

ALASKA STATE LEGISLATURE
SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

February 17, 2010

1:36 p.m.

MEMBERS PRESENT

Senator Bettye Davis, Chair
Senator Joe Paskvan, Vice Chair
Senator Fred Dyson

MEMBERS ABSENT

Senator Johnny Ellis
Senator Joe Thomas

COMMITTEE CALENDAR

SENATE BILL NO. 219

"An Act establishing a traumatic brain injury program and registry within the Department of Health and Social Services; and relating to medical assistance coverage for traumatic brain injury services."

- MOVED CSSB 219(HSS) OUT OF COMMITTEE

PRESENTATION: Fetal Alcohol Spectrum Disorder

- HEARD

PRESENTATION: Bring the Kids Home Initiative

- SCHEDULED BUT NOT HEARD

UPDATE ON OFFICE OF CHILDREN'S SERVICES

- SCHEDULED BUT NOT HEARD

PREVIOUS COMMITTEE ACTION

BILL: SB 219

SHORT TITLE: TRAUMATIC BRAIN INJURY:PROGRAM/MEDICAID

SPONSOR(s): SENATOR(s) MCGUIRE

01/19/10 (S) READ THE FIRST TIME - REFERRALS
01/19/10 (S) HSS, FIN

02/15/10 (S) HSS AT 1:30 PM BUTROVICH 205
02/15/10 (S) Scheduled But Not Heard
02/17/10 (S) HSS AT 1:30 PM BUTROVICH 205

WITNESS REGISTER

SENATOR LESIL MCGUIRE
Alaska State Legislature
Juneau, AK

POSITION STATEMENT: Sponsor of SB 219.

ESTHER CHA
Aide to Senator McGuire
Alaska State Legislature
Juneau, AK

POSITION STATEMENT: Provided an overview of the CS for SB 219.

ANGELA SALERNO, health program manager
Division of Senior and Disabilities Services
Department of Health and Social Services (DHSS)
Juneau, AK

POSITION STATEMENT: Answered questions about SB 219.

MARTHA MOORE, chair
Alaska Brain Injury Network (ABIN)
Anchorage, AK

POSITION STATEMENT: Supported SB 219.

JEFF JESSEE, chief executive officer
Alaska Mental Health Trust Authority
Anchorage, AK

POSITION STATEMENT: Supported SB 219.

SCOTT HAMMOND, representing himself
Kenai, AK

POSITION STATEMENT: Was not opposed to SB 219 but believed that it could result in unintended consequences.

NANCY MICHAELSON, representing herself
Palmer, AK

POSITION STATEMENT: Supported SB 219.

MARGARET CARLONI, representing herself
Anchorage, AK

POSITION STATEMENT: Supported SB 219.

JILL HODGES, executive director
Alaska Brain Injury Network
Anchorage, AK
POSITION STATEMENT: Supported SB 219.

DIANE CASTO, Manager
Prevention and Early Intervention Services
Division of Behavioral Health
Department of Health and Social Services (DHSS)
Juneau, AK
POSITION STATEMENT: Presented information on Fetal Alcohol Syndrome Disorder (FASD).

DR. STERLING K. CLARREN, clinical professor of pediatrics
Child and Family Research Institute
Vancouver, British Columbia, Canada
POSITION STATEMENT: Presented information about FASD.

SHERRI WES, representing herself
Juneau, AK
POSITION STATEMENT: Presented information about FASD.

RENEE LELAND, representing herself
Anchorage, AK
POSITION STATEMENT: Presented information about FASD.

MARYBETH MOSS, tribal administrator
Hoonah Indian Association
Hoonah, AK
POSITION STATEMENT: Presented information about FASD.

ACTION NARRATIVE

[1:36:17 PM](#)

CHAIR BETTYE DAVIS called the Senate Health and Social Services Standing Committee meeting to order at 1:36 p.m. Present at the call to order were Senators Dyson, Paskvan and Davis.

SB 219-TRAUMATIC BRAIN INJURY:PROGRAM/MEDICAID

CHAIR DAVIS announced the consideration of SB 219.

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SENATOR MCGUIRE, sponsor of SB 219, said the bill establishes a program and registry for traumatic brain injury (TBI) and acquired brain injury (ABI) within the Department of Health and Social Services (DHSS). Annually, over 800 Alaskans are

hospitalized with TBI due to accidents, domestic violence, shaken baby syndrome and other causes. Approximately an equal number of Alaskans suffer from ABI as a result of strokes, aneurism or tumors. TBI and ABI affect rural and urban Alaskans and record level of military members returning from Iraq. SB 219 will allow the state to track the number of brain injured Alaskans in hopes of leveraging much needed federal dollars and for rehabilitation, support and back-to-work programs.

Access to rehabilitation has allowed individuals with brain injuries to live at home and return to school or work and engage in a meaningful, productive life. She emphasized that T/ABI is not a death sentence but without treatment the statistics are grim. People with ABI and TBI can be a tremendous social cost to the state as they go on to commit crimes, live in poverty and homelessness or end up in jail. Service coordination and rehabilitation may reduce future medical and social costs.

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SENATOR MCGUIRE said that by trying to track data with a brain injury program and registry can help coordinate many efforts made throughout the state and to leverage the much needed federal dollars. A match of up to 60 percent federal funds would be available through a combination of sources, largely Medicaid.

She asked that the committee adopt the committee substitute and noted that Esther Cha has worked with DHSS on the changes.

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CHAIR DAVIS moved to adopt the proposed committee substitute to SB 219, labeled Version R, as the working document of the committee. There being no objection, the motion carried.

ESTHER CHA, aide to Senator McGuire, said the major change is including "acquired" along with "traumatic brain injury" in the title. Also, a pilot project in Section 6 of Version A was removed because DHSS thought more planning would be needed. On page 1, lines 13-14 establish the registry under AS 47.80.500(c)(1). Many changes in Version R relate to establishing the registry and the program under AS 47, which is "persons with disabilities" rather than Title 18, which deals with public health. This change was recommended by DHSS because the Senior and Disabilities Services currently manage Medicaid waivers, case management, aging and disability resource centers and hospital discharge grants.

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ANGELA SALERNO, health program manager, Division of Senior and Disabilities Services, Department of Health and Social Services (DHSS), said her division is the agency responsible for the TBI program in the state and would take on these duties. In Section 2 [amending AS 47.07.030(b)], DHSS gets authority to seek a Medicaid state plan amendment to add case management for people with TBI. Targeted case management is a straight state Medicaid service which would be added to the list of optional services currently in Alaska for Medicaid.

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MS. SALERNO said Section 3 [AS 47.07.030] of SB 219 adds a definition for case management that the division believes is problematic because it is not consistent with the federal definition of targeted case management. The division is concerned that if the definition goes into statute, the Centers for Medicaid/Medicare may disallow any claims the state made for targeted case management. She suggested changing SB 219 to refer back to the federal definition.

SB 219 requires DHSS to serve people with TBI under a Medicaid waiver; DHSS did not develop a fiscal note for a new waiver program because DHSS already serves people with TBI on its current waivers. Currently, DHSS is serving 102 people on Medicaid waivers with TBI because they meet the definition of nursing home level of care. DHSS does not feel developing another waiver is necessary.

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CHAIR DAVIS asked Ms. Salerno if changing the definition for case management in Section 3 back to the federal definition is her only suggested change to SB 219.

MS. SALERNO responded yes and said DHSS otherwise has a neutral position on SB 219.

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MARTHA MOORE, chair, Alaska Brain Injury Network (ABIN), supported SB 219. ABIN has done an assessment of the service system across Alaska for TBI survivors. She referred to a document called, "Fractured and Inadequate" which shows the continuum of care for a TBI survivor. ABIN identified the gaps in the system. Case management is needed, as well as data recording and rehabilitation after hospitalization. ABIN has written a 10 year plan and has gathered an array of partners to help accomplish this task, including the military, Mental Health Trust, Alaska Native Medical Center, state and private agencies.

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ABIN feels that SB 219 provides a framework to move forward. The TBI registry will track a patient from injury to functional outcomes, showing treatment and rehabilitation time-tables linked to the patient's recovery, functional outcomes and reintegration into society. This information will provide the standards of care, protocols, recommendations for treatment and the services that lead to independent living. The registry will also allow a continual reassessment of the gaps in the system.

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JEFF JESSEE, chief executive officer, Alaska Mental Health Trust Authority, said the Trust supports SB 219. He stressed the link to veterans returning to Alaska with TBI. Alaska three continuums of care for people with TBI: the tribal system, the Department of Defense and VA system and the state system. These systems need to be combined to create a comprehensive and cost-effective service but the state currently has nothing to offer as a partner. SB 219 starts a state response and gives the state something to offer to the other systems of care.

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SCOTT HAMMOND, representing himself, Kenai, said he is not opposed to SB 219 but believes that a provision in Version R could have unintended consequences: Article 5(a), Sec 47.80.500(3) on page 4. This provision could lead to a call for a mandatory motorcycle helmet law. He assured the committee that Alaska's lack of requirement for motorcyclists to wear helmets does not create a problem with TBI for motorcycle riders.

He recommended that the committee modify the provision by removing the words "and laws" and "to the prevention of traumatic or acquired brain injury". The provision would then read: "evaluation of standards pertaining to the treatment, care and support of persons with traumatic or acquired brain injury".

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CHAIR DAVIS asked if he was reading from Version R of SB 219 and if so, what page.

MR. HAMMOND replied, yes, he was referring to Version R, page 4.

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NANCY MICHAELSON, representing herself, Palmer, said she and her husband care for their 26 year old son, who lives with them, due to a disability resulting from TBI. SB 219 is comprehensive and

will be welcomed by Alaskans affected by TBI. Her son has been disabled for seven years. Without the Medicaid waiver program, her family could not have managed her son's round-the-clock care nor would he have the quality of life that he now has. The services available through the Medicaid waiver program are helping her son progress toward more movement and speech. She listed the following as the best aspects of SB 219: One, the clarification of the definition of TBI; two, assistance to find practitioners familiar with TBI who can be part of a coordinated care team; and three, smartly positioning Alaska for future funding for brain injury services.

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MARGARET CARLONI, registered nurse, Anchorage, supported SB 219. She said the inability to offer more to TBI patients is heartbreaking and frustrating. Acute rehabilitation is available in some locations but the real gap is for cognitive rehab or long-term housing for severely injured patients. About 34 percent of TBI's are Alaska Native people and very little is available in small communities. She hopes that SB 219 will help gather more data to consider the gaps around the state.

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JILL HODGES, director, Alaska Brain Injury Network, Anchorage, supported SB 219. She related a story about her brother and his brain injury five years ago. He and her family went through intense brain injury rehab, a period of gratefulness for his life and then realizing the difficulty managing his injury. He suffered severe depression, began drinking and had run-ins with the law. Now her brother is in college and understands his own disability. SB 219 gives families more opportunity for support.

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SENATOR MCGUIRE spoke to DHSS's concern with the definition of case management in Version R, page 2, section 3, line 21. She said DHSS's concerns centered around the inclusion of housing in case management on line 30. She noted that housing is a big part of the equation but eliminating "including housing", rather than incorporation the federal definition, should address DHSS's concerns.

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CHAIR DAVIS asked if Senator McGuire had spoken to DHSS about this suggested change.

MS. MICHAELSON said no.

SENATOR MCGUIRE said the committee can decide if the federal definition is used or the words "including housing" are removed. Asking DHSS would be the right thing to do.

Regarding Mr. Hammond's testimony about helmet laws, she understood his concern to be about the evaluation of standards and law that pertain to the prevention of TBI. She noted that the proposed statewide committee in SB 219 is not a law-making committee. Though the committee will have the ability to assess standards and laws, changing any law is still in the hands of lawmakers as influenced by people. She proposed keeping that provision the way it is.

CHAIR DAVIS said she agrees with Senator McGuire that the language on page 4, lines 7-9, does not need to be changed.

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SENATOR MCGUIRE referred to the discussion about whether or not a waiver is needed. Although 100 TBI people are now being served through various channels, many more TBI survivors would benefit from the kind of program laid out in SB 219. Having a specific waiver is appropriate.

SENATOR DYSON noticed that Version R has the phrase "acquired brain injuries". Looking at 47.80.590, which is the definition, he asked Senator McGuire to clarify whether or not her intent is to include brain injuries that are not as a result of a physical trauma, such as a stroke.

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SENATOR MCGUIRE replied that she believes something like Fetal Alcohol Syndrome (FAS) is an acquired brain injury. If the brain structure started out healthy and was exposed to drugs or alcohol in the womb, that person can go on to live a life with brain damage. She believes brain damage from a strangling or hypoxia, etc, is also acquired. DHSS was concerned about opening it up to all congenital brain injuries because DHSS already has places to deal with that. An acquired brain injury is one that a person did not start out with congenitally; the person had a normal brain structure at some point. She envisions things like blunt force trauma or deprivation of oxygen to be incorporated.

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MS. HODGES said states began defining brain injury in statute 30 years ago and it was solely traumatic. However, provider services are very similar for those with stroke, aneurism, tumors, encephalitis, etc., and providers cannot sustain a

program serving only those with TBI. Some states exclude congenital and degenerative brain injuries, such as Alzheimer's, because they have very different service needs. In Alaska, a person born with a developmental disability (DD) is served under the DD population and services.

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SENATOR DYSON said other than physical trauma, the issue [of brain injury] is blurred. Diagnosing fetal alcohol spectrum disorder (FASD) is difficult. He cautioned that Senator McGuire is introducing a subjective element that could have major fiscal consequences.

SENATOR MCGUIRE said that assessments are not made through the legislature but as part of DHSS's assessments by their physicians. She said she initially began advocating for blunt force trauma brain injuries but Senator Dyson's leadership has brought ABI issues to light too. The question is at what point people with ABI interface with DHSS to receive a waiver under another category. She is not prepared to exclude people with certain types of brain injury today. She is relying on the DHSS experts and their evaluation to determine if the legislation needs to be narrowed.

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SENATOR DYSON encouraged Senator McGuire and the experts to think about this issue and make her intention, as the sponsor, very clear because the courts will look at it.

SENATOR PASKVAN clarified that Senator McGuire is suggesting removing the words "including housing" from page 2, line 30, in order to avoid jeopardizing future available funding.

SENATOR MCGUIRE replied, "yes".

CHAIR DAVIS clarified that is the only change at this time.

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SENATOR PASKVAN offered Conceptual Amendment 1 to CSSB 219(), Version R: He moved to withdraw "including housing" from page 2, line 30. There being no objection, the motion carried.

CHAIR DAVIS asked Ms. Solerno to comment on that change.

MS. SALERNO said another item in the definition is problematic: the wording of strengthening local capacity [page 2, line 29]. She noted that case management services are for individuals, not

for communities or localities. She believed removing that wording would make the section work for DHSS.

SENATOR MCGUIRE said that was acceptable to her. After the word "expand" the words "and strengthen the local capacity for delivery of needed services, including housing" can be removed.

CHAIR DAVIS said SB 219 has another committee to go through, which will allow DHSS to check with their attorneys and address the issue again if needed.

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SENATOR PASKVAN offered Conceptual Amendment 2 to CSSB 219(), Version R: He moved to remove the words from line 29, after the word "expand" up to the word "for" on line 30. There being no objection it was so amended

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SENATOR PASKVAN moved to report the CS for SB 219, version R as amended, from committee with individual recommendations and attached fiscal note(s).

CHAIR DAVIS announced that without objection, CSSB 219(HSS) moved from the Senate Health and Social Services Standing Committee.

[2:28:26 PM](#)

FETAL ALCOHOL SPECTRUM DISORDER

CHAIR DAVIS announced the final order of business would be a presentation on fetal alcohol spectrum disorder.

[2:29:56 PM](#)

DIANE CASTO, manager, Prevention and Early Intervention Services, Division of Behavioral Health, Department of Health and Social Services (DHSS), Juneau, and, manager, Office of Fetal Alcohol Syndrome introduced herself and Dr. Clarren.

DR. STERLING K. CLARREN, clinical professor of pediatrics, Child and Family Research Institute, Vancouver, British Columbia, Canada, noted that he spent most of his career at the University of Washington and came to Alaska frequently where he did most of the state's fetal alcohol spectrum disorder (FASD) diagnoses for 10 or 12 years.

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MS. CASTO recognized Senator Dyson's efforts to address FAS and FASD in Alaska. An earmark of \$27 million from U.S. Senator Ted Stevens also launched many efforts. Limited diagnostic capacity made it difficult to understand the magnitude of the problem in Alaska until recently. Alaska now has 10 diagnostic teams and over 150 individuals are diagnosed every year. A thorough diagnosis is the first step to services.

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Getting the word out about FAS and FASD was also very important. In 1988, a lot of people still did not know that it was not ok to drink during pregnancy. A strong, comprehensive media message was spread to say alcohol during pregnancy is not ok. The state has changed the social norm around that issue.

Alaska has one of the most comprehensive surveillance systems through the Alaska birth defects registry program. She noted that Commissioner Bill Hogan will announce FASD prevalence rates at tomorrow's Southeast Alaska FASD conference. Alaska has seen a significant decrease.

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SENATOR DYSON interjected and said that Ms. Castro minimizes her own part in the progress. Alaska had nothing when Ms. Castro started and it now has one of the better programs in North America. He asked Dr. Clarren if FASD was first diagnosed at the University of Washington.

DR. CLARREN replied yes.

SENATOR DYSON recalled that the University of Washington research brought FASD to the attention to the whole world.

CHAIR DAVIS confirmed that the Alaska legislature has done a lot with FASD and is at the top of the list for something good.

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DR. CLARREN said a diagnosis is family wide and lasts a lifetime. That alcohol causes the FASD is only important for prevention; for the victims it is irrelevant - they have a traumatic brain injury that is prenatal in origin and will last a lifetime. It is up to the legislature to decide whether or not to incorporate people with FAS into SB 219. People with TBI often have trouble with motor skills which is an obvious disability but beyond that TBI people and FAS people have similarities: trouble with planning, judgment, communication, social relations, etc. It comes down to mal-adaptation. The

question is how to separate people who are maladapted due to carelessness or even a bad environment from people who are maladapted due to organic brain damage. It remains a medical challenge. The legislature's next mission is how to embrace people with FAS for a lifetime of need.

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SHERRI WES, representing herself, said she is the adoptive mother of an 18 year old with FASD. Her daughter does not look different but her biological mother drank through her pregnancy. Ms. West could not figure out why her daughter was struggling to learn. They moved to Juneau 18 months ago and a psychiatrist familiar with FASD diagnosed her daughter. Her daughter wants to be a normal 18 year old, on her own, but she can't. Ms. Wes structures her daughter's day, is her support system and her external brain. Her daughter does not fit anywhere; no services are available; her IQ is too high. If Brooke was on her own, she would forget to take her medicine, could not follow a schedule or handle money.

SENATOR DYSON interjected that Ms. Wes' daughter would be victimized.

MS. WES agreed. She said her daughter is excessively friendly and charming. She is excellent with babies and the elderly. However, she cannot filter out who is a risk and who is not. Ms. Wes is exhausted but no one can help. Transitional housing is not structured enough and she cannot get a case manager. She asked the legislature to take the next step to for services that fit FAS young adults.

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RENEE LELAND, representing herself, has a 10 year old son with FASD. Her son's birth mother was arrested when 3 months pregnant and was given the opportunity to go to Dena A Coy, a substance abuse center for pregnant women. Ms. Leland feels that without that treatment, her son would either not be alive or would be severely damaged. Her son missed developmental milestones but did have some services in Anchorage.

She told the story of her son's teacher calling to say everyone in the class, except her son, had memorized a poem. As a reward, the students were going to a water park and her son was not allowed to go. Ms. Leland tried to explain that her son could not memorize the poem. Her son was devastated and was receiving a message that he was stupid and would be punished. She took her son on another field trip that day. She asked the committee to

think of her son when they consider any legislation for education, prevention, therapies in rural areas, substance abuse treatment centers for moms, etc.

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MARYBETH MOSS, tribal administrator, Hoonah Indian Association, Hoonah, said her daughter is 3 years old and was given up by her 23 year old Tlingit mother. The baby came with a bundle of clothes, books, blankets and a journal filled with stories and poems that the girl's birth mother wanted her to have. The last page of the journal said the baby had been exposed to alcohol, marijuana, oxycontin and crack cocaine every day of her prenatal existence. Her daughter was initially happy and healthy and passed developmental milestones. However, in February, 2008, they came to Juneau for diagnostic tests and walked out shattered. They had to return to Hoonah which has no services or providers familiar with FASD, its affects or treatment options. Ms. Moss learns from the internet and talking to other parents. Her daughter's Tlingit name means "return to her rightful place". The tribal council thought the little girl would have the best of both the Western and Tlingit worlds and would be a powerful leader. Ms. Moss and her husband want their daughter to be a leader and for FASD children to grow and serve in their rightful place. She asked the legislature to support FASD funding now and in the future.

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CHAIR DAVIS apologized for having to cut the meeting short but advised that another meeting was beginning and the committee must adjourn. The other presentations would be rescheduled.

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CHAIR DAVIS, seeing no further business to come before the committee, adjourned the meeting at 2:58 p.m.