programs funded with dedicated funding usually from traffic related fines, and some states have both a waiver program and a state or trust fund program. There are some states that do not have any defined services specific to the needs of individuals with brain injury and their families.

## **RESEARCH AND DEVELOPMENT AGENDA**

### **Health and Function**

NASHIA supports research that addresses chronic health conditions as the result of a TBI. We also believe that this research needs to be translated into practice for health care providers and to caregivers, who are usually family members, in order to help identify health problems that may result from a brain injury and to treat appropriately. Additionally, in light of Congress and the

Administration's intent to repeal and replace the Affordable Care Act (ACA), NASHIA supports NIDILRR's intent to build on existing research initiatives to determine how policy changes impact the ability of people with disabilities to obtain needed rehabilitation and other health care and long-term services. This information will be critical to states should the Medicaid program be turned over for states to administer, since state policy makers will be determining benefits and the extent of health care coverage to be offered. Research data will help determine the type, scope and duration of rehabilitation, health care, and long-term services and supports which may be required for individuals with disabilities to live and work productively in the community, including individuals with a brain injury.

NASHIA also supports NIDILRR's funding of the TBI Model Systems which have created longitudinal databases that allow research with regard to long-term outcomes of individuals with TBI. NASHIA recommends that NIDILRR include states as a partner in addition to the Department of Defense, the Veteran's Administration, and the CDC, in order for states to use the information to inform changes in service delivery. Furthermore, we strongly recommend that the TBI Model Systems partner with the state TBI programs in the state where they are housed, as well as other states which may benefit from their research, materials and expertise. A number of states have benefitted from materials and consultative services provided by a few of the TBI Model Systems. States would welcome the opportunity to collaborate with all TBI Model Systems.

### **Employment**

Studies conducted to date indicate that individuals with TBI have poor employment outcomes in terms of obtaining and maintaining employment. It is not uncommon for individuals with TBI to participate in vocational training, be placed in to a job, only to lose the job within a few months, and then return to vocational rehabilitation programs again -- repeatedly. State vocational rehabilitation and TBI agencies would certainly like to change these outcomes. Tracking and analyzing state VR data with regard to drop out rates and recidivism rates, in addition to successful job placement and retention, for individuals with TBI seeking employment may help with identifying the extent of these issues. Research to identify best practices in pre-vocational, vocational strategies and employment models specific to TBI-related disabilities for better employment outcomes would be beneficial. This type of research not only needs to be conducted, but also translated so that state VR and TBI programs can institute best practices to achieve successful outcomes – similar to projects which are now funded to track employment statistics; research with regard to youth with I/DD, psychiatric disabilities, etc. NIDILRR indicates that it intends to continue building on its previous work in these areas in its proposed research and development agenda and NASHIA urges NIDILRR to extend employment related research to include individuals with TBI.

### **Community Living and Participation**

NASHIA has for many years advocated for the federal government to assist states in addressing and promoting short-term and long-term services and supports to enable individuals with brain injury to return to home and community to live as independently as possible. NASHIA has identified the need for research to identify individuals residing in institutional settings; to develop appropriate functional assessment tools to assess cognitive and behavioral deficits associated with brain injury for determining community living; and to help direct best practices for supporting individuals with brain injury. Furthermore, assisting states in developing program outcome measures and to aggregate that information nationally would result in information that currently does not exist with

regard to the number of individuals living in the community with supports and assistance from publicly funded programs.

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

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

NASHIA supports this section addressing technology for access and function. Technology is a valuable tool(s) for people with cognitive disabilities, especially with regard to memory. Brain injury rehabilitation involving compensatory strategies has evolved from a handwritten memory notebook to devices which can now accommodate cognitive, physical, and sensory deficits. Technology is critical to community living, including education achievement, vocational education and training, post-secondary education, employment, as well as activities of daily living.

### **Disability Statistics Research**

NASHIA supports NIDILRR's proposal to work on uniform disability identifiers, data mining, policy research, methodological quality, and usage of measures. Data is needed with regard to the extent of TBI and determining their needs.

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

NASHIA supports ADA Technical Assistance, training and research.

## **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. NASHIA strongly supports the NIDILRR's commitment to promoting all stages of research and development.

## **BUILDING CAPACITY**

NASHIA supports NIDILRR's continued investment in the field of disability, independent living, and rehabilitation research to ensure that well-trained research personnel are engaged.

## **KNOWLEDGE TRANSLATION**

NASHIA strongly supports the provision of Knowledge Translation and encourages information to be disseminated to states, individuals with brain injury and their families. In addition, information should be available to federal and state policymakers. Our members are interested in research that results in "best practices" with regard to service delivery and which may impact public policy.

## **CONCLUSIONS**

Thank you again for providing us with the opportunity to share our comments. If you have any questions, please contact Susan Vaughn, Director of Public Policy at [publicpolicy@nashia.org](mailto:publicpolicy@nashia.org).