



Proposed Rules for Centers for Independent Living

Submitted by the National Association of State Head Injury Administrators

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The National Association of State Head Injury Administrators (NASHIA) is pleased to respond to the ACL proposed rules for ILCs and independent living services. While ILCs have paved the way in the disability rights movement, individuals with traumatic brain injury (TBI) have often encountered barriers in accessing many state and federal programs created for individuals with disabilities. The ILCs, while established to serve cross disabilities, often do not have expertise in working with individuals with TBI nor do individuals with TBI always know about ILCs to avail their assistance. The recent transfer of the Federal TBI State Grant Program to the ACL's Independent Living Administration should help with promoting training, education, resources and collaboration across national and state TBI programs and Statewide Independent Living Council and centers within the states.

NASHIA commends HHS for requiring the ILCs to promote the person centered planning philosophy, but strongly urges that ILCs be trained in the process as it applies to individuals with TBI who tend to lack insight and awareness of resulting problems affecting their ability to self-assess, report issues, making decisions, make adjustments and understanding the need to participate in rehabilitation or tasks designed to assist with living more independently in the community. Understanding these fundamental issues will help to support individuals with TBI in the ongoing process that will lead to successful outcomes.

No two brain injuries are alike. However, the most common problems associated with individuals with brain injury are deficits in cognition and behavior. Executive dysfunction often occurs due to injury to the frontal lobes of the brain which affects a person's ability to plan and organize, and impacts flexible thinking, multi-tasking, solving problems, self-awareness, decision making, motivation, controlling or regulating emotions, concentrating and taking in information, impulse control, and integrating past experience with present action. Understanding these issues, will help ILCs to provide appropriate accommodations (i.e. aids to help with memory; shorter meetings in acknowledgement of possible fatigue; reducing environmental distractions) as they work with the individual.

To carry out the new 5th required core service (Sec. 1329.4) to facilitate the transition of individuals with disabilities from nursing homes to HCBS services and supports, NASHIA urges ILCs to be trained in TBI needs and available community resources in collaboration with state TBI trust fund/state funded programs and brain injury Medicaid HCBS waiver programs, including states with Federal TBI State Grants to be administered by the ACL. Not all states have these resources and certainly not to the extent needed. In most states, individuals with TBI

are not identified in nursing facilities or institutional settings, unless they fall under the I/DD definition which usually has an age limit with regard to the age of onset.

As TBI is an underreported disability with regard to special education and related services, some states and public schools have focused on better ways to identify, assess, and provide educational services that are tailored to the cognitive, behavioral, and physical problems associated with TBI. NASHIA recommends that ACL identify states that have developed models for transitional services for students with TBI and inform the ILCs of those initiatives in order to help ILCs carry out this requirement as it pertains to children and youth with TBI. In addition, a number of states are partnering with their juvenile justice systems to screen for TBI and to provide training to the juvenile justice educational programs. Most of this work is done through the Federal TBI State Grant Program and should be shared with the ILCs.

NASHIA supports ACL adding individuals who are unserved or underserved populations to the definition of "Cross-disability" and contends that individuals with TBI have been underserved in the states largely due to lack of resources.

In closing, NASHIA recommends that ACL work with our Association and partners, Brain Injury Association of America (BIAA) and U.S. Brain Injury Alliance, to identify resources, training and assistance within the states and nationally that could assist the ILCs to better serve individuals with TBI and for the brain injury community to learn more about the ILCs within their states in the spirit of coordinating and maximizing resources. Furthermore, it would be useful if ILCs could determine how many people they serve with TBI as states plan for improved service delivery. Thank you for your consideration.

NASHIA was created by state TBI programs in the early 1990's to assist states with promoting partnerships and building systems to better meet the needs of individuals with brain injury and their families.