



**January 7<sup>th</sup>, 2014**

**Human Services Interim Committee**

My name is April Fairfield and I am the Executive Director of the Head Injury Association of North Dakota. The Head Injury Association of North Dakota is primarily an advocacy organization whose mission is to raise awareness about head injury, support public policies that enhance the Traumatic Brain Injury (TBI) system of care in North Dakota and provide resources and tools in order to enhance the quality of life for individuals and their families who have been affected by head injuries.

As you have heard over the course of testimony by survivors of TBI and their families, brain injury is a misunderstood and often overlooked public health problem. It impacts the lives of thousands and thousands of North Dakotans every day.

Brain injury does not discriminate. It does not choose between the worthy and the unworthy. It does not hesitate to hurt a small child or spare an elderly Grandma. And it reaches out and affects every family member, friend and loved one of the brain injured person. No one, it seems, is left untouched.

Since I became the Executive Director of this organization, I have had quite an awakening and an education about the needs of the brain injured community. I have not had the baptism by

fire that many of HIAND's members and board members have had due to the traumatic brain injury of a loved one. Brain injury changes lives. In one moment, a brain injury will change everything. Indelibly. And for all time.

One of the most eye-opening pieces of information for me came from two HIAND board members that you know well, Lisa Anderson and Rhonda Boehm. They shared with me, something that may be helpful to you. They told me it is AFTER one leaves the hospital or in-patient rehab that it often becomes the most difficult for the individuals with brain injury and their loved-ones.

Despite the devastation of dealing with the initial injury, the time in the hospital is consumed by hope for recovery, grief, and often denial. Frankly, at this point of the TBI injury, there is little thought given to the long-term implications of life after TBI, eligibility requirements, paperwork and cost. It is all about being at the side of your child, spouse or friend.

And, there is a system set up in hospitals to guide people through the process of recovery for acute trauma and even in-patient rehab. It is upon discharge from this system of care, when the long-term implications become clear.

What the loved ones of individuals with brain injury will tell you (and have told you) is that working your way through the maze of services, resources and eligibility for brain injury is a confusing, time-consuming, and often frustrating process for people with NO brain injury, let alone someone in recovery from brain injury. That is why you now hear a united call from the

TBI community for a more coordinated and comprehensive system of care for long-term brain injury services and support.

Over the last few months, in this committee you have heard mothers talk passionately about the aftermath of a child's head trauma and the many challenges that they face. And you have heard those from government agencies tell you about the state of programs for TBI survivors and what needs may exist.

Both are equally necessary to hear and important to consider as you deliberate what directives this committee may or may not make when your work is complete.

Before I get into our specific recommendations, I would like to emphasize that the Head Injury Association of North Dakota would like to see a continuation of all programs and funding currently operating in the state. It is imperative we build on, and in no way diminish what we have built for the TBI community in North Dakota.

Today, Legislative Council presented a memo entitled 'Key Issues Regarding Brain Injury Services'. In the memo are key areas HIAND would like to see addressed.

- 1.) A comprehensive system of care for brain injury in North Dakota.
  - similar or parallel to DD system in North Dakota
  - coordinated effort that includes community based options and supports

- supplemental community-based programs that include day programs, vocational services, companion services, and speech/language/occupational therapies particularly in areas outside of urban hubs
  - lifetime case management services
  - assure services and assistance are available for mid-functioning TBI survivors
- 2.) Simplification and coordination of application process for brain injury services with multiple entry points and similar eligibility requirements for all services.
- automatic eligibility for multiple services and programs with single application
- 3.) Sliding fee for services and programs that do not discourage work, much like the current Medicaid Buy-In program
- 4.) Expanding definition of brain injury to include 'Acquired Brain Injury'
- 5.) Re-establish brain injury registry
- connection of registrants to entry into comprehensive system of care
  - greater visibility of programs and services (Perhaps a specific brain injury information link on the ND website or DHS website. Currently, there is no government information available on TBI related state services or programs)
- 6.) An expansion of medical eligibility (Level of Care Determination) for brain injury services under the 'Home and Community Based Services' program.
- 7.) Re-establishing the TBI specific waiver
- 8.) Increased residential, transitional and independent living options for individuals with brain injury
- 9.) Establish "Flex-Fund" geared toward mid-functioning TBI survivors who are capable of working and independent living. This program would encourage and promote work and

independent living and would only be accessed after other options and attempts to qualify for existing services has been exhausted.

Other areas not covered specifically in the memorandum but covered in testimony during previous hearings is the need for substance abuse treatment specifically geared to those with brain injury and the need for more TBI specific expertise available in communities and human service centers. Although, we are certainly aware and sensitive to the issues of employee shortages in this area, we believe this should be a priority area.

Again, I would like to thank you for your consideration of this very important topic and public health need. The kind of exposure and, hopefully, the dialogue and recommendations that result from this interim committee will help us move in the direction of greater awareness and understanding, as well as a more comprehensive system of care for brain injury in North Dakota.

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