KEY ISSUES REGARDING BRAIN INJURY SERVICES

This memorandum summarizes testimony presented to the Human Services Committee to date relating to concerns and suggestions regarding brain injury services.

Ms. Rhonda Boehm, Bismarck, said the most important types of assistance include financial assistance, reminders for meetings and appointments, and assistance with employment responsibilities. She said there needs to be a "more flexible sliding scale plan" according to each individual's earnings and general living expenses for traumatic brain injury (TBI) survivors that are considered midfunctioning. She asked the committee to review and evaluate the requirements of the sliding scale concepts and move forward to make some changes and adjustments to the assistance programs that are available for TBI individuals that are at the midfunctioning level.

Ms. Jennifer Buresh, Dickinson, said social services case workers should be trained in how to work with people with memory issues and those who have suffered brain injury. She also said there should be more flexibility in the assistance programs.

Ms. Lisa Anderson, Leeds, said to improve the lives of North Dakotans who have sustained a brain injury:

1. There should be a stronger coordinated advocacy effort from all interested parties in the state, who work with individuals who have sustained a brain injury;
2. The state should provide the right services and supports because this is crucial to good outcomes;
3. There should be community-based supports--residential and independent living services specifically for survivors of a brain injury; and
4. There should be case management services for the lifetime of the survivor.

Ms. Anderson said since 1992, Vermont's TBI program returns its citizens with moderate to severe brain injuries from hospitals and facilities to a community-based setting. She said Vermont offers case management--run by professionals experienced in brain injury--rehabilitation services, community supports, crisis support, respite, employment supports, and ongoing long-term services for those who qualify.

Ms. Anderson said the Tennessee General Assembly established a TBI program to address the needs of individuals with a brain injury as well as their family members and primary caregivers. She said Tennessee has service coordinators, whose role is to work with survivors and their families. She said they develop a comprehensive plan of care, provide referrals to available resources, coordinate services for the individual client, and bridge the gaps in the service delivery system. She said in Tennessee, hospitals are mandated to provide information to the Department of Health on all individuals with a brain injury that are admitted to the hospital overnight. She said all Tennessee residents listed on the registry receive a letter to inform them of the services available through the TBI program.

Ms. Anderson said Kentucky established a TBI trust fund in 1998 to provide flexible funding and support to those with brain injuries. The fund supports supplemental community-based efforts to meet the special needs of each individual with a brain injury. The services available in Kentucky include case management, community residential services, structured day programs, psychological services, prevocational services, supported employment services, companion services, respite care, occupational therapy, and speech/language services.

Ms. Anderson said in Florida, the brain and spinal cord injury program's purpose is to provide survivors the opportunity to obtain the necessary services that will enable them to return to an appropriate level of functioning in their community. Funding for this program is through traffic-related fines, temporary license tags, motorcycle specialty plates, and general revenue. Florida's services include case management, transitional living, assistive technology, home and vehicle modifications, nursing home transition facilitation, and long-term supports for survivors and families through community-based agencies. Florida law requires that all hospitals; attending physicians; and public, private, or social agencies refer all new traumatic moderate to severe brain or spinal cord injuries to the Central Registry. A case manager will contact the reported individual within 10 working days.

Ms. Anderson said a brain injury survivor in North Dakota would benefit from any or all of the services available in these four states, but the state does not currently have a comprehensive system of care for brain injury survivors. She said North Dakota could set up systems similar to those in place for the developmentally disabled and mold them to fit the TBI community. She said the basic framework of a TBI program in the state of North Dakota could be:

1. Person sustains a brain injury and goes to medical provider.
2. Medical provider, through mandatory reporting, reports the brain injury to the State Department of Health (or whomever maintains the TBI registry).
3. Survivor and his or her family are contacted by a case manager either by letter or phone to refer them to brain injury specialists in their region.
4. Family contacts the trained brain injury specialist in the family's region (perhaps located in the eight human service centers).
5. Brain injury specialist works with the survivor and his or her family to complete a simple application for brain injury services.
6. If eligibility is met, the specialist works with the survivor and the family to develop a comprehensive plan of care, provide referrals to available resources, coordinate services for the individual client, and help to bridge the gap in the service delivery system.
7. There would also be more community-based supports as well as residential living centers specifically for brain injury survivors.

Ms. Rebecca Quinn, Program Director, Brain Injury Programs, University of North Dakota Center for Rural Health, said the largest gap in services for brain injuries is the lack of long-term supports and actual day-to-day services. She said her list of priority areas is in line with the results of the 2005 needs assessment done by the Center for Rural Health and represents areas that should be examined by the Human Services Committee regarding areas for potential policy recommendations. The list includes:

1. Expand legislative language to include all acquired brain injuries instead of limiting it only to TBI.
2. Explore the benefits of establishing a brain injury registry.
3. Examine the responsiveness of the current aging and disability waiver against the possibility of reestablishing a TBI-specific waiver.

Ms. Penny Woodward, Case Manager, Home and Community-Based Services, Morton County Social Services, said legislative language has limited access to some programs to only traumatic injuries. She said this prevents individuals with other brain injuries from receiving certain aid. She said an amendment to legislative language to include acquired brain injuries is strongly encouraged.

Ms. Woodward said an area of access that has been a challenge for case managers is the level of care screening tool that is necessary to qualify for brain injury services under home and community-based services (HCBS). She said an expanded tool specific to the needs and challenges of brain injury survivors is a key step in improving access to the current programs offered through HCBS.

Ms. Woodward said another suggestion is to rework or expand the way provider rates are established for transitional services--the program that provides services in a survivor's own home. She said the current daily rate allows only up to 105 minutes of service depending on the provider. She said additional suggestions for improving survivor access to transitional services include expanding the monthly rate worksheet to include more tasks specific to survivor needs, increase point value for these tasks, establish a consistent rate for each provider, and create an opportunity for private qualified service providers to provide transitional services to brain-injured individuals.

Ms. Woodward suggested an addition of a service similar to the developmental disability community where people live in their own apartments but have onsite supervision provided to all the clients in the building. She said there is a wait to enter both residential facilities in North Dakota, and the average rate at these facilities is over $5,000 per month. She said a corporate adult foster care option would bridge the gap between those who do not need the level of care in a residential facility and those who cannot live alone with only two hours of transitional services per day. She said the support, companionship, and safety of an apartment building would allow more survivors to enjoy safe independence.