

2011 SENATE EDUCATION

SB 2163

2011 SENATE STANDING COMMITTEE MINUTES

Senate Education Committee
Missouri River Room, State Capitol

SB 2163
January 18, 2011
12997

Conference Committee

Committee Clerk Signature

T. Gogger

Explanation or reason for introduction of bill/resolution:

Relating to traumatic brain injury services.

Minutes:

See "attached testimony."

Chairman Senator Freborg called the hearing to order on SB 2163; fiscal note attached.

Senator Dever, District 32 introduced the bill, and explained parts of the fiscal note. This is an important issue; Traumatic Brain Injury (TBI) is more pervasive than we realize. People can get an injury that they don't even know of; it affects mental abilities, short term memory, speech, etc. Question might be why is this in education rather than human services—because it does involved education quite a lot. Education regarding TBI needs to involved the schools as they get students with a brain injury and don't know how to teach them; different than a learning disability.

Senator Flakoll: What is the connection between DPI and Human Services for the work that needs to be done? Where do they work together in a seamless fashion to make it all happen? **Senator Dever:** In a lot of different areas, different agencies end up working together on issues. An important part of the program is the way that schools deal with children that have had TBI's and provide the best education that they can.

Richard Ott, North Dakota Head Injury Association testified in support of SB 2167. (Testimony #1 attached) There are five major themes in the bill; there is an awareness gap of TBI.

1) DPI provide teacher training; special education has been fantastic, but other teachers need to be trained to work with these students in the classroom.

Role of Human Services in the bill:

2) Create a registry of those that have a traumatic brain injury.

3) Develop peer mentoring services—volunteers already in place.

4) Create a TBI supplemental services program; have facilitators with resources for those that suffer from TBI; Veteran Affairs, etc. Support for individual and their family.

5) Establishment of a TBI supplemental services program fund to help with unmet needs such as specialized services, supplies and equipment.

Senator Gary Lee: Section 3 mentions services for veterans; aren't there programs already available for veterans? **Richard Ott:** This is a *special condition*; veterans programs are available but they also need more specialized knowledge of TBI.

Senator Flakoll: It specifies helping teachers—what about counselors and administrators? **Richard Ott:** Anyone having contact with the student should have training.

Rebecca Quinn, Traumatic Brain Injury Program Director, UND School of Medicine and Health Sciences (Center for Rural Health) testified in support of SB 2163. (Testimony #2 attached) She works under a federal grant provided to the states for the purpose of developing brain injury infrastructure. It was a three year grant that she has stretched to four, but runs out in March. She shared personal experience with TBI; we can't see the repercussions in small children but it shows up later (10-15 years old) when they appear to have learning disabilities.

Veterans also need assistance and to utilize civilian services; support systems are needed. They don't know the number of TBI victims in the state as there hasn't been a good way to track them, which is why the registry would be useful. They do know there are a high number of TBI suffers in prisons; they often have emotional and substance abuse issues. Study statistics were provided (Attachment #3) The injury is life-long so they need support life-long; not just the acute phase.

Brain injury is a "new" disability; 30 years ago over half of the people with brain injuries died, so people weren't living with it. Now have more than 80% surviving because of advancements in health care, prevention, etc. People are now surviving with significant disabilities. Need to have a support system to help them, along with the amazing things that we've done to help them survive. (Quoted statistics from a Minnesota state prison study) Complex system for delivery of services; not solely in the medical system, or education system, or human services, etc.—a little bit of all of them and very difficult to navigate.

Senator Luick: Is there a way in testing to see TBI? **Rebecca Quinn:** Not really; it doesn't always show up on a scan. It is often cellular damage—likened to Alzheimer's Disease. Concussions are known to have an impact on brain injury.

Senator Luick: Do you rely on the history of an event? **Rebecca Quinn:** Yes, they rely on the history of an injury or event; not every person has long term problems. About 15% of those that get a concussion have long term problems.

Senator Flakoll: Your current grant runs out in March 2011? **Rebecca Quinn:** Yes, and the federal program is limiting the number of new grants.

Senator Flakoll: Will part of this bill replace those lost federal dollars? **Rebecca Quinn:** Yes, it would take over for it. **Senator Flakoll:** Sections 2 & 3 there is a reference to contracting with a private or public entity—would the Center for Rural Health be a potential place where it could be done? **Rebecca Quinn:** Potentially.

Senator Schaible: How is an IEP for special education different for a student with TBI? How would it change the services offered to this child due to a brain injury? **Rebecca Quinn:** All IEP's work with the students type of disability; we need more awareness of all educators about TBI. The disabilities are different for TBI than most learning disabilities. Students retain their intelligence, but may learn differently, have memory problems, behavior issues, etc. Need to be able to make sure the services being offered are pinpointed at the fact it is a brain injury and more accommodating to that.

Senator Schaible: When they evaluate the learning disability, how is this bill going to change the process; is treatment different? **Rebecca Quinn:** A learning disability is something that is innate in the brain and dealt with an accommodation or modification based on that disability. TBI needs to relearn how to learn and rehabilitate for OT/PT/ST. With a learning disability it is a question of this is HOW the child learns.

Senator Gary Lee: What was the \$\$ amount of your federal grant? **Rebecca Quinn:** \$118,000 with a 50% state match.

Senator Gary Lee: Seems a significant part of the fiscal note is the registry. What is the value of the registry other than collecting numbers? **Rebecca Quinn:** It is a registry of individuals so that once registered it can be connected with resource facilitation. It would provide not just a registry of numbers but also a registry that gives the ability to find people that may need services offered. **Senator Gary Lee:** Who determines who is on the registry list? **Rebecca Quinn:** Based on medical 1CD9 codes and those admitted to the hospital.

Senator Flakoll: What will be the look back for the registry; what will the duties of the registry be? Is the prison population included? **Rebecca Quinn:** no, with limited funding it will only be a "go forward" approach. Only new TBI persons will be included.

Senator Marcellais: What are the objectives of the federal grant? **Rebecca Quinn:** To establish a statewide advisory committee for the Department of Human Services, educational awareness (conferences, schools, medical, organizations), help TBI survivors, work with tribal population, veterans groups.

Senator Gary Lee: Would the registry be used to determine the point that one qualifies for services through the bill? **Rebecca Quinn:** No, we are not going backward with the registry, and some don't seek medical care.

Senator Marcellais: What programs did you work with in the tribal communities? **Rebecca Quinn:** Vocational Rehabilitation and the Indigenous Peoples Brain Injury Association.

Senator Luick: Why do we need the registry? **Rebecca Quinn:** To move forward with more accurate numbers and to use for statistics. Can create a better system of connecting those that are seeking medical care with services.

Rhonda Boehm, parent of TBI survivor, McClusky, North Dakota testified in support of SB 2163. (Testimony #4 attached)

Senator Flakoll acknowledges that Eric is very lucky with modern medicine to be alive and more fortunate to have a phenomenal mother to be there for him. Senator Flakoll asks, what role does tutor play and how were they assigned to you? Did they have specific skills that aligned with his needs and training or how did that work in matching him up with a tutor? Was it the first tutor that came along or was it targeting towards his specific needs, academic, writing, speech?

Rhonda Boehm states that it was one of the unfortunate things in our small school and may be in larger schools. They put the word out as soon as we had our first conference call at the Gillette Children's Hospital, with our school system, that Eric would need a tutor. No one was available. Eventually, it was the basketball coach in McClusky and he was 30 years old and he came to talk to the superintendent and to IEP meeting that was getting started. He knew Eric was his tutor and did everything. Eric could not use his right hand so he took notes for Eric, helped after school and would go over and repeat his assignments. He would help him reread his English, worked on math and did a great job for someone who had not done this before. Tutor did an excellent job and we were hoping there was more available for Eric but there was not.

Senator Flakoll states this question may be out of education jurisdiction but asks why was he in Gillette? Why Gillette, what services did they provide, that we have missing or are inadequate in ND?

Rhonda Boehm states that Eric was at St. Alexius Medical Center, ICU, for six weeks. They did fabulous job with him and his medical care was great. Then, 6 weeks later, we had to make decision where to transfer him, when he was not improving? We then transferred him, to SCCI Hospital in Mandan. He spent 6 weeks there. That was the Home Simulation Program he was in, at SCCI, but it was not specializing in brain injury. SCCI is a general hospital for long term care. Eric started talking, his first words after 2 ½ months, after accident and took his first steps and was able to kick a ball in therapy. The social worker, at SCCI, talked to us and Dr. Killen, from St. Alexius Medical Center, and asked if I had heard about St. Paul Hospital for Children in Gillette? She stated that she had not. Eric was 14 years old and had a TBI and he needed intense therapy. She wanted him to have 8-10 hours a day of therapy. He was in PT, OT, Speech Therapy, Hydrotherapy and he needed recreational therapy. We have option of coming back to St. Alexius or MedCenter One but it was not specialized in TBI and therapies were twice a day for half hour sessions. It was a difficult decision, due to distance of St. Paul, from family members and friends. At that point, we needed to do what was best for Eric and to get him into an intense rehab. At Gillette's Children's, the next day, he started 8 hours of therapy/day.. He received PT,OT, Speech, Hydrotherapy (3 times per day) plus recreational therapy every evening. His day was from 7am to 8 pm with therapies and hard work. He spent 4 weeks at Gillette's in St. Paul and was released from there to come back home. Upon returning to Bismarck, he took his out-patient therapy at MedCenter One in Bismarck. I drove Eric to Bismarck, three times per week, for 4 years for 4 hours of therapy at MedCenter One. He also had therapist come into school setting on his days that he didn't come down to Bismarck. Today, he continues to do therapy on his own, works out 2-3 hours, 4-5 days a week.

Senator Heckaman asks when therapy was provided at school, was it provided through the IEP process or were you responsible for payment of that too? **Rhonda Boehm** states that it was provided through the IEP process.

Lisa L. Anderson, parent of Hannah, with TBI, from Leeds, ND who is in favor of SB 2163. (Attached Testimony #5).

The question was asked if people from Gillette come to ND to talk to the school?

Lisa Anderson states that they did not actually come but had conference calls with them because we were still in the Gillette Hospital. So one month, prior to every week before we came home, we had a family conference with the school involved including Special Ed. teacher, Superintendent, Principal (High School and Elementary) and one other teacher.

Dr. Tracie Mallberg, Member of the Head Injury Association Board, Family Practice Physician and Owner of LilyCare Clinic in West Fargo, ND and parent of TBI child. (Attached Written Testimony #6). **Discussion ends on tape. Power Outage. (Meter: 90:36).**

THE REST OF THE DISCUSSION OF SB 2163 IS FROM NOTES TAKEN. DUE TO POWER OUTAGE, THE REST OF RECORDED DISCUSSION IS NOT AVAILABLE.

Tracie Mallberg states there is a difference between TBI and behavioral issues. She states Eric had inappropriate IEP. He had OT, PT, Speech Therapy and Orientation help. These needs are constantly changing.

Discussion ensues and it is established that there is an Imaging Test. Neuropsychiatric test is what we have now. Eric has a verbal processing problem. He has a full time paraprofessional.

The question is asked, "What is the difference between Gillette and home?" It is stated that ND does not have a TBI center.

Discussion ensues on the "value of the "Registry"?" How does it help? Information is hard to share on TBI due to HIPAA.

John Jacobsen, Chairman of the Legislative Committee of the North Dakota Veterans Coordinating Council. Favors a DO PASS on SB 2163. (Attached Testimony #7).

Gerry Teevens, Assistant Director of Special Education for DPI. In favor of SB 2163. (Attached Testimony #8).

Senator Flakoll asks if we need a template for TBI? Is DPI intending to do this? **Gerry Teevens** states that DPI (a team) is looking at a template for TBI people for IEP. They need to identify needs with appropriate strategies.

Senator Flakoll asks since TBI is not an everyday occurrence, do we need to bring in a "team"? **Gerry Teevens** states she is not sure that "team" exists. One of the committee's jobs is to form one.

Senator Freborg asks if there is any opposition to SB 2163? None.

Attached Testimonies 9 & 10 were handed to Clerk. Not read to committee.

Senator Heckaman asking if on SB 2163, Line 16-17, is this coming out of general funds?

Senator Flakoll states TBI person could qualify under DD and TBI in IEP.

Senator Heckaman states you could have multiple diagnoses for this condition. Could we get someone from DPI to explain?

Senator Flakoll asks if we could have feedback on technical correction?

Senator Heckaman states she thinks IEP category for TBI should be clarified from someone from DPI.

Senator Luick asks about "registry" itself. Would they be going into "registry" from this point forward or go back"?

Senator Flakoll states registry is all prospective.

Senator Freborg states "everyone" in directory.

Senator Heckaman states "registry" is \$300,000. Possibly "Council for Exceptional Children" could bring someone in for training for teachers who have TBI students.

Senator Lee asks if the 'registry' would benefit people before or after and the point of the "registry"?

Senator Luick states that we don't have 'registries' for other issues, such as people with one arm?

Senator Flakoll comments "if we go all or none", we will get none.

Senator Luick asks if we should have a 'team of experts' vs. just training teachers?

Senator Heckaman comments she could contact Minot State University, who gets grant money, to see if they have any information on TBI.

Richard Ott, Lobbyist, states he can provide information on census type data such as severity, age groups, preventative measures etc.

Senator Heckaman asks if "registry" is part of 211 services?

Senator Lee states "registry" needs to come out yet. Are there opportunities to "hook on" with someone else?

Senator Flakoll states "yes".

Senator Schaible asks what the 3 facilitators will be doing?

Richard Ott states "case managers" will help lead person through process of normal living.

Senator Heckaman asks, "What has collaboration with Veterans Services entailed"?

Richard Ott states a facilitator will be assigned to them to help them with everyday skills.

Senator Heckaman asks if this service would interfere with receiving Veterans Services?

Senator Lee asks if the facilitator position (Human Service) would be the best possible area for this position? Home Health?

Power came back on. Meter (1:18:03) for continuation of SB 2163.

Gerry Teevens, DPI, Asst. Special Education Department, returns for questions in the afternoon.

Senator Heckaman asks if there is a special IEP for TBI people? **Gerry Teevens** states there is no special IEP for TBI but services provided in an IEP are based on their unique needs, not on their disability determination.

Senator Heckaman asks if TBI one of 13 categories in disabilities or is it absorbed in other health impaired? **Gerry Teevens** states "yes" it is one of the 13 categories.

Senator Heckaman asks how does the department address continuing education for staff or teachers that are working with students with TBI? Is there any continuing education or classes for those staff members?

Gerry Teevens states that they do this through different conferences they put on. As I mentioned this morning, I am on the TBI Advisory Council. As part of that council, I have learned about and been in tuned to the increase in wanting more awareness of TBI. The last year there were changes in our office so TBI is a portfolio of mine. We are looking for putting out some guidance. The role of agency, Special Ed. unit, is to provide technical assistance and guidance to the units on the "Individuals with Disabilities Act". We have state guidelines on the IEP process that is based on IDA. We will support conferences or workshops, if there is a need.

Senator Heckaman states she is familiar with Council for Exceptional Children and they provide training opportunities, at least once a year, when conference is held. I participate in those and bring in speakers and address a variety of disabilities and this would be included in some of those. Not every year or every category.

Senator Flakoll asks that on FN has figure based on 50 teachers at \$350 per day. How do you determine who 50 teachers are?

Gerry Teevens states that they were doing an estimate. It was based on other trainings or workshops that we have held where we paid a teacher to attend and based it on a stipend

of \$350/day. We took that times approximately 50 teachers. The actual student count for this year with TBI is 57. It is an estimate. That is where we came up with \$20,000. Clarifying that, this would be if the districts needed to provide the training that we would create in that manner. We could possibly do it through a webinar or mode that districts could provide for their teachers when they had release time. This is the highest case scenario. It may not even produce that kind of cost, depending on how the work group or task force decides, if it should pass and if it was created, would decide the best way to deliver the training.

Senator Flakoll asks if this time would be outside of the contracted days? **Gerry Teevens** states she believes it would be. Again, up to school systems how they felt if a workshop or training on TBI would be something they would provide for all of their teachers or they might include it as one of their in-service days, which she thinks is out of the contract days.

Senator Flakoll asks if person is trained this year, would you need to be trained again? Is it an annual basis or what is expectation of teacher should receive this training?

Gerry Teevens states that it would depend on what would be after the initial training. In other areas of disabilities, it depends on what new strategies are new in the field. If there is a new student in a district or a number of new teachers and they need the training, we would provide that. We hope that after initial training with the general information about strategies to work with children with TBI that this would be assessable on a continuous basis so that it can be used again, as a new staff person came in. With other disabilities, we provide training in a different format.

Senator Flakoll asks if a teacher really wants this training, due to anticipating a student with this disability in the fall, could they take this class or training in July, without their schools approval?

Gerry Teevens states that this is not developed yet so depending on when it would get passed and become a state requirement, depending on when resources would be created and ready for providing the training. Also it would depend on when it starts and it would be up to the school district, depending if it would be online or on webinar, or face to face. Face to face would be a different situation because the trainer would have to come to them.

Senator Flakoll asks as a student in high school, you may have many touch points with many teachers during the day, 4-5, you may have only one teacher that has the training, is that correct, since we have 180 school districts, that is fairly thin?

Gerry Teevens states for the most part that is up to the school district, how they provide that training and to who to provide the training to. At state level, we make it available but we usually cannot tell the school districts who must attend this training. That is their call.

Senator Flakoll states that the one person who testified, referenced the Denver School System and how they went to them to get some sample assistance. How do you respond to concerns by parents that they don't feel they are having what they need? You mentioned TBI is one of the categories that families don't feel that their child is being properly identified and properly managed. Which is a terrible word, I guess.

Gerry Teevens states she would encourage them to work with their school district, if they don't feel their child is receiving what they need or the teacher is not receiving training they need. Our rule is if we are contacted by the parents or district, we would do what we can do to help them get the resources they need. Again, if we don't hear about it, we typically don't know that there is a need that is not being met. I would hope, in most cases, the parents and school district would work together to get information they need. Our state is rural, so some of very small districts don't have opportunities to hiring an expert to come in. I believe there is getting to be more awareness out there because of the ND Brain Injury Association. We can provide information to the district so if they need an expert or need a way to contact, we can help them do that.

Senator Lee asks if DPI has staff in development and delivery of professional development for this? **Gerry Teevens** states that yes they do. She states that is one of their roles and we have staff at State Office of Special Education, who has professional and development, as a portfolio. Also in regular ed. dept., there is an individual that has that as a portfolio also. That is part of our responsibility, as state Special Education staff, is to provide technical assistance (training, understand of federal requirements etc.) so this responsibility falls under what our responsive general supervision and technical assistance is. One thing, in the FN, it was referenced, very bottom part C, that appropriations is included in DPI's biennial budget request in SB 2013, because this is one of our responsibilities, if we were to develop these materials, the salary for our staff is included in our general budget. It would not be an extra expense for us at the state agency to do this. It would be setting up task force, travel for individuals to get together to meet on development and materials, would be the cost.

Discussion on why DPI would need \$20,000? Or is that the school districts? So DPI is not saying that they need additional money to provide Section 1 of this bill? **Gerry Teevens** states, "That is correct".

Senator Flakoll refers to question earlier in the day about "interconnectivity" between Human Services and DPI. When I see two FN, that doesn't give me the impression that there is "connectivity", in terms of earlier on. Anything you can share, that would address my concerns, about two silos that would create a "tug and pull between resources" and activities and everything else?

Gerry Stevens states "yes" and I will be very honest. Part of that was that the request for the FN came over and I believe, prior to that, we felt that this was going to be a bill in the Human Services committee and then it ended up in Education. So when request for FN came to DPI, when in fact, it should not have. My experience, since this is my first time working with legislative council and our legislative team, we immediately went ahead to fill out FN and worked with staff at DPI and we proceeded with our part of the FN. So it was ignorance on DPI's part, that there should have been one joint FN and I apologize for that. Legislative Council caught it the following Monday and stated it should of started with Human Services and we should of worked together.

That is what happened.

The collaborative effort of our office and my work at the office, additionally, I am the secondary transition coordinator, and I have worked hard at collaborating with other

agencies in our state related to transition services for youth disabilities so I feel I have a good working relationship with all the agencies, especially Human Services and I mentioned in testimony this morning, being part of TBI advisory council and TBI systems meeting, I feel we have a good relationship. Susan Wagner, who is in the Division of Mental Health and Substance Abuse, is on my transition committee. I wanted to say that I feel we do have a collaborative working relationship and we seem to find each other at so many different meetings because we are working on so many common issues.

Senator Heckaman asks when I look at the FN, where the funding for section 4 would be because it is establishing a special fund in the State Treasury. When I go to the top of the second page, Section 4, will establish a special fund...I don't know where any funds are or how much is wanted because when I add up funds I come up with what FN is. Any information on that? I don't know that it is though the Special Ed. Dept. Possibly Mr. Ott can answer that?

Richard Ott states that the funding for the FN (FLEX FUND OR SUPPLEMENTAL SERVICES FUND) is \$92,900 that was calculated by DPI.

Senator Heckaman understood that went with the facilitators so I understood that was part of their budget. Sorry for the mistake.

Senator Flakoll asks about the section with the \$92, 900 are those unspent dollars carried over or any unspent dollars revert back to general fund?

Richard Ott states I think they would be carried over but I am not sure of that.

Senator Luick asks if TBI is not in schools, how are they affected? **Richard Ott** states it is for everyone, not just students. We serve everyone. Any adult, child or person that has TBI.

Chairman Freborg adjourns meeting on SB 2163.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Education Committee
Missouri River Room, State Capitol

Committee Work - SB 2163
January 19, 2011
13092

Conference Committee

Committee Clerk Signature

T. Jorgensen

Minutes:

See attached amendment

Chairman Senator Freborg called the meeting to order regarding SB 2163.

Senator Flakoll produced amendments (see 11.0335.01001 attached). Basically change the wording on page 1, line 8 to replace "pertaining to the education of" with "to teachers and counselors serving". Deleting all of Section 2 to create a TBI registry and clarify pages 1 & 2 that the department of "human services" be specified.

Motion by **Senator Flakoll** to accept the amendments as presented; second by **Senator Heckaman**.

Discussion:

Senator Gary Lee: Does removing Section 2 reduce the fiscal note by \$300,000 then?

Senator Flakoll: Believes that is correct.

Motion carried 7-0-0.

Senator Flakoll moved for a Do Pass as amended to SB 2163, Rerefer to Appropriations. Second by Senator Heckaman.

Discussion:

Senator Heckaman spoke to her daughter-in-law who is the administrator at the veterans' clinic in Dickinson. She said they welcome any kind of services to help the veterans, especially in the western part of the state. She said they don't have access to the medical expertise as does the eastern half of the state because the veterans' hospital is in Fargo. Did mention that they do screen TBI; opened in September and had one TBI diagnosis, with a second one in transition right now. What they do when any veteran comes in is a TBI screening to look for red flags.

Motion carried 7-0-0; Senator Gary Lee will carry the bill.

FISCAL NOTE

Requested by Legislative Council
01/21/2011

Amendment to: SB 2163

1A. State fiscal effect: *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues	\$0	\$0	\$0	\$0	\$0	\$0
Expenditures	\$0	\$0	\$442,774	\$0	\$434,043	\$0
Appropriations	\$0	\$0	\$427,774	\$0	\$434,043	\$0

1B. County, city, and school district fiscal effect: *Identify the fiscal effect on the appropriate political subdivision.*

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts
\$0	\$0	\$0	\$0	\$0	\$20,000	\$0	\$0	\$5,000

2A. Bill and fiscal impact summary: *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB 2163 as amended provides for the establishment of:

- 1) Professional development for teachers with students with traumatic brain injuries (TBI);
- 2) TBI Peer mentoring services; and
- 3) A special fund for TBI supplemental services.

B. Fiscal impact sections: *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Section 1 of the amended Bill provides that the Department of Public Instruction is to coordinate the development and delivery of professional development activities pertaining to the education of students with a TBI. DPI indicated this requirement would include: 1) Development of training materials (facilitated through a workgroup or task force); and 2) Delivery of professional development through contracts with experts in the area of TBI, conference training, and web modules.

DPI estimates the cost of this to be \$15,000 all of which would be from the general fund and is already included in DPI's appropriation Bill (SB 2013).

In addition, DPI estimates there would be a \$20,000 impact on school districts for the 2011-13 biennium and a \$5,000 impact on school districts for the 2013-15 biennium. The fiscal impact to school districts would relate to release time, compensation, and travel for teachers to receive the training. This is based on approximately 50 teachers at \$350 per day.

Section 2 of the amended Bill requires the Department of Human Services to contract with a public or private entity for the provision of resource facilitation services. The entity is to employ 3 resource facilitators 1 of which has a focus on providing services to veterans with a TBI.

Section 3 of the amended Bill establishes a special fund in the state treasury, to be known as the traumatic brain injury supplemental services program fund. The fund may be used for meeting unmet needs of individuals with a TBI.

3. State fiscal effect detail: *For information shown under state fiscal effect in 1A, please:*

A. Revenues: *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and*

fund affected and any amounts included in the executive budget.

B. Expenditures: *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

The fiscal impact for the Department of Human Services for the 2011-13 biennium is comprised of:
A contract with a private or public entity to provide resource facilitation, which would include a facilitator for the eastern part of the State, one for the western part of the State and one specifically for veterans - \$334,874
Supplemental services to meet the unmet needs of individuals with a TBI. The services may include specialized services, supplies, and equipment - \$92,900

The fiscal impact for the Department of Human Services for the 2013-15 biennium reflects the above items with a 3% per year inflation factor for a total need of \$434,043 for the 2013-2015 biennium.

The fiscal impact for the Department of Public Instruction is for salaries and administrative costs to develop the training materials and to provide and assist with training for school personnel.

C. Appropriations: *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

The funding needed to perform the requirements provided for in amended SB 2163 are not included in the Department of Human Services appropriation Bill (SB 2012) therefore DHS would need a general fund appropriation of \$427,774 for the 2011-13 biennium and \$434,043 for the 2013-15 biennium.

The funding needed by the Department of Public Instruction is already included in the DPI appropriation Bill (SB 2013).

Name:	Brenda M. Weisz	Agency:	DHS
Phone Number:	328-2397	Date Prepared:	01/21/2011

FISCAL NOTE

Requested by Legislative Council
01/12/2011

Bill/Resolution No.: SB 2163

1A. State fiscal effect: *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues	\$0	\$0	\$0	\$0	\$0	\$0
Expenditures	\$0	\$0	\$742,774	\$0	\$747,678	\$0
Appropriations	\$0	\$0	\$727,774	\$0	\$747,678	\$0

1B. County, city, and school district fiscal effect: *Identify the fiscal effect on the appropriate political subdivision.*

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts
\$0	\$0	\$0	\$0	\$0	\$20,000	\$0	\$0	\$5,000

2A. Bill and fiscal impact summary: *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB 2163 provides for the establishment of:

- 1) Professional development for teachers with students with traumatic brain injuries (TBI);
- 2) The creation of a TBI registry;
- 3) TBI Peer mentoring services; and
- 4) A special fund for TBI supplemental services.

B. Fiscal impact sections: *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Section 1 of the Bill provides that the Department of Public Instruction is to coordinate the development and delivery of professional development activities pertaining to the education of students with a TBI. DPI indicated this requirement would include: 1) Development of training materials (facilitated through a workgroup or task force); and 2) Delivery of professional development through contracts with experts in the area of TBI, conference training, and web modules.

DPI estimates the cost of this to be \$15,000 all of which would be from the general fund and is already included in DPI's appropriation Bill (SB 2013).

In addition, DPI estimates there would be a \$20,000 impact on school districts for the 2011-13 biennium and a \$5,000 impact on school districts for the 2013-15 biennium. The fiscal impact to school districts would relate to release time, compensation, and travel for teachers to receive the training. This is based on approximately 50 teachers at \$350 per day.

Section 2 of the Bill requires the Department of Human Services to establish and maintain a registry of individuals who sustain a TBI. The Department would anticipate contracting with a private or public entity to develop, implement, and maintain a TBI registry.

Section 3 of the Bill requires the Department of Human Services to contract with a public or private entity for the provision of resource facilitation services. The entity is to employ 3 resource facilitators 1 of which has a focus on providing services to veterans with a TBI.

Section 4 of the Bill establishes a special fund in the state treasury, to be known as the traumatic brain injury supplemental services program fund. The fund may be used for meeting unmet needs of individuals with a TBI.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

The fiscal impact for the Department of Human Services for the 2011-13 biennium is comprised of:

A contract with a private or public entity to develop, implement and maintain a traumatic brain injury registry - \$300,000

A contract with a private or public entity to provide resource facilitation, which would include a facilitator for the eastern part of the State, one for the western part of the State and one specifically for veterans - \$334,874

Supplemental services to meet the unmet needs of individuals with a TBI. The services may include specialized services, supplies, and equipment - \$92,900

The fiscal impact for the Department of Human Services for the 2013-15 biennium reflects the above items with a 3% per year inflation factor for a total need of \$747,678 for the 2013-2015 biennium.

The fiscal impact for the Department of Public Instruction is for salaries and administrative costs to develop the training materials and to provide and assist with training for school personnel.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

The funding needed to perform the requirements provided for in SB 2163 are not included in the Department of Human Services appropriation Bill (SB 2012) therefore DHS would need a general fund appropriation of \$727,774 for the 2011-13 biennium and \$747,678 for the 2013-15 biennium.

The funding needed by the Department of Public Instruction is already included in the DPI appropriation Bill (SB 2013).

Name:	Brenda M. Weisz	Agency:	DHS
Phone Number:	328-2397	Date Prepared:	01/14/2011

FISCAL NOTE

Requested by Legislative Council
01/12/2011

Bill/Resolution No.: SB 2163

1A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues	\$0	\$0	\$0	\$0	\$0	\$0
Expenditures	\$0	\$0	\$0	\$0	\$0	\$0
Appropriations	\$0	\$0	\$15,000	\$0	\$0	\$0

1B. **County, city, and school district fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts
\$0	\$0	\$0	\$0	\$0	\$20,000	\$0	\$0	\$5,000

2A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

- Development of training materials (facilitated through a workgroup or task force).
- Delivery of professional development through the following possible modes of delivery:
 - o Contract with professional expert in area of TBI
 - o Conference training
 - o Web modules

B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Fiscal impact on the School District would pertain to release time, compensation, and travel for teachers to receive the training. This is based on approximately 50 teachers at \$350.00 per day.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

Salaries and administrative costs to develop the training materials and to provide and assist with training for school personnel.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

Appropriation included in DPI's biennial budget request (SB 2013).

Name:	Gerry Teevens	Agency:	Public Instruction
Phone Number:	328-3731	Date Prepared:	01/12/2011

Prepared by the Legislative Council staff for
Senator Flakoll
January 19, 2011

PROPOSED AMENDMENTS TO SENATE BILL NO. 2163

Page 1, line 1, replace "three" with "two"

Page 1, line 8, replace "pertaining to the education of" with "to teachers and counselors serving"

Page 1, remove lines 12 through 18

Page 1, line 22, after "department" insert "of human services" and replace the second "with" with "having"

Page 2, line 4, after "department" insert "of human services"

Page 2, line 18, after "department" insert "of human services"

Renumber accordingly

Date: 7-19-11
Roll Call Vote # 1A

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2163

Senate Education Committee

Check here for Conference Committee

Legislative Council Amendment Number 11.0335.01001

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment
 Rerefer to Appropriations Reconsider

Motion Made By Sen. Flakoll Seconded By Sen. Heckaman

Senators	Yes	No	Senators	Yes	No
Chairman Layton Freborg	X		Senator Joan Heckaman	X	
Vice Chair Donald Schaible	X		Senator Richard Marcellais	X	
Senator Tim Flakoll	X				
Senator Gary A. Lee	X				
Senator Larry Luick	X				

Total (Yes) 7 No 0

Absent 0

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

11.0335.01001
Title.02000

Adopted by the Education Committee

January 19, 2011

PROPOSED AMENDMENTS TO SENATE BILL NO. 2163

Page 1, line 1, replace "three" with "two"

Page 1, line 8, replace "pertaining to the education of" with "to teachers and counselors
serving"

Page 1, remove lines 12 through 18

Page 1, line 22, replace the second "with" with "having"

Renumber accordingly

Date: 1-19-11
Roll Call Vote # 1B

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2163

Senate Education Committee

Check here for Conference Committee

Legislative Council Amendment Number 11-0335.01001

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment
 Rerefer to Appropriations Reconsider

Motion Made By Sen. Flakoll Seconded By Sen. Heckaman

Senators	Yes	No	Senators	Yes	No
Chairman Layton Freborg	X		Senator Joan Heckaman	X	
Vice Chair Donald Schaible	X		Senator Richard Marcellais	X	
Senator Tim Flakoll	X				
Senator Gary A. Lee	X				
Senator Larry Luick	X				

Total (Yes) 7 No 0

Absent 0

Floor Assignment Sen. Lee

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2163: Education Committee (Sen. Freborg, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO PASS and BE REREFERRED to the Appropriations Committee (7 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2163 was placed on the Sixth order on the calendar.

Page 1, line 1, replace "three" with "two"

Page 1, line 8, replace "pertaining to the education of" with "to teachers and counselors serving"

Page 1, remove lines 12 through 18

Page 1, line 22, replace the second "with" with "having"

Renumber accordingly

2011 SENATE APPROPRIATIONS

SB 2163

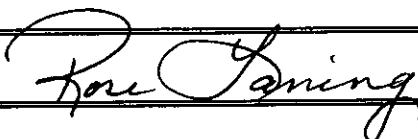
2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee
Harvest Room, State Capitol

SB 2163
January 31, 2011
13692

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A bill relating to traumatic brain injury services.

Minutes:

See attached testimony - #1 - 6

Chairman Holmberg called the committee hearing to order on SB 2163.

Becky J. Keller - Legislative Council; **Joe Morrissette** - OMB.

Richard Ott, Executive Director, Head Injury Association of North Dakota

Testified in favor of SB 2163.

Testimony attached - # 1. Reading from testimony -

Victims of traumatic brain injury (TBI) are not developmentally disabled nor are they mentally ill. Many have handicapping conditions, but persons with TBI do not fit into any of the existing categories.

They support facilitators and peer mentors and confirmed that none of the requested appropriation goes to his organization.

Senator Bowman asked of the chances that someone with TBI will be able to take care of themselves.

Richard Ott said there are varying degrees of recovery and not all are optimistic. For many with severe traumatic brain injury, there is never complete recovery.

Chairman Holmberg said the committee is actually dealing with two departments; the Department of Human Services and the Department of Public Instruction. There is no impact within the budgetary lines in DPI. The big question is whether or not the committee puts the money into the Department of Human Services to facilitate.

Senator Erbele: Have you worked with Protection and Advocacy within your organization because I noticed they have a line item in there for TBI? **Richard Ott** said they are one of the numerous agencies that we work with very closely and communicate weekly.

Rhonda Boehm, McClusky, mother of TBI victim.

Testified in favor of SB 2163. Written attached testimony # 2.

Reading from testimony –

Senator Kilzer – What is OCD? Rhonda Boehm replied that it is Obsessive Compulsive Disorder. It can be many things, but her son's OCD is a fear of germs. His doctor's showed them that when the brain heals, all of the connections and the part of the brain that controls these emotions didn't heal correctly. In high school, he was taking showers for 3 hours at a time and wash his hands until they were raw and chapped. Through his therapies and medications right now, he's down to about a 10 minute shower and washes his hands frequently but still has fear of germs.

Senator Kilzer: Does he have any type of seizures? None.

Senator Wanzek related a story about a friend who was married 33 years and became involved in a car accident. She sustained a TBI and her husband was told that your marriage situation might change. Their 30 year marriage ended in divorce. How might this help adults?

Rhonda Boehm said this will help adults as they go through life changes and how to deal with challenging times. The peer mentoring program is not limited to young adults, it's age baby to age 99.

Robin Wheeler, case manager, reading testimony from -
Rebecca Quinn, Program Director, UND Center for Rural Health
Testified in favor of SB 2163
Written attached testimony - # 3

Tracie Mallberg, Family Practice Physician, West Fargo, ND
Testified in favor of SB 2163.
Written attached testimony # 4

Senator Christmann asked if the improvements for many brain injured persons plateau? Or do they plateau generally at a certain age or after a certain time after the injury? Or will the improvements continue to be gradual his whole life?

Tracie Mallberg said it depends when the injury happened. Her son was injured at a point in his life where he had a foundation of learning, but he still had a lot of development to do. Most of the recovery happens in the first year – 60-70%. It's the small things, such as, the word finding, the maneuvering foreign places, dealing with sudden changes. Those are the things that come gradually over time. The older the person, the slower the recovery.

Senator Kilzer asked about the fiscal note -

Chairman Holmberg said it's \$435,000 and would have to be in DHS budget.

John L. Jacobsen, Chairman of Legislative Committee of ND Veterans Coordinating Council.

Testified in favor of SB 2163. Testimony attached - # 5.

Gerry Teevens, Assistant Director, Special Education, Department of Public Instruction

Testified in favor of SB 2163. Testimony attached - # 6

The Department is asking for an amendment in the wording of the bill. It is not actually the teacher or case manager that makes the medical diagnosis of a TBI, but would use the medical information when the team is determining what the primary disability is. She recommended that the wording in Section 1 of the bill be slightly modified.

Chairman Holmberg said the subcommittee should make note of her comments about Section 1 of the bill.

Tracie Mallberg asked to make one point about the veterans. There are not any VA programs for the treatment and rehab of traumatic brain injury so they have to tap civilian resources. As part of this, they would be servicing the rehab from the veteran's end of things.

Chairman Holmberg closed the hearing on SB 2163.

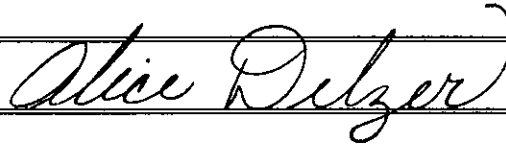
2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee
Harvest Room, State Capitol

SB 2163
02-17-2011
Job # 14672 (Meter 8.50)

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A SUBCOMMITTEE HEARING ON SB 2012 (SEVERAL BILLS WERE DISCUSSED AND ACTION WAS TAKEN BY SUBCOMMITTEE)

Minutes:

You may make reference to "attached testimony."

Senator Fischer opened the subcommittee hearing in reference to DHS. Senators Kilzer, Erbele, and Warner were present. Lori Laschkewitsch, OMB and Roxanne Woeste, Legislative Council were also present.

Senator Fischer states that SB 2163 is on traumatic brain injury services.

Senator Kilzer states that he would like to go through the nine "stand alone" bills.

The bills that this subcommittee is assigned to are: 2029, 2043, 2163, 2212, 2240, 2264, 2298, 2334, 2357.

Senator Kilzer states that traumatic brain injury is a very serious situation but it is a clinical situation. It is not very specific as to the breakdown of training and whether or not there is clinical application of the funds. For those reasons I would recommend a **DO NOT PASS**.

Senator Erbele seconds the motion on SB 2163.

Senator Fischer states he has a problem with it in DPI.

Roxanne Woeste states that in SB 2163, the only part of the bill that relates to the DPI is section 1 of the bill. Section 2 relates to a new section, Chapter 50, 06.4 and that is the Dept. of Human Services.

Senator Fischer states it is not very clear.

Roxanne Woeste states it is difficult being that the first section of the bill that relates to Century Code that relate to elementary and secondary education.

Roll call vote Yea: 4, Nay: 0. Motion carried. DO NOT PASS on SB 2163.

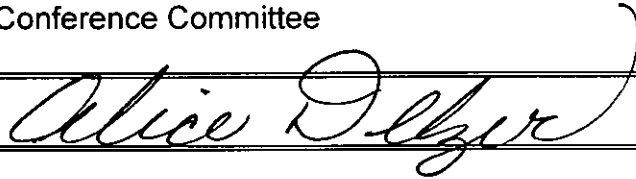
2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee
Harvest Room, State Capitol

SB 2163
02-17-2011
Job # 14716 (Meter 23.39)

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

Discussion on Traumatic Brain Injury

Minutes:

You may make reference to "attached testimony."

JOB # 14716 INCLUDES THE ROLL CALL VOTES ON THE FOLLOWING BILLS: SB 2345,2159,2029,2299,2298,2212,2334,2357.

There was discussion on SB 2163 at this time.

Senator Robinson: I know the Human Services subcommittee recommended a DO NOT PASS on SB 2163, the Traumatic Brain Injury Bill, Senator Lee's bill. I believe it was a \$400,000 fiscal note on it and I think that is the reason the bill received a do not pass. Since this morning I know we've had some discussions with Senator Lee and also with the traumatic brain injury folks. One of the key players in that organization is from my home district. We have a traumatic brain injury facility 1 ½ miles from where we live. In visiting with the folks since the decision the subcommittee made this morning, rather than get a do not pass on the full appropriation their question was would the committee consider an appropriation of \$110,000 for a case worker in the eastern part of the state where they have a significant case load of traumatic brain injury clients and that would basically pay their minimum salary and fringe they would have to find the rest of the money somehow some way. I am passing that on and I think I was accurate in my description of the situation.

Senator Kilzer: A very significant part of the recommendation for DO NOT PASS was the fact that this was a DPI type of situation and away from the clinical problems that we are more concerned with.

Senator Robinson : Would you explain DPI? I am confused on the DPI part of it.

Senator Warner: DPI is only mentioned in the first section of the bill. The rest of the bill refers to Health Department.

Senator Kilzer: I think we should possibly, at the subcommittee level, if we vote to reconsider it we might do these things but I am not going to make those recommendations myself.

Chairman Holmberg you are meeting at 8 in the morning, your subcommittee.

Senator Krebsbach I believe the testimony of Gerry Teevens (#6 testimony offered in hearing on 01-31-11) on page 3 clarifies that situation between the DPI and Department of Human Services. He asked for an amendment there.

Chairman Holmberg We will take that up on Friday.

There was discussion on other bills. (Meter 28.35)


2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee Harvest Room, State Capitol

SB 2163
February 18, 2011
Job # 14729

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

"Click here to type reason for introduction of bill/resolution"

Minutes:

You may make reference to "attached testimony."

Chairman Holmberg opened the hearing on SB 2163.

Senator Kilzer: Traumatic brain injury comes without subcommittee recommendation. This would set up a registry and the last fiscal note was for \$445,000.

Senator Robinson said this bill has a cost of \$445,000. We are circulating an amendment that would provide for a reduced cost on this bill, lowering the cost to \$110,000. What this amendment would do is to provide for some help in the eastern part of ND to deal with clients who are struggling with TBI. We have a person in Bismarck, but there is no one in Fargo or Grand Forks. The incidents of TBI in that part of the state are significant. Several are veterans coming home from Iraq and Afghanistan with TBI issues and often end up with addiction issues as well.

Senator Robinson moved Do Pass on amendment on 11.0335.02001.
Senator O'Connell seconded.

Senator Christmann asked for clarification. Is this instead of the \$440,000 because that's not what this amendment does. This adds another \$110,000.

Senator Robinson: We became aware late yesterday that there was no money in this bill and this amendment intends to add \$110,000 to the bill. That's the intent. There is no money in the bill and we wanted to put \$110,000 into the bill. The bill references a cost, but the money was not in the bill.

Senator Christmann If we require people to do something, we get a fiscal note and it says how much its going to cost – whether the money is in the bill or not, it's going to cost that much. This bill is going to cost \$440,000. If you want to replace that

with this, then this would have to be what is known as a hoghouse amendment. I'm still not sure what you want to do.

Roxanne Woeste, Legislative Council: The amendment does add a section to the bill to appropriate \$110,000 from the general fund for providing these services. The fiscal note does reference approx. \$400,000 that they would need. I believe what the Senator is trying to do is he's saying "Here's \$110,000 of it, maybe you can find the rest in your budget." Or perhaps \$110,000 will cover doing most of what the bill is tries to do. I believe that is the intent of the amendment.

Senator Warner said this is a mixed bill. The first section is DPI and the rest of the bill as it stands is Health, but the amendment is Human Services.

Chairman Holmberg suggested asking the department (Human Services) if they felt this bill gives them direction or does it create an issue or a problem.

Carol Olson, Executive Director of Human Services – We feel the Department of Human Services will have to find the rest of the monies that are in the fiscal note and we don't have it. We wouldn't have the monies to fill in the gap from the \$110,000 and the \$400,000.

Senator Robinson: If there is a way to correct this with an amendment because that was not the intent. I understand where you are coming from and the confusion. This is an eleventh hour attempt to save an important bill. We wanted these services to be provided in eastern ND.

Chairman Holmberg suggested they put everything on hold, Senator Robinson can withdraw his motion and it will be put on the agenda for Monday morning.

Senator Robinson withdrew his motion.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee
Harvest Room, State Capitol

SB 2163
February 21, 2011
Job # 14766

Conference Committee

Committee Clerk Signature

Rose Laning

Explanation or reason for introduction of bill/resolution:

A committee vote on SB 2163 relating to traumatic brain injury services.

Minutes:

You may make reference to "attached testimony."

Chairman Holmberg opened the hearing on SB 2163.

Senator Robinson handed out amendment 11.0335.02002 and said it had been agreed upon by the Department of Human Services and the folks from TBI. It appropriates \$110,000 to the Department of Human Services for the purpose of providing traumatic brain injury case management services in eastern ND. It hoghouses the former SB 2163 to this one section amendment.

Senator Robinson moved Do Pass on amendment 11.0335.02002
Senator O'Connell seconded.

A Roll Call vote was taken. Yea: 13 Nay: 0 Absent: 0

Senator Bowman questioned the wording of the amendment.

Chairman Holmberg said since this is a hoghouse amendment, Legislative Council took out the confusing language.

Senator Robinson moved Do Pass as Amended on SB 2163
Senator O'Connell seconded.

A Roll Call vote was taken. Yea: 13 Nay: 0 Absent: 0
Senator Robinson will carry the bill.

February 17, 2011

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2163

Page 1, line 2, after "services" insert "; and to provide an appropriation"

Page 2, after line 13, insert:

"SECTION 4. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$110,000, or so much of the sum as may be necessary, to the department of human services for the purpose of providing resource facilitation services, for the biennium beginning July 1, 2011, and ending June 30, 2013."

Renumber accordingly

Date: 2.18.11
Roll Call Vote # 1

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 21763

Senate Appropriations Committee

Check here for Conference Committee

Legislative Council Amendment Number 11.0335-02001

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment
 Rerefer to Appropriations Reconsider

Motion Made By Robinson Seconded By O'Connell
Withdrawn

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg			Senator Warner		
Senator Bowman			Senator O'Connell		
Senator Grindberg			Senator Robinson		
Senator Christmann					
Senator Wardner					
Senator Kilzer					
Senator Fischer					
Senator Krebsbach					
Senator Erbele					
Senator Wanzek					

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

February 18, 2011

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2163

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide an appropriation to the department of human services for traumatic brain injury services."

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$110,000, or so much of the sum as may be necessary, to the department of human services for the purpose of providing traumatic brain injury case management services in eastern North Dakota, for the biennium beginning July 1, 2011, and ending June 30, 2013."

Renumber accordingly

Date: 2-21-11
 Roll Call Vote # 2

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
 BILL/RESOLUTION NO. 2163

Senate Appropriations Committee

Check here for Conference Committee

Legislative Council Amendment Number HL 0335-02002

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment
 Rerefer to Appropriations Reconsider

Motion Made By Robinson Seconded By O'Connell

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg	✓		Senator Warner	✓	
Senator Bowman	✓		Senator O'Connell	✓	
Senator Grindberg	✓		Senator Robinson	✓	
Senator Christmann	✓				
Senator Wardner	✓				
Senator Kilzer	✓				
Senator Fischer	✓				
Senator Krebsbach	✓				
Senator Erbele	✓				
Senator Wanzek	✓				

Total (Yes) 13 No 0

Absent 0

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Date: 2-21-11
Roll Call Vote # 3

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2163

Senate Appropriations Committee

Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment

Rerefer to Appropriations Reconsider

Motion Made By Robinson Seconded By O'Connell

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg	✓		Senator Warner	✓	
Senator Bowman	✓		Senator O'Connell	✓	
Senator Grindberg	✓		Senator Robinson	✓	
Senator Christmann	✓				
Senator Wardner	✓				
Senator Kilzer	✓				
Senator Fischer	✓				
Senator Krebsbach	✓				
Senator Erbele	✓				
Senator Wanzek	✓				

Total (Yes) 13 No 0

Absent 0

Floor Assignment Robinson

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2163, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (13 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2163 was placed on the Sixth order on the calendar.

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide an appropriation to the department of human services for traumatic brain injury services.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$110,000, or so much of the sum as may be necessary, to the department of human services for the purpose of providing traumatic brain injury case management services in eastern North Dakota, for the biennium beginning July 1, 2011, and ending June 30, 2013."

Renumber accordingly

2011 HOUSE HUMAN SERVICES

SB 2163

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2163
March 14, 2011
Job # 15377

Conference Committee

Committee Clerk Signature

Vicky Crabtree

Explanation or reason for introduction of bill/resolution:

To provide an appropriation to the DHS for traumatic brain injury.

Minutes:

See attached Testimonies #1 - 7

Chairman Weisz: Opened the hearing on SB 2163.

Sen. Dick Dever: Sponsored and introduced the bill. I am really here to introduce Mr. Ott who I'm sure many of you know to discuss this bill. He has done a lot of work on it and got a lot of people with a lot of interest on it. The bill has gone through some evolution as you might be aware. It started in the Senate with a registry and several other things and ended up with an appropriation. Somehow in the Senate it went to one other committee and that is where it was dealt with in the House it was sent to Finance and Tax and then came to the right committee. Had it gone to the right committee in the Senate it might look different than it does now. I'll defer questions to those that follow me.

Chairman Weisz: As far as the amendment where it is strictly eastern ND is there a reason why that particular area?

Sen. Dever: I'll defer that.

Richard Ott: Executive Director for the Head Injury Association of ND. In answer to your question we have one part-time employee, me. I am located here in Bismarck. We are looking to get some help in the eastern part of the state where the bulk of our population is and need for our services. This bill is a shadow of its former self. We had asked originally for three persons to fill this function. One of them would be concentrating on veterans. A lot of people coming back from Afghanistan and Iraq are suffering from traumatic brain injuries. The question comes up, how come you don't see veterans your age, my age, with traumatic brain injury? The answer is very simple, they didn't come back when I was in that activity. Traumatic brain injury was a cause of death rather than a condition with which you came back home. We haven't until recently gotten to the point where we can save these people, survive and come back. The same thing in civilian life, they haven't heard that much about traumatic brain injury. We've gotten to the point now where we can save these folks whereas before we couldn't. Back to your question about why the eastern part of the state. Because we think we have some coverage in the western part, but we would like to

get someone in the part too. I feel very inadequate because there is so much I'd like to share with you folks. Awareness is such a big part of what we are trying to do and most people don't even understand what traumatic brain injury is. The first day of the session when I was up here I ran into two legislators I have known from times past. They asked me what I was doing now. I told them I was with the Head Injury Association. They are very sensitive people and decent folks, but their comment was, well they certainly picked the right person as their poster child. A little while later I ran into someone not a legislator, same question, same scenario, and when I told him what I was doing he kind of hung his head and said, you know ten years ago my oldest son was in an auto crash and we are still suffering the consequences and trying to work with it and when I left him, he said, "God speed to you". There is such a difference between these first two people who really didn't know or understand what it is I was working with and this third person has firsthand experience. What we really would like to do is somehow get ND from point A to point B without having them go through the horrible experience of living through a traumatic brain injury. That is one of our challenges. I feel inadequate because we really don't have time. With what we have done without much money, I'd like to spend some time on that too, but I don't have time. We just finished a week of our conference in Fargo with 180 people on traumatic brain injuries. One of the things I'm familiar with in legislative activity is when come before a committee like this if you can show them what you are going to do is going to save money in the long run you're your money (inaudible). One of the things we need in order to do that is a registry. We had a registry in the original bill and it has been taken out. We have trouble getting the scientific or hard or mathematical data that we need to make our case because we don't have this registry. Hopefully you take our word for it that this thing desperately needed. We could have filled the room. We have people who desperately want to come and testify in this area. And we say we only have 30 minutes and will have to hurry. I will introduce the bill a little bit and we have three folks who have personal experience with the TBI. (See Testimony #1)

Cheryl Hanson: Testified in support of the bill. (See Testimony #2.)

Lisa Anderson: From Leeds, ND testified in support of the bill. (See Testimony #3)

Ronda Boehm: From McClusky, ND testified in support of the bill. (See Testimony #4)

Rep. Paur: When was the Head Injury Association of ND formed?

Ronda: It started about 3-4 years ago and then it didn't have enough members to keep it active so it was silent for awhile and now in the last year and a half it has been a fast moving and fast paced association. We just had our conference last weekend and 188 people were there and a lot of them are brain injury individuals and their families looking for help and answers like what to do with their lives.

Elaine Grasl: I have two children with brain injury. (See Testimony #5)

Veronica Zietz: Executive Director of Arc. (See Testimony #6)

Rep. Porter: From your organization's standpoint do you do any current facilitating or any work with any traumatic brain injuries across the state.

Veronica: We do not provide specific resources for people with traumatic brain injuries. Some symptoms of traumatic brain injury can be cognitive delays and things like that. Something that would come into play would be more like information referral, that sort of thing. But, we would hope we could refer them to this case worker on the eastern side of the state because it sounds like there would be more specialist than we would be.

Rep. Porter: So if a family would call you today and explained the situation like what we have heard today so far. What would your referrals than be to that family?

Veronica: With each call you would probably give different information and we would line them up with the most appropriate services available. The problem with the head and brain injuries is there really are not appropriate services. Passing this bill could put some of those into place and we would hopefully refer them and they could get the support that they needed.

Craig Sinclair: Lawyer for the Protection and Advocacy Project testified in support of the bill. (See Testimony #7)

Rep. Holman: Since TBI is not often noticeable visually, what situations do you run into in this case? In other words to oppose to another type of disability which is probably noticeable right away. With TBI often times employers you're working with and other people say why is this a big deal? Can you address that?

Craig: It is of great significance as a legal rights protection agency we have worked with individuals who have had difficulties in obtaining and retaining employment. Memory is usually a major issue we run into. So one solution may be low tech or mid tech assisted technology devices to assist with memory. Many times clients that we are working with, have difficulty remembering sequencing events in the workplace even though they may have under taking the project many times. There can be many issues just getting to work on time. May be a need for further accommodations like maps and extended breaks. There may be needs for supported employment services on site. It might be available on some occasions through the human services center, but not always. There is definitely a need for assistive technology devices in many cases. A need for advocacy for employment. It is difficult. There is no one stop shopping to get answers and we have seen this problem for years and years and we think this is a step in the right direction. It is supported by previous studies as identified.

Rep. Holman: With TBI do you run into resistance from potential employers because in their mind it doesn't appear to be anything wrong?

Craig: Yes, it reminds me of some of the other disabilities. Obviously a broken bone; you take an x-ray. In some respects it reminds me of mental illness. It is difficult to discern (pauses) take a look at a person and say, oh, they have a mental illness. They have a Bipolar disorder it is another hidden disability. That is why the importance of accessing medical services where there are appropriate evaluations and assessments and recommendations and trying to incorporate these recommendations into the work environment is helpful. That is where the (inaudible) Disabilities Act comes into play as

well and is helpful in the process. Many times our clients are successful in the work environment, but with services.

NO OPPOSITION

Chairman Weisz: Closed the hearing on 2163.

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2163
March 14, 2011
Job 15413

Conference Committee

Committee Clerk Signature *Mark Kuehl*

Minutes:

No "attached testimony."

Chairman Weisz: In 2009 we passed a TBI bill and appropriated \$330,000 which basically set up the informal support that was for veterans, set up social recreational services, extended support for individuals that risk of moving their employment upon exhausting their vocational services, outreach activities with home and community based services. I think we definitely need the Department in here to answer some questions on what we are doing and how this bill would compliment or fits in. I have not had a chance to see Rep Pollert to see if there is current funding in the Human Service budget for these services.

Rep Holman: I was waiting to hear this morning about that UND program that we spend a lot of time on. It seems we heard a lot of testimony 2 years ago about things going on and we have not heard a thing if there is any connection or relation or coordination.

Chairman Weisz: I think we have to have those questions answered. Most likely tomorrow I will get the department down here to answer these questions. Is there any funding in the Governor's budget?
Is there anything from the committee that you want if you have any questions have them ready for tomorrow? I will talk to Rep Pollert.

Rep Conklin: I believe the bill we passed last session, most of the monies were taken out of it wasn't it? I was in that conference committee last year and most of the money was taken out.

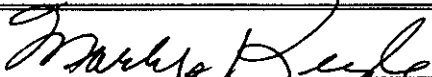
Chairman Weisz: That is what the question is, were they able to do anything with the 330,000? Did they make any progress? Is that money in the budget now, is it more or is it less? Did they take this money out?
We will be waiting till tomorrow and the Department can come down.

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2163
March 15, 2011
Job #15479

Conference Committee

Committee Clerk Signature 

Minutes:

No "attached testimony."

Chairman Weisz: Let's look at SB 2163. We have JoAnne Hoesel from the department to give us some information.

JoAnne Hoesel: We have a contract with HIT Inc. for the amount of around \$40,000 and they provide social and recreational activities for individuals that have traumatic brain injuries. We have contracted for up to 1400 hours and at this point they are working with 8 individuals. They have 3 referrals on hold. The bill had called for the possibilities of serving up to 9 individuals. Then we have 2 contracts with the Head Injury Association of North Dakota. The first one is for \$112,200 and that is for informal support, peer mentoring and education. The second contract is for \$5,460 for public awareness. We have a little over \$111,000 for contracts in community options. They are providing specialized prevocational support and consultation. They have worked with 12 individuals and are currently working with 8. That is to help individuals apply for jobs and to work through the vocational skills and preemptory work to get ready to take advantage of the vocational rehabilitation. We have \$57,000 for quality assurance and training. With these funds there has been training for home and community based case manager in the counties. It is when traumatic brain injury may qualify for personal care services. If they do we have made arrangements with the counties to track the numbers of individuals with traumatic brain injury. We are anticipating that in the next two years we'll have a better idea how many people we are looking at needing this type of services in the state. We have provided speakers for the Stanford conference which was recently held. We brought in a Physician that had expertise in TBI. We also had a speaker at the Mental Health Spring Conference and we will also be collaborating with Veterans Association with their training in April. That same funding level is currently included in SB 2012 which is the Dept of Human Service Appropriation bill.

Chairman Weisz: Same level.

JoAnne Hoesel: Yes

Chairman Weisz: I assume you are familiar with SB 2163.

JoAnne Hoesel: Yes I am.

Chairman Weisz: Based on what you are doing, if we pass out 2163 how do you see that integrating what we are doing here, will it be duplicating?

JoAnne Hoesel: My understanding is that its intention is to do exactly what our contract for \$112,200 is doing with the Head Injury Association except currently because of staffing only be able to do on the western side of the state. The additional funding would do the same thing but to the eastern part of state.

Chairman Weisz: When you guys looked at this from the budget perspective, why wasn't the additional funding in the Governors budget to do it statewide?

JoAnne Hoesel: We were asked to bring forth a whole different budget and I am sure you are aware of the General Fund increase in the budget because of the increase of the increase of the FMAP for the requirement of the states share. We certainly have to make choices in terms of what we are going to identify as needs. Since we were able to bring forward what was funded and we feel it is going very well, it would be up to the advocates to advocate with if you think more was needed.

Chairman Weisz: Are you finding feedback that is saying there is a greater demand to do more than what we are doing now?

JoAnne Hoesel: I believe this is a hidden disability. As of this month, along with the HCBS case managers out at the counties, the human service centers will also be screening all the individuals coming into their centers for services. Because sometimes people don't even know that they have a traumatic brain injury. It could be all ages and could have happened when they were a youngster and years latter all of sudden it is presenting itself. So we want to get a better feel of how many are out there. One of the problems we have in our state is we really don't have the extent of this problem. In the future we will have firmer numbers for you to make decisions with. It has been extremely helpful to have a place that they can call as the Head Injury Association. People are desperate out in the communities because they don't know what is wrong or know that something is wrong and we don't have a great deal of professionalism in the state that even knows what to do or how to treat someone with a head injury. This is a great a start but I wouldn't want to give you the impression that there isn't more need.

Rep. Porter: On SB 2198 two of the components on the home committee based services were things we heard from individuals yesterday that were old cases with their family members, where their concerns and reason for speaking in favor of the bill was the lack of the outreach, the public awareness, the availability of home and community based services for individuals with traumatic brain injury and the quality control activities and the training for case managers that would be dealing with them when they are still in the acute phase of the injury at the facility. I was wondering if they are still advocating for pieces we think in last session fixed. I read that verbatim out of the bill the two things we wanted to happen with the implementation of that bill last session. Are we getting the job done?

JoAnne Hoesel: I certainly believe the training piece is in place. We don't have individuals in our state, either in private or public sector, that exists to provides case management for individuals TBI. Unless they have a mental illness, substance abuse or developmentally

disabled they do not have anyone outside of what is in place with the Head Injury Association to help them maneuver as to where they should go, what they could access and if our existing case managers do not know how to recognize a traumatic brain injury when it presents itself, there will not be any benefit for the services that are even provided. In the last point that I made I believe we are making some head way because we now have training and have trained all the staff at the Human Service Centers how to do a TBI initial screen. We have done this training with the HCBS case managers in the counties. That front end recognition we are getting a handle on. After they are recognized that is the part that if you would have to identify a place that continues to have a need that would be it. Outside of this we don't have a TBI system and unsure if we would want to create a separate one but until people are better able to recognize it and for the individuals to benefit from the services you have to adjust those services for them as to how they learn and how they change over time.

Rep. Porter: The piece in the old bill 2198 also talked about; and other people providing services under this section. For example, say an isolated head injury in a motor vehicle crash, the acute case the person is in ICU, they pass the point of the acute case and are moved out of ICU and put on a neurological floor they start some rehab and the patient is not sick enough to be in the hospital any longer and is discharge to either the home or SCCI for the next level. At what point are those other persons providing service, that are specifically mentioned in 2198, brought into the educational loop of your training activities as part of your whole awareness of traumatic brain injury so that the families are talking to those case managers and social workers so that they are finding out the things that are provided by this grant?

JoAnne Hoesel: I think it is important to note that besides SB 2198 the Department did have a TBI grant that ends in March 31, 2011. I do believe we have done some of what you are talking about but I can't say that we have brought the medical field in a great deal. I think there is an assumption that they know this and this may be wrong. We really have concentrating on places where these individuals that are in places that aren't in the more traditional TBI medical environment such as County Social Services and Human Service Centers and the private substance abuse centers. Within that grant we have worked with UND School of Medicine. They were the lead on that grant and part of the intend was to do educational awareness. The Director of this initiative has provided many TBI 101 training throughout the state. We meet with the AG office, Department of Veterans Affairs, DPI and Dept. of Health to coordinate services and sure we aren't duplicating services which have been very helpful.

Rep. Porter: One of the areas of concern with the two individuals we heard from yesterday was their child was well enough to be non-hospitalized but sick enough or incapacitated enough from their injuries and they didn't know where to go next. It seems like that is at a key juncture in this care process where the patient is being discharged either from an acute care center, a rehab hospital or ICCI and are able to do the OT or PT as an outpatient and is ready to be taken home. That seemed to me as the void they were talking about. What other programs are there?

JoAnne Hoesel: We could build that into the next biennium. I do know that we have much work to do to assure that if someone sees the social worker in the hospital that they know

about this. I do know that they do not all know about this now. The next step is that we have to make sure that we educate these people also. I also did want the chairman to know that I did bring a summary of the SB 2043 fiscal note.

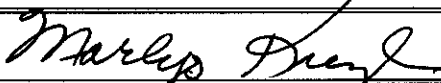
Chairman Weisz: Committee is there any more information that you think you will need on the TBI bill?

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2163
March 16, 2011
Job # 15500

Conference Committee

Committee Clerk Signature 

Minutes:

"Attached vote sheet."

Chairman Weisz: Committee we had JoAnne here to discuss what was given in 2009 and what they spend it on.

Rep Porter: The bill that we passed last session, SB 2198 which we got our arms around this whole traumatic brain injury situation, I think was a very important encompassing piece of legislation. I am not real comfortable moving SB 2163 any further than where we are at right now, given the fact that it is only 2 years old, that a lot of the outreach and the educational components that we are asking for haven't been completed yet. I think that there is still one more interim, yet to work on this program before we look at expanding it to the next level. I think it is a work in progress and I think the Department through their contracts with the various entities is doing what we have asked them to do all across the state and the information is getting out there where it needs to go. I am hesitant to even move the bill to appropriation with knowing the fact that the program is fully funded in the budget and going. I would move a do not pass on SB 2163

Rep Paur: Seconded the motion.

Rep Holman: I believe that the intent is to cover the east or the whole state. I did see this as adding this little bit extra to take care of a little more people, as it seems the program is working. That is probably why I won't support the motion.

Rep Damschen: I guess I won't support the motion either. I understand the view point but it probably will be an increased situation numbers to deal with. The one thing I didn't see and am not sure it should be a part of it, is the screening and not realizing it until much later. I understood this was a program for people who are having serious problems as a result of injuries.

Chairman Weisz: As far as the screening part, what they are trying to do is get the education out there, so the professionals look more for that. Often times it is not diagnosed initially and unfortunately it is diagnosed much later. So when they could have used the services and now much later they are struggling and now the services are finally pointed out. Some of this is definitely to do with our veterans coming home.

Rep Hofstad: One of the things I didn't get clear is the numbers. I do know that Ott was the guy, what is his case load? Is it possible to increase his case load?

Chairman Weisz: I am not sure what you mean by his case load because he is not a case manager?

Rep Hofstad: He is not a case manager but his responsibility is it not to coordinate services with those families that are experiencing TBI?

Chairman Weisz: That is correct.

Rep Hofstad: I was just wondering if there is any opportunity for him to expand his territory.

Rep Porter: I guess I would call his position more of an advocate than a case manager. I think the whole purpose of what we had done last session was to: number one is to link all the services that would help a family and individual who had suffered a traumatic brain injury into kind of a registry so that in the hospital or discharged from the rehabilitation facility or to the point where family is seeking help from a Human Service Center or a Counseling Center that they could be given all of the contacts and all of the services available for someone who is suffering from TBI. I personally think that the component that is missing the most is the one Ms Hoesel talked about which they haven't done yet and that is the point that the case managers, at the acute care centers at the rehab centers and the SCCI. So when it becomes time when the individual becomes discharged that the families have that packet of information as to who to call, where to call and where to go with their question. To me that seems to be the most important part of the component of all concept and it really kind of flows around educating the people. All this funding is really about coordination because this has nothing to do with services. All of the services are provided. This packet is to give the information as to what is going on with your family member and where you go to get further help. So the question is are we moving faster than what they are moving in the original coordination of the bill or do they need to be expanded before they complete the first components of what they have done? My thoughts are that it is not time to expand the program and that they need more time to complete all of the components asked of the in the 2009 session. We have gone leaps and bounds to go from nothing to where we are today. My question remains is it to early to expand and let them do the work we assigned them to do.

Rep Anderson: Do they have to make a personal visit with these people or do this on the phone?

Chairman Weisz: There is nothing that they have to do here. I don't look at this as expanding anything in the bill. I think what we are doing here is putting some coverage in the eastern part of the state that we are currently are doing in the western part of the state. The services won't change the intent the change is the whole state. Down the road I think we are going to have to take a look at where do we go next.

Rep Paur: If somebody with the DPI from Fargo calls Mr. Ott, he is going to refuse them because they are in the eastern part of the state?

Chairman Weisz: I am sure he will help anyone he can.

Rep Holman: My problem with not continuing this and delaying it for another 2 or 2 ½ years before it starts up again we may be putting the progress we have made on hold. Being it has been successful why not continue this program? We are talking about one more employee.

Do Not Pass 4 Yeas 8 Nays 1 absent Motion failed

Rep Devlin: Made a motion for Do Pass

Rep Hofstad: Seconded the motion.

Do Pass 8 Yeas 4 Nays 1 absent Carrier is Rep Hofstad

Date: 3-16-4
Roll Call Vote # 1

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2163

House HUMAN SERVICES Committee

Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment
 Rerefer to Appropriations Reconsider

Motion Made By Rep. PORTER Seconded By Rep. PAUR

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ		✓	REP. CONKLIN		✓
VICE-CHAIR PIETSCH		✓	REP. HOLMAN		✓
REP. ANDERSON		✓	REP. KILICHOWSKI	A	
REP. DAMSCHEN		✓			
REP. DEVLIN		✓			
REP. HOFSTAD		✓			
REP. LOUSER	✓				
REP. PAUR	✓				
REP. PORTER	✓				
REP. SCHMIDT	✓				

Total (Yes) 4 No 8

Absent 1

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Motion failed

Date: 3-16-11
 Roll Call Vote # 2

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
 BILL/RESOLUTION NO. 2163

House HUMAN SERVICES Committee

Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment
 Rerefer to Appropriations Reconsider

Motion Made By Rep. Devlin Seconded By Rep. HOFSTAD

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ	✓		REP. CONKLIN	✓	
VICE-CHAIR PIETSCH	✓		REP. HOLMAN	✓	
REP. ANDERSON	✓		REP. KILICHOWSKI	A	
REP. DAMSCHEN	✓				
REP. DEVLIN	✓				
REP. HOFSTAD	✓				
REP. LOUSER		✓			
REP. PAUR		✓			
REP. PORTER		✓			
REP. SCHMIDT		✓			

Total (Yes) 8 No 4

Absent 1

Floor Assignment Rep. Hofstad

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2163, as reengrossed: Human Services Committee (Rep. Weisz, Chairman) recommends DO PASS and BE REREFERRED to the Appropriations Committee (8 YEAS, 4 NAYS, 1 ABSENT AND NOT VOTING). Reengrossed SB 2163 was rereferred to the Appropriations Committee.

2011 HOUSE APPROPRIATIONS

SB 2163

2011 HOUSE STANDING COMMITTEE MINUTES

House Appropriations Committee
Roughrider Room, State Capitol

SB 2163
3/23/11
15866

Conference Committee

Committee Clerk Signature

Meredith Trubolt

Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide an appropriation to the department of human services for traumatic brain injury services.

Minutes:

You may make reference to "attached testimony."

Chairman Delzer: Opened discussion on SB 2163.

Representative Robin Weisz, District 14: The bill is very simple. It expands TBI (traumatic brain injury) services beyond strictly medical into social, helping them function in society once their major medical issues are taken care of. We received a lot testimony that they struggled after they were out, due to the effects of TBI. We spent \$330,000 to start, and this bill adds to that. It adds a person in the eastern part of the state; currently there is one person helping coordinate services, based out of Bismarck. There is an increasing amount of injuries, due to overseas conflicts and medical advances that allow us to save lives that in the past would have been lost due to accidents and such. We look at this as a way to save costs down the road, because if we can get these people back socially, they become much more productive members of society so we don't end up paying for them on the other end. Human Services asks you to approve the \$110,000 to continue the good work started last session.

Chairman Delzer: Did you amend the bill at all?

Representative Weisz: We did not amend the bill, this is as it came from the Senate.

Chairman Delzer: And that's strictly the appropriation?

Representative Weisz: The system is in place, so there is no need to look at program changes. We started that last session. This just adds that person in the east where there is a lot of demand for these services.

Chairman Delzer: This is supposedly to add an FTE. Is this a contract FTE?

Representative Weisz: This is not an FTE for the department of human services, it's through the Head Injury Association (HIA), just like the position in Bismarck.

Chairman Delzer: And their current level of funding, without this bill?

Representative Weisz: The HIA themselves currently gets \$112,000 out of that \$330,000, going directly to them. They also help with some of the other issues. There's \$40,000 for social, \$54,000 for public awareness, \$111,000 on job preparation, etc. They use \$112,000 for the west, and this would add \$110,000 for the east.

Chairman Delzer: The bill doesn't mention any organization, but you say that's the only one that would be available to do the work?

Representative Weisz: The bill doesn't mention anyone, that's the agreement the department has had with the HIA. There really isn't anyone else out there that would do that. There wasn't any discussion that anything needed to be specific in language.

Representative Skarphol: What's the total budget?

Representative Weisz: The budget that's in DHS for this upcoming biennium is \$343,200 currently. That will provide the same level of services that we did this last biennium for \$330,000. Of that, \$112,000 went directly to HIA to help coordinate this and provide the services. They've been trying to cover the whole state, but they've been directed to the west. This would provide a person in Fargo, to offer better coverage for the state.

Chairman Delzer: This is over and above the care for those that are in facilities, and over and above any VR money?

Representative Weisz: Correct. These funds that we allocated go to help them after the medical care, after they're done with VR. Now they struggle for a job because sometimes their brain injuries can cause different effects, and this helps them get through that. Some have real troubles with social situations after the injury.

Chairman Delzer: Wouldn't the VR go a lot further than that?

Representative Weisz: VR in some ways can be quite limited to what they do. Once they've reached the point where they can function at the job, it doesn't necessarily help them with the other social issues and other issues and challenges they face. It can be a real struggle, while they appear to be normal. Their brains react differently to different stimuli, and they have ongoing struggles after training and rehabilitation.

Representative Klein: I see the registry was dropped. Why was that?

Representative Weisz: Dollars. We were trying to keep the dollars down to an acceptable level. The feeling was, this was the most important issue today, though a registry should be looked at.

Chairman Delzer: Further questions? I think we'll set this aside in case anybody wants to check anything with the department. We'll move on to the next bill.

2011 HOUSE STANDING COMMITTEE MINUTES

House Appropriations Committee Roughrider Room, State Capitol

SB 2163
4/4/11
16298

Conference Committee

Committee Clerk Signature

Meredith Trachsel

Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide an appropriation to the department of human services for traumatic brain injury services.

Minutes:

You may make reference to "attached testimony."

Chairman Delzer: SB 2163 is next, about traumatic brain injury (TBI). It came from human services committee. The bill appropriates \$110,000 for TBI case management services in eastern ND. Are there any amendments?

Representative Nelson: I move Do Pass.

Representative Kaldor: Second.

Chairman Delzer: Can you refresh our memories on what is going on with this bill? How much do we spend on TBI? Do we do case management everywhere else in the state but the east?

Representative Nelson: I don't have any specific details. I know with the rise in the incidence and understanding of TBI, and its relationship to the armed services and the number of people coming back from conflict that Fargo is a natural place with the veterans' services there. That was why there was an intention for that part of the state have a regional center, that's my understanding of it.

Representative Metcalf: Also, the TBI cases are being experienced by younger people more and more all the time. Currently, they have one individual that travels the state in this particular area, and with the additional cases that have been added on, it's unsupportable for just one individual. That's the reason for the request.

Chairman Delzer: Further discussion? If not, we'll call the roll for a Do Pass on SB 2163. Motion carries 18-3-0. Representative Nelson will be the carrier.

Date: 4/4
 Roll Call Vote #: 1

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
 BILL/RESOLUTION NO. 2163

House Appropriations Committee

Legislative Council Amendment Number _____

Action Taken: Do Pass Do Not Pass Amended Adopt Amendment
 Rerefer to Appropriations Reconsider

Motion Made By Rep. Nelson Seconded By Rep. Kaldor

Representatives	Yes	No	Representatives	Yes	No
Chairman Delzer		X	Representative Nelson	X	
Vice Chairman Kempenich	X		Representative Wieland	X	
Representative Pollert	X				
Representative Skarphol	X				
Representative Thoreson	X		Representative Glassheim	X	
Representative Bellew		X	Representative Kaldor	X	
Representative Brandenburg	X		Representative Kroeber	X	
Representative Dahl	X		Representative Metcalf	X	
Representative Dosch		X	Representative Williams	X	
Representative Hawken	X				
Representative Klein	X				
Representative Kreidt	X				
Representative Martinson	X				
Representative Monson	X				

Total (Yes) 18 No 3

Absent 0

Floor Assignment Rep. Nelson

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2163, as reengrossed: Appropriations Committee (Rep. Delzer, Chairman)
recommends **DO PASS** (18 YEAS, 3 NAYS, 0 ABSENT AND NOT VOTING).
Reengrossed SB 2163 was placed on the Fourteenth order on the calendar.

2011 TESTIMONY

SB 2163

January 18, 2011

Testimony presented to Senate Education Committee in favor of **SB 2163**

Mr. Chairman and members of the Senate Education Committee, my name is Richard Ott and I am the executive director of the Head Injury Association of North Dakota. I am here today to speak in support of SB 2163.

Traumatic Brain Injury (TBI) is called the "Silent Epidemic" for several reasons. Often, the resulting problems are not always visible and another reason is that most people have only a little or perhaps incorrect information about TBI and it has a way of sneaking into lives with no prior warning whatsoever. One of our major challenges is to help bring awareness of this situation to the general public without them having first-hand experiences with TBI.

To illustrate this gap in awareness, may I share a true story. On the first day of the current legislative session, I was strolling the halls and ran into two legislators whom I hadn't seen for several years. We exchanged pleasantries and they asked what I was doing. I told them I was with the Head Injury Association of North Dakota and their response was, "Well, they certainly chose an appropriate poster child".

Later that same day, I encountered another old acquaintance. Same scenario, except this time, the person hung his head and a cloud descended over him. "Ten years ago, my oldest son was in an auto crash and we are still struggling with the problems today. God's speed in your work" was his reply.

What a difference it makes when you deal with a person who has actually goes through this tragedy.

My assignment this morning is to briefly summarize the four sections (five major provisions) of this bill. Other people have come long distances to testify here and I don't want to take time away from what they have to share with you.

Section 1 of SB 2163 is a provision that would enable DPI to coordinate the creation and delivery of professional development training for teachers who will be working with students, returning to classes following a brain injury. The education community has been eager and willing to participate in the recovery process, but too often, they just plain don't know what to do. They have done some remarkable things and deserve the tools they need to serve this element of the student population even better.

NOTE: The term Department as used above in the bill refers to the Department of Public Instruction. Hereinafter, that term refers to the Department of Human Services.

Section 2 enables the creation of a registry of individuals who have sustained TBI. Currently, there is no accurate way to know how many people are suffering this kind of injury, the extent of injuries, the location, or anything else about them. Legislative committees have asked about such census data but we are unable to provide it because there is no system in place to record the information. The individuals' privacy will be protected. A registry will help call attention to the problem, help get the appropriate services to those who need them, and will attract the attention necessary to secure adequate funding.

#1 Richard Ott

Section 3 (1) provides for a cadre of resource facilitators (three in number) who will work directly with TBI victims across the state. One of the facilitators will specialize in veteran's problems and will work with the large number of military personnel who return from war zones with TBI. The management of every-day activities becomes difficult for TBI victims and this program would assist them in accomplishing routine things such as financial activity, keeping appointments, etc.

Section 3(2) deals with a peer mentoring program already started by HIA/ND. Ten volunteer mentors have been trained and are primed to start working with those who can use this service. As soon as possible after a person is injured, a mentor will be available to advise and support the victim **AND THE FAMILY**. A single coordinator/supervisor will be provided for the peer mentoring program and for the resource facilitator program.

Section 4 calls for a flex fund that can be used for such services as substance abuse and addiction treatment for TBI victims. These people require a treatment program that is significantly different from those available nearby. A victim could be sent to a place like Vineland near Minneapolis.

In this bill, none of the money would come directly to HIA/ND. Our Association would, hopefully, be contracted for some, but not all, of the services described above.

I would be pleased to answer any questions you might have.

Respectfully submitted,

Richard D. Ott
Executive Director HIA/ND

#1 SB2163

Testimony to the Senate Education Committee
January 18, 2011
Submitted by Rebecca Quinn, Traumatic Brain Injury Program Director
Center for Rural Health, UND School of Medicine and Health Sciences

Good morning Chairman Freborg and other members of the Committee. My name is Rebecca Quinn and I am the TBI Program Director at the Center for Rural Health, UND School of Medicine and Health Sciences.

“Traumatic brain injury is the most misunderstood, misdiagnosed, underfunded public health problem our nation faces,” Susan Connors, president of the Brain Injury Association of America

Thirty years ago, less than half of all people with brain injury survived; now over 80% survive. **This means that many individuals now live with significant disability requiring a full range of services.**

I currently manage a Federal grant provided to states for the purpose of developing brain injury infrastructure. The ND Department of Human Services was awarded this three year grant in 2007; this was contracted to the Center for Rural Health to implementation. Due to great ND fiscal savings we have been able to make this money stretch into a fourth year, but unfortunately this March the Federal funds will be completed. At this time there are not more funds available in the federal program. During the four years the grant has been able to:

- Formed a TBI advisory committee
- Performed over 200 presentations and outreach events, including on four Tribal Reservations
- Made connections with Veteran groups and conducted trainings at Veteran events
- Assisted with the development of the Head Injury Association.
- Worked with DHS on implementing a TBI screening that will begin this spring

With the upcoming end to the federal program it is important to at this time develop a coordinated State supported system for the individuals and families impacted by brain injury.

According to the Centers for Disease Control and Prevention (CDC), each year, at least 1.7 million Americans sustain a traumatic brain injury (TBI). A TBI can happen to people of every age, race, gender, and socioeconomic status at any time. Brain injuries are caused by falls, motor vehicle crashes, assaults, sports/recreation accidents, and most recently, blasts from improvised explosive devices. The CDC numbers underestimate the true prevalence of TBI, since only individuals treated in hospitals, those seen in ERs and those who die are counted. Not included are those who receive care outside of hospitals (e.g., in medical offices) or who do not receive medical attention at all (e.g., people injured in assaults, domestic violence, falls and the like). Research suggests that for every person hospitalized with a brain injury, three to five others are injured but do not receive any care.^{1 2}

#2 SB 2163

Of significant concern is the impact of TBI on children. The highest prevalence of brain injuries occur during the ages of 0 to 4 and 15 to 19 and nationally TBI is the leading cause of death and disability in children and young adults. For many years it has been believed that children are more resilient and bounce back from brain injury quickly. In fact, often children who sustain a brain injury early in life may look "well" at that moment in time, but as the child gets older more serious cognitive and behavioral problems emerge. For example, frontal lobe functions develop relatively late in a child's growth, so an injury to the frontal lobes may not become apparent until the child reaches adolescence. Since the frontal lobes control social interactions and interpersonal skills, damage from the brain injury may not manifest until such frontal lobe related skills are called into play later in development.

Brain injuries are often misunderstood by society and do not fit well into any one particular system. Care and treatment often involves the need to access multiple public and private systems, as well as overlapping use of both the medical community and the human services field. Individuals are unprepared for how best to coordinate services and often do not know what services are available in their area.

Across the lifespan, TBI can lead to a wide range of functional changes affecting thinking, language, learning, emotions, behavior, and sensation. TBI can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.^{3 4} Even so called "mild" injuries can have devastating consequences that require intensive treatment and long-term care. It is estimated that at least 3.17 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI.⁵ Perhaps the biggest challenge when it comes to addressing brain injury is the fact that the brain is infinitely more complex than any other organ or organ system in the human body. Add to that the fact that every brain and every brain injury are unique, and it is easy to understand why it is often said that "there is much more that is unknown about the brain (and, accordingly, brain injury) than is known."

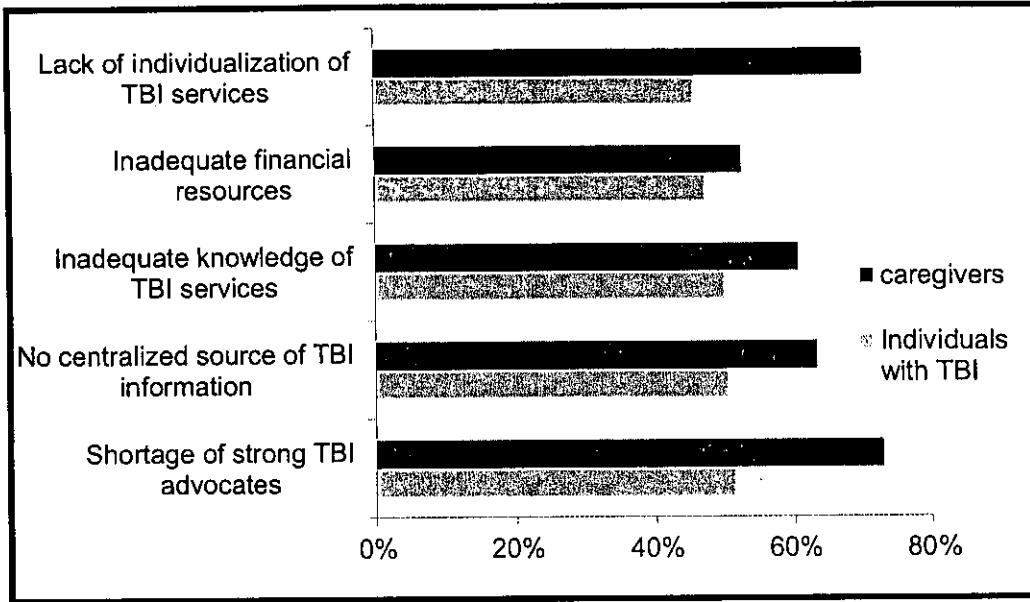
Many studies have looked at the connection between early brain injury and social problems. It is estimated that the prevalence of TBI within the prison population ranges from 42 percent to 87 percent;^{6 7 8} for most, the brain injury preceded the start of criminal activity. TBI is also common in inpatient psychiatric and substance abuse populations, and, similarly, the injury often precedes onset of psychiatric symptoms^{9 10} or substance abuse. Most of these brain injuries had gone unidentified prior to the respective studies. TBI is associated with high levels of co-occurring depression and anxiety.^{11 12}

In 2005 a previous Federal Grant provided funds for the completion of a needs assessment. This assessment included individuals with TBI, caregivers, agencies, and providers. Four prominent needs were identified as areas needed to be expanded. These included:

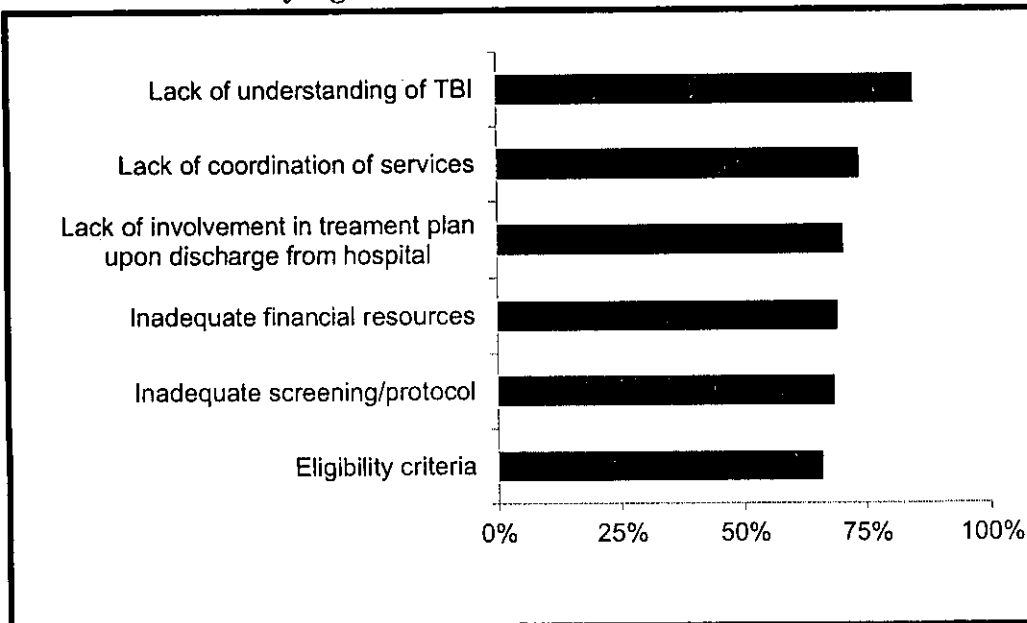
#2 SB 2163

- The need for increased access to TBI information and resources
- The need for increased TBI education, training, and awareness
- The need for enhanced and expanded TBI services
- Needed support services for persons with TBI and their families and caregivers

Barriers as Identified by Persons with TBI and their Caregivers

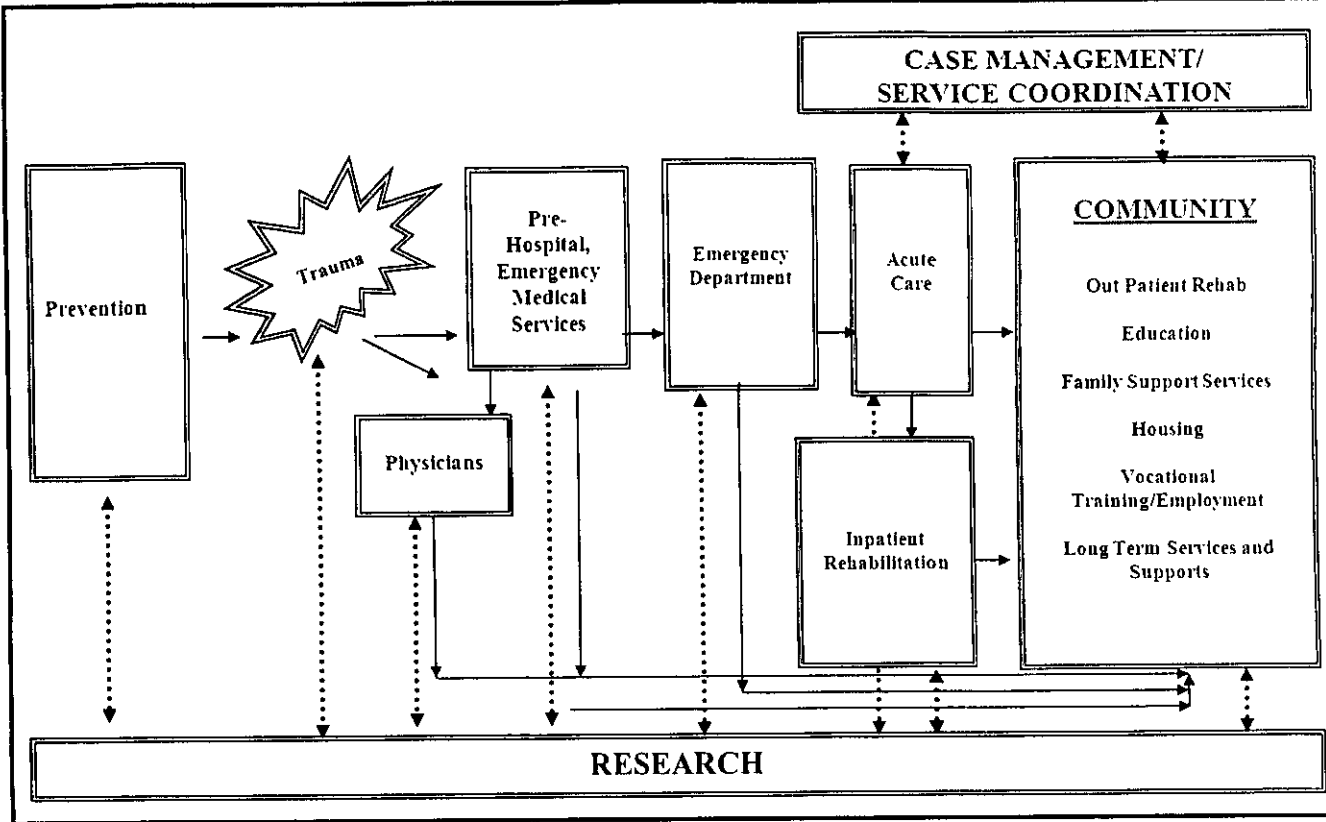


Barriers Identified by Agencies and Providers



#2 SB 2163

Complexity of the Possible System of TBI Care:



¹ J. F. Kraus and D. L. McArthur, "Epidemiologic Aspects of Brain Injury," *Neurologic Clinics* 14 (1996): 435-450.

² D. M. Bernstein, "Recovery from Mild Head Injury," *Brain Injury* 13 (1999): 151-172.

³ National Institute of Neurological Disorders and Stroke. Traumatic brain injury: hope through research. Bethesda (MD): National Institutes of Health; 2002 Feb. NIH Publication No. 02-158. Available from: www.ninds.nih.gov/disorders/tbi/detail_tbi.htm.

⁴ Ylvisaker M, Todis B, Glang A, et al. Educating students with TBI: themes and recommendations. *Journal of Head Trauma Rehabilitation* 2001; 16:76-93.

⁵ Thurman D, Alverson C, Dunn K, Guerrero J, Sniezek J. Traumatic brain injury in the United States: a public health perspective. *Journal of Head Trauma Rehabilitation* 1999;14(6):602-15.

⁶ K. Brewer-Smyth, A. W. Burgess and J. Shults, "Physical and Sexual Abuse, Salivary Cortisol and Neurologic Correlates of Violent Criminal Behavior in Female Prison Inmates," *Biological Psychiatry* 55 (2004): 21-31.

⁷ M. Sarapata, D. Herrmann, T. Johnson and R. Aycock, "The Role of Head Injury in Cognitive Functioning, Emotional Adjustment and Criminal Behaviour," *Brain Injury* 12 (1998): 821-842.

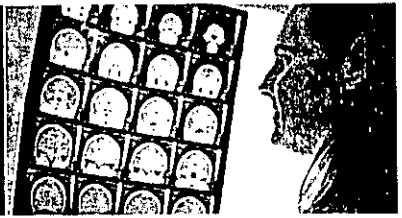
⁸ B. Slaughter, J. R. Fann and D. Ehde, "Traumatic Brain Injury in a County Jail Population: Prevalence, Neuropsychological Functioning and Psychiatric Disorders," *Brain Injury* 17 (2003): 731-741.

⁹ J. S. Burg, L. M. McGuire, R. G. Burreight and P. J. Donovick, "Prevalence of a Head Injury in an Outpatient Psychiatric Population," *Journal of Clinical Psychology in Medical Settings* 3 (1996): 243-251.

¹⁰ L. M. McGuire, R. G. Burreight and R. Williams, "Prevalence of Traumatic Brain Injury in Psychiatric and Non-Psychiatric Patients," *Brain Injury* 12 (1998): 207-214.

¹¹ M. Hibbard, S. Uysal, K. Kepler, J. Bogdany and J. M. Silver, "Axis I Psychopathology in Individuals with TBI," *Journal of Head Trauma Rehabilitation* 13, no. 4 (1998): 24-39.

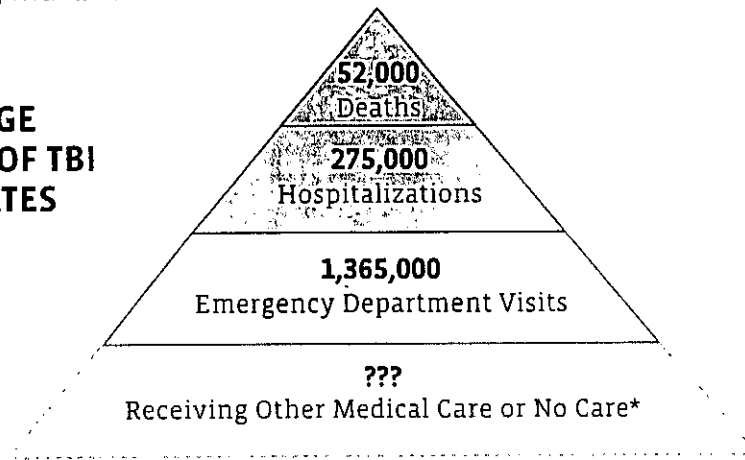
Get the Stats on Traumatic Brain Injury in the United States



Each year, traumatic brain injuries (TBI) contribute to a substantial number of deaths and cases of permanent disability. A TBI is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. The severity of a TBI may range from "mild" to "severe".

Data are critical to understanding the impact of this important public health problem. This information can help inform TBI prevention strategies, identify research and education priorities, and support the need for services among those living with a TBI.

ESTIMATED AVERAGE ANNUAL NUMBER OF TBI IN THE UNITED STATES 2002-2006¹



There is no estimate for the number of people with non-fatal TBI seen outside of an emergency department or hospital or who receive no care at all.

TBI in the United States

- An estimated 1.7 million people sustain a TBI annually.¹ Of them:
 - 52,000 die,
 - 275,000 are hospitalized, and
 - 1.365 million, nearly 80%, are treated and released from an emergency department.
- TBI is a contributing factor to a third (30.5%) of all injury-related deaths in the United States.²
- About 75% of TBIs that occur each year are concussions or other forms of mild traumatic brain injury (MTBI).²
- Direct medical costs and indirect costs of TBI, such as lost productivity, totaled an estimated \$60 billion in the United States in 2000.³

TBI by Age¹

- Children aged 0 to 4 years, older adolescents aged 15 to 19 years, and adults aged 65 years and older are most likely to sustain a TBI.
- Almost half a million (473,947) emergency department visits for TBI are made annually by children aged 0 to 14 years.

Adults aged 75 years and older have the highest rates of TBI-related hospitalization and death.

#3 SB2163 Rebecca Quinn



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention



TBI by Sex¹

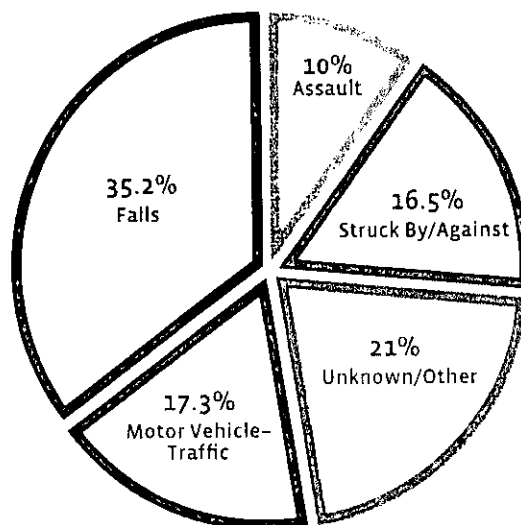
In every age group, TBI rates are higher for males than for females.

Males aged 0 to 4 years have the highest rates of TBI-related emergency department visits, hospitalizations, and deaths combined.

TBI by External Cause¹

- Falls are the leading cause of TBI. Rates are highest for children aged 0 to 4 years and for adults aged 75 years and older.
- Falls result in the greatest number of TBI-related emergency department visits (523,043) and hospitalizations (62,334).
- Motor vehicle-traffic injury is the leading cause of TBI-related death. Rates are highest for adults aged 20 to 24 years.

ESTIMATED AVERAGE PERCENTAGE OF ANNUAL TBI BY EXTERNAL CAUSE IN THE UNITED STATES 2002-2006¹



Additional TBI Findings^{1,*}

- There was an increase in TBI-related emergency department visits (14.4%) and hospitalizations (19.5%) from 2002 to 2006.
- There was a 62% increase in fall-related TBI seen in emergency departments among children aged 14 years and younger from 2002 to 2006.
- There was an increase in fall-related TBI among adults aged 65 and older; 46% increase in emergency department visits, 34% increase in hospitalizations, and 27% increase in TBI-related deaths from 2002 to 2006.

* Estimates based on one year of data can produce varied results.

CDC analyzed existing national data sets for its report, *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002-2006*. CDC's National Center for Injury Prevention and Control funds 30 states to conduct TBI surveillance through the CORE State Injury Program. TBI-related death and hospitalization data submitted by participating CORE states are published in CDC's *State Injury Indicators Report*.

References

- ¹ Faul M, Xu L, Wald MM, Coronado VG. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002-2006*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.
 - ² *Report to Congress on Mild Traumatic Brain Injury in the United States: Steps to Prevent a Serious Public Health Problem*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2003.
- Finkelstein E, Corso P, Miller T and Associates. *The Incidence and Economic Burden of Injuries in the United States*. New York (NY): Oxford University Press; 2006.

#3 5B2163

Get More Information on TBI in the United States

For more on TBI research, programs, and educational initiatives please visit: www.cdc.gov/TraumaticBrainInjury

January 18, 2011

Testimony presented to Senate Education Committee in favor of Senate Bill # 2163

Good Morning Mr. Chairman and members of the Senate Education Committee. My name is Rhonda Boehm and I am from McClusky, North Dakota. I am honored to have this opportunity to testify in favor of Senate Bill # 2163. I would have never imagined I would be here today talking to you about Traumatic Brain Injury; having endured every parent's most heartbreaking, un-imaginable, and helpless feeling. This has been the utmost challenging time for us since our son Eric has suffered a Traumatic Brain Injury.

The evening of May 17, 2002, my family was leading a routine, busy, fulfilled life, when our world was turned completely upside down, and our lives would never return to the way of life we were so accustomed to. At 8:00 pm I received a phone call that my son Eric was in a motor vehicle accident and I needed to get there immediately. I arrived there before the ambulance, which is a sight I will forever remember – very clear and yet a blur. Eric was laying facedown in the ditch about 100 yards away from the vehicle which he was driving to our family farm. His vehicle was on its side after many times of rolling on the embankment and ditch; which had scattered all of Eric's and his brother Levi's belongings everywhere. The Rodeo was smashed and every piece of glass was shattered. I ran to Eric, in tears, my heart pounding, and fearing the worst. He didn't seem to be breathing; and as I layed beside him and held his hand, I heard a very shallow breathing.he was alive. A family member got some blankets to keep Eric warm and I held his hand and told him mom was with him and so was God; and he had to be strong and he was going to be okay. When the ambulance arrived they took over and immediately called the Metro Ambulance from Bismarck because of the severity of Eric's condition. Our ambulance was intercepted with Metro and the EMTs came onboard because time was crucial and they didn't want to move Eric, as he had stopped breathing several times between McClusky and Wilton. I was allowed to ride in the ambulance to continue to talk to Eric as he was very unresponsive and was clinging to his life. To this day, my heart skips a beat every time a see an ambulance or an accident and I hope and pray.

Several hours later in the ER family room, when meeting with the Trauma Medical Team, they told us Eric's condition was very serious. He was in critical condition with a Brain Stem Injury, Contusions on both the right and left hemisphere of his brain, and both of his clavicles were broken. He had road rash all over his body with the exception of his face. Having no previous exposure or knowledge of Traumatic Brain Injury, we were about to embark on a very, very long and unknown journey.

Eric was always very athletic and on top of every sport possible in school, he carried a 4.0 GPA, was a leader in all aspects, was active in every school organization, was very well liked and a child with a great attitude. That night he was laying in a coma in the Bismarck Hospital in Intensive Care with tubes everywhere, monitoring machines of every kind imaginable connected to him. When I looked at his face he seemed almost like he was asleep for the night.....but he didn't wake up the next morning.

Eric remained in a coma and was unresponsive for nearly 2 months; with only very small signs of improvement. On day 7 he opened his eyes and blinked, stared at me and then closed them again. It was at that moment that I felt deep down in my heart, that my son would have his life back, and the long road of recovery was ahead of us. Eric's progress of improvement was very slow and we were given very little hope. He had a feeding tube,

#4 SB 2163

serial casting on his right leg and arm, botox injections, every kind of therapy, surgery on his right leg to extend his heel chord muscle, orthotics on his right leg and weights for his right hand to mention only a very minimum of everything he would experience in the next 4 months and years to follow.

I refused to believe that Eric would never awake again or that he would not regain his youthful enthusiastic way of life. I believed he survived this tragic accident for a reason, and we would some day know what that reason was. My family is very close and we remained with Eric, with a constant 24 hour vigil; playing his favorite music in his room, talking and reading to him, holding his hand, showing him pictures and surrounding him with as many familiar things from family and home as possible.

My parents were my godsend; as they stayed with us from the very first night and they brought their camper to the hospital parking lot for family members. My husband and I stayed in the family room in the hospital so we were close and with Eric. There was so much information to absorb, to try to understand, and so many questions that went unanswered which created a very lonely and fearful heart for me. I felt alone and that no one totally understood or knew what we were going through as we spent day after day, night after night by Eric's side for the next 4 months, in 3 progressive hospitals. I felt like I was the only mother on the face of the earth that was experiencing this.

It was very difficult to connect with someone and receive the information we so desperately were seeking. Where is the best place for our son? What more can we do for him? Many nights I cried myself into an exhausted sleep praying for more information and longed for some comfort in knowing that we were doing everything possible for Eric. Then one night, one of Eric's nurses talked to me and asked me if I would like to talk to a family that had walked the road we were on, just one year previously. I said yes and the family visited us the next day. This visit rejuvenated my faith, attitude, hope and energy and belief that there was hope and I again found my strength and kept pushing and searching for everything we could possibly do for Eric.

Eric relearned everything slowly and regained his life back bit by bit with his unending determination and a great attitude! We were told his strong will, love for life; determination and stubbornness were on his side and still are today. The day of leaving the Gillette Childrens Hospital in St.Paul was a long awaited milestone. We were finally going home to begin yet another chapter in our lives. We live in a wonderful small community, with a small school where there was absolutely no previous experience with a student with a Traumatic Brain Injury. Eric had to have a full time aide with him because his balance wasn't 100% , and he hadn't regained the use of his right arm yet. The school was unable to locate an aide at that time so Eric's grandpa volunteered to go to school with him. My dad (Grandpa) had been with us the entire time so he was well aware of what Eric needed assistance with. He was with him for two months in school and assisted Eric with many things. When Eric was then able to be alone physically, but required a full time tutor to assist him with his studies we were faced again with a difficult match in a small community, but finally a full time tutor was in school with Eric. Eric proudly walked with his class on Graduation Day; graduating with his McClusky High School Class in 2006 where he received an honorable plaque "Overcoming the odds" which was put together by his class of 6 students and the school. He received a standing ovation, and many hand shakes and hugs. He read the prayer at the graduation ceremony and there wasn't a dry eye in the entire gymnasium.

#4 SB2163

Then on to college, the next challenging chapter following a Traumatic Brain Injury. Eric wanted to be "normal" and wanted to move on with his life. He was accepted at UND and wanted desperately to be a physical therapist as he had a huge spot in his heart for therapy. He has attended four years of college part-time and has been working part time also. College has proved to be very, very difficult for Eric as he continues to struggle with his memory and cognitive abilities, therefore; he is currently taking a break from college and working fulltime at a job which he really likes and is proud to have, but his income will not provide for him to achieve his dreams of a good quality of living.

Employment for Individuals with Traumatic Brain is yet another challenging chapter; as without a college degree it creates great hardship to find employment in the comfortable income level in most cases. Eric is facing the road of adult life ahead of him, and wants to be the best he can be. He has a great attitude, tremendous zest for life, and outstanding personality, but with his limited learning capabilities he continues to struggle and wants to be completely independent in college and work. Young adults with traumatic brain injuries are often capable of being completely independent as Eric is today; and he strives to achieve a fulfilled and good quality of living. Now I ask myselfwhat can I do now to help my son? He is twenty- two and is a young man with a future of challenges because his dream has been changed. I know he will continue to move forward with his unending courage, and my hope is that along with public awareness, enhanced knowledge, and continuing recovery, that Eric and all individuals with Traumatic Brain Injury can live a comfortable life, with assistance when required to sustain employment, and support, so they can live their lives to the fullest.

When I received the phone call from the North Dakota Head Injury Association and was asked if I would consider becoming a board member I immediately said yes I would become a board member and a mentor. I have been involved with some mentoring in the past eight years on a basis of someone knowing about Eric and myself. We returned 2 years after Eric's accident to Gillette Children's Hospital in St. Paul when Eric had heel chord surgery on his right leg. We were connected with a family from Leeds, North Dakota; by a phone call I received from the Gillette Hospital. Lisa Anderson's daughter Hannah's accident was several years after Eric's and they were walking the same path we had. We visited them and Hannah was as much as inspiration to us as Eric was to them! Lisa is here today and is also on the board and mentoring for the North Dakota Head Injury Association. We have become mentors to each other as well, through our friendship and being mothers helping and encouraging our children to overcome enormous odds with enduring strength.

I whole-heartedly believe that the best medicine for the individual and family of a traumatic Brain Injury is someone who has been there...walked that path of a lifelong challenge. We have put together information, a care tote, along with our photo albums, diaries and most of all, understanding and support for individuals and families who will be feeling alone some day.....we will be there.

I am asking you to please support bill # 2163 so that the lives of many individuals who have suffered Traumatic Brain Injuries can fulfill their dream to live their lives to their fullest capabilities.

Thank You.

#4 SB2163

'I want to be normal'

McClusky youth grateful for a second chance at life

By JILL SCHRAMM

Staff Writer

jschramm@ndweb.com

MCCCLUSKY—Eric Boehm of McClusky is thankful to be alive. His family and friends are thankful, too, for what they consider to be a miracle.

It's been 1-1/2 years since Eric lay in a coma in St. Alexius Medical Center in Bismarck following a vehicle crash. Eric, 15, still undergoes therapy but he's nearing his goal.

"I want to be normal," he said. On May 17, 2002, Eric was moving his brother's Isuzu Rodeo home from the field on the family farm about 7:30 p.m. when something went wrong. The people who found the crashed SUV called the ambulance.

Eric, who had gone through the windshield, was hospitalized in critical condition with a brain stem injury and broken collarbone.

"The first 12 hours were very critical. We didn't know if he was going to make it," his father, Lee Boehm, said.

Eric didn't open his eyes for seven days. Then he opened them just long enough to blink.

"Lee and I were both sitting there. It was really exciting," said Rhonda Boehm, Eric's mother.

See P.14M — Page A8



Jill Schramm/Staff Writer

Just before his release home after four months in hospital and rehabilitation programs, Eric Boehm poses with the four casts he had graduated through during that time.

#4 SB 2163

Boehm

Continued from Page A1

just looked right at me and said a few times then closed his eyes."

It was the beginning of what would be a long recovery.

Talking with a parent who had been down that road before, Rhonda Boehm was urged to keep a diary. She didn't like the idea at first. But she began writing after being told the diary wasn't for her — it was for Eric.

The diary indicates Eric got off the ventilator on day nine. He left the intensive care unit on day 13 and lifted his head off the pillow, a sign of movement, on day 19. He stood for a couple of seconds on his own on day 33 and took his first two steps on day 50. He spoke his first words, in a whisper, on day 71.

Eric spent four weeks in St. Alexius, six weeks in a coma stimulation program at SCCI in Mandan and four weeks in intense rehabilitation at Gillette's Children's Hospital in St. Paul, Minn. He had suffered contusions of the left side of his brain, affecting his right side.

"We kept just a constant vigil," Rhonda Boehm, who spent all but three hours of the first four months at her son's side, reading him Bible verses every night. Lee Boehm and Eric's grandfather and both grandmothers were there most of the time as was Eric's older brother, Levi, now 18.

"They told us early on with Eric to stimulate him. So right away we got his music," Rhonda Boehm said. "That's where I learned to like his teenage music."

Eric's grandparents, Orrin and Mayola Holen of McClusky, later helped by reading or playing games with Eric.

Each week, a group of Eric's friends from McClusky would pile into a car to drive the 64 miles to Bismarck.

Even though Eric wasn't responsive initially, they would talk about things they knew Eric would be interested in and they tossed a football around. In time,

Eric did respond and even participated in their football tosses.

"You felt a lot better in that he was slowly getting better," classmate William Lipp said. "You felt like you were doing something to help a little bit."

"It was exciting," Eric's cousin Shawn Holen said of watching Eric's recovery. One special moment came Aug. 2, 2002, when after months on a feeding tube, Eric was allowed a hamburger.

"That was hilarious," Shawn said, recalling how Eric wolfed the sandwich down.

Rhonda Boehm said Eric had been downcast about the rice that the hospital served as his first solid meal. When the nurse suggested he order a cheeseburger and fries from McDonalds, Eric pushed his mother toward the door with a request to go immediately.

During all the time the Boehms had to be away from home, they felt their community's support. Neighbors pitched in to help Lee get 1,220 acres seeded in eight hours. Lee's mother, Emma Boehm, looked out for Levi, who kept things functioning at home.

The Boehms' thankfulness extends to the McClusky volunteer ambulance squad, whom they credit for saving Eric's life the night of the crash.

"I think everybody in town prayed for Eric and our family," Mayola Holen said. "And not just in our town. They had all their relatives and friends praying. It went many different directions."

"We had a pile of cards every day," Rhonda Boehm added. Friends brought food to the family's camper, parked by the hospital. They hosted a benefit supper. Rhonda received a basket of personal-care items, and her brothers in the family business gave her unlimited time off from her job.

The support from friends was one reason the Boehms entered Eric in rehabilitation in Mandan rather than going directly to St. Paul.

"Everybody could still visit here often, which they did," Rhonda Boehm said.

Eric underwent occupation, physical, speech and pool therapy.

He's inspired his therapists never to give up on anyone, Rhonda Boehm said.

"I am just thankful that Eric is with us and that he has recovered as well as he has," she said. "I am thankful for all of his personality changes because some of them are kind of nice — kind of neat."

Although a little quieter, Eric's witty sense of humor shows through much more now, say those who know him.

Eric re-joined his classmates two weeks into the school year in the fall of 2002. Fellow students gathered in a school assembly to greet him with a standing ovation.

His poor short-term memory and unsteady balance still presented problems, though. Eric needed a full-time aide. Eric suggested his grandfather for the job.

The retired construction contractor found himself back in the classroom.

"I didn't help him with anything except to go up and down the steps," Orrin Holen says with a smile. "I tried to help in algebra and I couldn't."

Holen got Eric safely through the first six weeks, though.

"It was fun," Eric said of having his grandfather with him.

Rhonda Boehm said having her father looking out for Eric gave her peace of mind. She knew there was no one as familiar with Eric's needs as someone who had been at Eric's side almost constantly from day one.

As Eric became more independent, his grandfather was replaced by a tutor, coach Kipp Sparrow. Last January, Eric had recovered well enough that he was able to attend classes independently.

His friends say they enjoy the

same relationship with Eric now as they did before his accident.

"It would be fun to play football again, though. It would be very fun," said Shawn Holen, who has been commiserating with Eric since getting sidelined with a knee injury.

Eric no longer participates in basketball or football but he attends the games. He's recovered the use of his right hand to play alto saxophone in band.

"This summer I went to therapy in Bismarck twice a week and almost every weekend we would go over to our lake. I would go jet skiing and boating and we had all kinds of family get-togethers," Eric said.

This fall, he also got his driver's permit and went hunting, bagging six ducks and a goose.

Rhonda Boehm is showing her thankfulness for Eric's recovery by becoming a mentor to parents in the pediatric department at Medcenter One, where Eric still takes therapy. Eric tells the kids to work hard to get better and Rhonda talks to parents as someone who has been there and can offer hope.

"I just feel that's the least I can do. It makes me feel good, and I know it helps them," she said.

Early on, the pastor of her church had given her a Bible verse, Isaiah 40:31: "They that wait upon the Lord shall renew their strength. They shall mount up with wings as eagles. They will run and not be weary, and they shall walk and not faint."

"I just clung to that. It was so like Eric," Boehm said.

She still repeats the verse regularly with her son.

"How can I be thankful enough," she said. "Eric has recovered so well. God has been so gracious."

#4

SB 2163

Testimony

Senate Education Committee

Tuesday, January 18, 2011

Good morning Mr. Chairman and members of the education committee, my name is Lisa L. Anderson from Leeds, ND. I am here today to testify in favor of Senate Bill #2163. My daughter, Hannah Anderson, sustained a traumatic brain injury and I know how important it is for all people with a head injury to be able to obtain services and support after their injury.

November 12, 2007, a day Hannah will never remember, yet never forget. Hannah was driving herself and 3 friends out to her grandmother's house to watch a movie in the middle of the afternoon. She was t-boned in her little Chevy Prism as she turned out onto Highway 2 on the outskirts of Leeds. The sheriff arrived and pronounced her dead, another passerby stopped to see if he could help and he was a volunteer firefighter from Minneapolis. He found a faint pulse and sat in the car holding Hannah's head up to open her airway until the Jaws of Life could extricate her from the car, which took 45 minutes. The ambulance left for the Rugby Hospital and I was called at work. I was told Hannah had been in car accident and I was to get to the hospital as fast as I could. Hannah's injuries were too severe, and the Rugby Hospital was not equipped to help her – she was transported to a hospital in Minot and airlifted to Hennepin County Medical Center in Minneapolis, MN, a level 1 trauma center with a Pediatric Traumatic Brain Injury Unit. Hannah remained in a coma for 12 days and was in HCMC for a month. When she was medically stable, she was transferred to the Gillette Children's Specialty Hospital for rehabilitation as they also specialize in helping kids with brain injuries.

Almost 3 months were spent in hospitals until finally; Hannah was able to come home. Gillette Hospital in St. Paul, MN was the first to contact the Leeds Public School. One month prior to discharge, Gillette started training our school on brain injury and what to expect when Hannah returned. We included our school

#5 SB # 2163

system in our weekly family conferences, so we heard the same information that the school was told and vice versa.

Our family came home from Minneapolis happy to be home, but very alone at the same time. We had nowhere to turn, no one who understood what we were dealing with and no one to answer all of our questions. We didn't know anyone else who had suffered a brain injury.

Some months later, I came across a web site for the Traumatic Brain Injury State Partnership Grant and I contacted them. I realized that someone somewhere in this state knew something about TBI and I needed to find them. Things progressed – this was the advisory committee working on the Brain Injury legislation for the 2009 legislative session. After many meetings and much preparation, we presented a bill last session and were able to obtain funding to start the Head Injury Association of ND. I was elected to the Board of Directors and have had the opportunity and privilege to serve on the board for the past two years.

HIA-ND got ourselves organized, hired an executive director, elected a board and we were off and running. A logo was created, a phone number was acquired, and a web site is up and running along with our facebook page. There have been public awareness campaigns, brochures have been created and sent out to every medical facility and public health facility in the state. We have had booths set up at a variety of conferences around the state. Outreach was done as training was provided at each of the 8 Human Service Centers around the state. Social and Recreational services have been provided for individuals through HIT, Inc. A TBI resource library is available through the Prevention Resource and Media Center at DHS. Brain Injury Awareness Month is held each year in March. Public libraries across the state had displays set up, there were press releases, a proclamation from the governor and we had a float in the St. Patrick's Day parade in Fargo. We had had opportunities to provide support for families and been advocates for others. Our two most current projects include our Peer Mentor program and our upcoming Brain Injury Conference that will be held in March in conjunction with Brain Injury Awareness month.

#5 SB 2163

We have made progress, but as you can see by SB 2163, our goals and aspirations are even bigger now. The needs are great, but the workers are few. By supporting this bill, we are supporting our educational system and assisting our teachers with knowledge on how to provide the best education for children with brain injuries. Hannah was fortunate; our school had been trained by the people who work with TBI every day, the people from Gillette Children's Specialty Hospital in St. Paul. They knew what her needs were going to be and they knew what the school was going to have to do in order to be ready to meet Hannah's needs.

Upon returning home, we were referred to the Human Service Center in Devils Lake, as they may have some services that would benefit Hannah. Someone came out to our home, had us sign a couple of consent forms, and gave us an appointment for another psychological evaluation as well as a handful of brochures. After three 60 mile round trips to Devils Lake to complete the psych eval, we were informed that there were no services available to Hannah because she tested too high. She did not qualify for any developmental disability services, as her intelligence test was not low enough.

What we did receive from the Human Service Center was a written report from a psychologist, a handful of pamphlets and an \$800 bill that insurance would not cover! I knew nothing about programs or services that the HSC had to offer, all I knew was the fact that we were home with a teenage girl who could not walk on her own, was on 24-hour supervision, could not use the bathroom without assistance, could not hold a pen or pencil to write and was barely able to be understood when she talked. Any services that Hannah was going to need, we were going to have to find them for ourselves and that is exactly what we did. I drove her all over ND and MN finding medical personal that could actually help Hannah recover from her TBI. This story speaks to the importance of the resource facilitators that we are asking for this bill. What do people do if they don't have parents who can quite their job and make their brain injured child their full time work – coordinating appointments, fighting with insurance to pay the bills, following up on all the prior authorizations that insurance requires in order to

#5 SB2163

have her therapies paid for and finding doctors and therapists who actually know how to treat people with a brain injury.

By establishing a traumatic brain injury registry, we will find out what the brain injury rates really are in ND. We have national numbers from the CDC, but what are we looking at as far as injuries right here at home. We learned at the National Brain Injury Conference this year that by the year 2020 head injury is going to be the #1 public health problem in the nation.

As of last week, we have 10 people who have completed the class to be a peer mentor. We have recruited volunteers and provided training, following the guidelines of the New York and New Jersey Brain Injury Mentoring Programs. Individuals with brain injury experience a variety of lifelong physical, cognitive and emotional challenges that affect their quality of life. The toll on family members is also significant. Peer support has been shown to be an effective buffer for stress, in both individuals with brain injury and family members. Peer mentoring has also been shown to increase one's sense of personal empowerment and self-efficacy. As peer mentors we are ready and willing to provide support to families and survivors of a brain injury.

Traumatic brain injuries leave people feeling exhausted, they have trouble with short term memory loss, they have exorbitant medical bills, they need to learn to live independently and they need support. People with TBI's have social deficits, are confused and agitated, have personality changes, have trouble with impulsivity, their reasoning and judgment is impaired. A TBI will affect a person for the rest of their life – it is not like a broken leg that will heal. TBI patients may need lifelong services in order to be taxpaying citizens.

If Hannah and I can take something terrible and make something good come out of it, then we have to say that perhaps it was all worth it. If anything can be gained by what we have experienced in these past 3 years to help others who are less fortunate than us, then perhaps it was worth it. Thank you for listening to my story today and for considering this bill for all ND citizens with brain injuries – we are worth it. Thank you.

#5 SB 2163

Good morning ladies and gentlemen. My name is Dr. Tracie Mallberg. I am a Family Practice physician and I own LilyCare Clinic which is an independent Family Practice Clinic in West Fargo, ND. Prior to my family and I opening my clinic in West Fargo, I was a partner in a locums firm and I travelled across ND providing services in many of our communities. I have logged countless hours in various ERs around ND and have managed many emergency and trauma situations.

My life changed, however on July 5, 2009. That afternoon, Dan and I had our 6 children at the lake for a weekend of relaxation. Both of our 9 year old children, Tatum and Bailey, were on the tube behind our boat. The events of that day still play out in my mind as if they run in slow motion. I remember seeing the other boat and the absolute panic when I realized he was on a direct course to hit my children. The driver of the other boat was not aware of our position or our tube. I remember every detail of the accident; the sounds of my other children screaming, the heat of that hot July day; the slow speed at which our bodies seemed to move, the pool of blood floating on top of the water. I had two children in the water, one crying hysterically that her brother was dead and the other face-down in his own blood. That was the most terrifying day of my life. I have been trained to handle trauma, to respond calmly and with purpose but that day changed me, changed our family forever.

I jumped into the lake and pulled Tatum over onto his back. I swam him to the side of our boat and Dan lifted him to the deck. I initially couldn't find the source of his bleeding as he and I were covered in blood. My whole body shuddered when I realized he was bleeding from the right side of his head and as I moved my hands to the area of bleeding to try and control it, I started to shake as I felt the depression in what was this powerful 9 year old wrestler's skull. I prayed through tears as I saw seizure-like posturing and very weak attempts at breathing. I know these signs all too well and the poor prognosis that usually follows. When the ambulance arrived I shouted orders and managed to process. I sent my older children on tasks to keep them focused and not panicked. It was when I turned my baby over to the hands of the paramedics that I thought I might pass out and I felt as helpless as I ever have. We were taken by ambulance to a rural hospital in Perham, MN from which we were life-flighted to Fargo.

I spent day after day and night after night sleepless and by his side. I hoped and prayed for a miracle, for a sound, for anything. I watched as he was extubated hoping that I would now hear his voice, but I did not. For 13 long days I waited....an nothing.

Through 13 days of coma and multiple episodes of near death, I was no longer a physician, I was the mother of a nine year old boy who lay bruised and bloodied with CT scans hanging on the light box that were a constant reminder to the physician in me, that my son may never wake up. I was bombarded with potential outcomes, discussion of nursing home placement, and doctors and staff moving in and out so quickly it made me dizzy. I was the interpreter of medical information to my family but I struggled to make sense of it myself. The experience was, for me, nearly unbearable.

You have heard Lisa's and Rhonda's testimony today with regard to the importance of this bill, but I feel that I am in a unique position. I feel that I have not only the responsibility of being the mother of a boy who survived a major head injury and is doing very well do to a fantastic team of doctors,

#6 SB 2163

nurses and therapists, but also the responsibility of a physician to ease the suffering of those who will come after us.

Tatum had the absolute blessing of my familiarity with the hoops and tediousness that often befall the medical world. I was able to hand pick his therapy team. I was able to ask questions of colleagues and gage his progress through the eyes of people who had managed brain injuries. Even with that help, I felt lost and helpless. I wondered everyday if his challenges were "typical" of brain injuries, was I doing enough? Would my son be able to attain the things in life that he had dreamed of? As I realized that the Tatum I knew was changed I grieved the loss. I felt like the only mother on the planet to have lived this sort of anguish. I can't tell you how much someone saying "I know how hard this is and we will help you" would have eased the burden on my soul.

The registry that is being proposed as a part of this bill is the first step in not only helping these families get through the trauma of the initial injury, but also to maneuver the road to recovery. It is not just for the victims like my son Tatum, whose injuries are clear, but also for the many, many other brain injuries that go unrecognized and unreported. Those are the children with multiple concussions, shaken baby syndrome, children of abuse, and so on. Part of the process is going to have to include educating physicians and providers to recognize to potential impact that traumatic brain injuries can and do have on individuals and families. As a physician who has seen and evaluated MANY concussions, assaults and other potential brain injuries, I can tell you there is no structure with regard to reporting, surveillance, follow up and supports for the individual and family, if necessary. Physicians are not teaching and watching because they do not know.

Much like the physicians in ND, we have found a similar lack of knowledge in the educators. We have been treated with love and compassion from the educators we have worked with in the West Fargo school system, but the simple fact remains that there is neither training nor structure for the professionals who are handed the task of helping these children reassimilate into the public school system. In my experience, because Tatum has few "physical" scars from his injury, it is all too easy to forget the road he has travelled. We have repeatedly been in meetings with neuropsychology, therapy and the education staff trying to create awareness and help them see the difference between the effects of brain injury and "behavioral" issues. There are currently no guidelines with regard to designing and Individualized Educational Program for children with traumatic brain injury in ND. This is simply not fair to the educators or to the children. Tatum is clearly not the first child to have dealt with this, but we struggle to get information and resources for our teachers and ourselves. This simply cannot be allowed to continue.

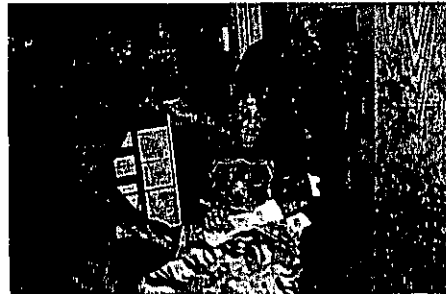
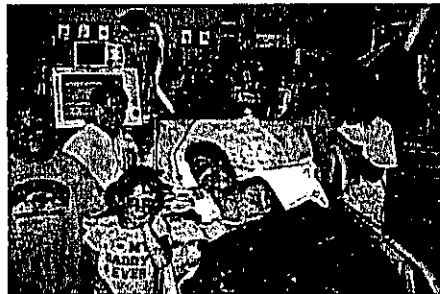
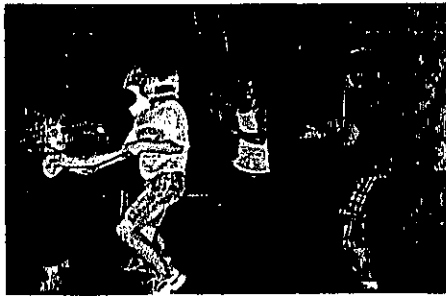
One point that I would like to make in this discussion is that there is great value in almost every challenge in "early intervention". This cannot be better illustrated than in the world of TBI. By intervening early with the family we can provide mentoring and guidance. By intervening early with those injured, we can provide greater potential for recovery. It must be realized that these people, our sons' and daughters', our spouses and friends will respond to the correct intervention but without it they will still require services; it will simply be a completely different set of services.

#6 SB 2163

Without guidance and intervention, these children will be at a much higher risk of unemployment and will lack vocational skills. They will be at high risk for drug and alcohol abuse and will likely require other service for medical issues or rehabilitation. And let's not forget that the numbers of people who are incarcerated with histories of TBI are simply staggering.

I stand before you requesting your support on this bill as a mother and as a physician, as a survivor and a teacher. Those of us who tread this path did so with tremendous pain and personal sacrifice. Please, with your support we can take what is now a small footpath and pave the road.

#6 SB 2163



#6 SB 2163

NORTH DAKOTA VETERANS COORDINATING COUNCIL

My name is John L. Jacobsen. I am the Chairman of the Legislative Committee of the North Dakota Veterans Coordinating Council. I am also a member of the American Legion and the Veterans of Foreign Wars.

I served in the North Dakota National Guard and the US Army Reserve for a total of 30 years. I retired in 1995 as a Colonel. I served on Active Duty in 1991 during Operation Desert Shield/Desert Storm in the Persian Gulf, stationed in the United Arab Emirates.

The Coordinating Council is made up of 15 members, 3 from each of the five Veterans Organizations in North Dakota:

- American Legion
- AMVETS
- Disabled American Veterans
- Veterans of Foreign Wars
- Vietnam Veterans of America

It is the policy of the Coordinating Council to support legislation that will benefit the welfare of the members of the Armed Forces. The committee MUST concur totally, that is all 15 members must agree on the legislation to be supported or else it does not get the support.

In this case, I have been instructed to recommend to this legislative committee that a "DO PASS" is supported by the Legislative Committee of the Veterans Coordinating Council.

TESTIMONY ON SB 2163
SENATE EDUCATION COMMITTEE
January 18, 2011
Department of Public Instruction

Mr. Chairman and members of the committee:

My name is Gerry Teevens and I am the Assistant Director of Special Education for the Department of Public Instruction. I am here to speak in support of SB 2163.

The Department of Public Instruction has participated for several years on the State TBI Advisory Council which is coordinated by the Department of Human Services. In the last legislative session SB 2198 required the DHS to conduct at least annual meetings with the NDDPI, Department of Health, the Adjutant Generals office, and Office of Veterans Affairs to coordinate services for individuals with traumatic brain injury. The meeting of these stakeholders has been referred to as the "TBI Systems Meetings". I have served as the DPI representative at the TBI Advisory Council and the TBI Systems Meetings. The Head Injury Association first introduced discussion on the proposed legislation of this bill during these meetings.

Through the Individuals with Disabilities Education Act (IDEA) public schools are responsible for providing special education and related services for students who have a traumatic brain injury and who qualify for special education and related services. For the current school year there are more than 13,000 students who receive special education services. Ten years ago there were only 31 students reported with traumatic brain injury. For the current school year 57 students with traumatic brain injury as a primary disability have been reported

despite overall flat or declining school enrollment. The Department has created guidance documents for school personnel related to other disabilities that occur with much greater frequency. With this increase in the number of North Dakota students who have traumatic brain injuries, there is recognition that additional training for school personnel about understanding and teaching these students more effectively is warranted.

In Section 1 of the bill there is language which may lead to some misunderstanding about the actual identification of traumatic brain injury. Line 9 of the bill currently reads that *"the activities must include methods for identifying and evaluating brain injuries..."*. School personnel follow an evaluation process to determine whether a child requires special education services. However, a traumatic brain injury is identified by medical personnel typically through follow-up to a head injury. Often a child may suffer a brain injury but the school may not be aware because they didn't receive information about this. When a child is being evaluated to determine the cause of learning problems, the use of an appropriate TBI screening instrument would introduce the question of whether the child may have experienced a head trauma. The Department suggests that some confusion about the requirements of this section of the bill may be prevented if lines 9-12 were revised to read: *"The activities must include training on the use of appropriate screening tools and the best practices in the provision of educational services to students with brain injuries."*

The Department envisions creation of a task force/work group involving school administrators, teachers, parents, and knowledgeable professionals who work with persons with TBI. This group would design training materials, plan methods for providing training for school personnel on the use of the screening instrument and appropriate strategies for working effectively with students who have TBI.

#8 SB 2163

This bill draft contains references to both the Department of Public Instruction (Section 1) and the Department of Human Services (Sections 2, 3, and 4). To prevent misunderstandings the Department of Public Instruction recommends that Sections 2, 3, and 4 of the bill clearly identify the Department of Human Services as the responsible agency.

Mr. Chairman, that concludes my testimony. I would be happy to answer any questions the committee may have.

#8 SB 2163

Senate Education Committee
Sixty-Second Legislative Assembly of North Dakota
Senate Bill No. 2163
January 18, 2011

Good Morning, Chairman Freborg and Members of the Senate Education Committee: I am Pamela Mack, testifying for the Protection & Advocacy Project. The Protection & Advocacy Project is an independent state agency that acts to protect persons with disabilities from abuse, neglect, and exploitation, and advocates for the rights of persons with disabilities. I am offering testimony in support of Senate Bill 2163 as submitted to you today.

As a disability rights organization, P&A has continued to see referrals in which individuals with traumatic brain injuries need support to navigate the service delivery system. Many of these have been in the priority areas of community integration, healthcare and employment.

Through SB 2198 during the 2009 Legislative session, lawmakers took significant strides in filling identified gaps within the Traumatic Brain Injury (TBI) service system. Services have continued to develop and have achieved many goals. SB 2163 now takes the TBI service system and continues to move it forward.

The current bill as it is presented to you today would allow for the Department of Human Services to contract to establish resource facilitators across the state.

Another strength of this proposed legislation is the professional development activities within the educational system across the State. Identification of a traumatic brain injury can be difficult and can sometimes be mistaken for behavioral issues, lack of effort or defiance. Providing tools and knowledge to our North Dakota educators, coaches, administrators and school faculty will better equip them to educate students with traumatic brain injuries.

The North Dakota Protection & Advocacy Project supports Senate Bill 2163 and encourages you to make a "do pass" recommendation to the full Senate. Thank you. I would be happy to answer any questions that you may have for me.



P.O. Box 2081
Bismarck, ND 58502-2081
701.222.1854
veronica.zietz@thearcofbismarck.org
www.thearcofbismarck.org

Testimony of Support Senate Bill 2163
Education Committee
January 18, 2011

Good morning Chairman Freborg and members of Education Committee. My name is Veronica Zietz (#99); I am the Executive Director at The Arc of Bismarck and I'm here today representing both The Arc of Bismarck and The Arc of Cass County. The Arc is an organization that provides education and advocacy to people with disabilities to foster empowerment and full inclusion in the community.

The Arc supports Senate Bill 2163, because it provides for much needed supports in the area of traumatic brain injury (TBI). TBI is a complex disability with a wide range of symptoms from headaches and memory loss to paralysis and cognitive delays. After an individual with TBI is initially treated and stabilized the next phase is rehabilitation, which mostly works to restore lost functions, though some are never restored. I believe Senate Bill 2163 would support recovery efforts for individuals with TBI. For instance, the peer mentoring services defined in section 3 could benefit individuals with TBI by pairing a person successfully living with a head injury with someone initially navigating the world of head injuries. Interactions such as this could provide people with a support system and enhance conditions for recovery.

The Centers for Disease Control reports more than 1.7 million people sustain a traumatic brain injury in the US each year, with most individuals never receiving the services and supports needed for rehabilitation. By creating a registry as suggested in section 2 the state would have the opportunity to monitor current cases and make efforts for prevention. This would also allow individuals with a head injury a means of accessing necessary services and supports in combination with the funds needed to get those supports through the appropriations provided in section 4.

I urge the committee to support SB2163. Thank you for your time and consideration.

#10 SB2163

TESTIMONY ON SB 2163
SENATE APPROPRIATIONS COMMITTEE
HEAD INJURY ASSOCIATION OF NORTH DAKOTA

Mr. Chairman and members of the Senate Appropriations Committee, my name is Richard Ott and I am the executive director of the Head Injury Association of North Dakota. We are appearing to support SB 2163.

There are many people who wanted to come this morning, but we decided to have only two of us present the basic position of the Association instead of flooding the room with very sincere people wanting to share some graphic and compelling experiences to make a point. We are going to concentrate mostly of objective information and reasons for your support, although I will be a slight bit subjective. Rebecca Quinn will follow me and will concentrate on some facts and figures about "The Silent Epidemic", which is traumatic brain injury (TBI).

There is a brief true story I want to share with you, again, to make an important point. The first day of the session --, etc. *I will relate an experience I had the first day of the session which illustrates our concern about people not being aware of the problem(s) surrounding TBI*

Victims of TBI are not developmentally disabled nor are they mentally ill. They are in a category by themselves and this is a big part of what we are trying to address with this bill and other activities. There are services that have evolved for numerous other handicapping conditions, but persons with TBI do not fit into any of the existing categories.

The bill before you covers four basic items and I will briefly describe each.

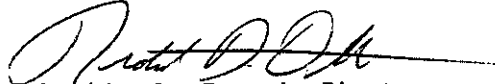
1. The first is a program that would enable DPI to develop and deliver a training program to teachers who are faced with the challenge of having a child with TBI return to the classroom after the injury. Across the state, DPI, teachers, school administrators, school boards, the student bodies, and the general communities have been nothing short of great. Everybody wants to do whatever they can, but since TBI is such a relatively unknown condition, many folks just don't know what to do. This would help reintegrate the victims into regular life activities.
2. The second feature is the creation of three positions across the state to handle resource facilitation for TBI victims. One of these three would specialize in the problems specific to veterans. Not only is the general population seeing a geometric increase in incidents of TBI, but so is the military. In both sectors, a major explanation is that people are now surviving who previously would have died -- and these survivors need some special attention. Some persons suffering from TBI need help organizing and keeping track of the things most of think of as routine. These resource facilitators would do that.
3. A third thrust if this bill is to help support our peer mentoring effort across the state. During the past year, we secured a grant from SCDD, (although our constituents are not DD), and have trained ten volunteers to be peer mentors. These mentors will try to become associated as soon as possible after a head injury occurs with the TBI victim and the families. The mentors will provide support and information in a major life-changing situation. The family is often as

affected by the tragedy as is the victim. We are asking for help in coordinating and supervising this activity.

4. The final provision of this bill would set up a flex fund that would provide equipment, supplies and services that would otherwise be unavailable to TBI victims. An example would be treatment for substance abuse problems. (and this is a common problem with TBI victims) Existing programs do not address the special needs of TBI victim and there are services, but they are out-of-state, such as Vineland in suburban Minneapolis. IPAT is a service headquartered in Fargo that provides state-of-the-art technology such as "Smart Pens" which can help a TBI person remember daily schedules, and this kind of technology can be purchased from this flex fund.

I will be pleased to answer any questions, however, Rebecca may answer some of your concerns in her presentation. We will both stay available until you are satisfied with the content of our testimony.

Respectfully submitted,



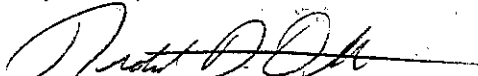
Richard Do. Ott, Executive Director
Head Injury Association of North Dakota

affected by the tragedy as is the victim. We are asking for help in coordinating and supervising this activity.

4. The final provision of this bill would set up a flex fund that would provide equipment, supplies and services that would otherwise be unavailable to TBI victims. An example would be treatment for substance abuse problems. (and this is a common problem with TBI victims) Existing programs do not address the special needs of TBI victim and there are services, but they are out-of-state, such as Vineland in suburban Minneapolis. IPAT is a service headquartered in Fargo that provides state-of-the-art technology such as "Smart Pens" which can help a TBI person remember daily schedules, and this kind of technology can be purchased from this flex fund.

I will be pleased to answer any questions, however, Rebecca may answer some of your concerns in her presentation. We will both stay available until you are satisfied with the content of our testimony.

Respectfully submitted,


Richard Do. Ott, Executive Director
Head Injury Association of North Dakota

Testimony ON SB #2163
Senate Appropriations Committee

January 31, 2011
11:00am

Good Morning Mr. Chairman Holmberg and members of the appropriations committee. My name is Rhonda Boehm and I'm from McClusky, North Dakota. In 2002, our Son Eric (at the age of 14), was in a motor vehicle accident and sustained a severe Traumatic Brain Injury. This day changed Eric's life, his entire families' lives, and his friends' lives forever.

We soon realized that recovering and treating a Traumatic Brain Injury was entering a vast unknown territory. There are many overwhelming challenges, emotional, physical, going back to school, then to college and moving forward with great hopes for a routine life.

I strongly feel the NDTBI's first program of Bill #2163 that enables DPI to develop a program to educate the school systems is vitally important. We experienced bringing Eric home to a small community, a wonderful and close-knit community, but there was absolutely very little knowledge regarding a Traumatic Brain Injury Student. Our school system wanted to do everything they could, but also had never had a child with a TBI in the school system. Eric's IEP plan was the same as a student born with a disability. Eric's disability began when he was fourteen and a freshman in high school; which is completely different than being born with a disability and entering the school system with the disability in kindergarten. This was a most challenging year ever, to say the very least; this is what happens with a young child that sustains a Traumatic Brain Injury. There is a definite need for a program to bring these students back to the classroom with educated school faculty, adaptive measures, tutors, and assistance for a Traumatic Brain Injury. I have since heard the same situation in many cases.

The second program of Bill # 2163 is a missing link that is needed to assist individuals with traumatic brain injuries to have a resource facilitator or a case manager. If not "totally disabled" the individual with a TBI faces a very challenging and difficult feat to progress their life to the normalcy they desire. I am dealing with this first hand with our son Eric as he is now almost 23, and he has recovered immensely and is living independently, and working and striving to obtain a degree in college which is what we prayed and dreamed for!!

Unfortunately, Eric's memory retention and certain cognitive and physical disabilities will more than likely never give him back the ability to return to the 4.0 GPA he was accustomed to and remembers attaining before his Traumatic Brain Injury. Memory and cognitive issues are very common with Traumatic Brain Injury Individuals. He has a difficult time qualifying for assistance because

he is able to be employed at a regular job; which is great and what we most definitely want!! But he will more than likely never be able to obtain employment with an income great enough to support a young adult or a married man with a family. We were told if he wasn't working he would more than likely meet total disability benefits because of his Traumatic Brain Injury. This is what happens to many individuals with a TBI who unfortunately end up down the wrong road. It would be very beneficial if there was a case manager to guide these young people in the right direction when they are again at a "critical" age in their lives, moving into adulthood, to continue to strive and move forward after surviving a Traumatic Brain Injury; and keep them on the advantageous path in life.

The NDTBI Peer Mentoring Program is a wonderful and very much needed program! I only wish it would have been available for us in 2002, I can't even begin to tell you how it would have provided us knowledge, peace of mind, and more. Our time of tragedy was so overwhelming that we were exhausted. If I would have had someone to help me, that had been down the road we were treading on, it would have changed so many of our time consuming struggles and challenges.

The NDTBI flex fund is also vital as many individuals with a Traumatic Brain Injury need assistance with many supplies and items that they may be in need of. Eric has had to have many orthotics, braces, and aides for walking. He also has had to have many memory assisting devices. Many individuals with a Traumatic Brain Injury later develop other medical issues due to the brain healing or inability to heal. Eric developed OCD and is receiving therapy and medications years after his initial Traumatic Brain Injury. Many of these items are not covered by health insurance. The issues are never-ending, and life goes on in a very good way and also with so many discouraging issues.

If Bill # 2163 is passed it will assist individuals with Traumatic Brain Injuries and their families with very useful and much needed assistance, information and support. They will continue to face obstacles for the rest of their lives. Isn't it what we wish for everyone? To live their lives to the absolute fullest potential? I feel a Traumatic Brain Injury survivor is unique because they indeed did survive, but they are living their lives differently. They are strong and want to move forward. As a board member of the North Dakota Traumatic Brain Injury Association, a mentor within the mentorship program, and a mom with a son who sustained a Traumatic Brain Injury at age fourteen and now is a young adult who has I am willing to work hard and assist where ever needed. We want the very best lives possible for each and every person who has sustained a Traumatic Brain Injury.

I am asking you to please support SB # 2163. Thank you for your time today. I will be happy to answer any questions you might have.

Thank You

Chairman Holmberg and members of the appropriations committee.

My name is Rebecca Quinn and I am a program director at the UND Center for Rural Health – For over three years, I have managed a Federal grant provided to states for the purpose of developing the North Dakota brain injury infrastructure. During this time I have had the opportunity to work with state agencies, providers, families, and individuals who have been impact by TBI.

My testimony today comes from two avenues:

1. Objective data from a variety of sources such as the Centers for Disease Control and Prevention, the HRSA Federal TBI program, and the Brain Injury Association of America.
2. My own experience which comes from having provided over 150 brain injury trainings in ND, coordinating the state TBI advisory committee, and serving on the board of the newly revitalized Head Injury Association.

The ND Department of Human Services was awarded a three year grant in 2007. The grant was contracted to the Center for Rural Health for implementation. Due to great ND fiscal savings, we have been able to make this money stretch into a fourth year. Unfortunately this March, the Federal funds will be completed. At this time there are not more funds available in the federal program.

During the four years the grant has been able to:

- Formed a TBI advisory committee
- Performed over 150 presentations and outreach events, including on four Tribal Reservations
- Made connections with Veteran groups and conducted trainings at Veteran events
- Assisted with the development of the Head Injury Association
- Worked with DHS on implementing a TBI screening that will begin this spring

With the upcoming end to the Federal Program it is important to at this time develop a coordinated State supported system for the individuals and families impacted by brain injury.

According to the Centers for Disease Control and Prevention (CDC), each year at least 1.7 million Americans sustain a traumatic brain injury (TBI). A TBI can happen to people of every age, race, gender, and socioeconomic status and at any time. Brain injuries are caused by falls, motor vehicle crashes, assaults, sports/recreation accidents, and most recently, blasts from improvised explosive devices. North Dakota may actually have a higher incidence of TBI due to a high traffic crash rate, the oil industry, and a high National Guard deployment rate. The CDC numbers underestimate the true prevalence of TBI, since only individuals treated in hospitals, those seen in ERs and those who die are counted. Not included are those who receive care outside of hospitals (e.g., in medical offices) or who do not receive medical attention at all (e.g., people injured in assaults, domestic violence, falls and the like). Research suggests that for

every person hospitalized with a brain injury, three to five others are injured but do not receive any care.

Of significant concern is the impact of TBI on children. The highest prevalence of brain injuries occur during the ages of 0 to 4 and 15 to 19. Nationally, TBI is the leading cause of death and disability in children and young adults. For many years it has been believed that children are more resilient and bounce back from brain injury quickly. In fact, children who sustain a brain injury early in life may look "well" at that moment in time, but as the child gets older more serious cognitive and behavioral problems emerge. For example an injury to the frontal lobes may not become apparent until the child reaches adolescence. Since the frontal lobes control social interactions and interpersonal skills, damage from the brain injury may not manifest until such frontal lobe related skills are called into play later in development.

Across the lifespan, TBI can lead to a wide range of functional changes affecting thinking, language, learning, emotions, behavior, and sensation. TBI can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age. Even so called "mild" injuries can have devastating consequences that require intensive treatment and long-term care. Perhaps the biggest challenge when it comes to addressing brain injury is the fact that the brain is infinitely more complex than any other organ or organ system in the human body. Add to that the fact that every brain and every brain injury are unique; it becomes easy to understand why it is often said that "there is much more that is unknown about the brain (and, accordingly, brain injury) than is known."

Many studies have looked at the connection between early brain injury and social problems. It is estimated that the prevalence of TBI within the prison population ranges from 42 percent to 87 percent. For most, the brain injury preceded the start of criminal activity. TBI is also common in inpatient psychiatric and substance abuse populations, and, similarly, the injury often precedes onset of psychiatric symptoms or substance abuse. Most of these brain injuries had gone unidentified prior to the respective studies. TBI is associated with high levels of co-occurring depression and anxiety.

Amazing advances in prevention (i.e. seatbelts) and emergency medical care are allowing for more individuals to survive TBI. Thirty years ago over 50 percent of individuals with TBI survived; today that number has increased substantially to approximately 80 percent survival.

Unfortunately, these amazing survival rates means that individuals are surviving with injuries that are leaving them with significant disabilities and a lifetime of trying to navigate a complex system of care. The CDC estimates direct medical costs and indirect costs (such as lost time at work) due to TBI to have been \$60 billion in 2000.

- For a mild TBI the cost is estimated at \$27-32,000 in the first year
- For a moderate to severe TBI the cost skyrockets to \$269-408,000 in the first year, all based on costs in the year 2000

every person hospitalized with a brain injury, three to five others are injured but do not receive any care.

Of significant concern is the impact of TBI on children. The highest prevalence of brain injuries occur during the ages of 0 to 4 and 15 to 19. Nationally, TBI is the leading cause of death and disability in children and young adults. For many years it has been believed that children are more resilient and bounce back from brain injury quickly. In fact, children who sustain a brain injury early in life may look "well" at that moment in time, but as the child gets older more serious cognitive and behavioral problems emerge. For example an injury to the frontal lobes may not become apparent until the child reaches adolescence. Since the frontal lobes control social interactions and interpersonal skills, damage from the brain injury may not manifest until such frontal lobe related skills are called into play later in development.

Across the lifespan, TBI can lead to a wide range of functional changes affecting thinking, language, learning, emotions, behavior, and sensation. TBI can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age. Even so called "mild" injuries can have devastating consequences that require intensive treatment and long-term care. Perhaps the biggest challenge when it comes to addressing brain injury is the fact that the brain is infinitely more complex than any other organ or organ system in the human body. Add to that the fact that every brain and every brain injury are unique; it becomes easy to understand why it is often said that "there is much more that is unknown about the brain (and, accordingly, brain injury) than is known."

Many studies have looked at the connection between early brain injury and social problems. It is estimated that the prevalence of TBI within the prison population ranges from 42 percent to 87 percent. For most, the brain injury preceded the start of criminal activity. TBI is also common in inpatient psychiatric and substance abuse populations, and, similarly, the injury often precedes onset of psychiatric symptoms or substance abuse. Most of these brain injuries had gone unidentified prior to the respective studies. TBI is associated with high levels of co-occurring depression and anxiety.

Amazing advances in prevention (i.e. seatbelts) and emergency medical care are allowing for more individuals to survive TBI. Thirty years ago over 50 percent of individuals with TBI survived; today that number has increased substantially to approximately 80 percent survival.

Unfortunately, these amazing survival rates means that individuals are surviving with injuries that are leaving them with significant disabilities and a lifetime of trying to navigate a complex system of care. The CDC estimates direct medical costs and indirect costs (such as lost time at work) due to TBI to have been \$60 billion in 2000:

- For a mild TBI the cost is estimated at \$27-32,000 in the first year
- For a moderate to severe TBI the cost skyrockets to \$269-408,000 in the first year, all based on costs in the year 2000

- If a person survives the first year after a moderate to severe TBI, life expectancy is not significantly diminished. This is why the CDC estimates approximately 2 percent of the population currently have long-term needs for assistance due to TBI.

Brain injuries are often misunderstood by society and do not fit well into any one particular system. Care and treatment often involves the need to access multiple public and private systems, as well as overlapping use of both the medical community and the human services field. Individuals are unprepared for how best to coordinate services and often do not know what services are available in their area. The components of SB 2163 have been thought out in order to continue to build on the work of the current Head Injury Association and based on the last four years collaboration of the Statewide TBI Advisory Committee.

One of the largest needs has is the lack of resource facilitation, or case management services. Often individuals do not qualify for these services through DHS. If an individual's disability after a brain injury happens to meet the criteria for a developmental disability or a serious mental illness they will qualify, but more often individuals do not qualify and the unique needs of post brain injury go without service coordination. Numerous times I have been asked why there is not case management for TBI. My response is always: Unfortunately, it was a disability that showed up too late and our current system had already been created before individuals with disability causing brain injuries were surviving at the rate they are now.

We have a moral obligation to families and individual who have literary survived death to make sure they have a system of support for the ongoing battles they face. The services proposed in SB 2163 would provide an avenue for families and individuals to navigate the complex system and return to productivity as quickly as possible.

Chairman Holmberg and members of the appropriations committee thank you for your time.

TESTIMONY

TO

SENATE APPROPRIATIONS COMMITTEE

62nd ND LEGISLATIVE ASSEMBLY:

TRACIE M. MALLBERG M.D.

LILYCARE CLINIC-WEST FARGO, ND

ASSOCIATE PROFESSOR UND SCHOOL OF MEDICINE

January 31, 2007

Dear Mr. Chairman and members of the committee

My name is Doctor Tracie Mallberg and I am a family physician in West Fargo, ND. I stand before you today to testify on the issues of Traumatic Brain Injuries and bill #2163. This is an issue that affects thousands of North Dakotans each year. The issue of traumatic brain injury has been forced into the public light recently by the tragic events of the Tucson, AZ shooting. Representative Gabrielle Giffords sustained a gunshot wound to the head at very close range. The bullet pierced the back of her skull and exited over her left eye. This is a tragic example of a traumatic brain injury but her recovery is also a testimony to the powerful effect of an appropriate treatment and rehabilitation process. She will likely survive the ordeal and her family has the knowledge and comfort of knowing that everything possible is being done to help her. In North Dakota it is very difficult to obtain that sort of reassurance as most traumatic brain injuries are not subjected to the rigorous rehab that is necessary to fully recover. The families are often left in charge of the recovery process and if able, they are often required to take months off of work, away from their families and take their loved one to one of the rehab centers around the country.

This is an issue that changed my life dramatically. On July 5th, 2009, my son Tatum sustained a severe brain injury. My family was at the lake over the July 4th holiday. Two of my children, Bailey and Tatum, were on the tube behind our boat. I watched in helpless horror as another boat set a direct path toward my children. The boat ran over our tube. Bailey was flipped under the tube and Tatum was not. I had two children in the water, one crying hysterically that her brother was dead and the other face-down in his own blood. That was the most terrifying day of my life. I have been trained to handle trauma, to respond calmly and with purpose but that day changed me and our family forever.

I initially couldn't find the source of his bleeding but as I moved my hands to his head, I felt the depression in my 9 year old son's skull. I saw seizure-like posturing and very weak attempts at breathing. I know these signs well and the poor prognosis that usually follows. When the ambulance arrived, I shouted orders and managed the situation. I turned my son over to the paramedics and I prayed. We were taken by ambulance to a rural hospital in Perham, MN. Because of the severity of his injuries we were life-flighted to Fargo.

I spent days sleepless and by his side. I hoped for a miracle, for a sound, for anything. I watched as he was extubated hoping that I would hear his voice, but nothing. Through 13 days of coma and multiple episodes of near death, I was no longer a physician; I was the mother of a nine year old boy who lay bruised and bloodied. The CT scans hanging on the light box were a constant reminder to the physician in me, that my son may never wake up. I was tormented with potential outcomes, discussion of nursing homes, and staff moving in and out so quickly it was dizzying. I was the interpreter of medical information to my family but I struggled to make sense of it myself. The experience was nearly unbearable.

I share my story with you to illustrate the tremendous emotional stress and hardship that the initial injuries bring with them, the long road to recovery is a different kind of stress. It is fraught with grueling uncertainty and fear, with personal and financial sacrifice on a gargantuan scale. My son and Congresswoman Giffords have had opportunities that not every family and victim of TBIs has. My son had the blessing of my familiarity with the hoops and

tediousness that often befall the medical world. I was able to hand pick his therapy team. I was able to ask questions of colleagues and gage his progress through the eyes of people who had managed brain injuries. Even with that help, I felt lost and helpless.

The registry that was initially proposed as a part of this bill is the first step in not only helping these families get through the trauma of the initial injury, but also to maneuver the road to recovery. It is not just for the victims like my son whose injuries are clear, but also for the many other brain injuries that go unrecognized and unreported. Those are the children with multiple concussions, shaken baby syndrome, children of abuse, and so on. All too often these families and children fall through the cracks. We need to have a way of identifying these families and individuals. The early intervention and point of contact are key to the success of the process of recovery. Our bill proposes a case coordinator to help with establishing all of the necessary pieces for appropriate recovery. This ranges from coordination of therapies to obtaining appropriate insurance benefits to appropriate educational modifications to vocational training programs. These individuals will be trained to guide families through the maze of recovery.

As members of the appropriations committee, you have the power to ensure funding for programs that are life changing for so many families. Education of educators is a huge hurdle in ND. There currently are no guidelines for teachers to initiate Individualized Education Program for children who are victims of TBI. My son's IEP was designed as a guideline for children with behavioral problems. My son does not have behavioral problems. He has memory and processing difficulties. The teachers have been wonderful but I have had to be the driving force behind this change and the process of dealing with TBIs in West Fargo. We have placed the burden of appropriate education on these people without offering the education and training to do so. This is not fair to the children nor the educators.

I recognize that the fiscal note attached to this bill seems large. It is important to see, however, that the funding will provide the financial structure to bring these survivors back to the world as productive, tax-paying citizens.

Without the appropriate rehabilitation these people and children will certainly draw on other programs. The risk of alcoholism and drug abuse after a TBI is staggering but is dramatically reduced by redirecting them into personally fulfilling programs and vocational training as well as keeping families intact and stable. The programs we are advocating will do just that. Also, in a recent study of prisoners in MN an alarmingly high percentage of those incarcerated have a history of at least one TBI. We will work to help them deal with the cognitive difficulties and impulsiveness that often leads them down that wrong road.

Thank you for the opportunity to testify before the committee today. On behalf of the Brain Injury Association and North Dakota Citizens, I ask that you consider the relatively small price of this bill and the potential impact that it can have on so many survivors and families.

NORTH DAKOTA VETERANS COORDINATING COUNCIL

My name is John L. Jacobsen. I am the Chairman of the Legislative Committee of the North Dakota Veterans Coordinating Council. I am also a member of the American Legion and the Veterans of Foreign Wars.

I served in the North Dakota National Guard and the US Army Reserve for a total of 30 years. I retired in 1995 as a Colonel. I served on Active Duty in 1991 during Operation Desert Shield/Desert Storm in the Persian Gulf, stationed in the United Arab Emirates.

The Coordinating Council is made up of 15 members, 3 from each of the five Veterans Organizations in North Dakota:

- American Legion
- AMVETS
- Disabled American Veterans
- Veterans of Foreign Wars
- Vietnam Veterans of America

It is the policy of the Coordinating Council to support legislation that will benefit the welfare of the members of the Armed Forces. The committee **MUST** concur totally, that is all 15 members must agree on the legislation to be supported or else it does not get the support.

In this case, I have been instructed to recommend to this legislative committee that a "DO PASS" on SB 2163 is supported by the Veterans Coordinating Council.

**TESTIMONY ON SB 2163
SENATE APPROPRIATIONS COMMITTEE
January 31, 2011
Department of Public Instruction**

Mr. Chairman and members of the committee:

My name is Gerry Teevens and I am the Assistant Director of Special Education for the Department of Public Instruction. I am here to speak in support of SB 2163.

The Department of Public Instruction has participated for several years on the State TBI Advisory Council which is coordinated by the Department of Human Services. In the last legislative session SB 2198 required the DHS to conduct at least annual meetings with the NDDPI, Department of Health, the Adjutant Generals office, and Office of Veterans Affairs to coordinate services for individuals with traumatic brain injury. The meeting of these stakeholders has been referred to as the "TBI Systems Meetings". I have served as the DPI representative at the TBI Advisory Council and the TBI Systems Meetings. The Head Injury Association first introduced discussion on the proposed legislation of this bill during these meetings.

Through the Individuals with Disabilities Education Act (IDEA) public schools are responsible for providing special education and related services for students who have a traumatic brain injury and who qualify for special education and related services. For the current school year there are more than 13,000 students who receive special education services. Ten years ago there were only 31 students reported with traumatic brain injury. For the current school year 57 students with traumatic brain injury as a primary disability have been reported

despite overall flat or declining school enrollment. The Department has created guidance documents for school personnel related to other disabilities that occur with much greater frequency. With this increase in the number of North Dakota students who have traumatic brain injuries, there is recognition that additional training for school personnel about understanding and teaching these students more effectively is warranted.

In Section 1 of the bill there is language which may lead to some misunderstanding about the actual identification of traumatic brain injury. Line 9 of the bill currently reads that *“the activities must include methods for identifying and evaluating brain injuries...”*. School personnel follow an evaluation process to determine whether a child requires special education services. However, a traumatic brain injury is identified by medical personnel typically through follow-up to a head injury. Often a child may suffer a brain injury but the school may not be aware because they didn't receive information about this. When a child is being evaluated to determine the cause of learning problems, the use of an appropriate TBI screening instrument would introduce the question of whether the child may have experienced a head trauma. The Department suggests that some confusion about the requirements of this section of the bill may be prevented if lines 9-12 were revised to read: *“The activities must include training on the use of appropriate screening tools and the best practices in the provision of educational services to students with brain injuries.”*

The Department envisions creation of a task force/work group involving school administrators, teachers, parents, and knowledgeable professionals who work with persons with TBI. This group would design training materials, plan methods for providing training for school personnel on the use of the screening instrument and appropriate strategies for working effectively with students who have TBI.

This bill draft contains references to both the Department of Public Instruction (Section 1) and the Department of Human Services (Sections 2, 3, and 4). To prevent misunderstandings the Department of Public Instruction recommends that Sections 2, 3, and 4 of the bill clearly identify the Department of Human Services as the responsible agency.

Mr. Chairman, that concludes my testimony. I would be happy to answer any questions the committee may have.

Prepared by the Legislative Council staff for
Senator Flakoll
January 19, 2011

PROPOSED AMENDMENTS TO SENATE BILL NO. 2163

Page 1, line 1, replace "three" with "two"

Page 1, line 8, replace "pertaining to the education of" with "to teachers and counselors serving"

Page 1, remove lines 12 through 18

Page 1, line 22, after "department" insert "of human services" and replace the second "with" with "having"

Page 2, line 4, after "department" insert "of human services"

Page 2, line 18, after "department" insert "of human services"

Renumber accordingly

#1 SB 2163

Introduced by

Senators Dever, J. Lee, Mathern

Representatives N. Johnson, Metcalf, J. Nelson

1 A BILL for an Act to create and enact a new section to chapter 15.1-18.2 and ^{two} ~~three~~ new sections
2 to chapter 50-06.4 of the North Dakota Century Code, relating to traumatic brain injury services.

3 **BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

4 **SECTION 1.** A new section to chapter 15.1-18.2 of the North Dakota Century Code is
5 created and enacted as follows:

6 **Students with brain injuries.**

7 The superintendent of public instruction shall coordinate the development and delivery of
8 professional development activities ^{to teachers and counselors serving} ~~pertaining to the education of~~ students with brain injuries.

9 The activities must include methods for identifying and evaluating brain injuries, the use of
10 appropriate screening tools, and best practices in the provision of educational services to
11 students with brain injuries.

~~12 **SECTION 2.** A new section to chapter 50-06.4 of the North Dakota Century Code is created~~
~~13 and enacted as follows:~~

~~14 **Traumatic brain injury registry.**~~

~~15 The department shall establish and maintain a registry of individuals who sustain traumatic~~
~~16 brain injury. The department shall develop a system for reporting incidents of traumatic brain~~
~~17 injury. The system must include education, training, and technical assistance to reporting~~
~~18 entities.~~

19 **SECTION ² 3.** A new section to chapter 50-06.4 of the North Dakota Century Code is created
20 and enacted as follows:

21 **Resource facilitation - Peer mentoring services.**

22 1. The department ^{of human services} shall contract with a public or private entity ^{having} ~~with~~ expertise in traumatic
23 brain injury for the provision of resource facilitation. To provide statewide services, the
24 entity shall employ three resource facilitators, one of whom has a designated focus on

#1

1 providing services to veterans who have traumatic brain injury. For purpose of this
2 subsection, "resource facilitator" includes care and service coordination for individuals
3 who have traumatic brain injury.
4 2. The department ^{of human services} in consultation with the head injury association of North Dakota, shall
5 provide peer mentoring services. For purposes of this subsection, "peer mentoring"
6 includes the recruitment of volunteers to provide peer mentoring services to an
7 individual with traumatic brain injury and to the individual's family and caregivers. A
8 specific focus of the recruitment of volunteers must be to work with veterans who can
9 fulfill the role of peer mentors for those veterans who have traumatic brain injury. The
10 department of veterans' affairs, the adjutant general, and military support
11 organizations shall work closely with the department and the head injury association of
12 North Dakota for the coordination of peer mentoring services.

13 SECTION ³ A. A new section to chapter 50-06.4 of the North Dakota Century Code is created
14 and enacted as follows:

15 Traumatic brain injury supplemental services program fund established.

16 There is established in the state treasury a special fund known as the traumatic brain injury
17 supplemental services program fund. Moneys in the fund, within the limits of legislative
18 appropriation and subject to criteria established by the department ^{of human services} may be used for meeting
19 the unmet needs of individuals with traumatic brain injury. The services provided may include
20 specialized services, supplies, and equipment.

TESTIMONY ON SB 2163
HOUSE HUMAN SERVICES COMMITTEE
Monday, March 14, 2011

Head Injury Association of North Dakota

Mr. Chairman and members of the House Human Services Committee, my name is Richard Ott, and I am the Executive Director for the Head Injury Association of North Dakota. We are appearing in support of SB 2163.

Registry need and value.

There are many people who want to come and testify at these hearings. It's frustrating because their stories are so compelling and informative, but time is such a precious commodity at these hearings.

We have tried to organize our presentation in a manner so that we can share some factual data and at the same time give some of the subjective input that is so vital to accomplishing our mission. We are dealing with people, not just numbers.

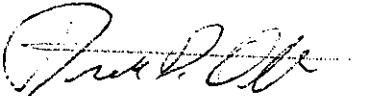
I will very quickly go through the provisions of the bill and then relinquish the floor to some of the others who have traveled so far to be here with you today.

There is one sentence left from our original proposal. It is: Read SB 2163 at this point:

The need for resource management. Veterans needs.

Rebecca's testimony.

Thank you Mr. Chairman and I'd be pleased to answer any questions.



Richard D. Ott
Executive Director
HIA/ND

Cheryl Hancock #2

TBI Testimony 3/14/2011

Committee members I appreciate your time today allowing me to explain why I feel this bill is important to the people of North Dakota.

A few of you, over the last few years have heard bits and pieces of my story as I testify in hearings like this. I think we all agree that services/supports are necessary for this group, as it is ONE OF the largest disability populations state/nationwide. I will tell you why I think this bill is a good investment. What I am about to share with you is the part of my brain injury that was the hardest to deal with. I would take all the pain I went through if only I could have back who I used to be. You see when someone goes through a brain injury they don't just lose another limb, or piece of their body. They lose their identity, their soul. All my life I knew God put me on this earth to be a social worker, and help other children the way my foster parents saved me. I can no longer do that.

Nine years ago on April 2 I got married. Nine days later I was rear ended by an F-350 going at least 30 mph when I was standing still. My mother had moved to California and my sister lived further away than could be helpful to me in the first months/years of my recovery. The legal system allowed independent medical examiners to manipulate data to discontinue my medical benefits through my auto insurance, and my husband became my only support system. He was a National Guard Member, and an over the road truck driver so that support system was available so little. Within three years he could no longer handle the changes I was going through and our marriage spiraled into a very nasty divorce. Now it was me and my children. I had trouble keeping jobs more than 6 months due to both physical limitations, and concentration issues. I failed two internships in college, and was starting to see myself as a failure, as did the rest of the world. My oldest daughter, who was 12 at the time of the accident became a second mother to my infant son who was born a year and a half after my accident. In 2005, (three years after the accident) they finally diagnosed my brain injury, along with major depressive disorder. I was suicidal every day of my life for somewhere between 3-5 years. When driving home, or to work I considered how hard I would have to hit a tree, or some concrete object to end everything.

After being diagnosed I decided to learn what a MILD "brain injury" was. Then I became even more depressed. I became very well aware with how long time had passed it was unlikely I would ever return to who I used to be. Everyone told me to "just deal with it, and move on"! How do you do that? I asked my medical doctors. I was referred to speech/cognitive therapy. But unfortunately BCBSND only pays for 60 days. I have to recreate my entire life, and what my purpose in life is and I got 10-15- 1 hour sessions to do it. Other than seeing a psychologist once a month there was nothing else available to help me. I read everything I could get my hands on to help myself. I vowed someday I was going to make a difference for people "like me".

Fortunately for me, God led me to a job at Southeast Human Service Center. In all my life I have never come across a work environment that strives to make the playing field equal for everyone. My supervisor there was the only support system I had outside of my family. She

listened to my problems, occupational and personal, and provided feedback that was entirely unbiased, even when she got reports of me saying or doing something that was not quite "appropriate". She helped me devise strategies to correct the concentration problems I had (which impacted how well I could do my paperwork). This basically was her keeping track of my paperwork/corrections, and extra supervision time to process through client issues. In the nine years since my injury, that supervisor, and the 60 days with my speech pathologist were the only examples of system supports I could find. Even though I only made about \$15K a year I was not poor enough to qualify for services under the TBI Waiver through Social Services. Since no one at Merit Care diagnosed my brain injury then no one thought to refer me else where for rehabilitation services since I did not present initially in a coma. Once I tried getting a doctor to refer me out to the Mayo Clinic to help control the pain I was suffering with, and that was quickly denied. I contacted Social Services after one of my co-workers, our Resource Coordinator (who knows Social Security inside and out, and every resource available to help anyone in our local area) told me what to say. I was denied. Well actually they refused to even do an assessment. As a social worker I knew what services were available, and what systems to help people put in place. But when I as a social worker cannot get services for myself how is someone else who doesn't know how to navigate the system going to do it?

Now here is my answer of how we can start to bridge that gap. With the direction of a Resource Facilitator, I think clients can be helped to find the direction they need whether it be counseling, vocational rehabilitation, help with daily living needs, cognitive therapy, budget planning, managing the overload, or financial management. When all of these items can be managed then, and only then, can Voc Rehab services be effective. Until all the things that overwhelmed me were controlled I was unable to function successfully in a work environment.

A resource coordinator will understand how mental health and brain injury feed off of each other. They will understand that controlling the "stressors" (i.e.: finances, housing, sleep hygiene, social service/social security navigation, substance use, and family support) impacts cognition. Once they help get supports in place for these issues then voc rehab can be successful.

This is not welfare, or a handout. Many times with a little additional help survivors can lead a life that is productive, tax paying, and happy. I believe with the monies of this bill many survivors can become gainfully employed, and reduce or eliminate the need for social assistance programs in their lives. Think of the tax savings if only half of the 9000+ survivors are able to work at least part time and reduce their reliance on the financial supports of the state by half! Many TBI survivors don't want to be on welfare, or Social Security, they would much rather be employed and feel that feeling of having a purpose and direction in their life. This bill will enable them to do that. Shouldn't everyone have the opportunity to feel that their life is meaningful, and they are giving back to their community?

Testimony

House Human Service Committee

Monday, March 14, 2011

Good morning Chairman Weisz and members of the Human Service Committee, my name is Lisa L. Anderson from Leeds, ND. I am here today to testify in favor of Senate Bill #2163. My daughter, Hannah Anderson, sustained a traumatic brain injury and I know how important it is for all people with a head injury to be able to obtain services and support after their injury.

November 12, 2007, a day Hannah will never remember, yet never forget. Hannah was driving herself and 3 friends out to her grandmother's house to watch a movie in the middle of the afternoon. She was t-boned in her little Chevy Prism as she turned out onto Highway 2 on the outskirts of Leeds. The sheriff arrived and pronounced her dead, another passerby stopped to see if he could help and he was a volunteer firefighter from Minneapolis. He found a faint pulse and sat in the car holding Hannah's head up to open her airway until the Jaws of Life could extricate her from the car, which took 45 minutes. The ambulance left for the Rugby Hospital and I was called at work. I was told Hannah had been in car accident and I was to get to the hospital as fast as I could. Hannah's injuries were too severe, and the Rugby Hospital was not equipped to help her – she was transported to a hospital in Minot and airlifted to Hennepin County Medical Center in Minneapolis, MN, a level 1 trauma center with a Pediatric Traumatic Brain Injury Unit. Hannah remained in a coma for 12 days and was in HCMC for a month. When she was medically stable, she was transferred to the Gillette Children's Specialty Hospital for rehabilitation as they also specialize in helping kids with brain injuries.

Our family came home from Minneapolis happy to be home, but very alone at the same time. We had nowhere to turn, no one who understood what we were dealing with and no one to answer all of our questions. We didn't know anyone else who had suffered a brain injury.

Upon returning home, we were referred to the Human Service Center in Devils Lake, as they may have some services that would benefit Hannah. Someone came out to our home, had us sign a couple of consent forms, and gave us an appointment for yet another psychological evaluation as well as a handful of brochures. After three 60 mile round trips to Devils Lake to complete the psych eval, we were informed that there were no services available to Hannah because she tested too high. She did not qualify for any developmental disability services, as her intelligence test was not low enough.

What we did receive from the Human Service Center was a written report from a psychologist, a handful of pamphlets and an \$800 bill that insurance would not cover! I knew nothing about programs or services that the HSC had to offer, all I knew was the fact that we were home with a teenage girl who could not walk on her own, was on 24-hour supervision, could not use the bathroom without assistance, could not hold a pen or pencil to write and was barely able to be understood when she talked. Any services that Hannah was going to need, we were going to have to find them for ourselves and that is exactly what we did. I drove her all over ND and MN finding medical personal that could actually help Hannah recover from her TBI. The reason I wanted to share this story with you is because I believe it speaks to the need for the resource facilitators that we are asking for this bill.

November 12, 2007, is the day of Hannah's accident, but also the day I had to leave my job and my career. After receiving the phone call at 1:22 p.m., that Hannah had been in a car accident, I walked out the door of my office and didn't know it at the time, but it would be my last day of employment for almost 3 years. Traumatic Brain Injury became my new full-time non-paying job!

What do people do if they don't have parents who can quit their job and make their brain injured child their full time work – coordinating appointments and school schedules, driving to appointments, equipping myself with any information I could get my hands on, so that I might learn about brain injuries, fighting with insurance to pay the bills, following up on all the prior authorizations that insurance requires in order to have her therapies paid for and finding doctors and

therapists who actually knew how to treat people with a brain injury. Hannah saw an occupational therapist, a physical therapist, a speech therapist, we had to find a family physician that had some knowledge of brain injury to coordinate all of her medications, at one point there were over 20 different medications! Hannah had to see a vision therapist as her eye site had changed and she needed bifocals, she had check-ups with the brain injury specialists in St. Paul, we had to find a neurologist and it goes on and on and on.

Traumatic brain injuries leave people feeling exhausted, they have trouble with short term memory loss, they have exorbitant medical bills, they need to learn to live independently and they need support. People with TBI's have social deficits, are confused and agitated, have personality changes, have trouble with impulsivity, their reasoning and judgment is impaired. A TBI will affect a person for the rest of their life – it is not like a broken leg that will heal and life goes on as normal. In fact having your brain shaken around inside of your skull like a bowl of jello, means that life as you knew it is gone!

Treating TBI isn't simple; it creates many challenges for the injured and their families. A report done in 2006, from the Institute of Medicine recognized the hardships that TBI creates and issues a report saying: "...many people with TBI experience persistent lifelong disabilities. For these individuals and their caregivers, finding needed services is far too often an overwhelming logistical, financial and psychological challenge. Individuals with TBI-related disabilities, their family members and caregivers report substantial problems in getting basic services, including housing, vocational services, neurobehavioral services, transportation and respite for caregivers. Yet efforts to address these issues are stymied by inadequate data systems, insufficient resources and lack of coordination. TBI services are rarely coordinated across programs except in some service sites. Furthermore, in most states, there is no single entry point into TBI systems of care." This speaks to the huge need for resource facilitators in ND, someone who can coordinate services for people with brain injuries.

I had to quit the job, a job that I loved and needed, in order to coordinate all of the services that I could find that would benefit Hannah in her recovery. Too

many of our ND citizens are not getting the services they need because they have no one who can look after them full time. Coordinating services for a loved one after a TBI is a full time job and if they have no one who can do that, they do not get services that will help them recover.

March is National Brain Injury Awareness Month. March 16th is National Brain Injury Awareness Day at our Nation's Capital. Here in ND we have a signed proclamation from the governor declaring March Brain Injury Awareness month. Last Saturday, 03-05-11, the Head Injury Association of ND in conjunction with Sanford Health of Fargo, held our Brain Injury Conference: Mind Matters. Our keynote speaker was Michael Paul Mason, author of the book Head Cases.

In conclusion, here is what he says about a brain injury: "A tap on the head and anything can go wrong. Anything usually does go wrong. You may not remember how to swallow. Or you may look at food and perspire instead of salivate and salivate when you hear your favorite song. You may not know your name, or you may think you're someone different every hour. Everyone you know and will ever know could become a stranger, including the face in the mirror. When you tell someone you're sad, you may shriek; your entire vocabulary may consist only of groans or hiccups. A brain injury can shatter your perceptions about the future, splinter your past, and send your sense of time whirling in any number of directions. And that's just the beginning.

A brain injury is never an isolated incident; it affects nearly everything associated with the survivor. It can collapse a family and flatten business, evaporate friendships and allegiances, overburden a community, and buckle a state's health-care system.

By going deeper into the aftermath of brain injury, we will eventually reach an earnest sense of awe about the brain and its mysteries. The survivor's life emerges as an ongoing pull between the changes that occur within an altered brain and the outward repercussions that follow. It is this tension between being and becoming that begs the intimate, soulful questions posed by every brain

injury. What are we other than our brains? Is there a part of me that can't be changed by a brain injury?"

Thank you.

March 14, 2011

Testimony presented to Human Services Committee in favor of Senate Bill # 2163

Good Morning Chairman and members of the Human Services Committee. My name is Rhonda Boehm and I am from McClusky, North Dakota. Thank You for allowing me this opportunity to testify in favor of Senate Bill # 2163. I would have never imagined I would be here today talking to you about Traumatic Brain Injury; having endured every parent's most heartbreaking, un-imaginable, and helpless feeling. This has been the utmost challenging time for us since our son Eric has suffered a Traumatic Brain Injury.

The evening of May 17, 2002, my family was leading a routine, busy, fulfilled life, when our world was turned completely upside down, and our lives would never return to the way of life we were so accustomed to. At 8:00 pm I received a phone call that my son Eric was in a motor vehicle accident and I needed to get there immediately. I arrived there before the ambulance, which is a sight I will forever remember – very clear and yet a blur. Eric was laying facedown in the ditch about 100 yards away from the vehicle which he was driving to our family farm. His vehicle was on its side after many times of rolling on the embankment and ditch; which had scattered all of Eric's and his brother Levi's belongings everywhere. The Rodeo was totaled and every piece of glass was shattered. I ran to Eric, in tears, my heart pounding, and fearing the worst. He didn't seem to be breathing; and as I layed beside him and held his hand, I heard a very shallow breathing.....he was alive. A family member got some blankets to keep Eric warm and I held his hand and told him mom was with him and so was God; and he had to be strong and he was going to be okay. When the ambulance arrived they immediately called the Metro Ambulance from Bismarck because of the severity of Eric's condition. Our ambulance was intercepted with Metro and the EMTs came onboard because time was crucial and they didn't want to move Eric; as he had stopped breathing several times between McClusky and Wilton. I was allowed to ride in the ambulance to continue to talk to Eric as he was very unresponsive and was clinging to his life.

Several hours later in the ER family room, when meeting with the Trauma Medical Team, they told us Eric's condition was very serious and he may not survive the night. He was in critical condition with a Brain Stem Injury, Contusions on both the right and left hemisphere of his brain, and both of his clavicles were broken. He had road rash all over his body with the exception of his face. Having no previous exposure or knowledge of Traumatic Brain Injury, we were about to embark on a very, very long and unknown journey.

Eric was always very athletic and on top of every sport possible in school. He carried a 4.0 GPA, was a leader in all aspects, was active in every school organization, was very well liked and a young boy with a great attitude. That night he was laying in a coma in the Bismarck Hospital in Intensive Care with tubes everywhere, monitoring machines of every kind imaginable connected to him. When I looked at his face he seemed almost like he was asleep for the night as always.....but one thing was different he didn't wake up the next morning for school... as he remained in a coma.

Eric remained in a coma and was unresponsive for nearly 2 months; with only very small signs of improvement. On day 7 he opened his eyes and blinked, stared at me and then closed them again. It was at that moment that I felt deep down in my heart, that my son would have his life back, and the long road of recovery was ahead of us. Eric's progress of improvement was very slow and we were given very little hope. He had a feeding tube, serial casting on his right leg and arm, botox injections, was given all available therapies, surgery on his right leg to extend his heel chord muscle, orthotics on his right leg and weights for his right hand to mention only a very minimum of everything he would experience in the next 4 months in hospitals and years to follow.

I refused to believe that Eric would never awake again or that he would not regain his youthful enthusiastic way of life. My family is very close and we remained with Eric, with a constant 24 hour vigil; playing his favorite music in his room, talking and reading to him, holding his hand, showing him pictures and surrounding him with as many familiar things from family and home as possible. I believed he survived this tragic accident for a reason, and we would some day know what that reason was. I believe I have found "some reason" as I have recently become a member of the Head Injury Association of North Dakota. Our Association is working very diligently to promote awareness, provide mentors (someone who has walked the winding path of Brain Injury to be there); and to help individuals and their families with all the unknowns. I would have given anything to have an organization like this that I could have contacted to obtain so much of the information I was so desperately seeking. For me and many families in my situation, there was no where to turn, no where to go, and I felt totally alone.

My parents were my family's godsend; as they stayed with us from the very first night and they brought their camper to the hospital parking lot for family members. My husband and I stayed in the family room in the hospital so we were close and with Eric. There was so much information to absorb, to try to understand, and so many questions that went unanswered which created a very lonely and fearful heart for me. I felt alone and that no one totally understood or knew what we were going through as we spent day after day, night after night by Eric's side for the next 4 months, in 3 progressive hospitals. I felt like I was the only mother on the face of the earth that was experiencing this. The Head Injury Association Of North Dakota has focused goals to help families who find themselves facing the long journey of recovering from a Traumatic Brain Injury; and my belief and hope is that no one will have to feel as alone, lost and helpless as I did.

It was very difficult to connect with someone and receive the information we were so desperately were seeking. Where is the best place for our son? What more can we do for him? Many nights I cried myself into an exhausted sleep praying for more information and longed for some comfort in knowing that we were doing everything possible for Eric. Then one night, one of Eric's nurses talked to me and asked me if I would like to talk to a family that had walked the road we were on, just one year previously. I said yes and the family visited us the next day. This visit rejuvenated my faith, attitude, and energy and belief that there was hope and I again found my strength and kept pushing and searching for everything we could possibly do for Eric.

Eric relearned everything slowly and regained his life back bit by bit with his unending determination and a great attitude! We were told his strong will, love for life; determination and stubbornness were on his side and still are today. The day of leaving the Gillette Childrens Hospital in St.Paul was a long awaited milestone. We were finally going home to begin yet another chapter in our lives. We live in a wonderful small community, with a small school where there was absolutely no previous experience with a student with a Traumatic Brain Injury. Eric had to have a full time aide with him because his balance wasn't 100%, and he hadn't regained the use of his right arm yet. The school was unable to locate an aide at that time so Eric's grandpa volunteered to go to school with him. My dad (Grandpa) had been with us the entire time so he was well aware of what Eric needed assistance with. He was with him for two months in school and assisted Eric with many things. When Eric was then able to be alone physically, but required a full time tutor to assist him with his studies we were faced again with a difficult match in a small community, but finally a full time tutor (a local past graduate and coach) was in school with Eric. Eric proudly walked with his class on Graduation Day; graduating with his McClusky High School Class in 2006 where he received an honorable plaque "Overcoming the odds" which was put together by his class of 6 students and the school. He received a standing ovation, and many hand shakes and hugs. He read the prayer at the graduation ceremony and there wasn't a dry eye in the entire gymnasium.

Then on to college, the next challenging chapter following a Traumatic Brain Injury. Eric wanted to be "normal" and wanted to move on with his life. He was accepted at UND and wanted desperately to be a physical therapist as he had a huge spot in his heart for therapy. He has attended four years of college part-time and has been working part time also. College has proved to be very, very difficult for Eric as he continues to struggle with his memory and cognitive abilities, therefore; he is currently taking a break from college and working fulltime at a job which he really likes and is proud to have, but his income will not provide for him to achieve his dreams of a good quality of living.

Employment for Individuals with Traumatic Brain Injury is yet another challenging chapter; as without a college degree it creates great hardship to find employment in the comfortable income level in most cases. Eric is facing the road of adult life ahead of him, and wants to be the best he can be. He has a great attitude, tremendous zest for life, and outstanding personality, but with his limited learning capabilities he continues to struggle and wants to be as independent as possible in college and work. Young adults with traumatic brain injuries are often capable of being independent as Eric is today; but they are still in need of guidance and assistance in many areas so that they may achieve a fulfilled and good quality of living. Now I ask myselfwhat can I do now to help my son? He is twenty- two and is a young man with a future of challenges because his dream has been changed. I know he will continue to move forward with his unending courage, and my hope is that there will be assistance available for Eric to take this next step, along with public awareness, enhanced knowledge, and continuing recovery, that Eric and all individuals with Traumatic Brain Injury can live a comfortable life, with assistance when required to sustain employment, and support; so they can live their lives to the fullest.

When I received the phone call from the North Dakota Head Injury Association and was asked if I would consider becoming a board member I immediately said yes I would become a board member and a mentor. I have been involved with some mentoring in the past eight years on a basis of someone knowing about Eric and myself.

We returned 2 years after Eric's accident to Gillette Children's Hospital in St.Paul when Eric had heel chord surgery on his right leg. We were connected with a family from Leeds, North Dakota; after I received a phone call from the Gillette Hospital. Lisa Anderson's daughter Hannah's accident was several years after Eric's and they were walking the same path we had. We visited them and Hannah was as much as inspiration to us as Eric was to them! Lisa is here today and is also on the board and is a mentor for the North Dakota Head Injury Association. We have become mentors to each other as well, through our friendship and being mothers helping and encouraging our children to overcome enormous odds with enduring strength.

I whole-heartedly believe that the best medicine for the individual and family of a traumatic Brain Injury is someone who has been there...walked that path of a lifelong challenge. The Head Injury Association Of North Dakota has put together valuable information, a care tote, have photo albums, diaries and most of all, understanding and support for individuals and families who will be walking the same winding path of surviving a Traumatic Brain Injury.....the difference isthe Head Injury Association of North Dakota will be there. It is so very important that the state Of North Dakota has available professional assistance in every area of the state to guide, assist and help individuals that have sustained a Head Injury; as they will live with their deficits for the rest of their lives.

I am asking you to please support SB # 2163 so that the lives of many individuals who have suffered Head Injuries can have available the assistance, guidance, and support they truly need to fulfill their dream to live their lives to their fullest capabilities.

Thank You.

'I want to be normal'

McClusky youth grateful for a second chance at life

By JILL SCHRAMM
Staff Writer
jschramm@ndweb.com

MCCLUSKY — Eric Boehm of McClusky is thankful to be alive. His family and friends are thankful, too, for what they consider to be a miracle.

It's been 1-1/2 years since Eric lay in a coma in St. Alexius Medical Center in Bismarck following a vehicle crash. Eric, 15, still undergoes therapy but he's nearing his goal.

"I want to be normal," he said. On May 17, 2002, Eric was moving his brother's Isuzu Rodeo home from the field on the family farm about 7:30 p.m. when something went wrong. The people who found the crashed SUV called the ambulance.

Eric, who had gone through the windshield, was hospitalized in critical condition with a brain stem injury and broken collarbone.

"The first 12 hours were very critical. We didn't know if he was going to make it," his father, Lee Boehm, said.

Eric didn't open his eyes for seven days. Then he opened them just long enough to blink.

"Lee and I were both sitting there. It was really exciting," said Rhonda Boehm, Eric's mother.

See PAGE 48 — Page 48



Just before his release home after four months in hospital and rehabilitation programs, Eric Boehm poses with the four casts he graduated through during that time.

Jill Schramm/Staff Writer

"Eric just looked right at me and blinked a few times then closed his eyes."

It was the beginning of what would be a long recovery.

Talking with a parent who had driven down that road before, Rhonda Boehm was urged to keep a diary. She didn't like the idea at first. But she began writing after being told the diary wasn't for her — it was for Eric.

The diary indicates Eric got off the ventilator on day nine. He left the intensive care unit on day 13 and lifted his head off the pillow, a sign of movement, on day 19. He stood for a couple of seconds on his own on day 33 and took his first two steps on day 50. He spoke his first words, in a whisper, on day 71.

Eric spent four weeks in St. Alexius, six weeks in a coma stimulation program at SCCI in Mandan and four weeks in intense rehabilitation at Gillette's Children's Hospital in St. Paul, Minn. He had suffered contusions on the left side of his brain, affecting his right side.

"We kept just a constant vigil," said Rhonda Boehm, who spent all but three hours of the first four months at her son's side, reading him Bible verses every night. Lee and Eric's grandfather and grandmothers were there most of the time as was Eric's older brother, Levi, now 18.

"They told us early on with Eric to stimulate him. So right away we got his music," Rhonda Boehm said. "That's where I learned to like his teenage music."

Eric's grandparents, Orrin and Mayola Holen of McClusky, later helped by reading or playing games with Eric.

Each week, a group of Eric's friends from McClusky would pile into a car to drive the 64 miles to Bismarck.

Even though Eric wasn't responsive initially, they would talk about things they knew Eric would be interested in and they tossed a football around. In time, Eric did respond and even participated in their football tosses.

help a little bit."

"It was exciting," Eric's cousin Shawn Holen said of watching Eric's recovery. One special moment came Aug. 2, 2002, when after months on a feeding tube, Eric was allowed a hamburger.

"That was hilarious," Shawn said, recalling how Eric wolfed the sandwich down.

Rhonda Boehm said Eric had been downcast about the rice that the hospital served as his first solid meal. When the nurse suggested he order a cheeseburger and fries from McDonalds, Eric pushed his mother toward the door with a request to go immediately.

During all the time the Boehms had to be away from home, they felt their community's support. Neighbors pitched in to help Lee get 1,220 acres seeded in eight hours. Lee's mother, Emma Boehm, looked out for Levi, who kept things functioning at home.

The Boehms' thankfulness extends to the McClusky volunteer ambulance squad, whom they credit for saving Eric's life the night of the crash.

"I think everybody in town prayed for Eric and our family," Mayola Holen said. "And not just in our town. They had all their relatives and friends praying. It went many different directions."

"We had a pile of cards every day," Rhonda Boehm added. Friends brought food to the family's camper, parked by the hospital. They hosted a benefit supper. Rhonda received a basket of personal-care items, and her brothers in the family business gave her unlimited time off from her job.

The support from friends was one reason the Boehms entered Eric in rehabilitation in Mandan rather than going directly to St. Paul.

"Everybody could still visit here often, which they did," Rhonda Boehm said.

Eric underwent occupation, physical, speech and pool thera-

py with us and that he has recovered as well as he has," she said. "I am thankful for all of his personality changes because some of them are kind of nice — kind of neat."

Although a little quieter, Eric's witty sense of humor shows through much more now, say those who know him.

Eric re-joined his classmates two weeks into the school year in the fall of 2002. Fellow students gathered in a school assembly to greet him with a standing ovation.

His poor short-term memory and unsteady balance still presented problems, though. Eric needed a full-time aide. Eric suggested his grandfather for the job.

The retired construction contractor with an eighth-grade education found himself back in the classroom.

"I didn't help him with anything except to go up and down the steps," Orrin Holen says with a smile. "I tried to help in algebra and I couldn't."

Holen got Eric safely through the first six weeks, though.

"It was fun," Eric said of having his grandfather with him.

Rhonda Boehm said having her father looking out for Eric gave her peace of mind. She knew there was no one as familiar with Eric's needs as someone who had been at Eric's side almost constantly from day one.

As Eric became more independent, his grandfather was replaced by a tutor, coach Kipp Sparrow. Last January, Eric had recovered well enough that he was able to attend classes independently.

His friends say they enjoy the

very full, said Shawn Holen, who has been commiserating with Eric since getting sidelined with a knee injury.

Eric no longer participates in basketball or football but he attends the games. He's recovered the use of his right hand to play alto saxophones in band.

"This summer I went to therapy in Bismarck twice a week and almost every weekend we would go over to our lake. I would go jet skiing and boating and we had all kinds of family get-togethers," Eric said.

This fall, he also got his driver's permit and went hunting, bagging six ducks and a goose.

Rhonda Boehm is showing her thankfulness for Eric's recovery by becoming a mentor to parents in the pediatric department at Medcenter One, where Eric still takes therapy. Eric tells the kids to work hard to get better and Rhonda talks to parents as someone who has been there and can offer hope.

"I just feel that's the least I can do. It makes me feel good, and I know it helps them," she said.

Early on, the pastor of her church had given her a Bible verse, Isaiah 40:31: "They that wait upon the Lord shall renew their strength. They shall mount up with wings as eagles. They will run and not be weary, and they shall walk and not faint."

"I just clung to that. It was so like Eric," Boehm said.

She still repeats the verse regularly with her son.

"How can I be thankful enough," she said. "Eric has recovered so well. God has been so gracious."

5

Senate Bill 2163 A Bill Relating to Traumatic Brain Injury

Chairman Weisz and members of the House Human Services Committee:

“The heart of the matter.” Possibly all my life I’ve heard and possibly you’ve heard all of your lives, this phrase, but I’d like you to consider the phrase “the brain of the matter.” Here, today, the heart of the matter is the brain and the care of its “owners”--us. “The brain of the matter” is that each brain is as unique as a finger print, but obviously infinitely more complex. Likewise, each individual brain injury, along with its variable causes, severity and points of location, is unique. “The brain of the matter” is our brains have commonalities; within the brain are controls for emotionality, movement, sight, hearing, memory...all we do... all we say.. all of “us”, until something causes a disruption. Even then, it is more and more discovered that, especially with timely intervention, functions most often can improve over time--that is, timeliness is key to the optimum recovery. Timely knowledge of and access to resources ... key.

A tragic example of severe injury was brought to us in Gabby Giffords. Even in the midst of terrible tragedy she had access, thank goodness, to great care and great resources--but that is not so for many others especially in follow up care. Sadly enough, too, one can have a brain injury that is not recognized and is not visible--hidden within one’s skull--and its often not understood by the persons themselves as a danger. This was evidenced in the story of Natasha Richardson, the actress, who suddenly died after an accident on the ski slopes, a couple of years ago. Insidious, also, are the invisible injuries from the so-called “mild brain injuries” which also can cause behavioral and other changes that the person may little expect or sometimes understand especially in view of having had an injury. To compound the effect, these changes may cause the negative judgments and actions of others, which further undermines the person’s success in life.

Each of us and our loved ones someday will be in a situation beyond our control, be it like the other day, the weather and icy roads, a fire alarm, or maybe only at the end of days, but whatever the cause, it is good to have guidance and support in matters of great importance and great need. I hope you support this bill. “

For me, this is “the heart of the matter”, “the heart of the brain”, and for me, as a family member, “a matter of the heart” and as a citizen, a matter of the common good.

Thank you. If you have any questions, I’ll be glad to answer.

Elaine Grasl
7314 Sunshine Lane
Bismarck, ND 58503



P.O. Box 2081
Bismarck, ND 58502-2081
701.222.1854
veronica.zietz@thearcofbismarck.org
www.thearcofbismarck.org

H 10

Testimony of Support Senate Bill 2163

House Human Services Committee

March 14, 2011

Good morning Chairman Weisz and members of the Human Services Committee. My name is Veronica Zietz (#99) and I am the Executive Director at The Arc of Bismarck. I'm here today on behalf of both The Arc of Bismarck and The Arc of Cass County. The Arc is an organization that provides education and advocacy to people with disabilities to foster empowerment and full inclusion in the community.

The Arc supports Senate Bill 2163, because it provides an appropriation for much needed supports in the area of traumatic brain injury (TBI). TBI is a complex disability with a wide range of symptoms from headaches and memory loss to paralysis and cognitive delays. After an individual with TBI is initially treated and stabilized the next phase is rehabilitation, which mostly works to restore lost functions, though some are never restored. I believe Senate Bill 2163 would support recovery efforts for individuals with TBI.

The Centers for Disease Control reports more than 1.7 million people sustain a traumatic brain injury in the US each year, with most individuals never receiving the necessary services and supports for rehabilitation. By allocating funds for case management services as suggested in this bill, the state would have the opportunity to provide much needed services for individuals with TBI. In addition, the state would have the opportunity to monitor current cases and make efforts for prevention.

I urge the committee to support Senate Bill 2163. Thank you for your time and consideration.

7

House Human Services Committee
Sixty-Second Legislative Assembly of North Dakota
Senate Bill No. 2163
March 14, 2011

Good morning, Chairman Weisz and Members of the House Human Services Committee, my name is Craig Sinclair. I am a lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project (P&A) is an independent state agency that acts to protect people with disabilities from abuse, neglect, and exploitation, and advocates for the disability-related rights of people with disabilities. I am offering testimony in support of Senate Bill 2163 as submitted to you today.

As a disability rights organization, P&A has continued to see referrals in which individuals with traumatic brain injuries need support to navigate the service delivery system. Many of these have been in the priority areas of community integration, healthcare and employment.

Through SB 2198 during the 2009 Legislative session, lawmakers took significant strides in filling identified gaps within the Traumatic Brain Injury (TBI) service system. Services have continued to develop and have achieved many goals. SB 2163 takes another important step forward in improving the TBI delivery service system.

SB 2163 would enable the Department of Human Services to provide traumatic brain injury case management services in eastern North Dakota. Access to case management was identified as a vital service in the "Findings from the North Dakota Assessment of Traumatic Brain Injury Needs and

Resources" study completed by the University of North Dakota's School of Medicine Center for Rural Health in 2005.

TBI case managers would be able to develop and coordinate a tailored service plan, identify and connect with service providers, and regularly review the support plan in place to ensure that each individual would receive the highest level of customized service possible. Case managers would be able to assist with procurement of services and supports for development of independent living skills, homemaking, personal care services, supported employment, transportation, behavioral services, and day program services.

The North Dakota Protection & Advocacy Project supports Senate Bill 2163 and encourages you to make a "do pass" recommendation to the full Senate. Thank you. I would be happy to answer any questions that you may have for me.