ALASKA STATE LEGISLATURE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE
February 4, 2010
3:11 p.m.

MEMBERS PRESENT

Representative Wes Keller, Co-Chair
Representative Tammie Wilson, Vice Chair
Representative Bob Lynn
Representative Sharon Cissna

MEMBERS ABSENT

Representative Bob Herron, Co-Chair
Representative Paul Seaton
Representative Lindsey Holmes

COMMITTEE CALENDAR

PRESENTATION: BUILDING ALASKA'S SYSTEMIC CAPACITY TO DEAL WITH BRAIN INJURY

- HEARD

PREVIOUS COMMITTEE ACTION

No Previous Action to Record

WITNESS REGISTER

JILL HODGES, Executive Director
Alaska Brain Injury Network (ABIN)
Anchorage, Alaska
POSITION STATEMENT: Testified and presented a PowerPoint entitled "Alaska is Combating Traumatic Brain Injury."

JEFF JESSEE, Chief Executive Officer
Alaska Mental Health Trust Authority
Department of Revenue (DOR)
Anchorage, Alaska
POSITION STATEMENT: Testified about the role of the Alaska Mental Health Trust Authority with relation to Traumatic Brain Injury.

PAT HEFLEY, Deputy Commissioner
Office of the Commissioner

Department of Health and Social Services (DHSS)
Juneau, Alaska
POSITION STATEMENT: Testified and answered questions during the Traumatic Brain Injury presentation.

DR. NIKOOSH CARLO, Intern
to Representative Bob Herron
Alaska State Legislature
Juneau, Alaska
POSITION STATEMENT: Read a statement from Representative Herron with regard to the seriousness of Traumatic Brain Injury.

MARGARET CARLONI, RN
Alaska Native Medical Center (ANMC)
Anchorage, Alaska
POSITION STATEMENT: Testified to the need for better Traumatic Brain Injury care.

SHANNON COGSWELL
Juneau, Alaska
POSITION STATEMENT: Testified as a patient to the difficulties of Traumatic Brain Injury.

JODY WADE
Juneau, Alaska
POSITION STATEMENT: Answered questions about the challenges for Traumatic Brain Injury support.

MARTHA MOORE, Chair
Alaska Brain Injury Network (ABIN)
Juneau, Alaska
POSITION STATEMENT: Testified about the ABIN program.

ACTION NARRATIVE

3:11:06 PM

CO-CHAIR WES KELLER called the House Health and Social Services Standing Committee meeting to order at 3:11 p.m. Representatives Keller, Wilson, Lynn, and Cissna were present at the call to order.

PRESENTATION: Building Alaska's Systemic Capacity to Deal with Brain Injury

3:11:25 PM

CO-CHAIR KELLER announced that the first order of business would be a presentation on Alaska's systemic capacity to deal with traumatic brain injury.

3:12:08 PM

JILL HODGES, Executive Director, Alaska Brain Injury Network (ABIN), introduced the other panel members and mentioned that this was the fourth year for a presentation to the legislators. [Included in the committee packets was the PowerPoint entitled "Alaska is Combating Traumatic Brain Injury."]

3:13:31 PM

MS. HODGES pointed to slide 2, "Past legislative hearings," and reviewed the presentation topics since 2007, which included "What is traumatic brain injury," "Military issues related to TBI," and "Importance of Medicaid Waiver..."

3:14:16 PM

MS. HODGES quickly reviewed the outline of the topics and speakers featured on slide 3, "Today's presentation."

3:15:02 PM

MS. HODGES moved on to slide 4, "TBI Systems Development in AK," and shared that this was a time when the Department of Health and Social Services (DHSS), the Alaska Mental Health Trust Authority, the Alaska Brain Injury Network, the state provider network, and the tribal communities were all working together to start developing TBI treatment in Alaska. She opined that this was a good opportunity to include the military in this partnership. She reflected on the history of the TBI movement in Alaska, and shared that the Brain Injury Association of Alaska was organized and advocacy begun in 1990. She pointed out that, in 1995, the State of Alaska became much more involved, and, with the award of federal money, an infrastructure began to form.

3:17:45 PM

MS. HODGES acknowledged slide 5, "TBI Systems Development in AK 2000-2007," and affirmed that federal grants were the key to development of a greater awareness for the needs. She spoke about the formal needs assessment and the state action plan to access federal funding for treatment of brain injury.

3:18:39 PM

CO-CHAIR KELLER clarified that this focus was for the sub acute treatment.

3:19:00 PM

MS. HODGES, in response to Co-Chair Keller, agreed. She continued and discussed the role of the full time brain injury coordinator and the advocates, who formed the TBI Advisory Board. This advisory board ultimately became the Alaska Brain Injury Network (ABIN) in 2003. She explained that, at the time, the Division of Behavioral Health was the lead state agency, and it utilized brain injury screening questions to identify that almost 34 percent of its new behavioral health clients had brain injury. She relayed that the momentum for TBI awareness and advocacy slowed during 2005-2007 for a variety of reasons. She shared that this time period brought recognition of the need for a cohesive TBI workforce.

3:21 :36 PM

MS. HODGES detailed slide 6, "Momentum builds- 2007-2009," and said that a lot was happening very quickly. She discussed the ten-year plan, which included hundreds of recommendations to improve care in Alaska. She pointed to the partnership of ABIN, the Alaska Mental Health Trust Authority, and four advisory boards for brain injury services, which included information referral and case management. She noted that legislation was introduced for a Medicaid waiver, and that providers had started meeting regularly.

3:23:02 PM

MS. HODGES directed attention to slide 7, "Key Points," and explained that Phases 1-4 (1990-2005) focused on advocacy, planning, and increasing awareness, while Phases 5-6 (2005-2009) focused on direct services and workforce development. She identified that Phase 7 (2010-2020) would focus on treatment and rehabilitation.

3:23:59 PM

JEFF JESSEE, Chief Executive Officer, Alaska Mental Health Trust Authority, Department of Revenue, lauded the work and the advocacy by Ms. Hodges on behalf of the TBI population. He

pointed to slide 10, "The Trust's Role," and noted that people with TBI faced many of the same functional and service limitations as several other beneficiary groups. He observed that TBI was not mental health, disability, or senior services, consequently, it did not fit into the existing structure. He offered his belief that Alaska was too small to support three separate systems of care: tribal, Veterans Affairs (VA), and state. He opined that it was difficult to work with the VA bureaucracy. He reported that, over the prior 10 years, the Alaska Mental Health Trust Authority had invested $2.8 million in brain injury systems development, with $628,000 budgeted for FY09.

3:27:30 PM

CO-CHAIR KELLER asked for details of the designated areas for funding.

3:27:48 PM

MR. JESSEE pointed out the difficulty of finding the available resources. He explained that there was an information and referral specialist at the ABIN.

3:28:22 PM

MS. HODGES reported that the FY09 funding was for: information referral, which to date had served more than 600 Alaskans; case management and coordination of care, which had proven to be a cost effective means of connecting patients to care; technical assistance for planning, which was one of the four focus areas, and included long term care planning; anti stigma campaign, which funded public awareness programs; workforce development, which funded academic and vocational courses and programs; and the ABIN.

3:31:09 PM

REPRESENTATIVE CISSNA asked how this worked in other states, and if it was affected by Alaska's ratio of doctors to patients.

3:32:09 PM

PAT HEFLEY, Deputy Commissioner, Office of the Commissioner, Department of Health and Social Services (DHSS), said that he had found that about 50 percent of the states had waiver programs, but that some states had a limit for the number of

patients that could be served. He detailed that some waivers focused on vocational rehabilitation. He noted that, along with federal waivers and state general funds, funding was also from the private sector. He shared that some care service required very specialized training.

3:34:39 PM

MR. HEFLEY, directing attention to slide 11, "Department of Health and Social Services Role," discussed his trip to seven states in seven days. He reported that he had met with state, private, and military providers. He described his visits to acute and post acute service providers, and he emphasized that these were now developed professions. He pointed out that 24 states had a waiver for TBI programs.

3:38:50 PM

MR. HEFLEY said that he would focus on four critical areas in preparation for participation with the Medicaid waiver: what is offered, how it is offered, how many people will receive the services, and how much will it cost. He shared that there was a huge array of services from hospital discharge to day service, and it would be necessary to narrow down which services to be provided. He spoke about how these services would be provided, and indicated limits and caps that might be necessary. He deliberated on how many people would be included for each service, and how much would it cost. He mentioned that it was only 13 months until the writing of renewable waivers. He shared that many TBI patients were not receiving any rehabilitative service.

3:41:38 PM

MR. HEFLEY reflected on his research of treatment outcomes, and how well they worked. He reminded the committee that HHSS had added "productive" to its overall mission. He commented that success was often measured by an active involvement in society.

3:42:39 PM

CO-CHAIR KELLER, referring to the array of services, asked when it was most effective.

3:43:02 PM

MR. HEFLEY said that, although more research was needed, the studies of groups admitted to rehabilitative services right after discharge, and admitted one year later, reflected no significant difference in most of the treatment outcomes. The review concluded that it was not too late to begin treatment. He complimented the military for its excellent research and rehabilitation work, but opined that it was often a closed system. He referred to slide 8, "2010 Session: SB 219 and House Companion," which the Department of Health and Social Services was reviewing. He moved on to a discussion about maladaptive behavior, patients who did not fit into managed programs. He opined that many of these patients were TBI, and that DHSS and ABIN were reviewing proposed plans for services.

3:47:35 PM

MR. HEFLEY reiterated that the upcoming waivers would be for "true clinical services."

3:48:32 PM

REPRESENTATIVE T. WILSON asked how a person would find out whom to call for services.

3:48:51 PM

MS. HODGES replied that it depended on the severity of the brain injury. She clarified that most of this discussion had centered on moderate to severe injury. She compared the Alaska response to breaking a leg: one goes to the hospital, is treated, receives some physical therapy, is discharged, and goes home. She stressed that going home should not be that next step, as the transitional level for post acute rehabilitation and therapy was necessary, but was not currently included in the direct Alaska treatment network.

3:51:45 PM

REPRESENTATIVE LYNN asked about the who and the where of the aforementioned military contacts.

3:52:14 PM

MS. HODGES listed the contacts she had made at the VA, Elmendorf Air Force Base, the Alaska Federal Health Care Partnership, the Defense and Veterans Brain Injury Center, and the National Intrepid Center of Excellence.

3:54:11 PM

REPRESENTATIVE LYNN suggested that she contact the Surgeon General.

3:54:44 PM

DR. NIKOOSH CARLO, Intern to Representative Bob Herron, Alaska State Legislature, shared that she has a Ph.D in Neuroscience, and that TBI was important to her field. She read from a prepared statement [original punctuation provided]:

> Rep. Herron could not be here today and he asked me to make a few comments with regard to the seriousness of traumatic brain injury. I know that Rep. Herron was at the Alaska Brain Injury Networks' meeting in Bethel earlier this year and he wants to help in any way that he can with efforts towards getting treatment to individuals suffering from traumatic brain injuries.

- 800 Alaskans are treated in hospitals for TBI
- 34% of those treated are Alaska Native

> As someone who studies the brain, I think there are a few things about the brain that are important for you to know:

- The brain itself is the consistency of jello and it is protected by layers of tough tissue, then surrounded by fluid, and finally by the skull bones and skin.
- Egg floating in a Tupperware analogy
- A traumatic brain injury breaks through these protective barriers and is a direct insult on brain matter.
- The special thing about the brain is that it has some plasticity, meaning that it is adaptable:
- Traumatic brain injury to a part of the brain breaks the connections between that brain region and the areas to which it communications.
- Connections can be rebuilt through intensive therapy.
- Treatment is critical to helping individuals cope with TBI.

Rep. Herron is a co-sponsor on the House Companion bill to SB 219, which will be read across the house floor tomorrow. Some of the things this bill will do are to establish a traumatic or acquired brain injury registry, and provide case management for treatment. I believe that clinical data on TBI will help providers offer essential services to individuals suffering from a traumatic brain injury.

3:57:53 PM

MARGARET CARLONI, RN, Alaska Native Medical Center (ANMC), stated that she traveled throughout Alaska to teach trauma nurse courses. She worked in TBI care and shared that there was not much needed rehabilitation service after discharge. She said that this was especially true in rural areas. She detailed that self medication with alcohol and drugs was a problem. She expressed the need for better rehabilitative care and TBI partnerships in Alaska.

4:00:33 PM

SHANNON COGSWELL shared that she was 27 years old and had been in a car accident in 2002. She said that she started her physical rehabilitation at a retirement home, where she had to re-learn to walk and feed herself. She disclosed that her dad would leave her lists of things to do, which kept her occupied and challenged. She thanked her mom for help with phonics, cooking, and brain exercises during this road to recovery. She stated that University of Alaska Southeast (UAS) had asked her what help she needed, but that she was not capable of knowing even that. She mentioned that UAS gave her a tape recorder, and a person to help with notes and review after her classes. She revealed that she was only capable of one class at a time. She said that having a therapist was really helpful, and that neuro biofeedback with Patrick Neary at Wellspring had brought her a lot of success, including the retrieval of her taste, smell, and memory. She pointed out that a consistent routine and checklists were very important. She analyzed that she was still very early in her recovery. She acknowledged how difficult it had been to know where to look for help, and that without her family, she would not have been able to succeed. She shared that the expectation upon release from physical rehabilitation was for her to resume her life, but that she was not even remotely capable of that.

4:06:29 PM

REPRESENTATIVE T. WILSON asked for her suggestions of help for the transition.

4:06:49 PM

MS. COGSWELL replied that she had to "re-learn how to live life," and how difficult it was to get up and even remember to eat.

4:10:43 PM

REPRESENTATIVE LYNN asked the Wades [Ms. Cogswell's parents] what they had learned about TBI and for their suggestions of what could be done.

4:11:05 PM

JODY WADE said that after Shannon's accident, she came home to look for rehabilitation resources in Juneau. She shared that a neurologist did an assessment, but that the family did much of the work, as they did not know where to go for any help. She reiterated the importance of maintaining a day after day routine, with a lot of repetition. She recounted that she had found the resources, including speech therapy and anger management. She described the anger issues that result from TBI, and the difficulties this brought to the entire family. She stressed that "can't" was not a part of the vocabulary, and that, as there were no guidelines, each day was a challenge. Both of Ms. Cogswell's parents [Mr. and Ms. Wade] extolled the virtues of the bio-feedback program and the success that it brought.

4:15:20 PM

REPRESENTATIVE LYNN complimented Ms. Cogswell's parents, and opined on the difficulties faced by TBI patients without this support.

4:16:02 PM

MS. WADE reiterated that TBI patients had no idea of where to go for help.

4:16:42 PM

MARTHA MOORE, Chair, Alaska Brain Injury Network, detailed that ABIN had 18 volunteers, 6 liaisons with boards and other committees, and 4 paid staff in Anchorage. She presented the continuum of care which had been prepared to illustrate the gaps of services for TBI survivors. She offered to distribute copies to the committee. She explained that the network was diligently trying to find out what people needed. She stressed the two most important needs to be post acute care rehabilitation and case management. She offered her belief that the first two years were the most critical for maximum recovery.

4:21:42 PM

MS. MOORE summarized that ABIN had formulated a 10 year plan, after an assessment of the gaps of service. She detailed that the plan philosophy was not to build from scratch, but to connect the pieces of the TBI system which already existed. She noted that research into other agencies and other states for existing programs was a priority.

4:23:15 PM

REPRESENTATIVE LYNN asked about the similarities between stroke and TBI.

4:24:41 PM

MS. MOORE replied that the functional outcome and the services were often the same.

4:25:07 PM

MS. HODGES cited that TBI was defined in federal statute in 1996, and, after that, states were required to develop a strategy for the capacity to serve TBI patients. She pointed out that many states had then recognized that acquired brain injuries, such as strokes, aneurisms, and tumors, often needed the same services as TBI. She reported that it was necessary to have a Medicaid waiver for both, and she directed attention to SB 219 and its House Companion bill. She clarified that "acquired" referred to after birth, and was the umbrella classification for both traumatic, defined as a jolt or blow to the head, and non-traumatic, defined as a stroke or aneurism.

4:27:13 PM

ADJOURNMENT

There being no further business before the committee, the House Health and Social Services Standing Committee meeting was adjourned at 4:27 p.m.