2009 SENATE HUMAN SERVICES

SB 2198

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-21-09

Recorder Job Number: 7439

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee opened the hearing on SB 2198 relating to the development and maintenance of a traumatic brain injury registry and the provision of services to individuals with traumatic brain injury; and to provide an appropriation.

Sen. Tim Mathern (District 11) introduced SB 2198 and suggested an amendment addressing a drafting error. See attachment #1.

Senator Dever was confused about the appropriations and the Department of Health and the Dept. of Human Services.

Sen. Mathern said he was hoping the committee would be helpful in the process. One of the things they struggled with was should it all be in the Dept. of Human Services or Department of Health. It is a continuing discussion. He hoped the departments would have suggestions with that.

Bruce Murry (ND P&A) testified in support of SB 2198 and the amendment suggested by Sen. Mathern.

Mary Simonson (Director, Open Door Center /Valley City – HI Soaring Eagle Ranch) testified in favor of SB 2198 – Attachment #3.

Senator J. Lee asked what NISH was.

Ms. Simonson – National Institute for the Severely Handicapped. It provides contracts for people with severe disabilities.

Senator J. Lee asked if there are any existing programs, like the one in Minot with the workshop, that aren't specifically dedicated to individuals with traumatic brain injury. Is there a limited venue in which individuals with TBI can find jobs?

Ms. Simonson – Typically people with brain injury, especially with the more severe injury, have a problem with stamina so to work 20 hours is often very difficult for them. Because of that it is hard for them to get services from that.

Lisa Anderson and daughter Hannah (Leeds, ND) testified in favor of SB 2198 and told their personal story.

Cheryl Hanson testified in support of SB 2198 and told her personal story.

Elaine Grasl (member of District 47) testified in support of SB 2198 and told her story. Attachment #5.

Senator Dever said it seemed there might be a problem with the doctors making the diagnosis.

Ms. Grasl – Yes, I believe so.

James Yantzer testified in support of SB 2198 and told his personal story. Attachment #6.

There was no opposing testimony.

Susan Wagner (Dept. of Human Services) provided testimony about the history of services and activities related to individuals who have sustained a traumatic brain injury (TBI) in ND. Attachment #7.

Senator Dever asked (1) if the department was involved in the development of this bill and

(2) if the money for the bill is in the Governor's budget, and if not, if it was proposed to the department and from the department to the governor.

Ms. Wagner – This is not included in the governor's at this time. The department has not been directly involved in the development.

Senator Dever – Are the proposals in this bill consistent with the program you just described? Would it be duplicative?

Ms. Wagner said what they are focusing on with the grant is infrastructure building and more education and awareness.

Senator J. Lee asked if there was anything with the medical school on curriculum or primary care providers who would be seeing these individuals in the first place.

Ms. Wagner said her understanding is that their project director for this grant is working with the school of medicine to become involved in some of the grand round discussions that are held on a regular basis.

Senator Marcellais asked if she had statistics for Native Americans.

Ms. Wagner said she didn't have them with her but would provide it for the committee. (Additional information she provided. Attachment #9)

Diana Read (Department of Health) presented information on SB 2198. Attachment #8.

Senator J. Lee said it would be helpful to the committee to have some estimates on what the costs might be. She was interested in seeing people from both the Department of Health and Dept. of Human Services discuss how to make sure there isn't a redundancy or overlapping of responsibilities.

Senator Dever said there is a cancer registry in the Department of Health asked if there were other examples.

Ms. Read said they are varied. The cancer registry gets federal funds, has 3.5 FTE's attached to it. Immunization has a registry.

Senator J. Lee asked if she would provide information on where the money comes for those registries. (That information was provided – Attachment #10.)

The hearing on SB 2198 was closed.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-27-09

Recorder Job Number: 7921

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee opened SB 2198 for committee work.

The committee reviewed the testimony from the hearing and the amendment proposed by Sen. Mathern. An option with the amendment was to not put it on and send it to appropriations and let them add it.

There was general discussion on prioritizing.

Senator J. Lee reported that she has some figures and information she wanted to give to legislative council for an amendment. She said she would visit with them about it.

Committee work on SB 2198 was recessed until **Senator J. Lee** could get that amendment drafted from legislative council.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-28-09

Recorder Job Number: 8050 (Meter 03:45)

Committee Clerk Signature Mary K Monson

Minutes:

Senator J. Lee opened SB 2198 for committee work and provided the committee with an amendment she had drafted by legislative council dated 1-28-09 – Attachment # 11.

She had it drafted to have a place to start but also to maintain the integrity of the concept of traumatic brain injury services. Part of it is removing the section that talks about the brain injury registry.

She asked Arvy Smith from the health department if she had comments she wanted to make about it.

Ms. Smith (Department of Health) said they got an estimate form ITD on what the trauma registry would cost. It's about $56,000. She talked about who should house the registry. The thought was since Dept. of Human Services would be the prime user of this it might be better housed in that department.

Senator J. Lee asked if she saw enough value in the TBI registry to include it.

Ms. Smith said she couldn't answer that. The Department of Health doesn't have a need for it.

Senator Dever didn't see what else they were doing except the registry to reduce the appropriation.

After more review of the amendment by the committee and not seeing where the reductions were **Senator J. Lee** said she would visit more with legislative council about it.

Committee work was recessed.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 2-04-09

Recorder Job Number: 8606

Committee Clerk Signature Mary K Morson

Minutes:

The committee was brought to order to discuss SB 2198.

Senator J. Lee reported that Bruce Murry was present to help them figure out the funding with the amendments.

Mr. Murry referred the committee back to his testimony. Page 4 is a worksheet of what the funds would be used for within the appropriation to the Dept. of Human Services. The two largest items are personal care services and other related within the personal care option to the Medicaid state plan and the service payments to the elderly and disabled program.

The idea emerged that it might be better to rely on the appropriations to fund the existing programs rather than creating a dedicated funding source within this bill.

He talked about reducing the contract for informal support services.

The funding for the brain injury registry was also removed.

Senator Heckaman moved to adopt the amendments.

Seconded by **Senator Erbele**.

Roll call vote 5-0-1 (The vote was left open for **Senator Dever**).

Final vote 6-0-0. Motion carried.

Senator Heckaman moved a **Do Pass as Amended on SB 2198 and rerefer to Appropriations.**

Seconded by **Senator Erbele.**

Roll call vote 5-0-1 (Vote was left open for **Senator Dever**.)

Final vote 6-0-0. Motion carried.

Carrier is **Senator J. Lee**.

FISCAL NOTE

Requested by Legislative Council
04/29/2009

Amendment to: Engrossed SB 2198

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.*

	2007-2009 Biennium		2009-2011 Biennium		2011-2013 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			$330,000		$343,200	
Appropriations						

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

2007-2009 Biennium			2009-2011 Biennium			2011-2013 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

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).*

This bill relates to the provision of services to individuals with a traumatic brain injury, to include outreach, training and quality control measures.

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.*

The bill requires the Department to provide outreach services and conduct public awareness efforts regarding the prevention and identification of traumatic brain injuries along with quality control activities and training. The bill also requires the Department to contract with entities to provide informal supports, such as information sharing and referral services, mentoring, and training to those with such an injury. The Department is also required to provide or contract for increased and specialized vocational rehabilitation and consultation. When these services do not meet the individuals' needs, the Department is to provide or contract for social and recreational services, including day supports.

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 is estimated as follows:
Public awareness - $5,460; Training and Quality Assurance - $57,600 Informal Supports - $112,200; Vocational Rehabilitation - Extended Services - $111,540; and Social Recreation - day supports - $43,200.

   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 bill contains an appropriation to fund the expenditures.

Name:	Brenda M. Weisz	**Agency:**	DHS
Phone Number:	328-2397	**Date Prepared:**	04/29/2009

FISCAL NOTE

Requested by Legislative Council
03/24/2009

Amendment to: Engrossed SB 2198

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.*

	2007-2009 Biennium		2009-2011 Biennium		2011-2013 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			$864,000		$898,560	
Appropriations			$864,000		$898,560	

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

2007-2009 Biennium			2009-2011 Biennium			2011-2013 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

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).*

This bill relates to the provision of services to individuals with a traumatic brain injury, to include outreach, training and quality control measures.

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.*

The bill requires the Department to provide outreach services and conduct public awareness efforts regarding the prevention and identification of traumatic brain injuries along with quality control activities and training. The bill also requires the Department to contract with entities to provide informal supports, such as information sharing and referral services, mentoring, and training to those with such an injury. The Department is also required to provide or contract for increased and specialized vocational rehabilitation and consultation. When these services do not meet the individuals' needs, the Department is to provide or contract for social and recreational services, including day supports.

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 is estimated as follows:
Public awareness - $24,000; Training and Quality Assurance - $162,000; Informal Supports - $150,000; Vocational Rehabilitation - Extended Services - $480,000; and Social Recreation - day supports - $48,000.

   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 bill does not contain an appropriation section and funding would be necessary to carry out the requirements of

this bill.

Name:	Brenda M. Weisz	**Agency:**	DHS
Phone Number:	328-2397	**Date Prepared:**	03/24/2009

#1

90495.0301
Title.

Prepared by the Legislative Council staff for
Senator Mathern
January 20, 2009

PROPOSED AMENDMENTS TO SENATE BILL NO. 2198

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

Page 3, after line 6, insert:

"**SECTION 7.** A new section to chapter 50-06.4 of the North Dakota Century Code is created and enacted as follows:

Vocational rehabilitation and consultation. The department shall provide or contract for the provision of increased and specialized vocational rehabilitation and consultation to individuals with traumatic brain injury. Services under this section include extended support for individuals at risk of losing their employment upon exhausting their vocational services."

Renumber accordingly

90495.0302
Title.0400

Prepared by the Legislative Council staff for
Senator J. Lee
January 28, 2009

2-5-9

PROPOSED AMENDMENTS TO SENATE BILL NO. 2198

Page 1, line 1, replace "three new sections to chapter 23-02.1, two" with "five"

Page 1, line 2, remove the first comma

Page 1, line 3, remove "development and maintenance of a traumatic brain injury registry and the"

Page 1, remove lines 8 through 12

Page 1, line 13, replace "23-02.1" with "50-06.4"

Page 1, line 18, replace "23-02.1" with "50-06.4"

Page 3, after line 6, insert:

"**SECTION 6.** A new section to chapter 50-06.4 of the North Dakota Century Code is created and enacted as follows:

Vocational rehabilitation and consultation. The department shall provide or contract for the provision of increased and specialized vocational rehabilitation and consultation to individuals with traumatic brain injury who receive case management for personal care services. Services under this section include extended support for individuals at risk of losing their employment upon exhausting their vocational services."

Page 4, line 20, replace "$2,634,864" with "$864,000"

Page 4, remove lines 24 through 29

Renumber accordingly

Date: 2-4-09

Roll Call Vote #: 1

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2198

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 90495.0302

Action Taken ☐ Do Pass ☐ Do Not Pass ☐ Amended ☐ Rerefer to Appropriations

☒ Adopt Amendment ☐ Reconsider

Motion Made By Sen. Heckaman Seconded By Sen. Erbele

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V.Chair	✓		Senator Richard Marcellais	✓	
Senator Dick Dever	✓		Senator Jim Pomeroy	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment

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

Date: 2-4-09

Roll Call Vote #: 2

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2198

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 90495.0302 Title .0400

Action Taken ☒ Do Pass ☐ Do Not Pass ☒ Amended ☐ Rerefer to Appropriations

☐ Adopt Amendment ☐ Reconsider

Motion Made By Sen. Heckaman Seconded By Sen. Erbele

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V.Chair	✓		Senator Richard Marcellais	✓	
Senator Dick Dever	✓		Senator Jim Pomeroy	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment Senator J. Lee

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

REPORT OF STANDING COMMITTEE

SB 2198: Human Services Committee (Sen. J. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2198 was placed on the Sixth order on the calendar.

Page 1, line 1, replace "three new sections to chapter 23-02.1, two" with "five"

Page 1, line 2, remove the first comma

Page 1, line 3, remove "development and maintenance of a traumatic brain injury registry and the"

Page 1, remove lines 8 through 12

Page 1, line 13, replace "23-02.1" with "50-06.4"

Page 1, line 18, replace "23-02.1" with "50-06.4"

Page 3, after line 6, insert:

"**SECTION 6.** A new section to chapter 50-06.4 of the North Dakota Century Code is created and enacted as follows:

Vocational rehabilitation and consultation. The department shall provide or contract for the provision of increased and specialized vocational rehabilitation and consultation to individuals with traumatic brain injury who receive case management for personal care services. Services under this section include extended support for individuals at risk of losing their employment upon exhausting their vocational services."

Page 4, line 20, replace "$2,634,864" with "$864,000"

Page 4, remove lines 24 through 29

Renumber accordingly

2009 SENATE APPROPRIATIONS

SB 2198

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2198

Senate Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: 02-13-09

Recorder Job Number: 9550

Committee Clerk Signature

Minutes

Vice. Chairman Bowman called the committee back to order at 3:30 on SB 2198 regarding the provision of services to individuals with traumatic brain injury.

Senator Judy Lee, District 13, Fargo, introduced SB 2198 providing written testimony #4, stressing the importance of the bill. She indicated right now we are looking at veterans but they have lifelong issues. Veterans fall through the cracks in the other programs. The policy committee looked at this but dropped the fiscal note; we would encourage this committee to give it consideration.

Senator Mathern, District 11, Fargo, explained the bill further, testifying in support of SB 2198. He provided written testimony # 1 which is a summary of Senate Bill 2198.

Additional written testimony # 2 was distributed (Hannah's story).

Vice Chairman Bowman questioned whether there is any money for this program in our budget now and whether we have been funding the center south of Valley City.

Senator Mathern stated we have been doing some funding. The amount reflects the amount that the Human Services provides.

Vice Chairman Bowman questioned whether it is in governor's budget.

Senator Mathern thought a fair amount is, but not all of it. The amount we have left is not in the governor's budget.

Senator Kilzer questioned whether this is included in the Health dept budget?

Senator Mathern right now services are not funded or delivered by the Department of Health.

Senator Kilzer stated there have been studies like this in the past and we now have two places that provide this service to people who need this.

Senator Mathern agreed. The emphasis is to see if we can have more of these folks stay in their homes and not be in a facility and so bill would be helpful.

Bruce Murry, North Dakota Protection and Advocacy Project (P&A) testified in support of SB 2198, providing written testimony # 3.(14.10)

Elaine Grasl from District 47 (15.57) testified in support of SB 2198 and shared circumstances of her own children and their injuries She indicated she assumed her son had whiplash injuries. She stressed that soldiers coming back can look normal and may act normal, but ...

Senator Christmann questioned the kind of help she gets in her situation.

Elaine Grasl responded that she didn't call in help indicating when you have been through a system that didn't believe you, it is hard. Her son eventually got his GED.

Senator Warner questioned Maggie Anderson asking her to discuss the finances of this and how much of this could be covered by Medicaid, federal help and veterans.

Maggie Anderson, Medical Services, stated the funding in this bill is not Medicaid. She listed several areas that could provide services. There is no budget specifically for traumatic brain injury. She then addressed the issue of returning veterans, whether they are eligible for Medicaid and that coverage is very limited. 23.10

Senator Christmann questioned the personal care service and how much was left in the 07-09 budget.

Maggie Anderson responded that she can provide the information but doesn't have that with her. She did indicate they would not have a lot of turn back. She further discussed the different programs. (26.54)

Vice Chairman Bowman closed the hearing on SB 2198.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

Senate Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: February 16, 2009

Recorder Job Number: **9602 (starting at 16:55)**

Committee Clerk Signature Rose Laning

Minutes:

Senator Holmberg opened discussion on SB 2198 relating to the development and maintenance of a traumatic brain injury registry.

Senator Mathern said that persons who are institutionalized, but develop skills and go into the workforce will have the support so they can continue work and stay employed. There has been a turning of these people in and out of the system. The other part of the bill that offered a full range of services has been taken out.

Handed out an email from Bruce Murry, Public Policy Advocate

(see attached #1)

V. Chair Bowman: This supports someone who is trained for a job, but does the funding for the bill ever quit? .

Senator Mathern: The goal is to provide support as long as they need it to stay on the job; otherwise they go to institutional care. Some people are able to stay employed permanently and no longer need help, but employment is still better than total dependence.

V. Chair Bowman: How many people fall into this category?

Senator Mathern: We're talking about 40 more people who would become employed rather than fulltime dependence. Brain damaged people need assistance, so that when they begin work, they can continue working.

Senator Christmann The $24 M dollars for personal care services didn't get used up. It's an entitlement, so even in the next biennium if it gets used up, it has to find money somehwere. I think it's important to address brain injury people, but are we already doing this. If we are, there's no sense just adding more bills.

Senator Mathern: The services described by Maggie Anderson is for services on person who is totally independent and said it's important to take the other step and keep those people out of those services.

Senator Christmann asked if this bill was his idea or was it the governor's consultation with Human Services and Health Dept. and they looked at it and felt it wasn't necessary or the services were already available and they rejected it.

Senator Mathern replied that a task force was formed with all organizations that provided services, and both he and Sen. Lee were on committee. Then the task force asked legislators to introduce bill.

Senator Kilzer asked about the appropriation on other side whether it was in the House Human Services or somewhere.

Senator Mathern replied that the appropriation for the human services is in the House. This bill says those folks who can move out of the care cycle and go to work, so they don't have to come back to budget area of human services.

Senator Kilzer commented that he wishes the funding were in this bill, because how do you separate the two groups?

Senator Mathern People where there is greatest likelihood where work could continue when in work environment.

Senator Kilzer stated that it costs $20,000 per patient per biennium and asked if there had been anything in the past for this category?

Senator Mathern replied that in the past, there has been funding to keep people into institutions. This is to help folks so they can go to work. They won't need services if we can keep them on job.

Senator Fischer said the traumatic brain injury bill should be left in Human Services since it is the lead agency and could be melded into their budget.

Senator Mathern said part of goal is to make sure all the other departments of government are connected, not just Human services. Things in original bill are no longer there. Create work supports.

V. Chair Bowman If there is money in the Human Services budget for the people who are on this program that are dependent and now we train them to get job and we put money into that situation. Isn't that a wash to the Human Services budget because those are no longer clients of Human Services. Now they are in a different field, so the money in Human Services should just transfer over to this program – unless this is way more expensive than the Human Services program.

Senator Robinson said they expect the numbers to increase, and there is a need for a residential facility since some need 24 hour supervision.

Senator Fischer replied if that's the case, save SB 2198 and pull the funding for the program out of the Human Services budget. Now we're creating another level.

Senator Mathern said this is an informal support. It's another level of understanding as brain injury is to be recognized because there is a difference between mental illness, traumatic brain injury and intellectual disability..

Senator Krauter moved Do Pass.

Senator Wardner seconded.

A Roll Call vote was taken. Yea: 9 Nay: 5 Absent: 0

It goes back to Human Services.

Date: 2-16-09

Roll Call Vote # 1

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2198

Senate **Senate Appropriations** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended

Motion Made By Sen. Krauter Seconded By Sen. Wardner

Senators	Yes	No	Senators	Yes	No
Sen. Ray Holmberg, Chairman	✓		Sen. Aaron Krauter	✓	
Sen. Bill Bowman, VCh		✓	Sen. Elroy N. Lindaas	✓	
Sen. Tony S. Grindberg, VCh		✓	Sen. Tim Mathern	✓	
Sen. Randel Christmann		✓	Sen. Larry J. Robinson	✓	
Sen. Tom Fischer		✓	Sen. Tom Seymour	✓	
Sen. Ralph Kilzer		✓	Sen. John Warner	✓	
Sen. Karen K. Krebsbach	✓				
Sen. Rich Wardner	✓				

Total Yes 9 No 5

Absent 0

Floor Assignment Human Services

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

REPORT OF STANDING COMMITTEE

SB 2198, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman) recommends **DO PASS** (9 YEAS, 5 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2198 was placed on the Eleventh order on the calendar.

2009 HOUSE HUMAN SERVICES

SB 2198

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. **SB 2198**

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: **9 March 2009**

Recorder Job Number: 10474

Committee Clerk Signature

Minutes:

Chairman Weisz opened the hearing of SB 2198.

Senator Tim Mathern, District 11, introduced the bill. **(Testimony 1)**

Representative Porter: In Section I we are saying the Department of Human Service; shouldn't the prevention and identification activities contribute back to the Department of Health?

Senator Mathern: In the senate hearings we came to the conclusion that it was best to focus this on one agency. We talked about the appropriations that would have to go to the Department of Health and the Department of Human Service and came to the conclusion to narrow that down and to deal with the Department of Human Services

Representative Porter: On page 2, section 3, what is that certain chapter of the Century Code?

Senator Mathern: It requires us to go to the public for bids. This situation really suggests there are some special service providers in the state so the Department has options for an exemption to make a choice of that other process in place.

Representative Conrad: How did you come up with the dollar amount?

Senator Mathern: It was the interim committee's work describing what would be comparable to other states. The Senate brought the focus down to rehabilitation services that permits people to stay in their homes and looking at what is the number of people that would be served. Essentially here we are increasing people's employability and increasing people's ability to stay on the job. The stimulus package was not yet released when we dealt with this bill.

Bruce Murry, lawyer with the ND Protection and Advocacy Project, testified in favor of the bill. **(Attachment 2)**

(He stopped in the midst of his testimony to allow Senator Lee to speak.)

Senator Judy Lee, District 13, sponsor, testified in favor of the bill. We recognize there is a tremendous need in this area especially with returning veterans. You will hear from others about that. We recognize that we couldn't do all that we would like to do. As is true with all budgets you have to figure out where to start. We tried to be really responsible in determining a good place to go with this. If you felt amenable to increasing the funding we would be supportive of that as well.

Representative Conrad: So it was the Appropriations Committee and not your Committee that took the money out?

Senator Lee: We took the money out. We wanted to have something to say about where the priorities are. In looking at the table full of bills we were trying to figure out where we could demonstrate a responsible attitude in the policy committee about moving forward and not jeopardize the survival of the entity itself. The policy committee was very involved as were the stakeholders in determining that this is a good place to start with this program and grow

something that needs to be looked at. We need to give help to those who are not able to entirely help themselves. That's really what we have here. This is a way to make people more independent and be able to live a fuller life.

Bruce Murry continued with his testimony.

Chairman Weisz: Is this different from current VR support or is it complementary?

Murry: Complimentary is the right term. Current VR services are oftentimes limited to about 18 months of services. If a person wouldn't be expected to achieve permanent self sufficiency or to be able to stay on the job for an unlimited period of time during the 18 months they usually can't even start. This provides funding so that if a person needs periodic tune ups for their work environment, the state is funding that so that VR can make the federal money available to provide the bulk of the intensive rehabilitation services. The $500 per month is based on an estimate of about $25 per hour for a job coach for about 20 hours per month. It is just an estimate and if voc rehab thought that number should be adjusted I would yield to their expertise.

(He continued with his written testimony.)

Representative Frantsvog: On attachment A, informal support it says "one professional . . ." could you explain what you are telling us there?

Murry: We are thinking that to have a private contractor to have a full time director who did these activities try to do some travel to visit people. They would gather the national resources and have the information ready when the person calls about a brain injury. He could also line them up with other families that have had some success perhaps in a mentoring type of relationship.

Representative Frantsvog: Is someone applying for that social security funding now?

Murry: I believe that voc rehab routinely applies for that when they are offering rehab to someone on social security.

Representative Frantsvog: So this would be an existing part of the revenue?

Murry: I'm thinking it would not be for these people because they probably haven't ever gotten started down the rehab road because of the disconnect on the back end with the extended services. If the extended services are not there the main rehab activity cannot begin. It would not be viable alternative without the extended supports. If you added in the extended supports it would be a viable partial offset of the costs.

Rebecca Quinn, UND Center for Rural Health, read the testimony of a survivor of a brain injury who was not able to attend: **Skip Miller, Williston ND. (Attachment 2)**

Representative Holman: I believe we all got a copy of that by email.

Representative Conrad: Are we in here helping university faculty to understand what's going on here? In the situations you are talking about people were trying to change their orientation in the system. They were worried about academics but not about people.

Quinn: That where the brain injury association would be a real vital part of providing that training and that information.

Lisa Anderson, Leeds ND, testified in favor of the bill. **(Attachment 3)**

Mike Remboldt, CEO of HIT, Inc. testified in favor of the bill. **(Attachment 4)**

Representative Conrad: Mr. Murry testimony was that there for 40 people it would be $480.0. If we had more money are there people who need the service beyond this point.

Remboldt: That's a hard one to guess. Sometimes it's a difference between how you screen.

Representative Conrad: We have a situation now where we have this money we are putting in to the bank and we also have the stimulus money. From your perspective is it okay to

provide a service today even though we might not provide it in three years or should never offer the service?

Remboldt: It is okay to do that. We have been providing service to people with brain injuries for a long time. I can't say that the requirement is going to go away. We know there is definitely a trend downward as time goes on as to the amount of support they need. It decreases the dollars required for that person. There is no harm in providing those services for a period of time to help all those people in transition.

Elaine Grasl testified in favor of the bill. **(Attachment 5)**

Susan Wagner, LSW, Human Services Program Administrator, provided information to the Committee. **(Attachment 6)**

Chairman Weisz: Do you have any idea how many people from ND suffer from TBI?

Wagner: That is a difficult one to answer. If you look at the fact sheet it talks about state population and brain injury. This is based on the population in 2004. It is the most current information I could get. It indicated that are 2281 TBI related emergency department visits per year. There are 431 TBI non fatal hospitalizations per year and 153 TBI related disabilities per year.

Representative Conrad: In the Senate they deleted the registry. Would that help us in planning?

Wagner: Our Department and the Department of Health would really work together to determine what numbers we have available in ND to work with and honestly a TBI registry would help.

Representative Conrad: How much money would that cost?

Wagner: We can provide that for you.

James Moench, executive director of ND Disabilities Advocacy Consortium, testified in favor of the bill. **(Attachment 7)**

There was no testimony in opposition to SB 2198.

Chairman Weisz closed the hearing.

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. **SB 2198**

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: **11 March 09**

Recorder Job Number: 10763

Committee Clerk Signature

Minutes:

Chairman Weisz opened discussion of SB 2198. $864.0 for support services for TBI.

Representative Conklin: I Move Do Pass.

Representative Holman: Second

Representative Frantsvog: This is new, correct?

Chairman Weisz: We have two TBI facilities.

Representative Frantsvog: Do we provide funding for them too. The residential treatment centers.

Chairman Weisz: Yes, those are for those in residential treatment. This is for support services for non-residential treatment where the goal was to keep them in work or get them jobs. We already are taking care of the severe cases in residential treatment centers.

Representative Conrad: I was really impressed with the HIT representative and what he said about getting people early and how if you work with them they would not need this. . . inaudible.

Chairman Weisz: How many are in the center in Mandan.

Representative Frantsvog: A total of 41 in both places.

Representative Kilichowski: There are only two places in ND: Valley City and Mandan. Are there others that would be able to contract to supply the services?

Chairman Weisz: I don't think the intent of this is necessarily that it would have to be those in residential treatment. It doesn't mean that HIT may not offer the support services, but obviously they have—I'm not sure what their role might be. It does not lock it in to these facilities. That was one of my concerns that the Department doesn't have to get an RFP or go through the bid process they could just contract. . . It's probably not a big deal. It would be a statewide service.

Representative Porter: The two main things with this bill: Page 3, section 7, my problem with this bill is and we talked about several times during this session about the coordination and the single point of access which each group doing it differently rather than having a true single point of access system in place. All of the groups want that but none of them are going to work together to have a single point of access. Here we are again with this group being the single access point for about 30-35 people across the state when it could be rolled in to the Alzheimer's type system. It is just that each group has to have their own point of entry program, public awareness and outreach when it could be a coordinated effort.

Representative Potter: I think you have a point and that might be a good study for next time to figure out how to do some coordination because we have all these different groups. There could possibly be some sort of organization to a single point of access.

Representative Conklin: I think there is a big need for somewhere people could go to find out where all these little niche groups are.

Representative Kilichowski: I agree.

. . . Unstructured discussion . . .re statewide program/point of entry.

Representative Nathe: Is this a bit of duplication of what the state is already doing?

Chairman Weisz: This is to be an expansion of certain programs like voc rehab. The intent is to go beyond what is currently available and provide support on and on-going basis since TBI is a lifelong condition.

Representative Potter: Just to add on—it's typically short term memory problems. This will help them get a job and keeping them on task and on that job. This service helps them continuously.

Representative Conrad: The numbers are $153 per year.

Representative Holman: One of the problems with TBI is the variability and severity of the brain damage. There is no pattern. The treatment has to be different for each individual.

Representative Damschen: I agree with concept that combining some of these, but I don't know that it can happen right now. I would hate to not do this for this specific need.

A roll call vote was taken on the DO PASS and rerefer to Appropriations.

Yes: 8, No: 5, Absent: 0. Representative Hofstad will carry the bill.

There was further open discussion about whether this project would qualify for stimulus package funding.

Date: 3-11-09

Roll Call Vote #:

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2198

House HUMAN SERVICES Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended

Motion Made By Rep. Conklin Seconded By Rep. Holman

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN ROBIN WEISZ		✓	REP. TOM CONKLIN	✓	
VICE-CHAIR VONNIE PIETSCH	✓		REP. KARI L CONRAD	✓	
REP. CHUCK DAMSCHEN	✓		REP. RICHARD HOLMAN	✓	
REP. ROBERT FRANTSVOG		✓	REP. ROBERT KILICHOWSKI	✓	
REP. CURT HOFSTAD	✓		REP. LOUISE POTTER	✓	
REP. MICHAEL R. NATHE		✓			
REP. TODD PORTER		✓			
REP. GERRY UGLEM		✓			

Total (Yes) 8 No 5

Absent 0

Bill Carrier Rep. Hofstad

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

DO PASS Re-Refer Approp.

REPORT OF STANDING COMMITTEE

SB 2198, as engrossed: Human Services Committee (Rep. Weisz, Chairman) recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (8 YEAS, 5 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2198 was rereferred to the **Appropriations Committee.**

2009 HOUSE APPROPRIATIONS

SB 2198

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

House Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: March 19, 2009

Recorder Job Number: 11234

Committee Clerk Signature C. Mae Kuehn

Minutes:

Rep. Weisz: SB 2198 is a bill for traumatic brain injury. It has a $864,000 Fiscal Note. $480,000 of the total is for jobs. It is targeting 40 persons. The next area is for informal support organization for $150,000. That would pay for professional/private contractor similar to Alzheimer's Assn., ARC, etc. to provide independent counseling and advocacy. The next amount of $24,000–public awareness, to make the public aware of TBI and who to contact for services. $48,000 is for day services and social and recreational services for clients. $162,000 is for training and quality assurance. The total then comes to $864,000.

We are seeing many veterans returning from Iraq with traumatic brain injuries. Once they are capable of getting a job, they come off VR. (3:23) Without support services, they may not be able to function at a level that will help them maintain a job.

Rep. Wald: (4:44) We all have empathy for returning veterans who suffer from TBI, but I understand the VA is already doing this. Are we duplicating efforts?

Rep. Weisz: That was part of our discussion. The continuing support isn't there. The intent was to expand and go beyond that. There's no question that the VA provides good services. This isn't duplicating that. It is going beyond that.

Rep. Kempenich: Did anyone bring up the Adjutant General's program that was started about a year ago?

Rep. Weisz: No, and they were there and testified during the hearing. This is specifically for Traumatic Brain Injury. Not the whole range of support services for our veterans.

Chm. Svedjan: This is not specifically for veterans. It is for anyone who suffered a brain injury?

Rep. Weisz: Correct.

Rep. Kreidt: Do we know how many people will be served?

Rep. Weisz: (7:00) The VR extended services is hoping to take care of 40 at $500\month. Informal support would be 200 individuals. I believe the estimates were around 150 individuals. The number is increasing because of returning veterans. Injuries are common as a result of falls and car accidents. The current program serves about 35 individuals.

Rep. Skarphol: How many of the 35 are military?

Rep. Weisz: We did not get that breakdown.

Rep. Skarphol: I have an extended family member who suffered, and I'm not sure that we shouldn't push the military to fund more of this that is a result of military service. I'm not sure this mechanism is right.

Rep. Metcalf: Not until 1995, did the military recognize there was a problem with TBI. If we are going to press the military to accept this, we may have 25 years to wait.

Rep. Delzer: (10:33) The reintegration program that was started should do some of this. Where are you going to find the caregivers? I don't know that they're out there. This really belongs in DHS. When I was on Human Resources section, most of the TBI injuries at that time were from motorcycle accidents. I have some problems with this bill the way it is designed.

Rep. Wald: Moved a Do Not Pass.

Rep. Kempenich: Seconded.

Discussion:

Rep. Skarphol: I would like a little input from the Human Services Subsection of what is included in the budget for TBI. I'm supportive of what they are trying to accomplish, but I'm not sure of supporting Section 9 with that appropriation.

Rep. Pollert: I do not have that information at hand. There are dollars appropriated for TBI programs and this would be an enhancement. I know we have VR (Vocational Rehabilitation) programs for it.

Rep. Weisz: That is correct. We already have special facilities for TBI. We have one in Valley City and one in Mandan. We already offer VR services to TBI people. The state is already providing a fair amount of TBI services. This is over and above.

Rep. Pollert: Are those the worst cases of TBI or are they trying to train them? (14:00)

Rep. Weisz: Those are typically at the highest level of injury. Sometimes they can transition out of those and get into some type of vocational rehab.

Rep. Pollert: So you are trying to fill in a gap?

Rep. Weisz: Ideally we want them to become functional members of society. This was to fill the gap to help them once they are in society and we can continue to keep them there and keep them out of facilities. The hope is to keep them functional so they don't regress and have to go back into the facility and require extended services.

Rep. Wald: There is someone in the back of the room who may have information.

Chm. Svedjan: What is the level of appropriation for TBI Services now and the population it serves?

Susan Wagner, Program Administrator, Division of Mental Health and Substance Abuse: (16:49) In terms of services, they are primarily served through the home and community based waiver services. They have to screen out at needing nursing home level care. This bill is in

reference to expanding support services for individuals with TBI related to employment. This would be beyond what we are able to do at this point. We do not have a traumatic brain injury registry or surveillance project in ND. It's very difficult to provide information about the specific numbers of people affected. Because we do not have a one-stop shop, individuals who have sustained an injury do not have a single place to go in order to obtain information. That's what the informal support organization funding could provide as well the public awareness in addition to the training and quality assurance. I would offer to get more information from Maggie Anderson if the committee so desires.

Chm. Svedjan: This bill is brought forth independent of the budget. The DHS did not see the need to do what this bill would do.

Ms. Wagner: A subgroup worked on drafting this legislation. DHS did prepare information as we were working on our budget but that was not included in the Governor's budget.

Rep. Metcalf: Is there any possibility you could give me the cost of keeping one TBI person in Valley City for one year.

Ms. Wagner: I could get that for you.

Rep. Kaldor: (20:14) Did the working group come up with the level of appropriation in this legislation? The $864,000?

Ms. Wagner: Yes.

Rep. Skarphol: I'm not sure that the Appropriations sections in either chamber has taken a hard look at the number. I would suggest we take Section 9 out of the bill, pass the bill out and put it into Conference Committee. That would give both sides some time.

Rep. Nelson: I believe Rep. Skarphol has a good idea.

I would make that a substitute motion.

Chm. Svedjan: We have a substitute motion to amend Section 9 out of SB 2198.

Rep. Metcalf: Seconded.

Voice Vote taken. (Vote 2) Motion carried.

Rep. Nelson: Moved Do Pass as amended.

Rep. Metcalf: Seconded.

A Roll Call vote was taken. (Vote 3) **Yes:** 17, **No:** 6, **Absent:** 2, (Representatives Bellew & Onstad).

Representative Nelson will carry the bill.

Date: 3/9/09
Roll Call Vote #: 1

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2198

Full House Appropriations Committee

☐ Conference Committee

Legislative Council amendment Number _____

Action Taken: ☐ Do Pass ☑ Do Not Pass ☐ As Amended

Motion Made By: Wald Seconded By: Kempenich

Representatives	Yes	No	Representatives	Yes	No
Chairman Svedjan					
Vice Chairman Kempenich					
Rep. Skarphol			Rep. Kroeber		
Rep. Wald			Rep. Onstad		
Rep. Hawken			Rep. Williams		
Rep. Klein					
Rep. Martinson					
Rep. Delzer			Rep. Glassheim		
Rep. Thoreson			Rep. Kaldor		
Rep. Berg			Rep. Meyer		
Rep. Dosch					
Rep. Pollert			Rep. Ekstrom		
Rep. Bellew			Rep. Kerzman		
Rep. Kreidt			Rep. Metcalf		
Rep. Nelson					
Rep. Wieland					

Total Yes _____ No _____

Absent _____

Floor Assignment: _____

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

90495.0401
Title.0500

Prepared by the Legislative Council staff for
House Appropriations
March 19, 2009

3/19/09

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2198

Page 1, line 3, after the semicolon insert "and"

Page 1, line 5, remove "; and to provide an appropriation"

Page 4, remove lines 21 through 25

Renumber accordingly

STATEMENT OF PURPOSE OF AMENDMENT:

This amendment removes the $864,000 general fund appropriation included in the bill.

Date: 3/19/09
Roll Call Vote #: 2

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2198

Substitute motion

Full House Appropriations Committee

☐ Conference Committee

Legislative Council amendment Number TBD

Action Taken: ☐ Do Pass ☐ Do Not Pass ☐ As Amended

Motion Made By: Nelson Seconded By: Metcalf

Representatives	Yes	No	Representatives	Yes	No
Chairman Svedjan					
Vice Chairman Kempenich					
Rep. Skarphol			Rep. Kroeber		
Rep. Wald			Rep. Onstad		
Rep. Hawken			Rep. Williams		
Rep. Klein					
Rep. Martinson					
Rep. Delzer			Rep. Glassheim		
Rep. Thoreson			Rep. Kaldor		
Rep. Berg			Rep. Meyer		
Rep. Dosch					
Rep. Pollert			Rep. Ekstrom		
Rep. Bellew			Rep. Kerzman		
Rep. Kreidt			Rep. Metcalf		
Rep. Nelson					
Rep. Wieland					

Total Yes _____ No _____

Absent _____

Floor Assignment: _____

If the vote is on an amendment, briefly indicate intent: Voice Vote - carries

Amend section 9 out of bill

Date: 3/19/09
Roll Call Vote #: 3

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2198

Full House Appropriations Committee

☐ Conference Committee

Legislative Council amendment Number TBD

Action Taken: ☑ Do Pass ☐ Do Not Pass ☑ As Amended

Motion Made By: Nelson Seconded By: Metcalf

Representatives	Yes	No	Representatives	Yes	No
Chairman Svedjan	✓				
Vice Chairman Kempenich	✓				
Rep. Skarphol	✓		Rep. Kroeber	✓	
Rep. Wald	✓		Rep. Onstad	—	—
Rep. Hawken	✓		Rep. Williams	✓	
Rep. Klein	✓				
Rep. Martinson	✓				
Rep. Delzer		✓	Rep. Glassheim	✓	
Rep. Thoreson		✓	Rep. Kaldor	✓	
Rep. Berg		✓	Rep. Meyer	✓	
Rep. Dosch		✓			
Rep. Pollert		✓	Rep. Ekstrom	✓	
Rep. Bellew	—	—	Rep. Kerzman	✓	
Rep. Kreidt		✓	Rep. Metcalf	✓	
Rep. Nelson	✓				
Rep. Wieland	✓				

Total Yes 17 No 6

Absent 2

Floor Assignment: Nelson

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

REPORT OF STANDING COMMITTEE

SB 2198, as engrossed: Appropriations Committee (Rep. Svedjan, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (17 YEAS, 6 NAYS, 2 ABSENT AND NOT VOTING). Engrossed SB 2198 was placed on the Sixth order on the calendar.

Page 1, line 3, after the semicolon insert "and"

Page 1, line 5, remove "; and to provide an appropriation"

Page 4, remove lines 21 through 25

Renumber accordingly

STATEMENT OF PURPOSE OF AMENDMENT:

This amendment removes the $864,000 general fund appropriation included in the bill.

2009 SENATE HUMAN SERVICES

CONFERENCE COMMITTEE

SB 2198

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

Senate Human Services Committee

☒ Check here for Conference Committee

Hearing Date: 04/20/2009

Recorder Job Number: 12020

Committee Clerk Signature Mary K Monson

Minutes:

Chairman J. Lee Opened the conference committee. All members were present. Requested that the house explain their amendments

Rep. Pietsch As the record shows, the house human services passed the bill as was presented to us by the senate with the dollars in it. As such, the bill was rereferred to appropriations. The house appropriations committee looked at it and decided that for at least the moment, they are going to take the money out. It came back to the floor and we all agreed that we liked the policy but the money wasn't there.

Chairman J. Lee So how do you provide the service if you don't have the money?

Rep. Pietsch I asked that same question. I think that it is still on their back burner, they have not given up on this. HB 1012 has not been completed yet. At this point I would at least like to give them some time and suggest that we meet again at a later date. Another question that I did get out of them is, they were looking at numbers that were given to them like 40 people here, and it is an expensive policy. They are looking at the possibilities of what money can be given or can be found hidden someplace. I request that we give them a little extra time.

Chairman J. Lee We did spend a fair amount of time getting acquainted with these programs. There is an increasing need for this with returning veterans. This is going to be a really big

issue. We do need to recognize the need to address this issue. Spoke about testimony given in the Senate committee hearing. We would hope that there would be a way to find some funding. Have you had any visits with the appropriation people on what areas are priorities? Or, are they kind of looking at the whole thing to figure out what they can do at this point?

Rep. Pietsch I believe they are looking all over. They have some amendments coming through apparently on HB 1012. One of them is for the military, which is something people are looking at right now. However, they could expand that, they don't need to leave it at just that. Right now their hands are tied a little bit. We were in agreement that we like the policy but we were leaving up to the appropriations committee.

Chairman J. Lee Any other comments from committee members at this point? Mr. Murry, do you have any observations?

Bruce Murry ND Protection and Advocacy. There are four areas of funding in the senate version of the bill and all of those policy areas are unchanged. The largest being the extended vocational supports, employment supports. The second largest is the quality assurance and training and more coordination within DHS not only on these services but on the ones they are already doing as well. The third area is the brain injury association, a similar nonprofit group to do matching of families to those that have had some successful recovery. The final, smallest funding area would have been for recreational/social services for a small number of people who are extremely isolated and do not have employment prospects. Among those, I think the informal services through a nonprofit can match people up may have the very highest bang for the buck. I would also recommend the enhancement training. We would recommend that the vocational number for forty people in each year might be a little difficult to achieve right from the get go. If you were to have a ramping up process, that might give you some flexibility.

Chairman J. Lee Mr. Murry might be a good resource to help work through some of these issues.

Rep. Pietsch They do have the copies and documentation. Whether or not you presented it or if it came through Rep. Weisz, that 40 is questionable. I know that they have talked about it. Talked about was is happening in the appropriations committee

Murry In my own personal opinion, speaking only for my own agency, I think that is important but I wouldn't put that at the top of my list. I think there might be other ways to do that.

Rep. Pietsch If you were going to put these five services in order of priority listing, how would you do that?

Murry I would recommend that the social be put at the end. I would recommend the informal support as the most important, the vocational support being the second most important and the quality assurance and training activities as third and the rest as fourth.

Rep. Pietsch At one particular point I think there was some reference to the ARC—Alzheimer based—were you thinking of using some of that funding?

Murry I would recommend more that it would be looked to as a model. Over time the ARC has become completely self-sufficient, I think that is what you would want the brain injury association or something similar to do over time. They really should be nongovernmental once they have their own money.

Chairman J. Lee I don't really see the TBI (traumatic brain injury) population fitting into the ARC or the Alzheimers population. They are all issues things but I think it is a distinct population that should be addressed in that fashion.

Rep. Pietsch I think they just meant those organizations more as models.

Rep. Nathe In the original senate bill the appropriation was for $2.6M dollars, was that going to be used on those five categories as well?

Murry The bulk of that money was to go for beefing up existing programs according to existing priorities. The senate human services checked into those programs and confirmed that they had not had turn anyone away last biennium. People who are already eligible now may or may not qualify again, we are not sure who will be involved next biennium. We were ok with using existing funds and then coming back if we needed more.

Rep. Nathe How do we get to 864,000 then?

Murry I can send a spreadsheet to the committee.

Chairman J. Lee Is there any further information needed? Adjourned the meeting until next week so that appropriations will have time to discuss the bill.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2198

Senate Human Services Committee

☑ Check here for Conference Committee

Hearing Date: 04.27.09

Recorder Job Number: 12307

Committee Clerk Signature Mary K Monson

Minutes:

Chairman J. Lee Opened the conference committee on SB 2198. All members were present. Introduced the information from Mr. Murry, see attachment #1.

Bruce Murry ND Protection and Advocacy. Explained attachment #1

Rep. Pietsch You mentioned something about the 15 were readily available, are they right here in Bismarck, Mandan....so it would be more of a pilot program?

Murry The people who would be readily available tend to congregate near Valley City and near Bismarck. They would be people who were formerly on the brain injury waiver but are now ineligible. The 15-40 are people we are pretty sure are out there and we hear about.

Rep. Nathe I have a question about the social and recreation, one thing, what is it?

Murry Another thing you may hear this called is day supports. This is for activities that do not have a direct vocational outcome. It may be something as simple as getting together for arts and crafts or something as complex as learning how to exercise (therapeutically). It is social and recreational programming. Whether that would ever lead to that person having more capabilities would be unknown which is why vocational services can't fund it. Spoke about different cases

Rep. Nathe How did you get to the number 10 as I see the first time around you did 40? Why did you stay at ten when everything else dropped?

Murry We recommend meaning that need is fairly well known once again in Valley City and Fargo. We could almost name names for this group of people which is why I did not recommend dropping it.

Chairman J. Lee Would you be willing to take a minute and refresh our memories about High Soaring Eagle Ranch and other TBI services in ND.

Murry Spoke about the High Soaring Eagle Ranch and other services

Chairman J. Lee Spoke about some of her personal experiences with people dealing with TBIs

Senator Heckaman While it is certainly a decrease from what we looked at earlier, I would guess that all of the organizations are in line with this and can come up with some programming and people to help with; I will go along with it. I would still like to see more money in there.

Rep. Pietsch I have worked with a number of people on this budget and they have those figures too but the most money that they have been able to find in appropriations is $330,000. That is a decrease. See attachment #2. Those were the dollars I was able to find which I said I would do. I guess the next step would be to move the amendment or discuss.

Chairman J. Lee Did you visit with any of the stakeholders about this number?

Rep. Pietsch I visited with appropriations and the appropriations had visited with the department. I did not visit with anyone else. I was interested in getting some dollars. We don't have to go back to appropriations if we pass it at $330,000.

Chairman J. Lee So nobody wants to lose the program but I am sure that it is a disappointment to everyone that we can't get to the $391,000. The trigger is not going to kick

in for the oil tax so there is going to be a lot more money available; it is just a matter of sitting on it.

Rep. Pietsch I think that is your option.

Rep. Nathe Next session we can have another run at that and increase that.

Rep. Pietsch The department did not come in support of this but they came with information. Maybe if this really works, then it will become a part of their budget next time.

Chairman J. Lee Just so you know that was done consciously, not because the department didn't want that in there but because we thought that having it as a free standing bill would give it greater exposure to other legislators. It means there gets to be hearing on that subject, it is not a line item in the budget. I do think we have accomplished that goal.

Rep. Pietsch That is a first step.

Chairman J. Lee I still think with these new programs it is a good idea to stick them outside of the budget not because it shouldn't be in the budget but so they get exposure.

Rep. Conklin Those of us that live north of 94 and west of 83 would like money once in awhile. (laughter)

Chairman J. Lee I think some of the concentration of people in Valley City came because of the people at High Soaring Eagle Ranch. Hopefully we won't ever have to serve lots of people with this program but this is a start and they do need support so that they can have a higher quality of life.

Senator Heckaman Just for the record, I think the money is out there for this and I am a little disappointed that appropriations couldn't see to fund it. I'm looking at some of the other bills that they are stacking money away at and it really disappoints me that they can't but $61,000 more in this. I will support it, but with regret.

Rep. Pietsch I move the **House Recede from its Amendments and Further Amend.**

Rep. Nathe Second

The Clerk called the role on the motion. **Yes: 6, No: 0, Absent: 0.**

Chairman J. Lee will carry the bill.

Date: 4-20-09

Roll Call Vote #: _____

2009 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB2198 as (re) engrossed

Senate Human Services Committee

☒ Check here for **Conference Committee**

Action Taken
- ☐ SENATE accede to House Amendments
- ☐ SENATE accede to House Amendments and further amend
- ☐ HOUSE recede from House Amendments
- ☐ HOUSE recede from House amendments and amend as follows

Senate/House Amendments on SJ/HJ pages(s) _____--_____

☐ **Unable to agree**, recommends that the committee be discharged and a new committee be appointed.

((Re)Engrossed) _____ was placed on the Seventh order of business on the calendar.

Motion Made By _____ Seconded By _____

Senators				Yes	No		Representatives				Yes	No
Senator J. Lee	P						**Rep. Pietsch**	P				
Senator Erbele	P						**Rep. Nathe**	P				
Senator Heckaman	P						**Rep. Conklin**	P				

Vote Count _____ Yes _____ No _____ Absent

Senate Carrier _____ **House Carrier** _____

LC NO._____._____ of amendment

LC NO._____._____ of engrossment

Emergency clause added or deleted _____

Statement of purpose of amendment _____

#2

90495.0402
Title.

Prepared by the Legislative Council staff for
Representative Pietsch
April 25, 2009

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2198

That the House recede from its amendments as printed on pages 1029 and 1030 of the Senate Journal and page 1047 of the House Journal and that Engrossed Senate Bill No. 2198 be amended as follows:

Page 4, line 22, replace "$864,000" with "$330,000"

Renumber accordingly

Date: 4-27-09

Roll Call Vote #: _____

2009 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB2198 as (re)engrossed

Senate Human Services Committee

☒ Check here for **Conference Committee**

Action Taken
- ☐ SENATE accede to House Amendments
- ☐ SENATE accede to House Amendments and further amend
- ☐ HOUSE recede from House Amendments
- ☒ HOUSE recede from House amendments and amend as follows

Senate/House Amendments on SJ/HJ pages(s) 1029 -- 1030

- ☐ **Unable to agree**, recommends that the committee be discharged and a new committee be appointed.

((Re)Engrossed) 2198 was placed on the Seventh order of business on the calendar.

Motion Made By Rep. Pietsch Seconded By Rep. Nathe

Senators				Yes	No	Representatives				Yes	No
Senator J. Lee	P			✓		Rep. Pietsch	P			✓	
Senator Erbele	P			✓		Rep. Nathe	P			✓	
Senator Heckaman	P			✓		Rep. Conklin	P			✓	

Vote Count 6 Yes 0 No 0 Absent

Senate Carrier Sen. J. Lee **House Carrier** Rep. Pietsch

LC NO. 90495 . 0402 of amendment

LC NO. _____ . _____ of engrossment

Emergency clause added or deleted _____

Statement of purpose of amendment _____

REPORT OF CONFERENCE COMMITTEE

SB 2198, as engrossed: Your conference committee (Sens. J. Lee, Erbele, Heckaman and Reps. Pietsch, Nathe, Conklin) recommends that the **HOUSE RECEDE** from the House amendments on SJ pages 1029-1030, adopt amendments as follows, and place SB 2198 on the Seventh order:

That the House recede from its amendments as printed on pages 1029 and 1030 of the Senate Journal and page 1047 of the House Journal and that Engrossed Senate Bill No. 2198 be amended as follows:

Page 4, line 22, replace "$864,000" with "$330,000"

Renumber accordingly

Engrossed SB 2198 was placed on the Seventh order of business on the calendar.

2009 TESTIMONY

SB 2198

#1

Human Services Committee

January 21, 2009

Senator Tim Mathern

Madame Chairman Lee and Members of the Human Service Committee

My name is Senator Tim Mathern. I am a Fargo resident with a social work background and I am here to introduce SB 2198. Passage of this bill will give us more information about the prevalence of traumatic brain injury and expand services to individuals and families dealing with traumatic brain injury.

I served on a statewide committee this past interim and became convinced that we need to do more to address the specific need that persons with brain injuries have. Our past efforts often included this population in our services to persons with intellectual disabilities or mental illness which is not always appropriate. SB 2198 is the expression of the committee's work in the public policy aspect of their deliberations.

Thank you for the attention you will be giving to presenters coming before you. I ask for the opportunity to see this bill in the Appropriations Committee by your Committee giving this bill a Do Pass recommendation and referring to the Appropriations Committee.

Thank you for your consideration.

#12 #12

TESTIMONY – PROTECTION AND ADVOCACY PROJECT

BILL 2198 (2009)

SENATE HUMAN SERVICES COMMITTEE

Honorable Judy Lee, Chairman

January 21, 2009

Chairman Lee, and members of the Senate Human Services Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A). P&A recommends the policy and funding priorities of SB 2198 and supports an amendment to address a drafting error.

INTRODUCTION

You and all the North Dakotans you serve and care about are at daily risk of moderate to severe brain injury. If so injured, your journey to recovery may feel like "feast or famine."

If you sustain a serious brain injury, civilian emergency medical treatment is better able than ever to help you survive. Military medicine, along with vastly improved armor and equipment, saves lives that would likely have been lost in previous conflicts. The best rehabilitation programs and facilities the world has ever seen are available to help you recover many basic abilities. When your rehabilitation begins to plateau, you approach a fork in the road.

If you still technically qualify for nursing facility level of care, you might receive specialized TBI services to continue your recovery under a Medicaid Waiver. If not, government and informal services specialized for TBI largely end. People nearest the threshold of nursing facility care fall into the deepest crack.

This bill partially fills this crack using three main tools. First, it establishes new specialized services to help survivors continue in their recovery. Second, it refers survivors to existing services, and ensures those systems have the resources to serve additional North Dakotans.

Third, it supports informal services to to help North Dakotans with brain injury navigate their new and even more complex world.

SUMMARY OF BILL

Section 1 creates traumatic brain injury registry to track who is injured and therefore should receive a packet of information.

Section 2 calls for outreach and public education on preventing and identifying brain injury.

Section 3 clarifies the authority of state government to accept or expend financing from any source for brain injury services.

Some of the roles of the Department of Human Services (DHS) and the Department of Health (DOH) may need to be clarified in Sections 2 and 3.

Section 4 calls for an active brain injury or similar association to provide the informal services and information that can make existing resources so much more useful.

Section 5 asks the Department of Human Services to annually convene a meeting of some of the key state government stakeholders in brain injury.

Section 6 creates limited social and recreational outlets for the few survivors of brain injury for whom a return to work is not an option.

Section 6 should also contain language to expand and enhance Rehabilitation and Consultation (Vocational Rehabilitation) Services to survivors of brain injury. This language was inadvertently deleted as the Legislative Council finalized the bill language.

Section 7 refers survivors to existing programs to obtain personal care services they may need to live independently.

Section 8 ensures the states drug and alcohol treatment programs include veterans, and accommodate survivors of brain injury.

Sections 9 and 10 fund the foregoing sections. Please see Attachment A for the budget explanation. The majority of the appropriation goes to existing programs to serve people who could apply for and receive services today. However, advocates wanted to ensure those systems would be able to serve survivors of brain injury without harm to their existing caseload. Some witnesses today may call for a formalized role for the Department of Public Instruction, and perhaps a related appropriation.

With the permission of the Committee and the Chairman, I want pause my testimony to introduce Mary Simonson, the Executive Director of the Open Door Center in Valley City, North Dakota. I salute Ms. Simonson and Open Door for pioneering many of the existing services for North Dakotans with brain injury. She will discuss how the cracks in the current system have come to her attention, and tripped up people she serves.

CONTINUATION OF TESTIMONY

These stories represent a mix of pseudonyms with actual situations I have encountered had reported to me.

CASE STUDY: Bruce survived a brain injury in an employer's motor vehicle. He has good insurance that covers critical care, intensive rehabilitation, and extended physical rehabilitation. Bruce has volunteered half-time and been offered a job if he can bring in many of the supports he needs. However, he has no viable way to pay for extended vocational supports he would likely need to remain employed. RCS (VR) rules and policies prevent them from initiating services if the person would likely need extended services that are unavailable. State funded extended vocational supports have been exhausted this biennium. Bruce now spends his time doing puzzles in his apartment. His neighbors report he drinks a lot and is belligerent.

CASE STUDY: Kathryn survived a brain injury on a recreational vehicle. After many months of rehabilitation she had the physical health and stamina to return to professional work. She encountered many barriers well known to brain injury survivors -- fatigue, a new need for memory and organizational tools, needing more breaks, and needing to avoid over-stimulation. She sets a timer at home to avoid leaving the stove on, and carefully watches her carbohydrates and caffeine intake. She discovered these issues through trial and error. She maintained employment only because she is a natural self advocate and worked for an enlightened employer. She wants to mentor others so they can have a more successful return to employment and independent living.

CASE STUDY: Lisa lost a leg to an improvised explosive device in Afghanistan. She lost consciousness and seemed to recover very well from her moderate brain injury. She recovered in Army medical care enough to return to active duty Stateside. She did not re-enlist at the end of her tour because she had a new tendency toward insubordination and becoming stressed out. She returned to Edgeley, North Dakota. She has experience as a web designer and an Army communications specialist but has not done well in interviews. She missed a deadline and lost her major freelance client. She downplayed her suspected brain injury to return to active duty, but now questions that decision. She wants to know if she should be evaluated for issues from her brain injury, but doesn't know where to start. Lisa is depressed but has not benefitted from seeing a counselor -- it all sounds like psychobabble to her. She is beginning to show signs of addiction to alcohol and prescription medications.

CASE STUDY: Perrin had a severe brain injury on a college road trip. He was hospitalized out of state, returned to a skilled nursing facility, and lived in a TBI Basic Care/Group Home. He continued to recover and moved into an apartment with help from his family and a

[Morton or Barnes] County case manager. He received notice he did not qualify for the Medicaid Waiver with TBI services anymore. He moved home to his parents' house in mid-sized city. His family has refinanced their house twice and exhausted their resources. Perrin considered changing his career goals from medicine to laboratory science to capture his intact analytical skills and manage his stress as part of a team. His plans to return to college are on hold because VR can't be certain he will get the extended services he probably needs to keep a job.
The household relationships are becoming strained and he can't stand his parents' constant criticism. They say he acts like his cousin who has Asperger's syndrome, but none of the ideas his aunt offers seem to work for him. He needs help with housework, preparing meals, and transportation. He has no health care insurance.

CONCLUSION

SB 2198 stands upon three main legs: services needed to be more independent, adequate vocational services, and informal services so people can better help each other and themselves.

P&A asks that you give a positive recommendation to SB 2198 as amended and forward it to appropriations so they can include the resources necessary to carry it out.

ATTACHMENT: Budget Overview

SERVICES			EXPENSES			
	Contract FTE	participants*	progr. Mo. Cost	months	total	Cost per Partic.
Vocat'l Ext. Supp.		40	500	24	$ 480,000.00	$ 12,000.00
MA Pers. Care 37%		30	799.2	24	$ 575,424.00	$ 19,180.80
SPED		30	1602	24	$ 1,153,440.00	$ 38,448.00
Informal Supp. Contract	2	200	8000	24	$ 192,000.00	$ 960.00
Public Awareness		12000	1000	24	$ 24,000.00	$ 2.00
Social & Recreation		10	200	24	$ 48,000.00	$ 4,800.00
Training & Qual Con.		135	50	24	$ 162,000.00	$ 1,200.00
				ND Funds Total	$ 2,634,864.00	

POSS FUNDING & OFFSET	Bienn. Incidence	Per Incident	Revenue
Charit. Tax Credit	100	1000	100000
Vehicular Fees¤	6000	10	60000
Vehicular Offenses±	8000	50	400000
SSA Empl. Incent.	10	1000	10000
Recip Liab/Fee	280	25	7000
Net General Fund			Remainder^
		Total less GF	$577,000.00
		Estim. Net GF^	$ 2,057,864.00
		Total	$2,634,864.00

¤ATV/PWC/Helmet, /etc.¤

±DUI, BUI, Reckless, Drag racing, Seatbelt/etc.±

#3

Madame Chairperson and Members of the Committee, my name is Mary Simonson. I am here to testify in favor of Senate Bill 2198. I am the Director of Open Door Center in Valley City. We own and operate HI Soaring Eagle Ranch a basic care facility that serves individuals with a brain injury. We are also licensed to provide transitional services for people with a brain injury. I am personally involved in maintaining the necessary documentation to keep the Head Injury Association of North Dakota a legal entity with hopes that eventually it will return to its hay-day and assist the State of North Dakota in meeting the needs of its citizens who have a brain injury. Senate Bill 2198 would help this outcome.

I believe that there is a need for a registry because brain injury is often called the hidden disability. Without a diagnosis, it is difficult to discern memory problems, lack of insight, difficult with initiation and problem solving without being cognizant of a possible problem. Instead, family and friends wonder what has happened to the individual. Why can't he remember appointments? Why is she always so tired? Why does it take so long for him to respond? Why does she have so much trouble making a decision now?

Last week when we were in the Great Hall visiting with people regarding brain injury there were legislators, pages, and others at the Capitol who told us of their concerns of family, relatives or friends who have had to try to overcome a brain injury without the benefit of or the availability of appropriate services. A registry is one step toward determining the scope of the problem and in helping family and friends understand the complexity of the diagnosis.

A registry could also help design and direct prevention activities. There is no cure for a brain injury; consequently prevention is the best medicine. With the current economic state, we need to be prudent with our dollars. We need to spend them where we receive the best bang for the buck.

Several years ago I was employed as a Rehabilitation Counselor by the State of North Dakota. I believe that Vocational Rehabilitation provides excellent services. However many times the services available through Vocational Rehabilitation are unable to meet the needs of individuals who have a brain injury. A brain injury affects each person differently. However we do know that a brain injury creates problems with short-term memory, problem solving, processing, following multiple-step directions, initiation, planning, insight and stamina. These are the activities most often called

upon for job completion. These are the activities that cause the most problem for people who have a brain injury. The inclusion of "day supports" would help to alleviate some of these problems.

"Day Supports" as defined in NDAC Chapter 75-04-05 means a day program to assist individuals to acquire, retain and improve skills necessary to successfully reside in a community setting. Services may include assistance with acquisition, retention or improvement in self-help, socialization and adaptive skills; provision of social, recreational and therapeutic activities to maintain physical, recreational, personal care and community integration skills, development of task oriented prevocational skills such as compliance, attendance, task completion, problem solving and safety. These activities would assist the individual in understanding the consequences of their brain injury. These services could be instrumental in helping them move forward with their life, possibly access Vocational Rehabilitation and Extended Services and once again becoming "a productive citizen."

Open Door Center and other community providers have used many vehicles as a means to assist individuals with disabilities develop skills. In our program we have established our own businesses to provide prevocational and vocational experiences. We have a bookstore that is used

solely for training for people with a brain injury. We run a restaurant, we have a NISH contract, we do janitorial work and have a product, a down spout caddy, we sell. Some people even volunteer in the community by delivering meals-on-wheels, cleaning the roadways, helping at the National Guard, etc. However many more prevocational and vocational opportunities are needed. We need a variety of jobs in an supportive environment conducive to rehabilitation. Many individuals that we serve do not have the stamina, the problem solving skills, the socialization know-how or insight needed to maintain a competitive job. More avenues of employment options either through Day Supports or Vocational Rehabilitation and Extended Services are needed to assist our citizens with a brain injury. We expect the number of North Dakota citizens with brain injuries to grow because of the conflicts in the Middle East.

Senate Bill 2298 would help provide more opportunities to our Veterans and non-veterans who sustain a brain injury.

Thank you for the opportunity to share my thoughts. I would be willing to attempt to answer any questions the Committee may have.

#4

Madam Chairman and members of the committee, my name is Lisa L. Anderson from Leeds, ND. I am here today to testify in favor of this bill, Senate Bill #2198. 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, 1:20 p.m. I received a call at work – your daughter has just been in a car accident and they are taking her the Rugby Hospital – get there as fast as you can. I left work and drove the 50 miles from Cando to Rugby, setting my cruise control, so that I myself would not have an accident. Upon arriving at the ER – one of the Leeds ambulance members – a good friend of mine told me it was bad, very bad – I did not let go of her until my husband arrived. Hannah's injuries were too severe for the Rugby hospital to treat her – they were going to airlift her to Minot, but the plane was out on another call. They loaded her up in a second ambulance and left for Trinity Hospital in Minot where they were better equipped to deal with her fractures and injuries.

Hannah was eventually airlifted to Hennepin County Medical Center in Minneapolis as they are a Level 1 Trauma Center and have much experience with pediatric traumatic brain injury. Hannah was in a coma and remained in a coma for approximately 2 ½ weeks. She had multiple contusions and a fractured clavicle along with a fractured pelvis. Hannah was on life support for 3 weeks and we were not sure how severe her brain injuries were, although we knew there was bleeds all over her brain. The hospital provided a family room for us where we remained for 3 weeks. The first 2 weeks we sat by her bed not knowing if or when she would wake up. Eventually the doctors decided to start bringing her out of her medically induced coma – she would get "sedation holidays" as they called them because the physicians wanted to see if she would respond to any commands. The first 3 days there was nothing. The 4th day when asked to squeeze the doctors hand – she did ever so slightly. Within the next day or two, the doctor asked Hannah how many fingers and I holding up – he held up one and she held up one, he held up two and she held up two – there many tears as Dr. Karagu looked up at us and said "this just changed her whole prognosis".

Next it was time to wean Hannah from the respirator – another scary time in the ICU. Hannah's lungs were strong and seemed to be working well, even after having pneumonia while on the ventilator. First they turned down the machine and let Hannah practice breathing around the respirator for a few minutes, then for a few hours eventually she did this for 6-8 hours. Once it was determined she was strong enough they set out to remove the respirator. The respiratory therapist came in and removed the ventilator – turned it off and removed all tubes from Hannah's beautiful face. It was a scary 20 minutes. Hannah started off fine, but within minutes it was obvious she was in distress. She was the re-intubated and had to do more work with respiratory therapy to gain good lung function again. Two days later we tried it again, only this time with success – Hannah was breathing on her own and did so without any problems – a huge milestone after being on the ventilator for over 16 days.

Finally, she could begin receiving physical therapy and occupational therapy which mainly consisted of doing range of motion exercises to see where she was at as far as muscle tone. I will never forget the day that 3 therapists got Hannah up out of bed and she was like a limp rag doll – no muscle control what so ever. Someone had to literally hold her feet down on the floor and hold her knees in order for her to

remain upright. Each day the therapists would come in, hold her body upright while the other one moved her feet in an attempt to start to retrain her brain how to walk again. Once Hannah was medically stable, she was moved to a children's rehabilitation facility in St. Paul to begin her journey back. At this point, Hannah was unable to walk, sit up, talk, feed herself or do anything; she was like a newborn baby in a 15-year-old body.

While at the rehab facility, Hannah had a very intense daily schedule which included physical therapy, occupational therapy, speech therapy, recreational therapy, school and psychology along with all her medical issues. Hannah had to relearn everything – initially when she was tested the scores showed she was between 5-7 years old as far as her brain function. Every day for six weeks the therapists, nurses' doctors and teachers worked with her to improve skills and brain function. Her improvement was very rapid with such rigorous therapy and by the time we left rehab, Hannah was up to approximately a 12-year-old level of functioning.

Finally, on January 24, 2008, Hannah was discharged home to Leeds. We were finally leaving the Twin Cities after spending 10 weeks there and leaving our 17-year-old son back at home to work on his senior year of high school alone – we were coming home. As much progress as Hannah had made, we knew she had a lot more work ahead of her. She was able to walk on her own, but required a gait belt, so that we could assist her, she was very impulsive and did not have good judgment or reasoning skills yet at this point.

Monday, January 28, 2008 - Hannah returned to school – I was very frightened to leave her alone there, but she was not alone. The Leeds Public School was phenomenal. They had special in-services for the staff and for the kids before we came home to prepare everyone what it would be like for Hannah. They had to hire a para-professional to work one-on-one with our daughter as it was too much to expect her to go from class to class, remember what to bring with her to class, and she still could not write or even hold a pencil in her hand. The therapists from the Lake Region Special Education Department were at the Leeds school to evaluate Hannah and see how they best could help her with her educational needs. Occupational therapy provided different supports to help Hannah strengthen and use her left arm. She is left handed and her entire left side was affected by the accident. As I stated previously, she could not even hold a pencil. The para-professional would do all of Hannah's writing for her – Hannah would give verbal answers and the para would do all the writing. Each instructor that had Hannah gave her a printed out copy of the notes for their class along with a highlighter, which used to try and follow along and highlight things that she thought were important. We met with the special education department at the school to get Hannah's individual education program, or IEP set up. She has to have special accommodations when testing as the smallest noise will distract her. Hannah tests in a separate room where her tests were read aloud to her and she would verbalize the answer to her para.

Hannah attended speech, occupation and physical therapy three times a week in Devils Lake and also received these services at school through the Lake Region Special Ed. Her class schedule had to be re-evaluated as Hannah suffers from extreme exhaustion. She took a class then had a break, took another class then had a break – and so went her day. The school provided a place where she could rest when she needed it. The lunch room was a very noisy place and it was very over stimulating for Hannah. With

her left sided weakness, she could not even carry her own lunch tray. Hannah also did not have good enough balance to get in and out from the lunch tables. The school provided another room for her to eat in and some of her friends were allowed to eat lunch with her, in a room where the chairs pulled in and out from the table rather than the long benches that one had to step over to get into. The school also provided transportation for Hannah to get to school. We live across the street from the school, so this was not something we had thought of. They were going to send a school bus to pick her up, but she could not do stairs at all, let alone bus steps which are very high. They were going to send the mini bus but there were still steps. We finally figured out that they had a minivan and with some assistance, Hannah could get into the minivan without having to worry about steps and this worked out very well.

Hannah continued to improve with all the therapy and all the support that the school offered. She qualified for summer school. Through the Lake Region Special Education Department, Hannah attended summer school two days per week. It was not so much to help her catch up as to keep her moving forward and keep her from digressing. She worked on reading, comprehension, writing and math skills over the summer.

Hannah asked her doctors to consider letting her start her junior year of high school without a para-professional and they did not think she was ready, but she has proved them wrong. Not only has Hannah been able to handle school without any one-on-one support, but in a small school setting, she has flourished. The instructors there know what she is dealing with and what she has gone through, the kids will help her if she just asks for it. The school has made is possible for her to take part in extra-curricular activities, but some in a much different capacity. Last year she played volleyball, this year she went along with the team and videotaped. She is on the cheerleading squad, she plays in the band, and she sings in the choir and is in a special music group called the banner girls. The Leeds School system continues to be supportive and accommodating for Hannah and her needs following this very serious injury.

While we have found most of our support through the school system – I wonder, where do the people of North Dakota find support after their traumatic brain injury if they are not in the school system? When we were in Minnesota, we were given books, pamphlets and web sites to help educate my husband, my family and myself about TBI's. We were given a consumer guide for services available in the state of MN for people with head injuries. We were so very happy to be going home after our daughter's long hospitalization in MN that we did not even begin to imagine the road to recovery for Hannah and the difficulties that we would face once we were home.

I started researching the internet for the North Dakota TBI association only to find there was nothing. I could not call the MN Association as their phone numbers only worked in state. I almost panicked. We were 8 hours away from our TBI support system – it was frightening. Who would we look to for help when we had questions about Hannah's head injury? Every professional you asked questions of gave you different answers, no gave us anything consistent. We traveled to Bismarck to see the medical doctor who came once a month from the Gillette Children's Specialty Hospital to see patients. We traveled to Grand Forks once a week to see a psychologist who had dealt with head injury patients before. We traveled to Devils Lake three times per week to see OT, PT and speech therapists. We were

referred to the Benson County Social Services to see if there were any programs that Hannah might be eligible for – we did not qualify. We were referred to the Lake Region Human Service Center for neuropsych testing as someone mentioned Hannah might be eligible for a developmental disabilities program. All that did was leave us with another $900 bill to pay and no services were provided as she was not eligible. She tested too high to qualify under the developmental disabilities program. It left us as parents very frustrated, but we were not willing to leave any stone unturned. We tried to follow through on every available lead if there was a program that could help our daughter; we wanted to know about it.

I have had to all but give up my job as office manager of a dental office, a job that I love, to be a caregiver to our daughter. My husband and I farm near Leeds and so Duane has his hands full with running the farm. What do people do who cannot give up one income to stay home and take care of their child, their spouse or their brain injured relative? How do people with brain injuries who are not able to live independently figure out ways to get help? How do they follow-up on services that may help them if they are not even able to remember they have appointments to go to?

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 groups. 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 independent taxpaying citizens.

By passing this bill, you will be providing much needed resources for the thousands of North Dakota citizens that have head injuries. We need to do outreach and education to everyone in the state. By passing this bill, you will provide support to everyone whose life has been changed by a head injury. We will have a place to turn to for help rather than every person having to do their own research and try and find help on their own.

If Hannah and I can take something terrible and make something good come out of it, then we have to say it was all worth it. If anything can be gained by what we have experienced in these past 14 months to help others who are less fortunate than us, then it was worth it. Thank you for listening to our story today and for considering this bill for all ND citizens with brain injuries – we are worth it.

#5

Senate Bill 2198 A Bill Relating to Traumatic Brain Injury

January 21, 2009

Human Services Committee
Senator Judy Lee, Chair

Madame Chair Lee and Members of the Human Services Committee:

My name is Elaine Grasl; I am a member of District 47. I am here in support of Senate Bill 2198; a bill regarding traumatic brain injury. Brain injury–head injury is a subject about which I have testified in past sessions--our story may seem familiar.

Our little guy's smile was sunshine. A cheerful child, he'd already had some odd occurrences in his life. An early talker, he'd stopped speaking for several months; about six, I think, when he was very small. At some point he quit crying, not whimpering even when he got a cut next to his eye and he had to have it stitched. Never-the-less, he was a smart happy child who used to, as a toddler, welcome me at the door even if I left for a moment, with his arms open wide, to give me a hug. He had been doing at home "pre-school" lessons (for about 8-9 months) with me and was progressing nicely. He loved swimming since he was a baby. The summer he was four, the swim instructors would often stop to watch as he made his way strongly across the narrower part of the Mandan Community Center pool. It was such a happy time.

Not long after the end of the season, my older son and I were doing our usual stint working at his boy scout troop's breakfast which took place in

the community area of a church. From the far side of the room, I saw the rest of the family enter the room. After the latest crowd had disbursed, I stepped out to speak to my husband, and having seen our daughters as we spoke, I asked where our young son was–only to see him perched at the very edge of the tall platform of the stacked portable stage, with its tempting rope handles–but it was forbidden to our kids. He fell face first on-to the hard tiled floor. I flew to him in seeming slow motion and stopped to assess the damage to his still form, but he was scooped up, head lolling, by my husband who took him to the men's room. I gathered the kids, soon thereafter, insisting that we hurry to the emergency room where his bleed-ing, many loose tooth face was examined. They were mainly concerned about his teeth; an appointment was set for his dental surgery. As was usual, I was advised to keep him quiet for a while. (I can't think now, when, but he cried for the first time in years, sometime after that injury–I recall one particular heartbreaking incident in the wee morning hours, when I heard the deep sobs of a then 15 or 16 year old young man.)

I sat in the rocking chair with him the next day quietly speaking to him, when he apparently took offense at something, grabbed a 8" scissors which I had been using earlier, crossed the remainder of the room, ran up 15 steps, down a short hall and plunged it through an upstairs hollow core door. I was astonished–never had this gentle child ever done anything

like this. Certainly, it was an extreme occurrence and did not happen again at that time, but it signified a unquantifiable change. Days later, we re-started our at home lessons–it was as if the forms and sounds of the letters, numbers and words (I think he'd begun reading his book) were nonexistent–and it was harder to learn and write the second time. As time passed, he started to tell me his legs were "sleepy"–that summer he could not swim. Now, I am no doctor, but from my own experience, I would say he had been suffering uncomplainingly from a whiplash injury. Many years later, a specialist said, unofficially, that, from the symptoms that I had reported from that time, my son had received significant brain trauma.

I went from the parent who was tapped on the back and told, "What a lovely, well behaved family you have" to "Can't you get that kid to sit still?" His lovely, gentle first grade teacher was perfect for him but, as is common, with each passing grade, even though intelligent, his life became more difficult. A second injury occurred at school which resulted in amnesia for the event and required an investigation by the principal, after I noticed my son was not himself. He was devastated when a relative asked him why he was a "bad boy." He was diagnosed with ADHD due to a head injury. In 1992, my mother who, like me, had an attitude to direct his energy towards positive activities and reward him with kind words (but, wise enough to distin-gursh

the usual childhood transgressions, passed away unexpectantly.(school systems traditionally have taken away activities). In 1993, his older sister nearly died and became chronically disabled with a disorder that also affected her brain–the kids were scared to death having been told that they could likewise be affected (but were declared okay). He had always been an industrious little boy. He loved the outdoors and biking. He helped the neighborhood kids repair their bikes and he built "forts", but he was struggling with depression. Though he led his class forward in a state-wide reading contest in sixth grade, the second half of sixth grade (probably before that) he struggled to get up and get to school–we struggled together. His wonderful sixth grade teacher, tried to advocate for him before he went to junior high. The next years were mind numbingly difficult; hardly a credit received due to being late, tardies...even with good grades...(I drove him every day). A ninth grade teacher said my son would help kids with their math assignments, but when it came time for tests, they would do well, but he could not recall how to proceed. A seventh grade teacher, gestured, and said he wanted to strangle him when he played with his shoe laces as the teacher spoke; I later figured out, it was an accommodation–it helped him to listen such as when some people doodle or take notes. He did not get a 504 until just before he left high school. He was refused a school evaluation for years. We had provided our own; I was told

that doctors were just covering for him. Mike Ahman had begun to work with the school, but they had just dropped the credits again. My son gave up his dream to graduate with his friends; he went first to South Central and then studied for and achieved his GED with wonderful total grades. He had been called a faker (he later had surgery for one problem- which was congenital); we were both called liars; he was called worse. I have said that people's judgements likely caused more problems than the original head injury--the brain can be wonderfully resilient--or unmerciful, dependent on details. While some people are not to be excused for their bad actions, his behavior was frustratingly difficult at times. I'd often say, in those days, that if I could just keep him alive until he was twenty; he would have a chance. I guess I hoped (correctly) with time and maturity, would come progress. I hoped with mistakes, the harsh lessons (many undeserved) that were provided, would temper impulsivity and promote better reasoning skills to join with his intelligence and fun loving and industrious nature. He made mistakes. All of us made mistakes, we were not perfect. Some were cruel. I wished to support him to stand on his own two feet.

This brings me to the 1.4 million people diagnosed (not including the undiagnosed) injured every year in the U.S. and the veterans with likewise unseen wounds that are returning after serving their country. As I feared some years ago, our soldiers are returning with brain injuries. I went through

an extensive history and here's one reason why...if many in society could not see the needs of a small boy, will we now be better prepared for those others? Will we see symptoms of depression, anxiety, anger, frustration, lack of reasoning skills, feelings of loss, substance abuse.....and recognize the humanity? Will we recognize the value...the worthiness...? Perhaps the desire for education? These individuals deserve to return to a society where education, law enforcement, and other systems and society, in general, does not make them the problem, but rather works together to support them to stand on their own two feet. Please acknowledge and support those with the wide ranges of brain injury. (A couple years ago I downloaded information from the Brain Injury Assn.–good resources.)

My son, the last time I saw him before he left, opened his arms wide and said, "I guess you want a hug." I did.

Elaine Grasl
7314 Sunshine Lane
Bismarck, ND 58503-9134

*Individuals do not need to be in an everlasting spotlight–like specimen under a microscope in an artificial "gotcha" world.

This has not reflected the emotions dealt with individually by each member of the family.

#6

SENATE BILL NO. 2198

My son suffered a Traumatic Brain Injury in 1998. He was a healthy 20 year old when he contracted Blastomychosis Menijitis. This was an infection that attacked his brain. This infection caused damage to the left and central lobes of the brain resulting in a short term memory loss. He does not remember activities that happen in his daily life. He doesn't remember what he has eaten, where he has been, or who he saw when he is out for a walk.

This infection not only affected his brain, it changed his personality, coordination, cognitive abilities as well as social behaviors and impulse control. Our son cannot live an independent life.

When we began our search for services that would address his disabilities it was like looking for a needle in a haystack. We were referred from agency to agency, because no one knew where to direct us. The services we did find are very limited and they do not address our son's needs. Most services cover people who have mental disabilities or people who have suffered a stroke.

Our son falls in a grey area. He does not qualify for services in these areas, therefore our son's needs have not been provided for. He cannot live independently; he is able to work but needs supervision in order to succeed.

North Dakota services fail to meet the needs of Traumatic Brain Injuries citizens. We encourage North Dakota to step up and begin to provide services for people who have Traumatic Brain Injuries.

#7

Testimony
Senate Bill 2198 – Department Human Services
Senate Human Services Committee
Senator Lee, Chairman
January 21, 2009

Senator Lee and members of the Senate Human Services Committee, I am Susan Wagner, LSW, Human Services Program Administrator, with the Division of Mental Health and Substance Abuse Services, for the Department of Human Services (DHS).

On behalf of the Department, I am here to provide testimony about the history of services and activities related to individuals who have sustained a traumatic brain injury (TBI) in North Dakota.

Efforts to address the problem of TBI in North Dakota began in the 1980s with the formation of the Head Injury Association of North Dakota (HIAND). The Association's board of directors consisted of representatives from a mix of public and private entities whose concerns and interests spanned the spectrum of TBI from prevention to treatment and rehabilitation. The organization did obtain federal IRS 501c3 status and began accepting charitable donations. A grant from the Rocky Mountain Brain Injury Center further strengthened the organization and increased visibility.

In 1987, the HIAND introduced legislation that established TBI as a mandated reportable medical condition and required the North Dakota Department of Health (DoH) to establish a TBI registry. The legislation passed, mandating TBI as a reportable condition by a physician or medical facility, and required the DoH to establish and maintain the registry. There was no fiscal note attached to establish and maintain the

registry. DoH received a Center for Disease Control (CDC) surveillance and prevention capacity building grant that was used to establish the registry. A significant drawback to the system was the reliance on participating medical facilities to voluntarily complete the injury report card and forward to DoH. In most instances, the report cards were completed by emergency room departments and reflected only preliminary diagnoses, no treatment or discharge information.

In 1989, the HIAND introduced legislation that established the Department as lead agency in North Dakota for the delivery of TBI services. This legislation also required DoH to provide DHS with names and addresses of individuals who were listed in the registry. DHS was then to forward to these individuals information on medical, rehabilitation, and social services that were available in North Dakota. A joint effort between DoH and DHS produced a brochure with service-related information.

The DoH maintained the registry until 1994, when the CDC funding ended. Due to the reliance on voluntary submission of the report cards, reporting compliance fell off significantly. In 1999, the TBI reporting and registry statute was repealed by the legislature at the request of DoH. During this same time, grant funding for the HIAND ended and the association became inactive.

The Indigenous People's Brain Injury Association (IPBIA) was established in 1994. The IPBIA was established for the benefit of all tribes in North Dakota and is comprised of individuals who have sustained a TBI, family members, and service providers. The IPBIA has become a recognized leader in the field of Native American TBI issues and has hosted a

national conference. The organization continues to exist today and hosts an annual conference.

On April 1, 1994, North Dakota received approval for a Medicaid waiver for TBI that enabled eligible individuals to choose between receiving care in an institutional care setting or in their home with the assistance of various community-based services. The TBI waiver was merged with the Aged and Disabled Waiver which was renamed the Home and Community-Based Services waiver. This was effective on March 31, 2006.

More than 5.3 million Americans live with a disability as a result of a TBI. Many of these individuals and their families are confronted with inadequate or unavailable TBI services and supports. Passage of the Traumatic Brain Injury Act of 1996 (PL104-166) signaled a national recognition of the need to improve state TBI service systems. The Act authorized the Health Resources and Services Administration to award grants to states and territories for the purpose of planning and implementing needed health and related service systems changes.

North Dakota received a TBI planning grant in April 2003. The DoH selected the University of North Dakota School of Medicine's Center for Rural Health as a contractor to form the TBI Advisory Committee, conduct a statewide TBI needs assessment, and write a plan of action to address the needs of North Dakotans with TBI and their families. The advisory committee met regularly, the needs assessment was completed, and an action plan was developed. The action plan, designed to be executed during the three-year implementation phase of the TBI federal grant

program, set forth a number of intended outcomes and steps for achievement. Those outcomes are:

- TBI will have a presence in the state with accessible, available, appropriate, and affordable services and supports for individuals with TBI and their families.
- Individuals with TBI, family members, significant others, and providers of support and services to have timely information, resources, and education regarding TBI.
- Ensure a coordinated system for individuals with brain injuries and their families to access and receive services and supports.
- Increased quality and availability of key supports for individuals with TBI and their families.
- Native American individuals with TBI and their families to have access to culturally appropriate TBI information, services, and supports.

In partnership with the University of North Dakota's School of Medicine Center for Rural Health, the Department applied for and was awarded a TBI Implementation Partnership Grant in April 2007. This is a three-year grant in the amount of $118,000 each year. The action plan developed as a result of the TBI planning grant laid the groundwork for this implementation grant. The goals of the grant are:

- To build a formal presence and infrastructure for the advancement of TBI focused issues
- To provide timely information, resources, and education regarding TBI to individuals with TBI, family members, other caregivers, and service and support providers.
- To ensure a coordinated system to access and receive services and support for individuals with brain injuries and their families.

- To improve access for American Indian individuals with TBI and their families to culturally appropriate information, services, and supports.

Progress on the goals is as follows:

- The Advisory Committee is established and active in planning and sustainability efforts.
- Partnerships have been developed with military support organizations in an ongoing effort to assess their needs. The project coordinator and state TBI program administrator serve on the Interagency Family Assistance Committee.
- Research has been completed on peer mentoring with Native American individuals who have sustained a TBI and preliminary discussion has been had about the most effective way to develop a project on each reservation in North Dakota.
- Seven educational presentations on TBI at various statewide conferences have been conducted. Plans are in place for presentations at the eight regional human service centers and the North Dakota State Hospital.
- A strategic plan for state government funding was developed.
- Resource packets for individuals who have sustained a TBI and their family members are in the development stage.
- Two spots on Good Health TV provide education and prevention of TBI to Native American individuals who are in the waiting room areas of the Indian Health Services clinics and hospitals in North Dakota.
- A resource library is in the development phase and will be operated out of the Prevention Resource Center, which is part of the Division of Mental Health and Substance Abuse Services.

- The state program administrator is working on a project to implement a screening tool at the regional human services.

Please see the attached FACT SHEET.

That concludes my testimony. I will answer any questions you have at this time. Thank you.

Federal Traumatic Brain Injury Program State Grant Fact Sheet

NORTH DAKOTA

Implementation Partnership Grant: 4/1/07-3/31/10

Same handout given to House.

Federal TBI Program

More than 5.3 million Americans live with a disability as a result of a traumatic brain injury (TBI). Many of these individuals and their families are confronted with inadequate or unavailable TBI services and supports. Passage of the Traumatic Brain Injury Act of 1996 (PL 104-166) signaled a national recognition of the need to improve state TBI service systems. The Act authorized the Health Resources and Services Administration to award grants to States for the purpose of planning and implementing needed health and related service systems changes.

Lead State Agency

North Dakota Department of Human Services

North Dakota's Grant History

North Dakota has received $381,404 in Federal TBI Planning and Implementation Partnership Grants. The State has provided $190,702 as matching support. North Dakota was awarded a TBI Implementation Partnership Grant in April 2007 for $118,000 a year for three years. Local funds will provide $59,000 in match each year.

State Population and TBI

State population in 2004: 634,000
Est. TBI-related emergency department visits per year: 2,281
Est. TBI-related non-fatal hospitalizations per year: 431
Est. TBI-related disability per year: 153

Note: State population is from the 2004 Census. TBI data are estimates of the number of individuals and are from the CDC TBI Surveillance Grant Program and NCHS data.

Infrastructure-at-a-Glance: 1997-2008

Added by 2007 Maintained or Regained

Advisory Council or Task Force	TBI Registry/ Surveillance	TBI Medicaid Waiver	Head Injury Division in State Department	Dedicated Funding for TBI Programs	State Funding for TBI Programs

Grant Objectives

Sustainability: To build a formal presence and infrastructure for the advancement of TBI focused issues.

Education and Awareness: To provide timely information, resources and education regarding TBI to individuals with TBI, family members, other caregivers and service and support providers.

Enhancement of Services: To ensure a coordinated system to access and receive services and support for individuals with brain injuries and their families.

Tribal Issues: To improve access for American Indians with TBI and their families to culturally appropriate information, services and supports.

Progress

- ***Advisory Committee established and active in planning/sustainability efforts.***
- ***Developed partnerships with military support organizations and tribal organizations in an ongoing effort to assess their needs.***
- ***Conducted seven (7) educational presentations on TBI at statewide conferences.***
- ***Developed a strategic plan for state government funding.***

Continuing Effort

The Advisory Committee is very vested in assisting in achieving sustainability and developing actionable strategies. Work has begun to develop a Resource Packet for survivors and family members. Resources are also being added to the Prevention Resource Center.

For Further Information

State TBI Program
Susan H. Wagner, LSW
Program Administrator
Department of Human Services
(701) 328-8941
shwagner@nd.gov

Federal TBI Program
CAPT Jane Martin Heppel
Director, Federal TBI Program
(301) 443-2259
jmartin-heppel@hrsa.gov
http://www.mchb.hrsa.gov/programs/tbi.htm

#8

Testimony
Senate Bill 2198
Senate Human Services Committee
Wednesday, January 21, 2009; 9:15 a.m.
North Dakota Department of Health

Good morning, Madam Chair and members of the Senate Human Services Committee. My name is Diana Read, and I am the Injury and Violence Prevention Program director for the North Dakota Department of Health. I am here today to provide information about Senate Bill 2198.

As the bill is written, the Department of Health is appropriated the sum of $40,000 for the purpose of implementing and maintaining a traumatic brain injury registry and conducting public awareness activities regarding the prevention and identification of traumatic brain injury.

If the bill is passed, the appropriation is not sufficient for the Department of Health to conduct the activities required by the bill.

Our preliminary research indicates that it will cost as much as $80,000 to develop an electronic data registry and would require a part-time data entry position to manage the registry. Additional funds will be required to conduct other related activities, such as educating physicians, developing and implementing forms, and conducting public awareness activities. We do not have a final estimate of these costs, but will be happy to provide an estimate to the committee if you so desire.

Finally, the Department of Health feels that it may be more appropriate to house the registry in the agency that will be providing services to those affected with traumatic brain injuries.

Madam Chair, members of the committee, this concludes my testimony. I am happy to answer any questions you may have.

Center *for*
Rural Health
University of North Dakota
School of Medicine & Health Sciences

http://medicine.nodak.edu/crh

North Dakota Statewide Needs and Resources Assessment for Traumatic Brain Injury (TBI)

University of North Dakota
Center for Rural Health
June 21, 2005

Connecting resources and knowledge to strengthen the health of people in rural communities.

Survey Instruments

- Modified version of the federal TBI questionnaire template
- Received and implemented feedback on questionnaire design from North Dakotans with TBI, caregivers of persons with TBI, North Dakota TBI Advisory Committee members, and federal TBI program personnel

Objectives

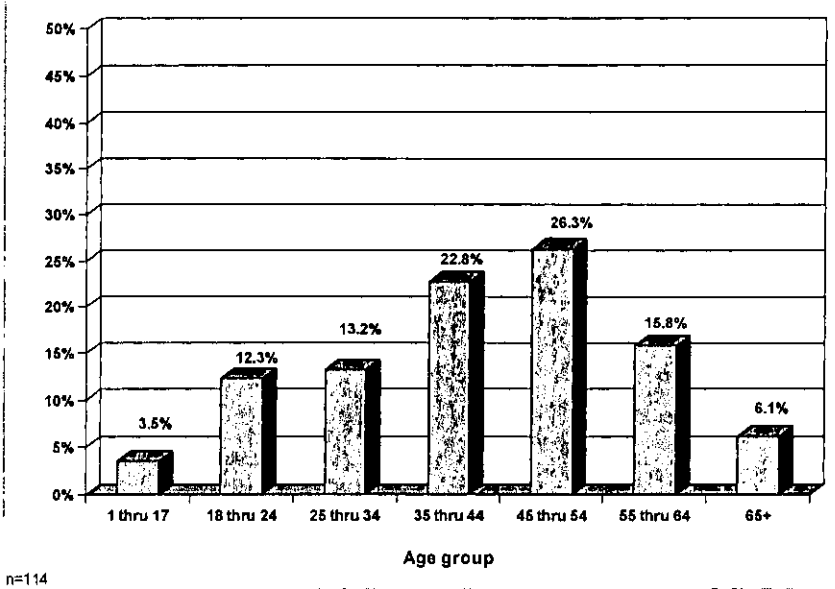
- Identify the demographic characteristics of North Dakotans with TBI and their caregivers
- Discover the perceived behavior problems and barriers faced by North Dakotans with TBI and their caregivers
- Determine the assistance and support available to persons with TBI and their caregivers
- Determine the services provided by North Dakota agencies and service providers
- Identify training opportunities and needs of North Dakota agencies and providers

Individual Survey

Methodology

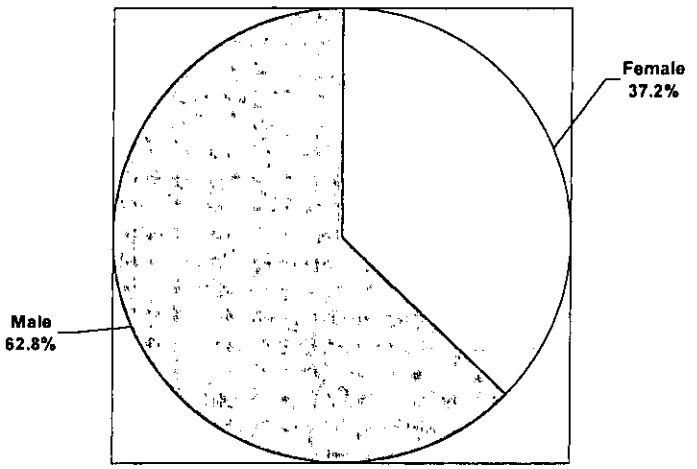
- Surveys mailed 1-13-05
- Surveys accepted thru 4-12-05
- Persons not returning a survey were mailed a second survey 2-15-05
- Convenience Sample
  - Individual (29% response rate)
    - 425 mailed
    - 21 invalid contacts
    - 117 returned

Age



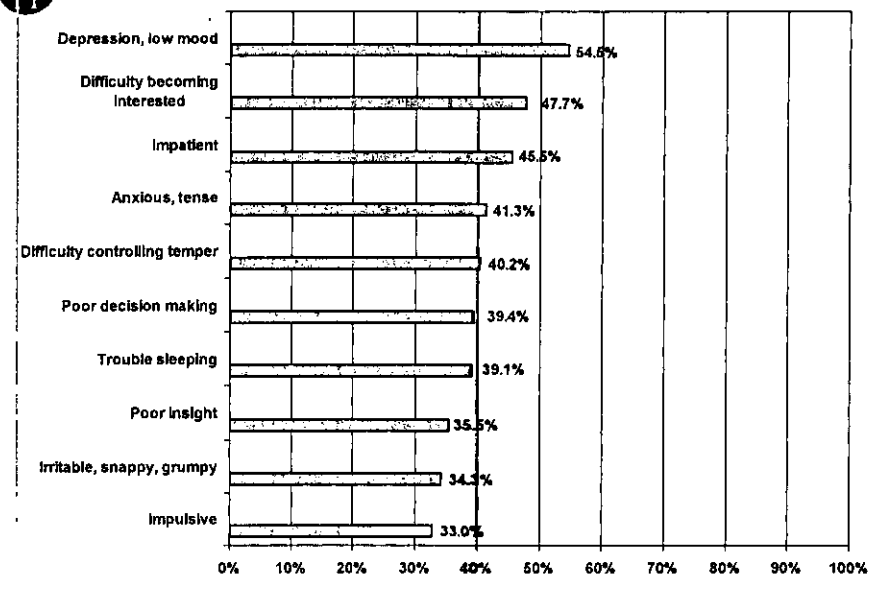
n=114

Gender

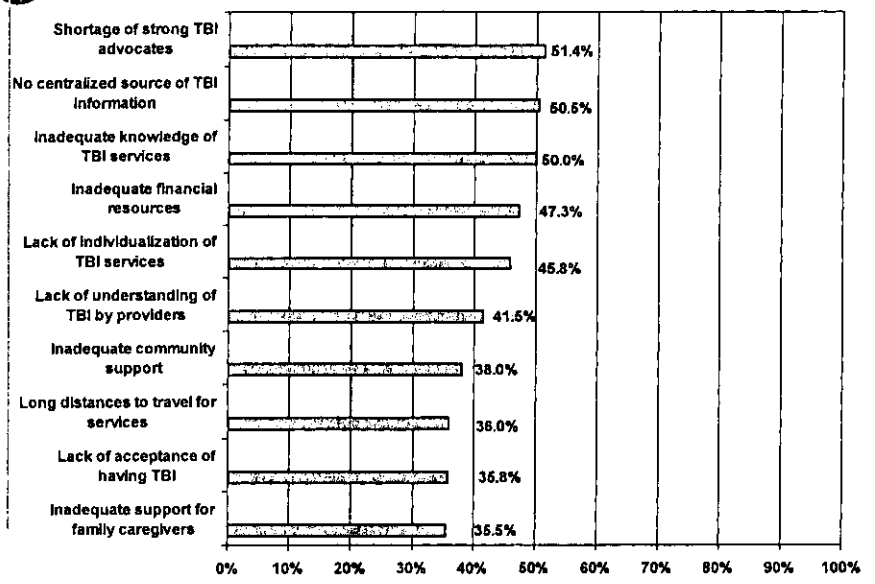


n=113

Behavioral Issues Identified by Individuals with TBI



Barriers Identified by Individuals with TBI

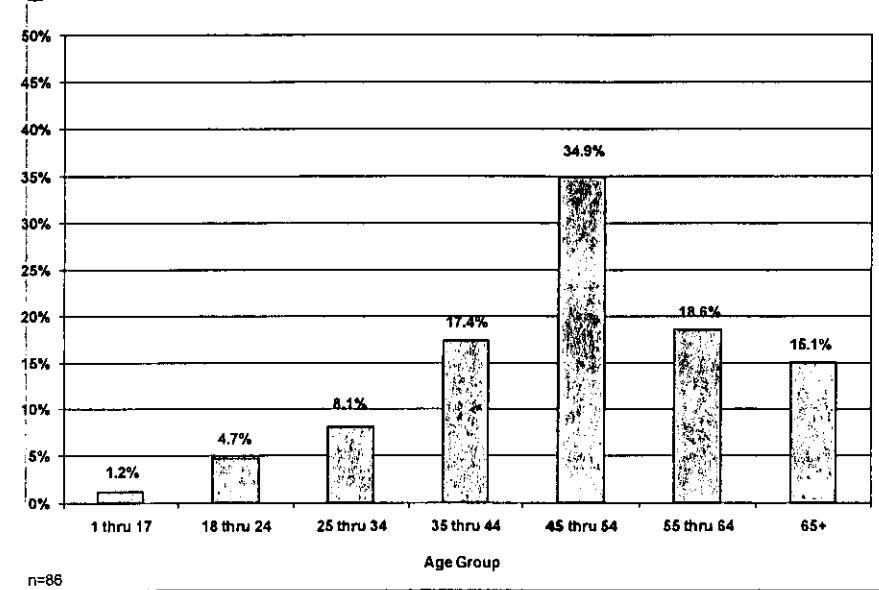


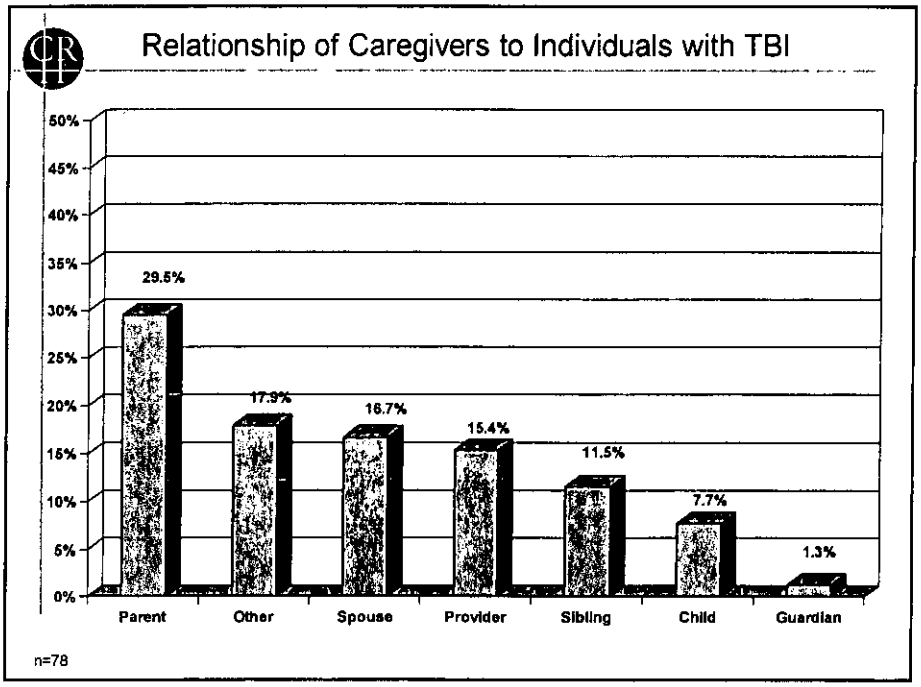
Caregiver Survey

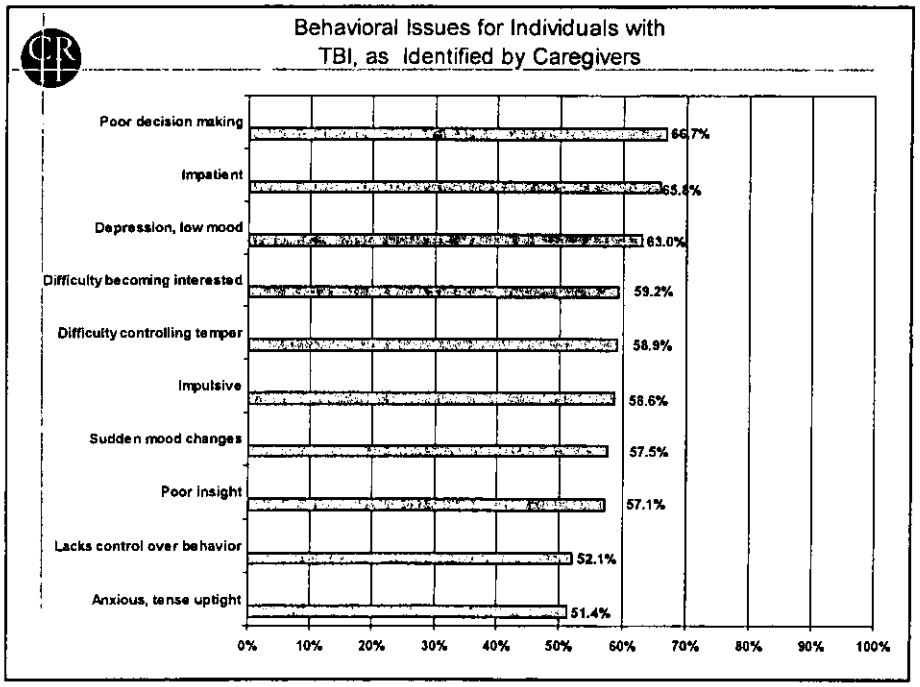
Methodology

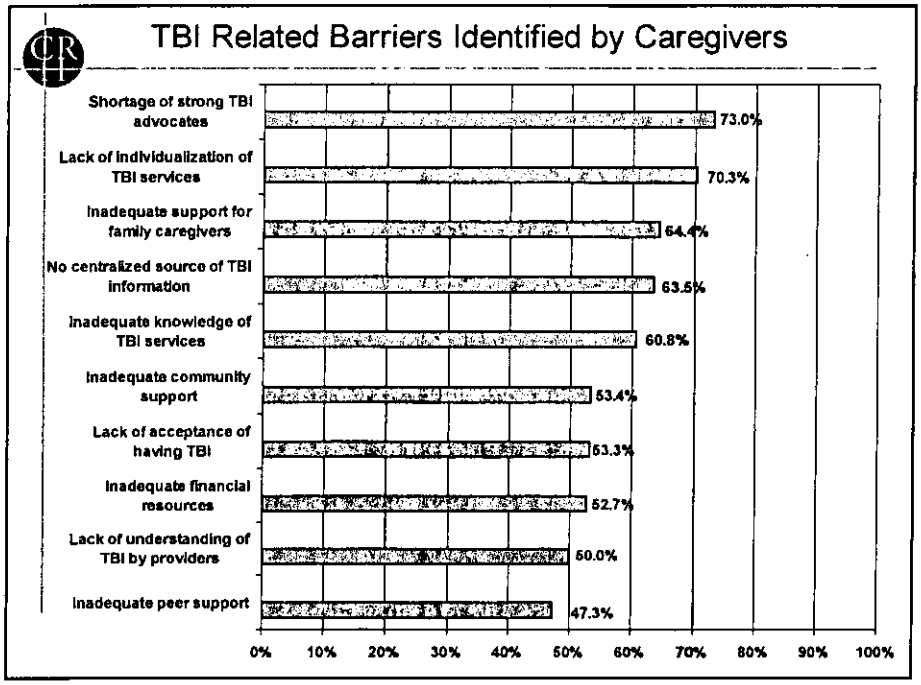
- Surveys mailed 1-13-05
- Surveys accepted thru 4-12-05
- Persons not returning a survey were mailed a second survey 2-15-05
- Convenience Sample
  - Caregiver (23% response rate)
    - 425 mailed
    - 19 invalid contacts
    - 94 returned

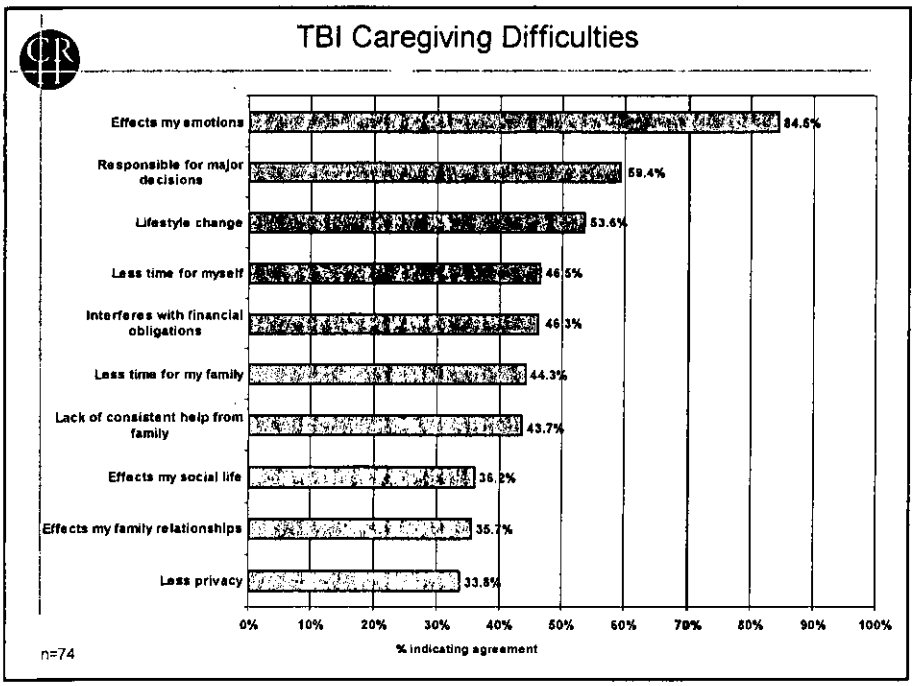
Age of Caregivers for Individuals with TBI




Relationship of Caregivers to Individuals with TBI
50%
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
29.5%
17.9%
16.7%
15.4%
11.5%
7.7%
1.3%
Parent
Other
Spouse
Provider
Sibling
Child
Guardian
n=78

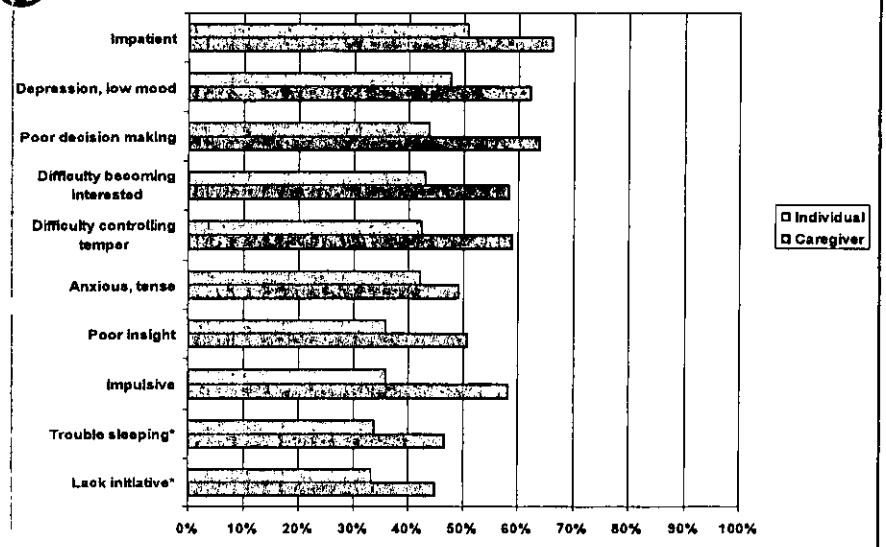

Behavioral Issues for Individuals with TBI, as Identified by Caregivers
Poor decision making
66.7%
Impatient
65.4%
Depression, low mood
63.0%
Difficulty becoming interested
59.2%
Difficulty controlling temper
58.9%
Impulsive
58.6%
Sudden mood changes
57.5%
Poor insight
57.1%
Lacks control over behavior
52.1%
Anxious, tense uptight
51.4%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%


TBI Related Barriers Identified by Caregivers
Shortage of strong TBI advocates
73.0%
Lack of individualization of TBI services
70.3%
Inadequate support for family caregivers
64.4%
No centralized source of TBI information
63.5%
Inadequate knowledge of TBI services
60.8%
Inadequate community support
53.4%
Lack of acceptance of having TBI
53.3%
Inadequate financial resources
52.7%
Lack of understanding of TBI by providers
50.0%
Inadequate peer support
47.3%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

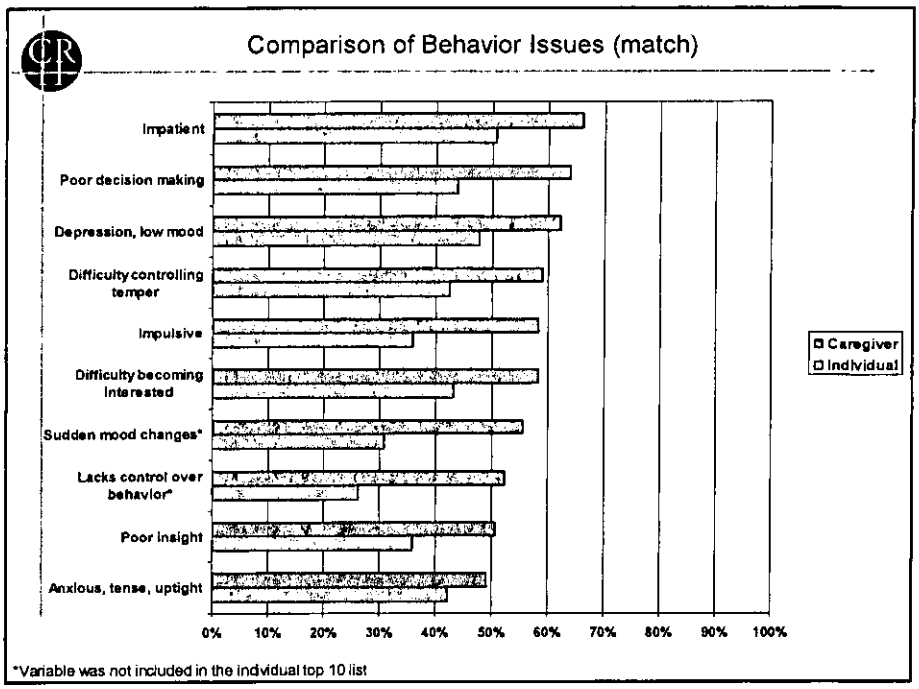

TBI Caregiving Difficulties
Effects my emotions
84.6%
Responsible for major decisions
59.4%
Lifestyle change
53.6%
Less time for myself
46.5%
Interferes with financial obligations
46.3%
Less time for my family
44.3%
Lack of consistent help from family
43.7%
Effects my social life
36.2%
Effects my family relationships
35.7%
Less privacy
33.8%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
% indicating agreement
n=74

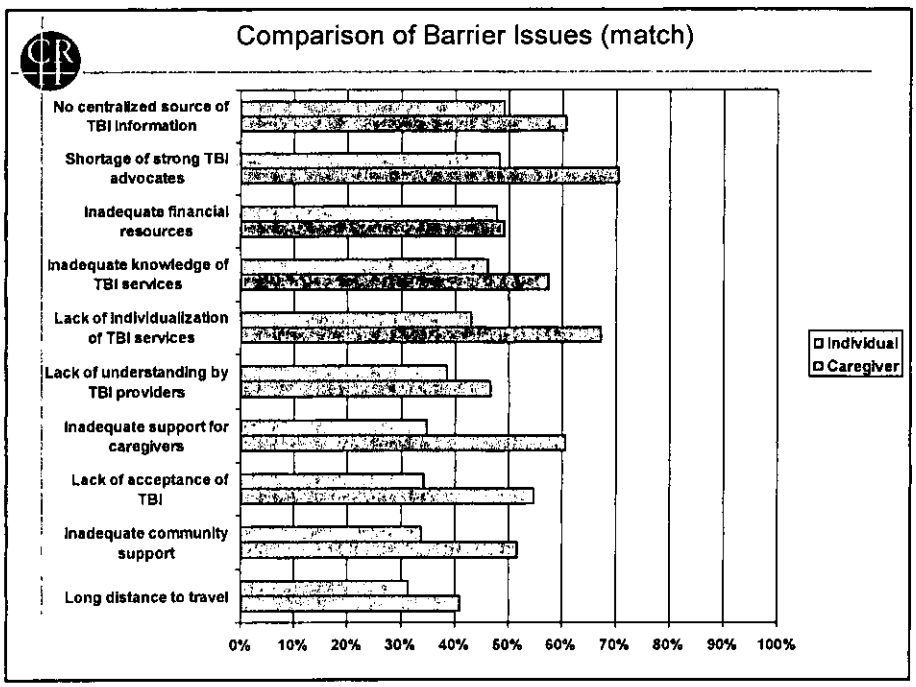
Comparative Summary of Individuals with TBI and Their Caregivers

Comparison of Behavior Issues (match)

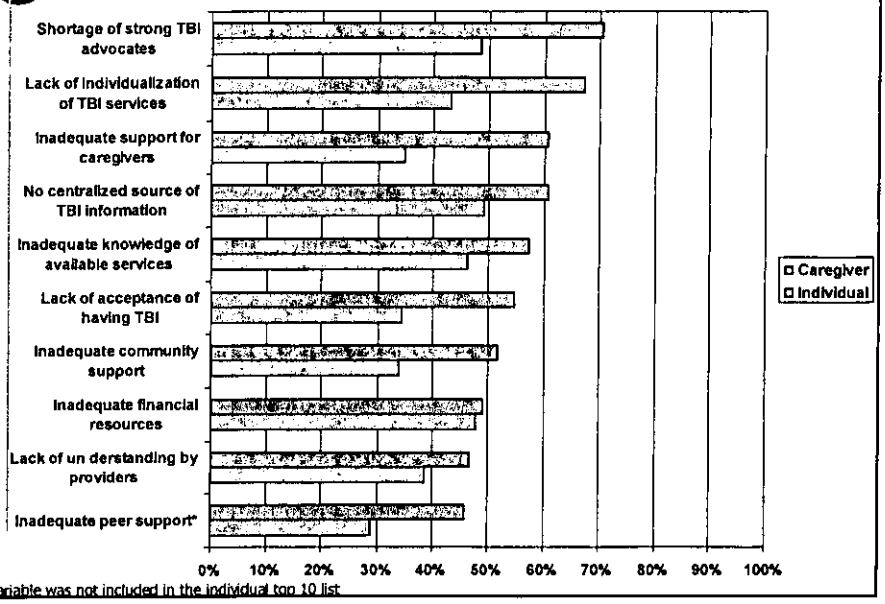


*Variable was not included in the caregiver top 10 list


Comparison of Behavior Issues (match)
Impatient
Poor decision making
Depression, low mood
Difficulty controlling temper
Impulsive
Difficulty becoming interested
Sudden mood changes*
Lacks control over behavior*
Poor insight
Anxious, tense, uptight
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Caregiver
Individual
*Variable was not included in the individual top 10 list


Comparison of Barrier Issues (match)
No centralized source of TBI information
Shortage of strong TBI advocates
Inadequate financial resources
Inadequate knowledge of TBI services
Lack of individualization of TBI services
Lack of understanding by TBI providers
Inadequate support for caregivers
Lack of acceptance of TBI
Inadequate community support
Long distance to travel
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Individual
Caregiver

Comparison of Barrier Issues (match)

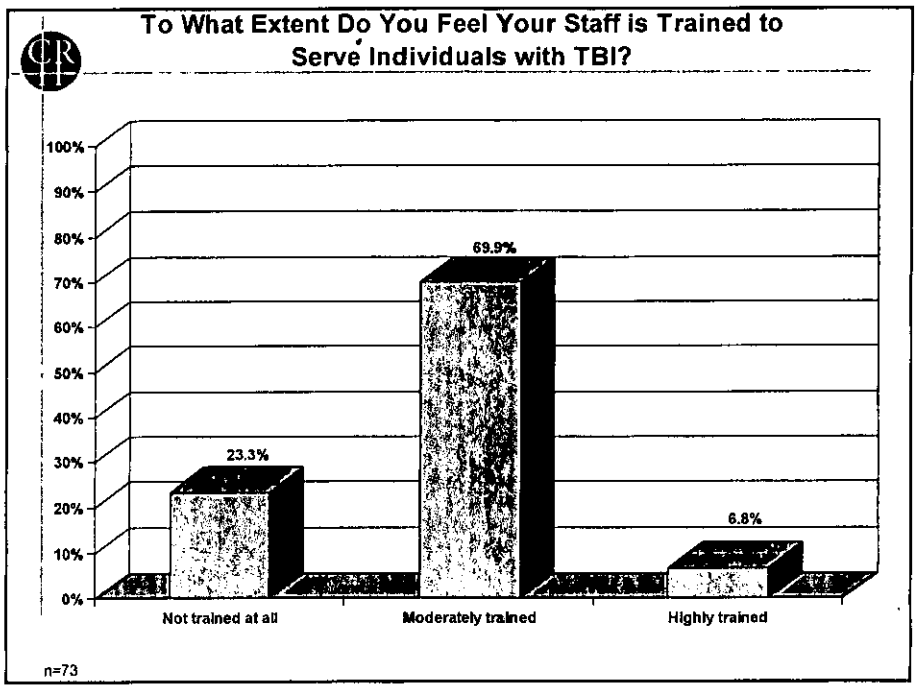


*Variable was not included in the individual top 10 list

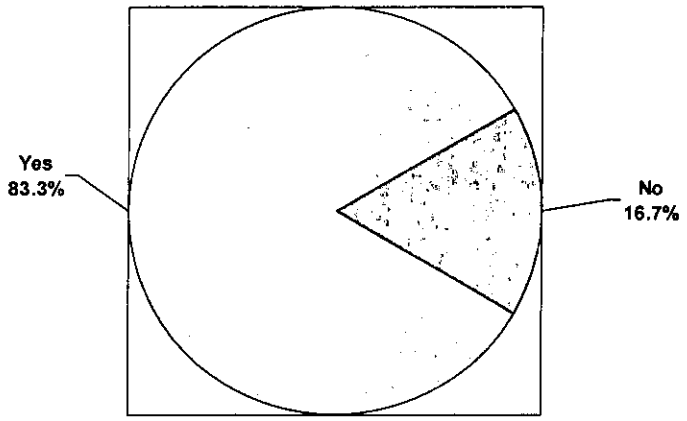
Agency Summary

Agency Response Information

- Surveys mailed 2-4-05
- Surveys accepted thru 4-22-05
- Convenience Sample
  - Agency (32% response rate)
    - 365 mailed
    - 117 returned

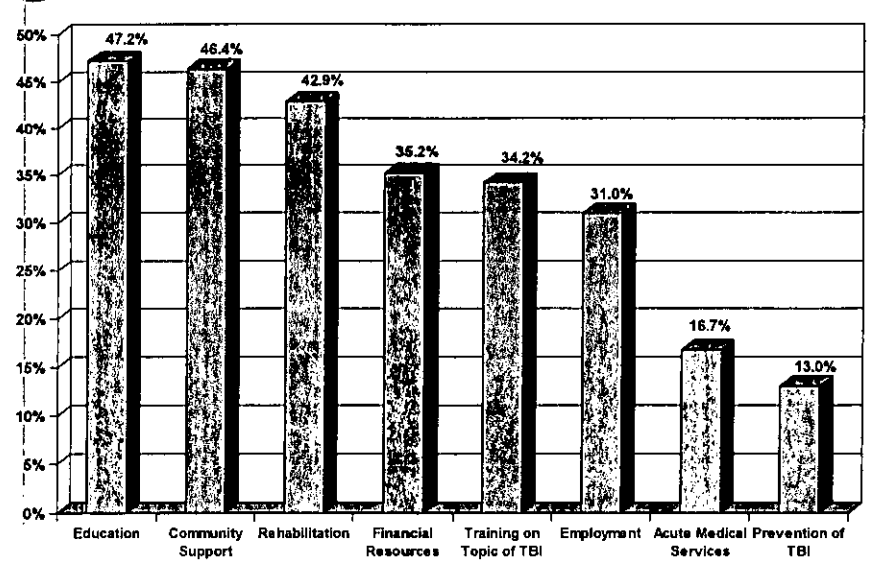


Do You Feel that Your Staff Needs Additional Training Specific to TBI?

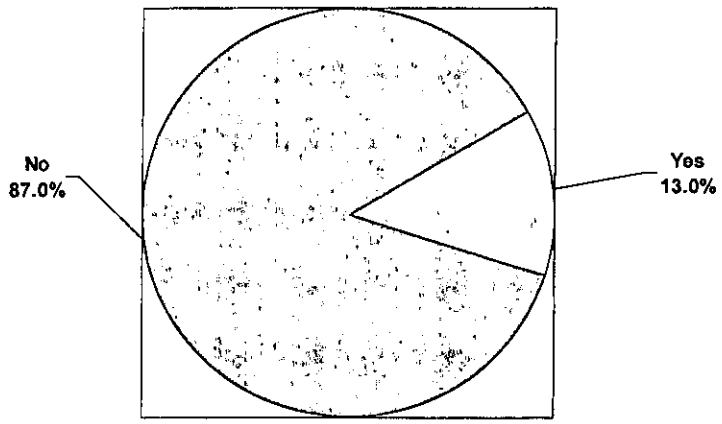


n=72

Does Your Agency Provide Services Related to...

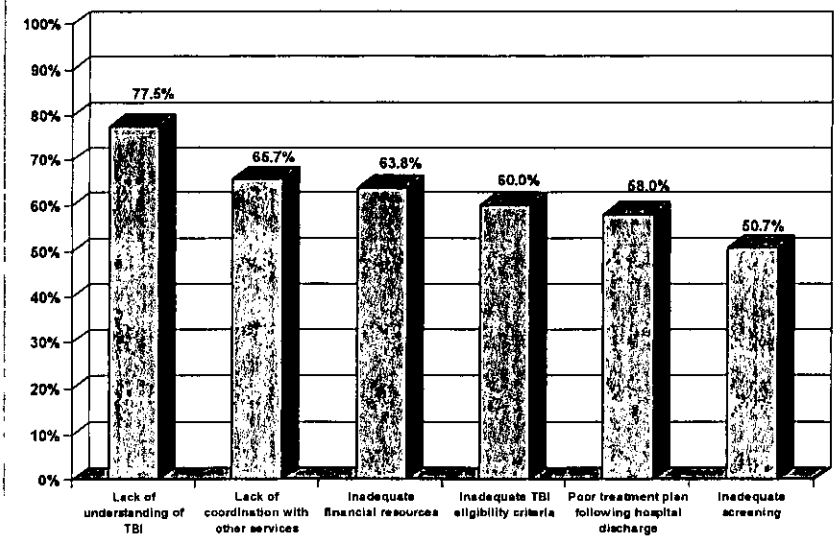


Does Your Agency Provide Prevention Services for Persons with TBI?

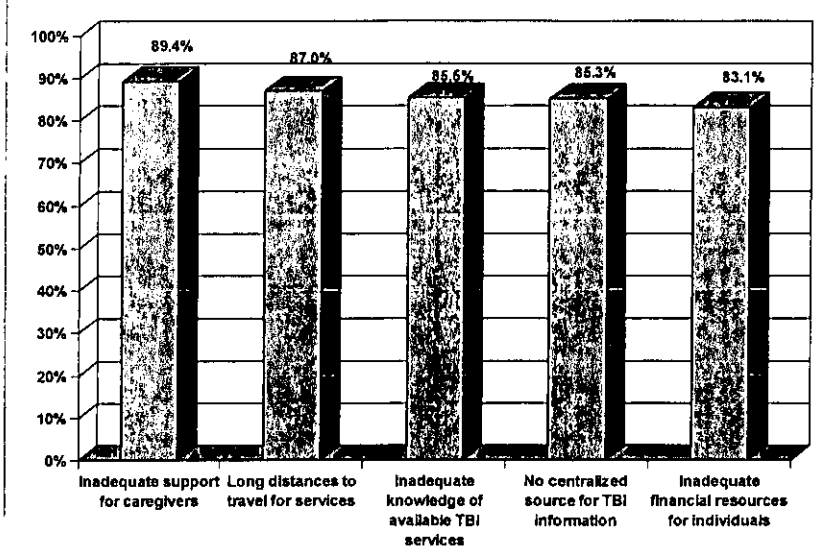


n=69

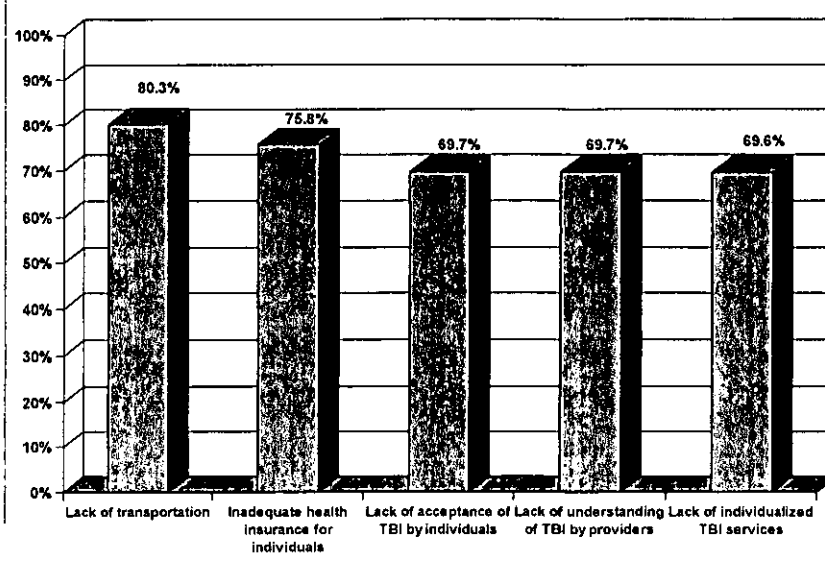
Agency Perceived Barriers Related to Providing Services to Individuals with TBI



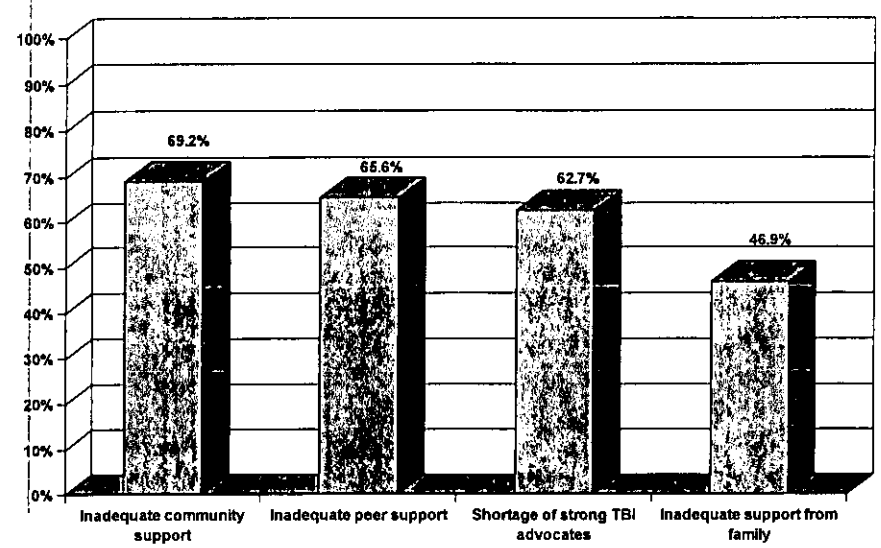
Agency Perceived Barriers to Accessing/Using Services for Individuals and Their Families (1 thru 5)



Agency Perceived Barriers to Accessing/Using Services for Individuals and Their Families (6 thru 10)



Agency Perceived Barriers to Accessing/Using Services for Individuals and Their Families (11 thru 14)

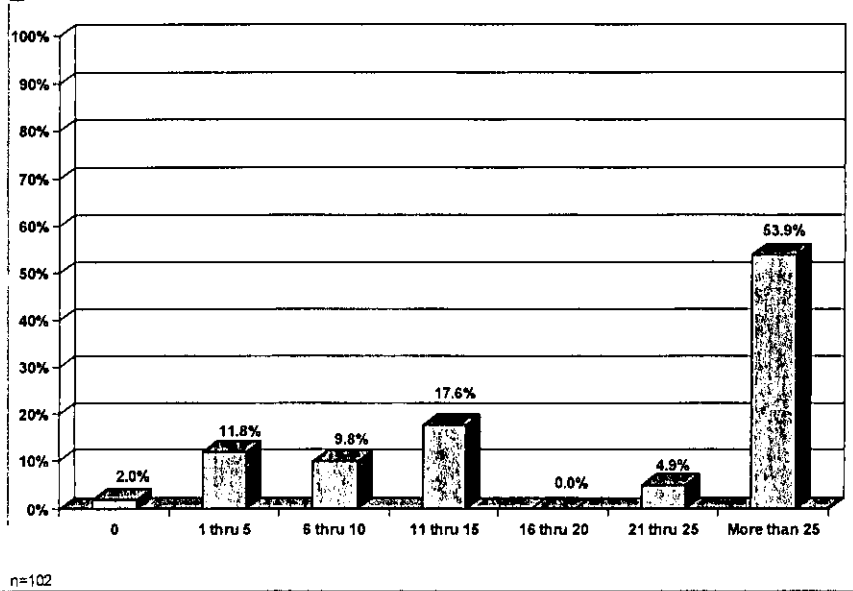


Service Provider Summary

Service Provider Response Information

- Surveys mailed 2-4-05
- Surveys accepted thru 4-22-05
- Convenience Sample
  - Service Provider (20% response rate)
    - 859 mailed
    - 173 returned

Number of Individuals You Serve



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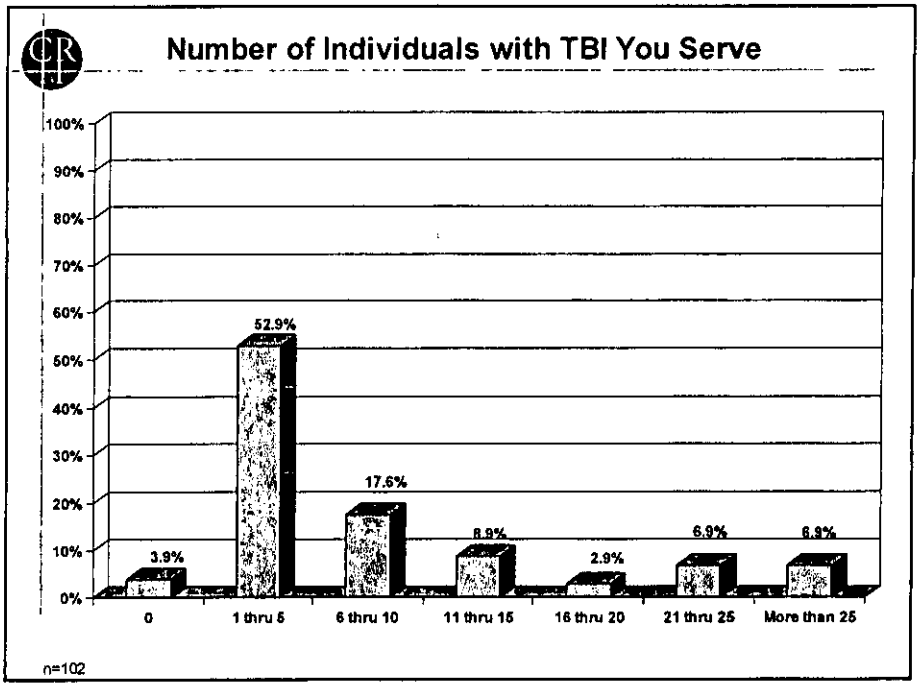
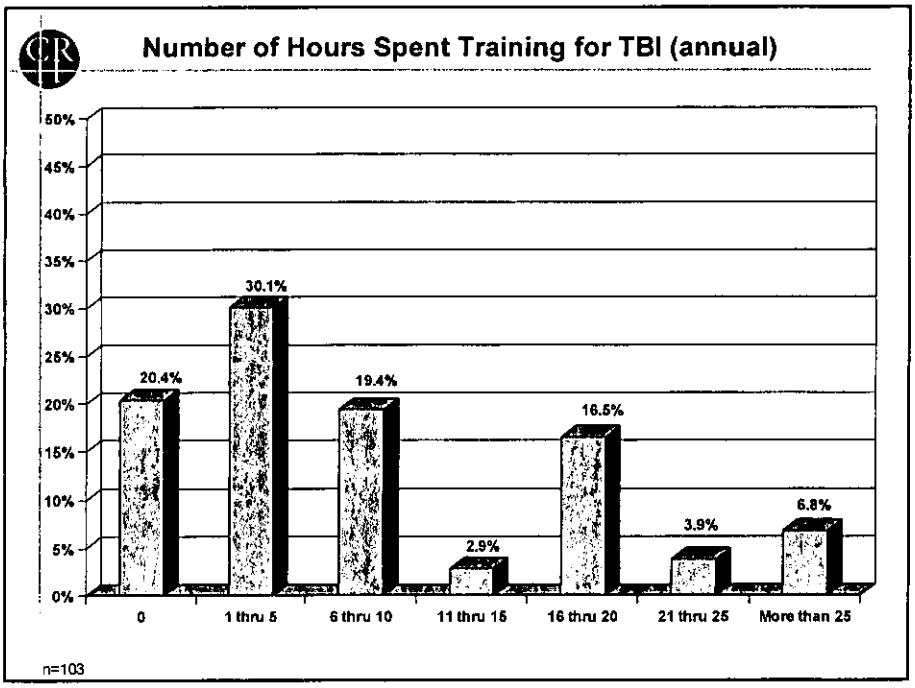
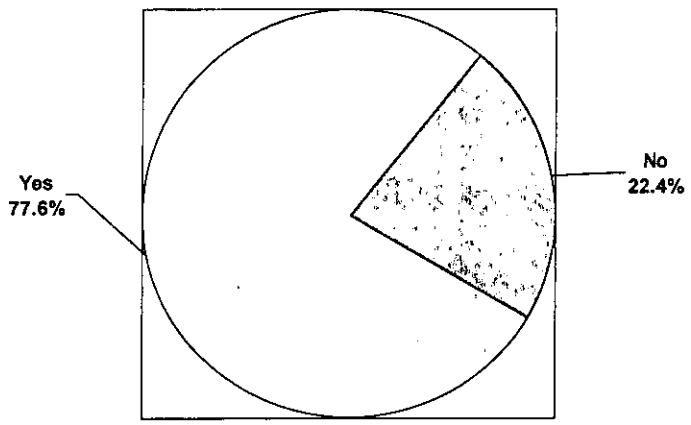

Number of Individuals with TBI You Serve
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
3.9%
52.9%
17.6%
8.9%
2.9%
6.9%
6.9%
0
1 thru 5
6 thru 10
11 thru 15
16 thru 20
21 thru 25
More than 25
n=102

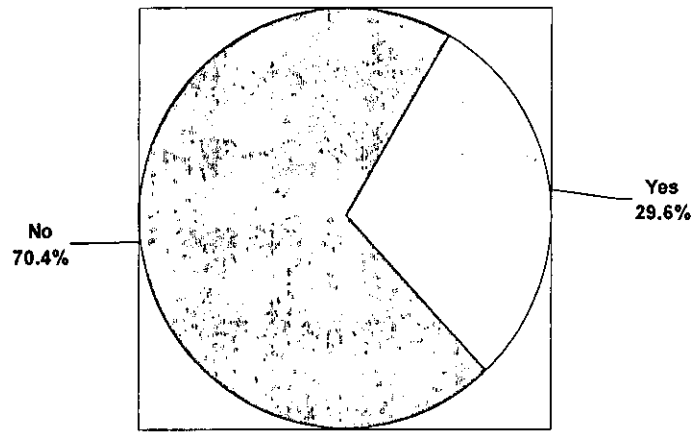

Number of Hours Spent Training for TBI (annual)
50%
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
20.4%
30.1%
19.4%
2.9%
16.5%
3.9%
6.8%
0
1 thru 5
6 thru 10
11 thru 15
16 thru 20
21 thru 25
More than 25
n=103

Do You Have a Need for Additional Training Specific to TBI?



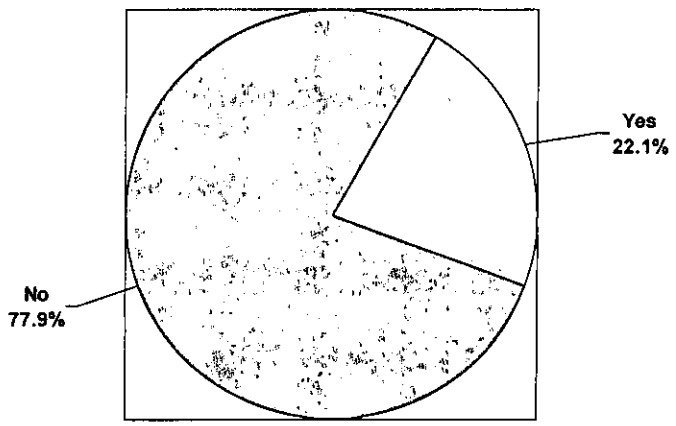
n=108

Do You Provide Direct Services for Individuals with TBI?



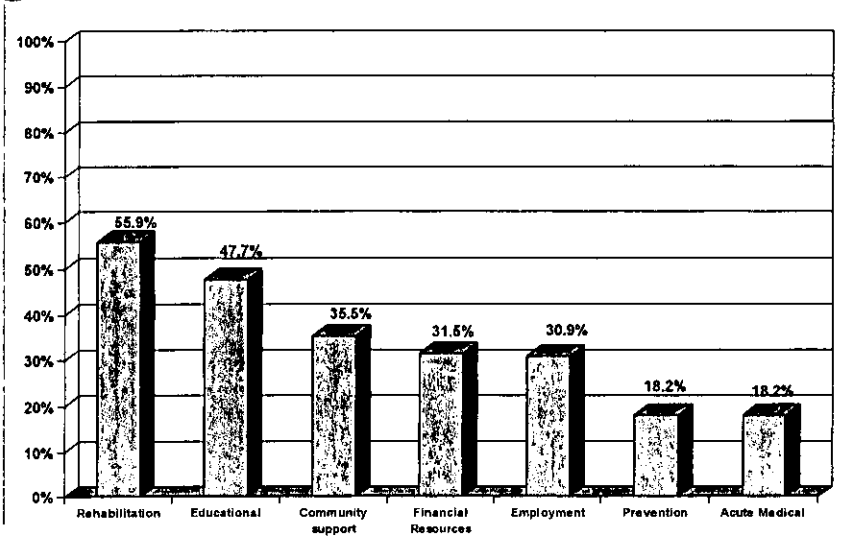
n=108

Do You Offer Training Programs on the Topic of TBI?

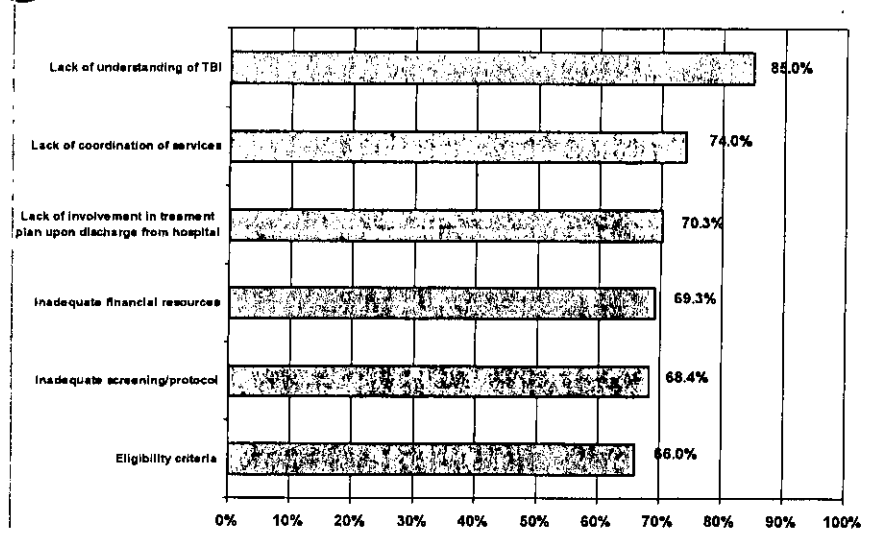


n=104

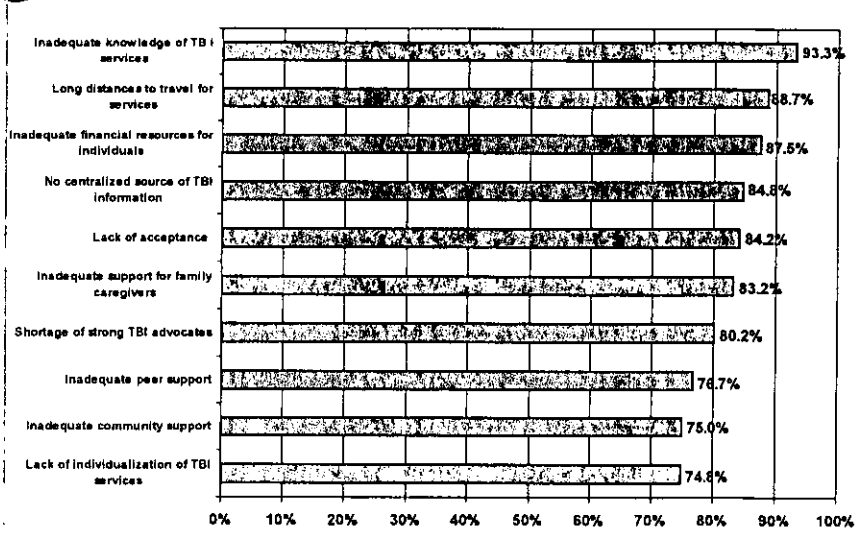
Do You Provide the Following Services to Individuals with TBI?



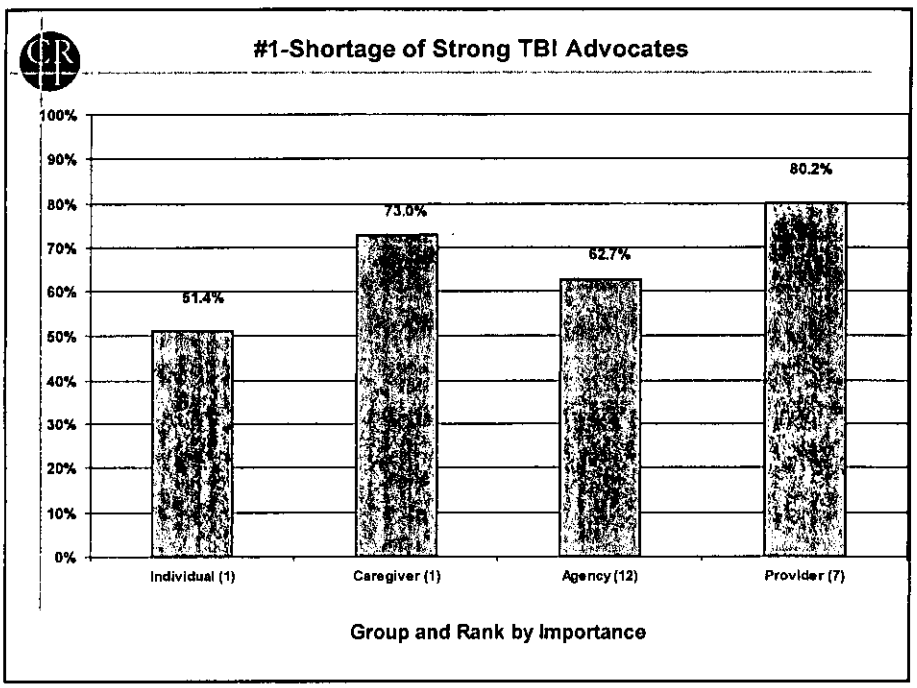
Barriers to Agencies and Providers when Providing Services to Individuals with TBI

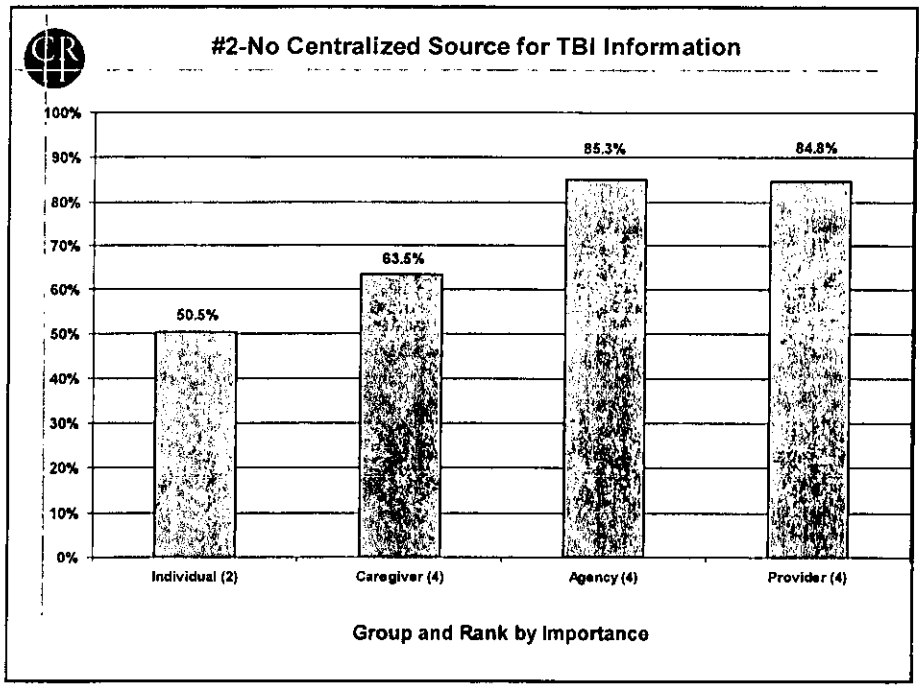


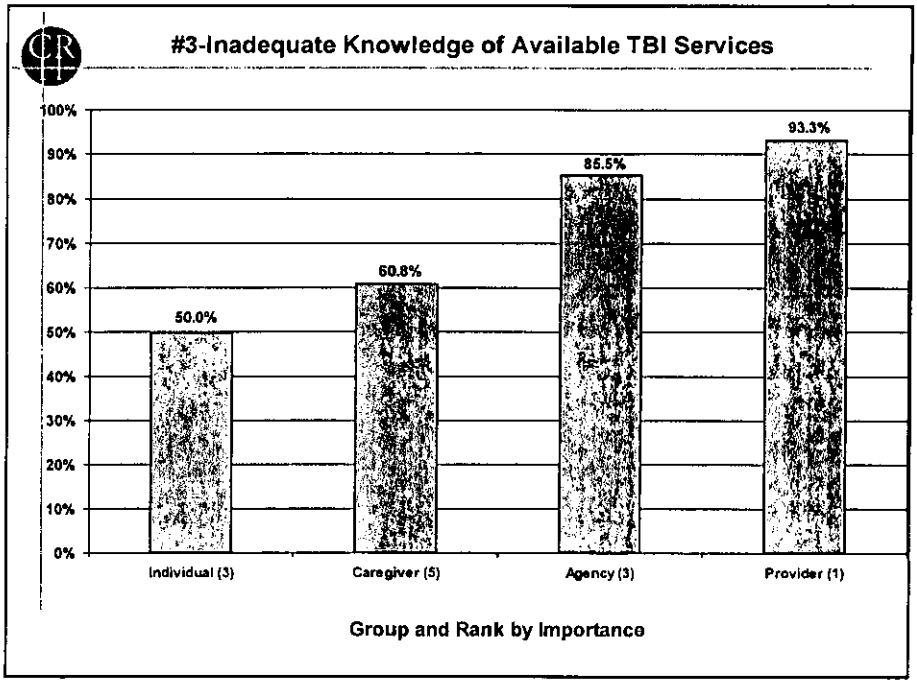
Barriers to Accessing Services Needed by Individuals with TBI as Identified by Providers

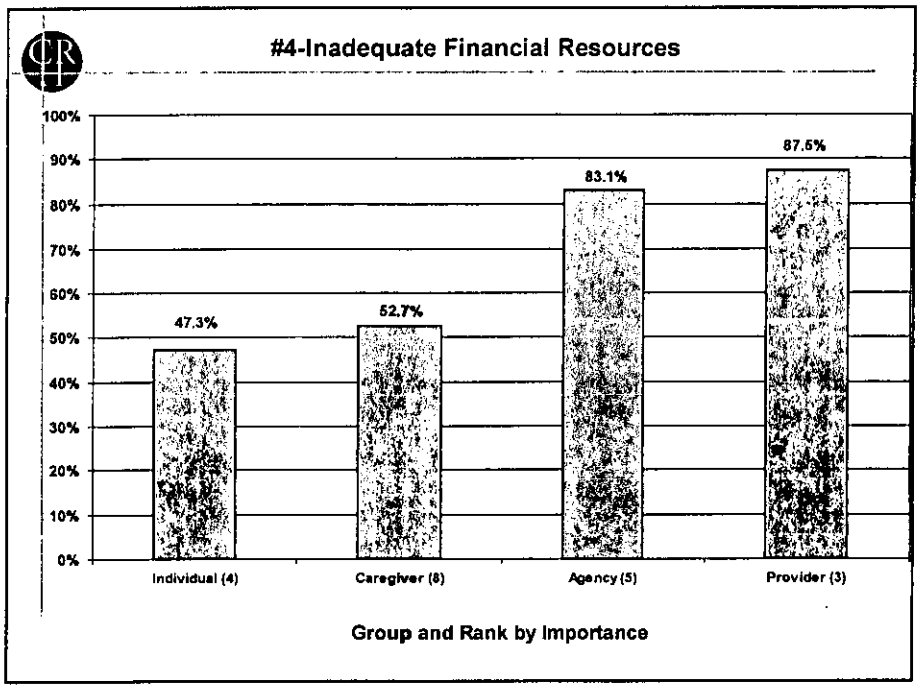


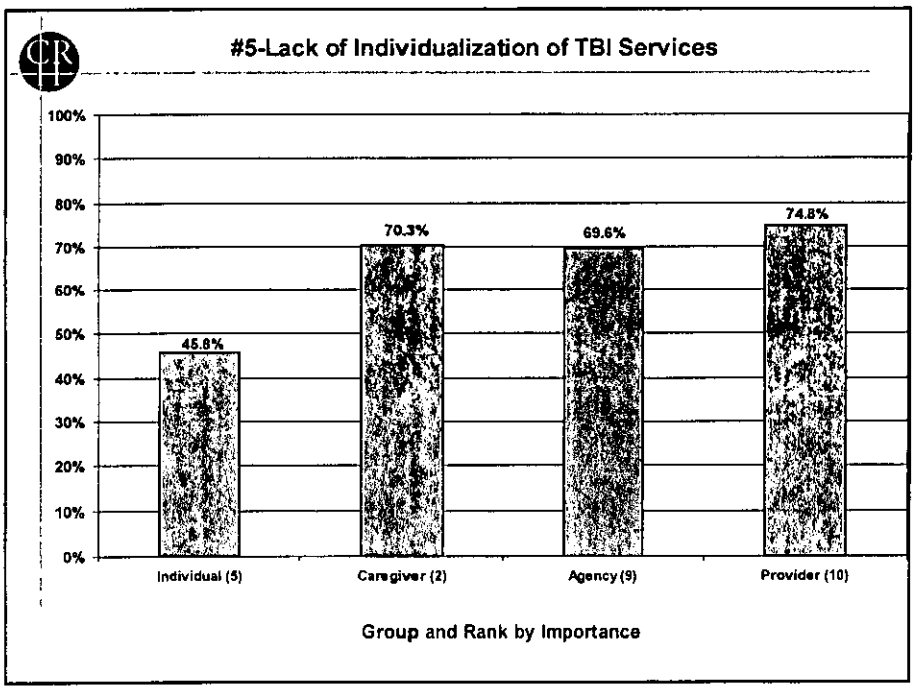
Comparative Summary of Barriers

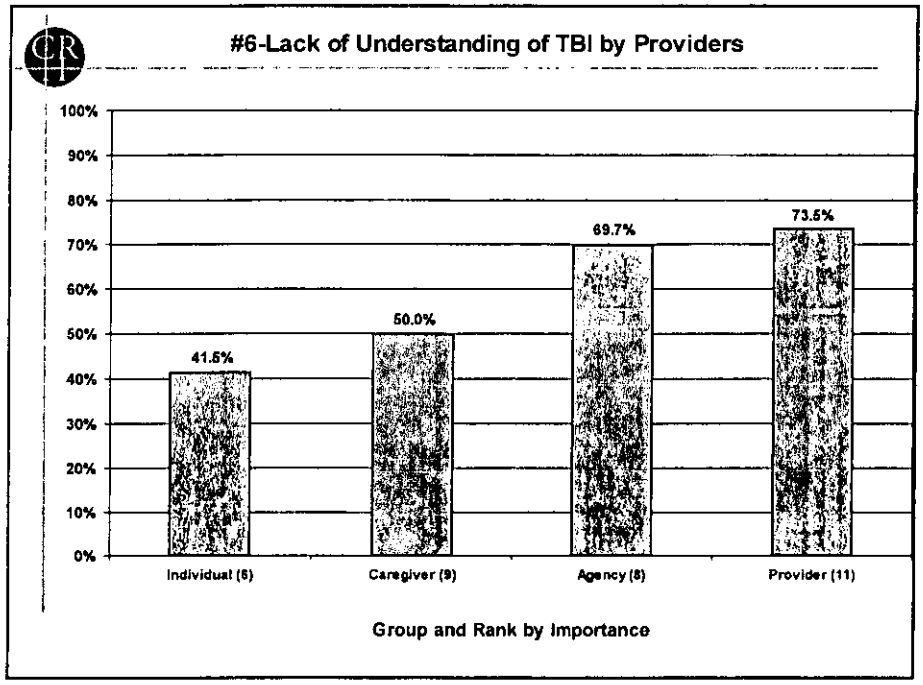


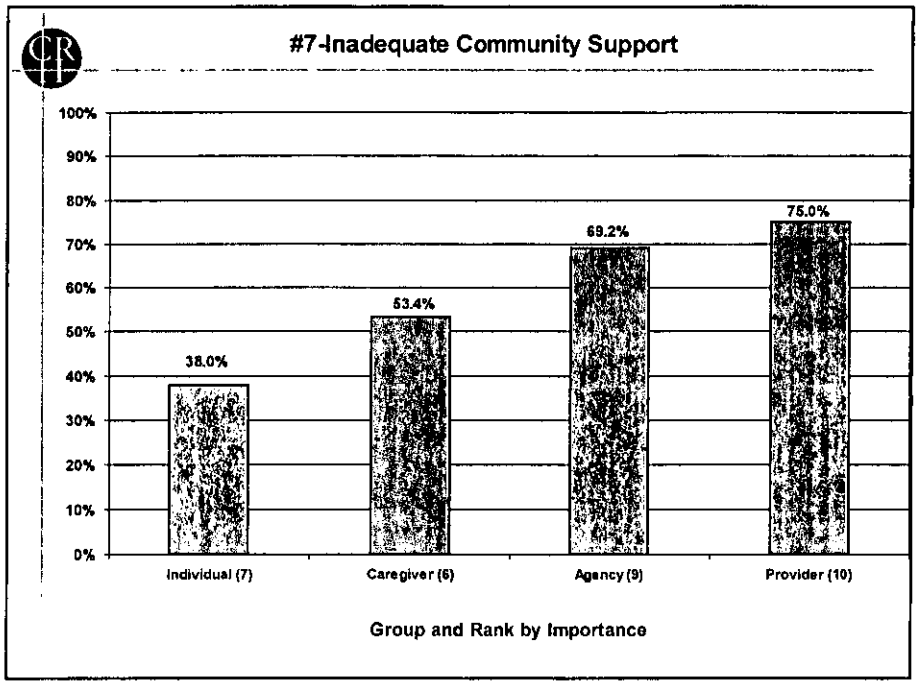

#2-No Centralized Source for TBI Information
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
50.5%
63.5%
85.3%
84.8%
Individual (2)
Caregiver (4)
Agency (4)
Provider (4)
Group and Rank by Importance

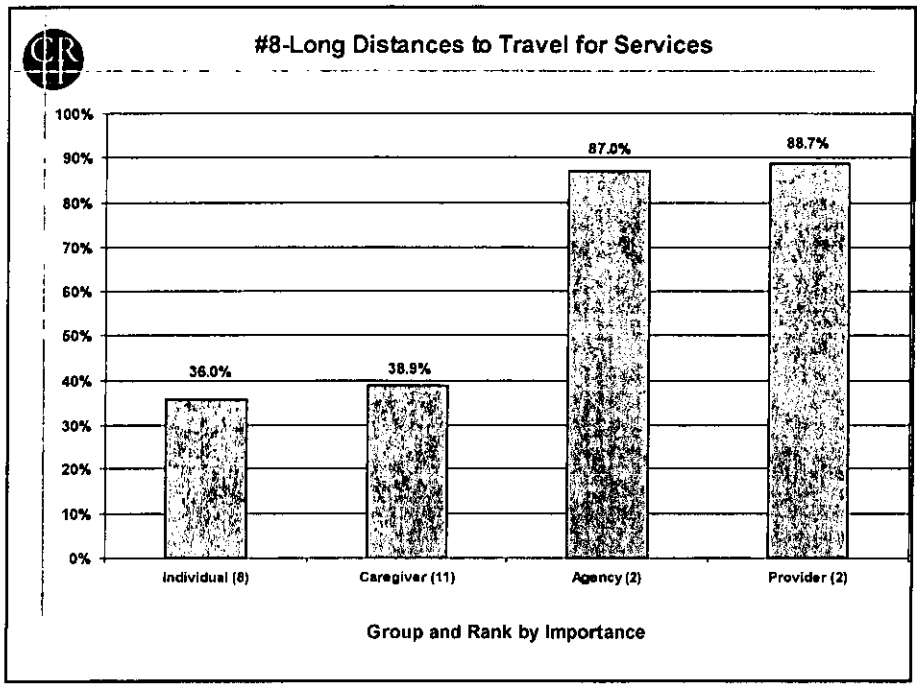

#3-Inadequate Knowledge of Available TBI Services
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
50.0%
60.8%
85.5%
93.3%
Individual (3)
Caregiver (5)
Agency (3)
Provider (1)
Group and Rank by Importance

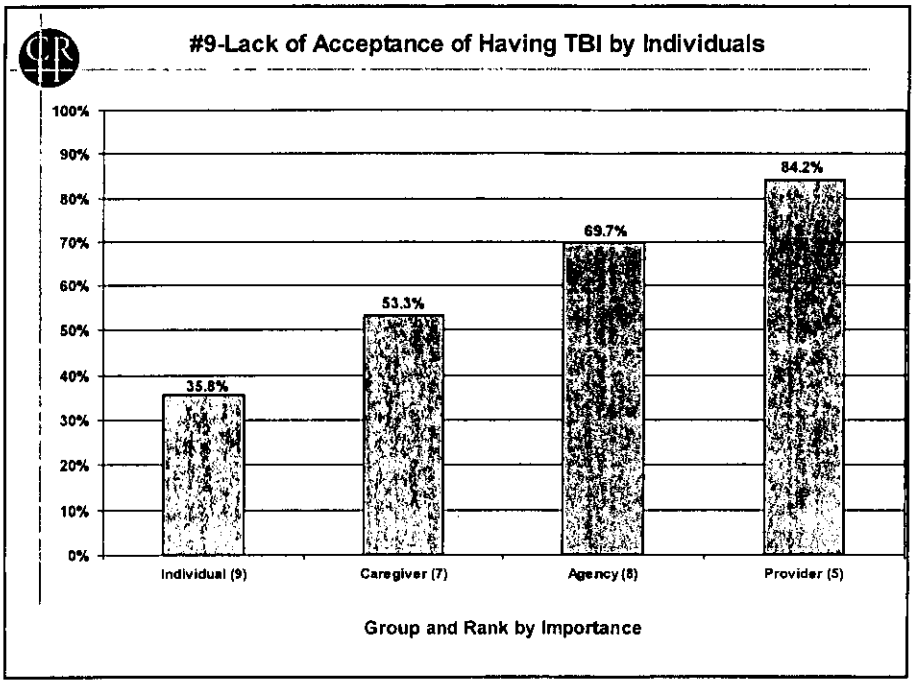

#4-Inadequate Financial Resources
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
47.3%
52.7%
83.1%
87.5%
Individual (4)
Caregiver (8)
Agency (5)
Provider (3)
Group and Rank by Importance

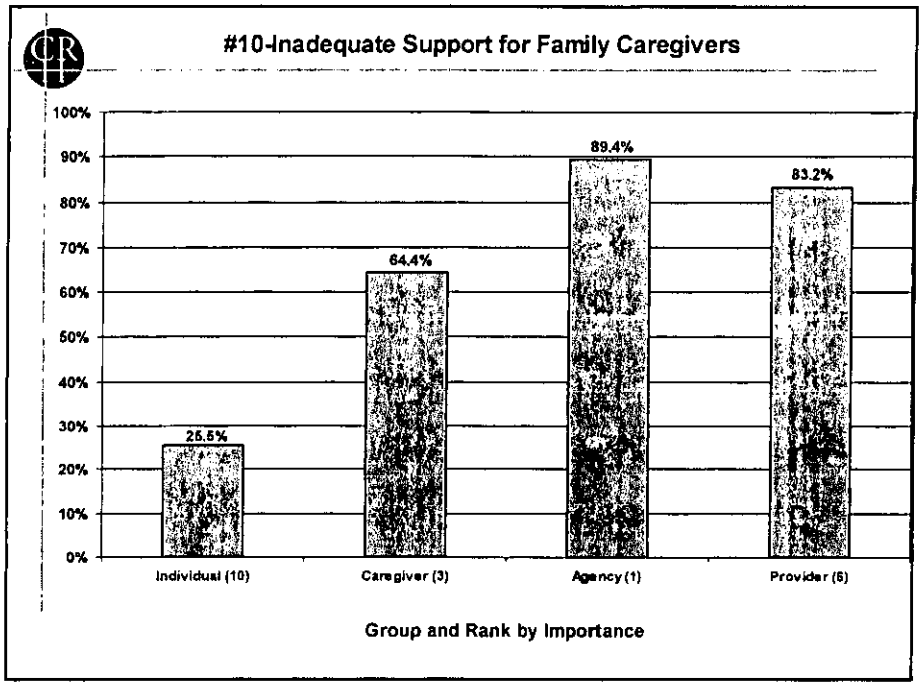

#5-Lack of Individualization of TBI Services
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
45.8%
70.3%
69.6%
74.8%
Individual (5)
Caregiver (2)
Agency (9)
Provider (10)
Group and Rank by Importance

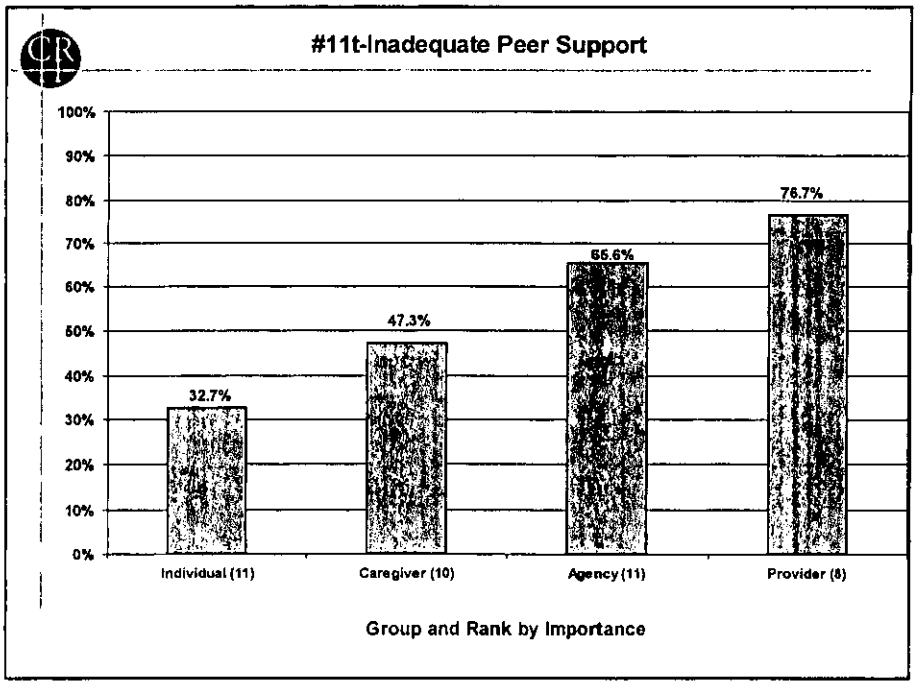

#6-Lack of Understanding of TBI by Providers
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
41.5%
50.0%
69.7%
73.5%
Individual (6)
Caregiver (9)
Agency (8)
Provider (11)
Group and Rank by Importance

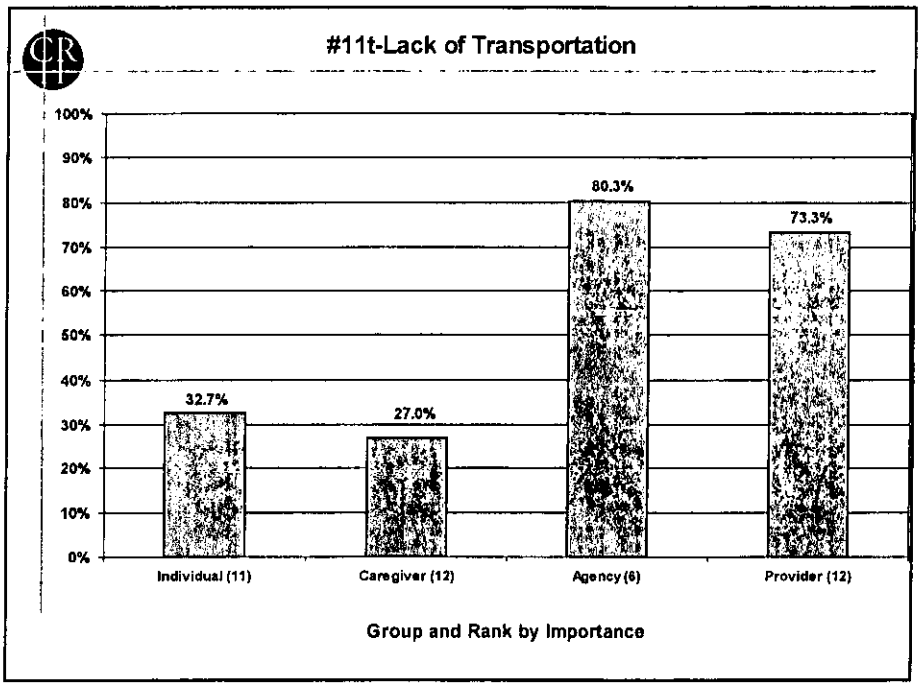

#7-Inadequate Community Support
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
38.0%
53.4%
69.2%
75.0%
Individual (7)
Caregiver (6)
Agency (9)
Provider (10)
Group and Rank by Importance

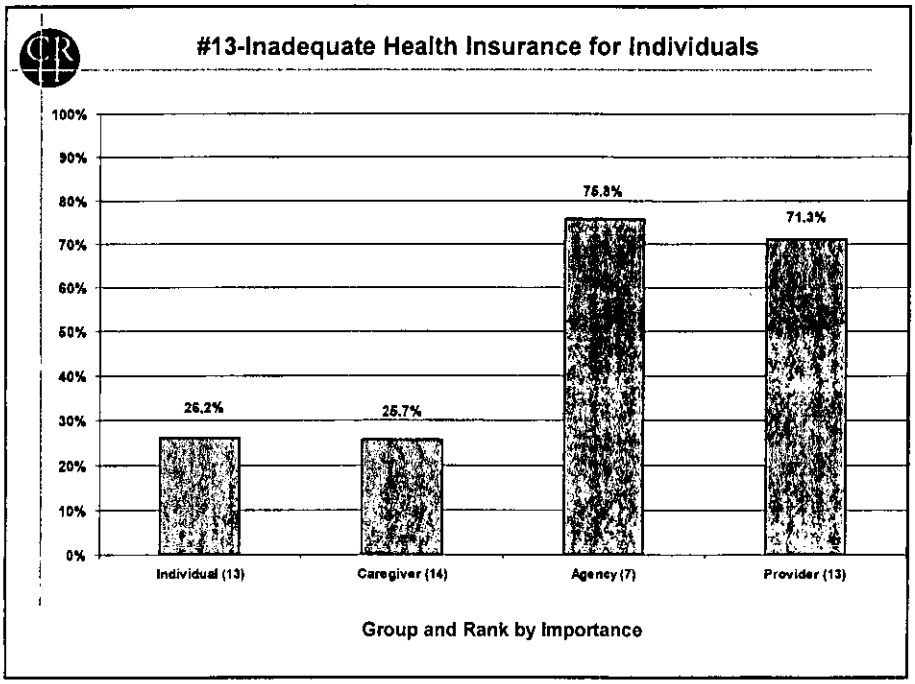

#8-Long Distances to Travel for Services
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
36.0%
38.9%
87.0%
88.7%
Individual (8)
Caregiver (11)
Agency (2)
Provider (2)
Group and Rank by Importance

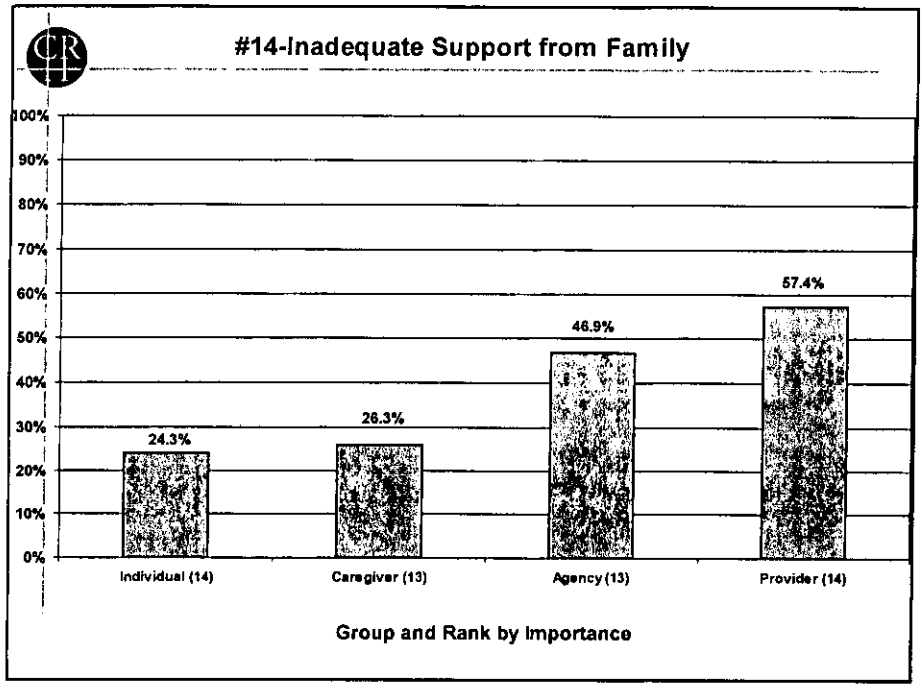

#9-Lack of Acceptance of Having TBI by Individuals
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
35.8%
53.3%
69.7%
84.2%
Individual (9)
Caregiver (7)
Agency (8)
Provider (5)
Group and Rank by Importance


#10-Inadequate Support for Family Caregivers
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
25.5%
64.4%
89.4%
83.2%
Individual (10)
Caregiver (3)
Agency (1)
Provider (6)
Group and Rank by Importance


#11t-Inadequate Peer Support
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
32.7%
47.3%
66.6%
76.7%
Individual (11)
Caregiver (10)
Agency (11)
Provider (8)
Group and Rank by Importance


#11t-Lack of Transportation
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
32.7%
27.0%
80.3%
73.3%
Individual (11)
Caregiver (12)
Agency (6)
Provider (12)
Group and Rank by Importance


#13-Inadequate Health Insurance for Individuals
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
26.2%
25.7%
75.8%
71.3%
Individual (13)
Caregiver (14)
Agency (7)
Provider (13)
Group and Rank by Importance



Key Findings

- Differences in perception between the groups surveyed:
  - Caregiver support
  - Transportation and distance
  - TBI Advocates
- Need for Training
- Need for TBI specific information and services
- Caregiver age


http://medicine.nodak.edu/crh
Center for
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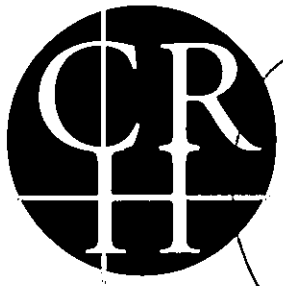
http://medicine.nodak.edu/crh
Connecting resources and knowledge to strengthen the health of people in rural communities.

http://medicine.nodak.edu/crh



Center *for*
Rural Health

University of North Dakota
School of Medicine & Health Sciences

Findings from the North Dakota Assessment of Traumatic Brain Injury Needs and Resources

Contact Center for copy

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Robin Medalen, M.S.W.
Erin Haugen, M.A.

November 2005

Funded by: Health Resources and Services Administration (HRSA)
Maternal and Child Health Bureau (MCHB)

Connecting resources and knowledge to strengthen the health of people in rural communities.

#10

Various Examples of Registries in ND

ITD - budget quote - see attached budget estimate

Set up $55,770
Maintenance - $400 per month

North Dakota Department of Health Registries

2004 Costs for the ND Department of Health Trauma Registry
A trauma registry is a disease-specific data collection of uniform data elements that describe an injury event, demographics, pre-hospital information, diagnosis, care, outcomes, and costs of treatment for injured patients. The trauma registry is used for improving trauma patient care, evaluating the adequacy of the system, and assessing compliance of various regions within the state trauma system.
1) INITIAL SETUP - Approximately $130,000 (not including education)
2) YEARLY MAINTENANCE - $18,000 per year (plus individual hospital yearly maintenance ranging from $400 - $2000)
3) FTE - At minimum .5 FTE

2004 Costs for the Emergency Medical Services Registry
An EMS registry is a data collection system of uniform data elements for all EMS calls. The North Dakota State Online Ambulance Registry or SOAR is made of a web portal (WebCur) and desktop software (EmStat). SOAR is used for improving patient care, evaluating the adequacy of the system, and assessing compliance of ambulance services licensed in the state of North Daktoa.
1) INITIAL SETUP - Approximately $75,000 at a substantial discount (not including education)
2) YEARLY MAINTENANCE - $15,000 per year; Hospital Access $5,500(plus individual ambulance services using the EmStat program pay a maintenance fee of $200)
3) FTE - At minimum .5 FTE

Immunization Registry

The North Dakota Immunization Information System (NDIIS) is a confidential, population-based, computerized information system that attempts to collect vaccination data about all North Dakotans. The NDIIS is an important tool to increase and sustain high vaccination coverage by consolidating vaccination records of children from multiple providers and providing official vaccination forms and vaccination coverage assessments. Children are entered into the NDIIS at birth, through a linkage with electronic birth records. An NDIIS vaccination record also can be initiated by a health care provider at the time of a child's first immunization. The NDIIS has the capability of collecting vaccination data on adult patients, as well as children.

Century Code: 23-01-05.3 refers to laws governing Immunization Records.

The original price of the NDIIS was $153,785. Federal funds from the National Immunization Program (CDC) covered the cost. Originally, the NDIIS didn't have much functionality. Since 1995, numerous upgrades have been done and continue to be done. The federal immunization grant supports upgrades and maintenance. Emergency preparedness funds have supported certain upgrades for the NDIIS in the past. State funding, as far as I can determine, has never been used to fund the NDIIS. The yearly maintenance, starting in July 2009 is $137,903.

The immunization program doesn't have a FTE devoted to the NDIIS. BCBSND supports the NDIIS through the maintenance contract and immunization program staff split NDIIS duties amongst each other. Last year, the immunization program was awarded a grant for a NDIIS sentinel site coordinator to analyze and report NDIIS data for the CDC.

Registry numbers information for North Dakota residents:
Children under 6 - 52,599
Children 19 to 35 months old - 12,001 with 2 or more immunizations
Children 11 and 12 years - 16,183
Adults older than 18 years - 479,252

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Immunization Program Manager
North Dakota Department of Health
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701.328.4556
msander@nd.gov

North Dakota Cancer Registry

In 1992, Congress responded to the need for local, state, regional and national cancer incidence data by passing the Cancer Registries Amendment Act, Public Law 102-515. This act authorized the Centers for Disease Control and Prevention [CDC] to establish the National Program of Cancer Registries [NPCR]. Funds are provided through Congressional appropriation to the Division of Cancer Prevention and Control, Cancer Surveillance Branch for NPCR.

In 1994, the North Dakota Department of Health and Consolidated Laboratories, Division of Health Promotion and Education applied for and received $146,069 in NPCR funding for statewide cancer registry implementation. The first grant application for NPCR funding was $171,265. At that time, the NDCR employed only one FTE. Presently, maintaining the NDCR costs between $300,000 and $357,000 yearly and employs 3.5 employees.

The NDCR is required to follow the 3:1 match formula. Seventy-five percent of NDCR's funding is federal funding. The required 25 percent match is generated through state general funds and in-kind soft match from other sources.

The Cancer Registries Amendment Act or Public Law 102-515 states that NPCR funded states must provide a means to assure complete reporting of cancer cases to the statewide cancer registry by all hospitals, facilities or health care practitioners diagnosing – treating – screening or providing diagnostic or therapeutic services to patients with cancer.

The NPCR guideline regarding complete reporting states that federal funds cannot be used for direct data collection or abstracting from reporting facilities or other reporters. NDCR does receive general funds amounting to $90,000 biennially in general funding for abstracting expenses. Currently 150 data items are collected on each cancer case. This will increase to 200 data items per case in 2010.

Marlys C. Knell CTR
Program Director
North Dakota Cancer Registry
Division of Cancer Prevention and Control
Telephone: (701) 328-2419
Email: mknell@nd.gov

ND Early Hearing Detection and Intervention (ND EHDI)
Web-based Data System – Oz eSP

The ND EHDI program utilizes Oz-eSP, a web-based data system, as its data collection tool. Oz eSP is a HIPPA and FERPA compliant web-based data system that is used by ND EHDI to collect data on all infants that have been screened and require any further testing that may lead to the diagnosis of a hearing loss. Each year over 9,000 infants are entered into the web-based system. Current cost for this system is based on the number of users. Primary users are the 17 birthing hospitals (some hospitals have more than one user seat), five audiologists, and state EHDI program staff; however, other providers could potentially access the system with a paid user fee.

Estimated user costs for the Oz eSP web-based data system for the 2009 – 2011 biennium:

o 50 users ($324.50 per user/year * 2)	$32,450.00
o Oz eSp Training fee (16 hours/biennium)	$2,400.00
	$34,850.00

The above figures do not include costs for design, development, on-going programming, maintenance (data storage) or staff time that may be required as part of a new registry, which would significantly increase the cost.

The information I am providing is regarding the ND Early Hearing Detection and Intervention (ND EHDI) electronic data system costs. This system does not provide all the components of a registry. The ND EHDI data system is currently funded by a grant that was received by the ND Center for Persons with Disabilities.

Sue Burns, RN, BNSc
Program Administrator
Children's Special Health Services
701.328.4669 or 800.755.271

Wendy Thomas
NDCPD
701.858.4367
Wendy.Thomas@minotstateu.edu

Department of Emergency Services

Maintenance to 211 services $70,000 over the biennium
$3,000-$4,000 is a one time fee to set up the website
40 hours for set up man power

Cecily Fong
Public Information Officer
ND Department of Emergency Services
Office: 701.328.8154
Cell: 701.391.8158
cfong@nd.gov

Software Development Division
Budget Estimate

To:	Date Issued:1/23/2009	Prior Est. Date:
Darin Meschke	From: Paula Dosch	
ND Department of Health	Prepared By: Christopher Heyne	
Project Description: Traumatic Brain Injury Registry		
WMS Work Order Number: 69442	WMS Service Request: 1167550	

ITD is recommending your agency budget **$55,770** for this project. This amount includes an estimated **$46,475** based on requirements we received during the interview process plus an additional **$9,295** for scope changes. The additional **20%** is based on ITD's experience with scope changes in projects this size. Including this additional amount will give your agency the flexibility to cover typical scope changes, and remain within your budgeted amount. A more accurate estimate will be prepared once this project has started and the analysis phase is completed. The cost to complete the analysis phase is estimated to be approximately **$8,678**.

What you get for your money from ITD

ITD estimates this project to take **4 months**. This timeframe is a projected timeframe based on typical project staffing levels. The actual timeframe will be determined during the Planning Phase and will be based on the availability of customer and ITD resources at that time.

ITD suggests you budget **$400** per month for the on-going cost of running the application. This amount includes the hosting charges, estimated storage and Software Development maintenance costs. All ITD services will be billed to your department monthly at actual cost.

Should you decide to proceed with this project, please approve the cost estimate via the online Work Management System. Upon your approval, you will be prompted to submit a service request under the existing work order. All ITD services relating to this project will be billed to your department monthly at actual cost.

At the start of the project ITD will review any estimate over 90 days old. If necessary a revised estimate will be issued.

ITD Request Number: 1167550 **Project:** TBI Registry

Project Description

This estimate is for the development of a Traumatic Brain Injury Registry web application. This application will allow DOH and DHS staff to enter injury reports and add notes/follow-up with existing injuries. The system will store data in an Oracle database and department staff will be able to query existing injuries and generate reports.

Assumptions

The one-time costs (development) of the routines are based on the following assumptions:

- Since little is known about the specific requirements of the application, the estimate was built based on basic requirements for an online application, speculation on what else may be required and allowing for a larger than normal budget for scope increases.
- This cost estimate is based on a blended hourly rate of $95 due to the unknown availability of ITD Software Development staff at the time this estimate was issued. If only ITD Software Development staff work on the project, billing will be at normal ITD Software Development 09-11 biennium rates.
- ITD will assign a project manager to the project.
- Data will be stored in an Oracle database.
- The application will be developed using J2EE technology.
- The application will secure user access to functionality using Microsoft Active Directory accounts/groups.
- Cognos will be used for generating 3 reports.
- All application data will be transmitted securely using a SSL certificate.
- Application will be available from within the state network only.
- The application will be load tested to ensure the application performs under stress and does not cause any server performance issues.
- Department staff will produce any necessary Help documents/user manuals, implementing the documents as HTML web page(s) available from a department's web site.
- Department staff will provide any necessary training documents or training sessions for application users.
- The application will have quality assurance functional test scripts recorded for project system testing and ongoing testing for application maintenance and server/platform upgrades.
- The application will have usability testing conducted by ITD along with the (dept.) staff. The results, of this testing, will be applied to the application which may require additional usability testing.

Determining Costs

The cost estimate includes the following processes:

Process	Description
Login	This process will allow a secure login for customer to application
Add Injury Report	Add a new injury to the system
Edit Injury Report	Modify an existing report, amending data or adding notes
Search & View Reports	Query existing reports by name, injury type, etc.
Reporting	Create PDFs of existing reports and details, display injury summaries by area, type, timeframe.

One-Time Cost for System Development

The cost for development is estimated to be $55,770. This amount includes an estimated $46,475 based on requirements and an additional $9,295 for scope changes. The additional 20% is based on ITD's experience with scope changes in projects this size. Including this additional amount will give your agency the flexibility to cover typical scope changes, and remain within your budgeted amount. A more accurate estimate will be prepared once this project has started and the analysis phase is completed.

On-Going Monthly Costs

On-going monthly costs are estimated as follows:

ITD Systems/Programming	$ 190 (2 hr @ $95/hr (blended rate) – used as necessary)
Application Server	$ 190
Oracle Disk Storage	$ 20
Total	$ 400

Application Server costs cover the hosting of the application as well as monitoring the servers and applications for availability.

Providing Customer-Centric Services

The Information Technology Department (ITD) provides technology leadership for state government and the people of North Dakota. ITD exists solely to help State agencies discover, assess, and implement information technologies. ITD's Software Development Division develops, implements, operates and supports software solutions that meet our customer's need as provided in this cost estimate. ITD also provides server computing, local and wide area network support, voice and data technologies, video conferencing, and other emerging technologies. The following overview describes the services ITD considers valuable to our customers. We hope you'll find this helpful in assessing the value of our services.

State Government IT Partner
ITD knows the business of North Dakota State government and understands inter-agency relationships. We've been servicing State agencies since 1968. Upon request, we'll provide references offering honest referrals about our services.
Our customer relationships are long-term partnerships.

Affordable Cutting Edge Technology
ITD helps agencies discover best fit solutions for their agency at affordable rates. ITD charges only to recover costs – we retain no profit with our low rates. Our staff is trained in many new and existing technologies, so we can readily assess customer requirements and provide solutions that best fit an agency's needs. ITD implements and supports IT solutions on modern hardware in modern facilities, using operating systems and software no older than current version minus 1.
Whenever it's necessary to extend our capabilities, we augment our current staff with outside vendors to meet demands.

Quality
ITD develops applications within the processes of a structured systems development methodology. This includes functional testing and all applications are tested for usability and performance (load tested). ITD Meets State & Federal Audit Compliance. Our infrastructure and operation processes are reviewed by and meet state and federal audit requirements. ITD Supports State Enterprise Architecture Standards, and our software and infrastructure meet North Dakota Enterprise Architecture standards.
We build compliance into our service offerings which relieves the customer of State standard compliance conc

Dedicated & Experienced Staff
ITD employees submit to an FBI background check and are bound by the same confidentiality requirements as agency staff. ITD's staff is cross-trained to provide continuous backup. We provide dedicated architects to design effective, top-notch infrastructure for security, system hosting, software development, and telecommunications. Our staff applies formal project management practices to all projects.
ITD strives to retain innovative, talented, and dedicated staff. ITD's staff is tenured with an average of 13 years of service.

Support Structure
ITD offers several levels of customer support, including 24 x 7 support for applications and infrastructure.
Customer Service Surveys indicate 99% of customers are very satisfied with our support.

Flexible Infrastructure
ITD's infrastructure and support structure are designed to meet varied needs. ITD designs and builds applications that can operate in a redundant environment. If one server fails, another server picks up the workload with little or no down time.
We can design and host any size application.

Disaster Recovery
ITD has the tools and resources required to monitor software applications and computer system infrastructure to assure adequate performance and up-time. Applications can be monitored on a 24 x 7 basis. If a disaster occurs in our Computer Systems area or Statewide Network, customer applications can be running within hours.
ITD's standard practice is to keep all data, applications, and systems backed up in a secure location to meet customer expectations.

Security
By investing in the infrastructure and training required to prevent malicious activity within our IT environment, ITD has dedicated sta
that customer data and applications are secure.
We use source code control software to provide sound source code management.

Back to Estimate

#11

90495.0302
Title.

Prepared by the Legislative Council staff for
Senator J. Lee
January 28, 2009

PROPOSED AMENDMENTS TO SENATE BILL NO. 2198

Page 1, line 1, replace "three new sections to chapter 23-02.1, two" with "five"

Page 1, line 2, remove the first comma

Page 1, line 3, remove "development and maintenance of a traumatic brain injury registry and the"

Page 1, remove lines 8 through 12

Page 1, line 13, replace "23-02.1" with "50-06.4"

Page 1, line 18, replace "23-02.1" with "50-06.4"

Page 3, after line 6, insert:

"**SECTION 6.** A new section to chapter 50-06.4 of the North Dakota Century Code is created and enacted as follows:

Vocational rehabilitation and consultation. The department shall provide or contract for the provision of increased and specialized vocational rehabilitation and consultation to individuals with traumatic brain injury who receive case management for personal care services. Services under this section include extended support for individuals at risk of losing their employment upon exhausting their vocational services."

Page 4, line 20, replace "$2,634,864" with "$864,000"

Page 4, remove lines 24 through 29

Renumber accordingly

SUMMARY OF SENATE BILL 2198

Section 1 directs the Department of Human Services (DHS) conduct public awareness efforts on preventing and identifying brain injury, and to provide outreach services to survivors of brain injury.

Section 2 gives DHS broad authority to seek and accept funding for brain injury services.

Section 3 directs DHS to contract with one or more entities to provide informal supports to people with brain injury. This might be a statewide brain injury association.

Section 4 expands the duties of DHS as the lead state agency on brain injury services by requiring it to hold annual meetings with key brain injury stakeholders including other state agencies. Stakeholders include the Department of Veteran's Affairs and the National Guard.

Section 5 provides social and recreational services to the few survivors of brain injury who are extremely isolated and for whom work is not a viable option.

Section 6 provides extended employment support services to people with brain injury who otherwise could not gain or keep employment. This will allow Vocational Rehabilitation (DHS-Rehabilitation & Consultation Services) to serve people who currently must be denied services.

Section 7 directs DHS to provide home and community based services to people who qualify for current programs. It also directs outreach and quality control activities. This section does not change eligibility for services.

Section 8 clarifies the duties of DHS to provide alcohol and substance abuse services to veterans.

Section 9 provides an appropriation of $864,000 to DHS to carry out these activities.

Elaine Grasel

Hannah's story

Tim Mathera TBI

November 12, 2007 – 1:20 p.m. 15-year-old Hannah Anderson was driving to her grandmothers to watch movies with her friends. As they leave Leeds – Hannah's car is t-boned by a pick-up. The kids in the backseat are fine and call for help immediately. A passerby – a MN hunter – is first on the scene of the accident. He is a volunteer firefighter from Andover, MN. Chris Wallace realized Hannah had a pulse, although weak – he got into the car from the backseat and was able to hold Hannah's head up to open her airway, cut her seatbelt and clean some of the glass off of her. It took 45 minutes for the Jaws of Life to cut Hannah out of the car and get her into the ambulance. She was only breathing 4-5 breaths per minute and no one expected her to survive the 30 mile ride to the Rugby Hospital.

Hannah's injuries were too severe for the Rugby Hospital to be able to handle her case. The lifeline plane from Minot was out on another call – they loaded Hannah up in a second ambulance and drove as fast as they could to Trinity Hospital in Minot. Hannah somehow managed to hang on and had made it this far – she was in the emergency room for about 6 hours where they ran all kinds of tests before moving her to the ICU. We were in Minot for two days before it was decided it was safe enough for her to be airlifted to a hospital in Minneapolis that specialized in pediatric traumatic brain injuries.

We sat by Hannah's bedside in the pediatric intensive care unit for 2 ½ weeks before she started to regain consciousness. There were six different medicines being pumped into her little body – she ran a constant fever – she was on a respirator and there was not much sign of brain activity. By week two the doctors would give her a "sedation holiday" to see how Hannah would respond and if she was ready to start coming out of the coma. It took 3-4 days before she could even open her eyelids and at that it was only a tiny bit. Finally, Thanksgiving weekend she gave us a sign that she still there – we got a precious "thumbs up". This is the sign we had hoped for – she heard and understood the doctors and could respond back to them. Dr. Karagu looked at Duane and me and said, "This just changed her whole prognosis". The doctor, the nurse, the medical students and residents all cheered. We were overjoyed. Sometime within the next week, Hannah was able to respond back to the doctor when he held up one finger, she held up one finger – when he held up two fingers, she held up two fingers, etc. this was another milestone – we all rejoiced.

Finally the day came when they said we are going to try and wean her off the respirator to see if she can breathe on her own. The doctor and respiratory therapist turned off the ventilator and she seemed to be doing fine, so she was extubated. Within the hour, it was apparent that she was having some distress. We waited – 20 minutes more and they decided she needed to have the breathing tube put back in. The next week was spent strengthening her lungs and

having her breath without the aid of the ventilator, but it was there if she needed. First 20 minutes, then 40 and pretty soon she was going 6 hours with the aid of the ventilator. It was a great day when we were finally able to be rid of the respirator. Hannah developed pneumonia while on life support, so it took time for that to clear and her lungs to become strong again. Also, the brain had to be retrained – how to get the body enough oxygen.

It was exciting yet terrifying the day they said we could finally move out of the PICU and onto the pediatric unit. We were not under the watchful eye of one-to-one nursing and Hannah was still running a fever. After being in the hospital for three weeks, the doctors did discover the reason for the continued fevers – Hannah had become infected with MRSA. More antibiotics were added to her already large list of medications and by the time we left Hennepin County Medical Center for the rehab hospital, the fevers were gone.

While in the PICU, Hannah was started on physical therapy and occupational therapy. Her feet were starting to contract and she was losing muscle mass. To prevent that – three therapists came twice a day to do stretching of her limbs. They actually sat her up in bed and then brought her to a standing position. She was like a limp rag doll – on one hand it was the saddest thing I had ever seen, but on the other hand – she looked beautiful to us. Her head was hanging and she had no muscle strength to hold her head up – her arms just hung by her side and she was not able to use them and her feet had to be held down on the floor with someone holding her knees in a locked position or she would have just fallen to the floor. By the last week at HCMC the therapists were holding Hannah up and the other therapist was moving her feet and knees to try and retrain her brain how to walk.

December 12, 2007 – Hannah was discharged from HCMC and ambulanced over to Gillette Children's Specialty Hospital for 6 weeks of rehabilitation. Due to her MRSA infection, Hannah was given her own room. There was a fold out couch in the room, so I was able to be with Hannah the entire time she was in the hospital. Rehab is very intense. Hannah had to be up and ready to work by 9:00 and usually had therapy until 4:30 p.m. five days per week. On Saturday therapy was only in the morning and Sunday's there was no therapy. She had occupational therapy twice a day, speech therapy twice a day, physical therapy twice a day, school sessions, music therapy, therapeutic recreation and psychology every day. There was the stander that she was supposed to be in at least an hour a day, cathing that had to be done every 4 hours as her bladder was not functioning yet, medications to take and meals to be eaten. Each evening there were group activities that one could attend for the kids – either arts & crafts – dog shows, or other forms of entertainment. The rehab hospital was an amazing place. Hannah was only using her right arm for activities and not using the left. Well, the therapists put a stop to that – they put her right arm in a cast and made her use the left arm. It was hard to see her struggle using her left arm after all she had been through, but with a lot of

tough love from the nursing staff, therapists and her parents – Hannah persevered and was able to retrain her brain to use that left arm again.

When a person sustains a brain injury they almost always deal with extreme exhaustion. Hannah also was exhausted and continues to struggle with being tired. We found there is a fine line between pushing through the exhaustion to do her therapy and having to just leave her alone for a period of rest. We must always weigh the pros and cons and decide what is best for her in the long run. Hannah had amnesia from the accident and once she started getting her voice back, she asked if she was a senior or a freshman in high school – she was a sophomore. She did not remember anything that happened to her six months prior to the accident. She will never have any recall of the accident, as the psychologist told us, because her brain was not able to make a mental picture of it.

Finally, January 24th, we were discharged from the rehab hospital in St. Paul, MN and able to come back home to our house in Leeds after being gone for 10 weeks. Our son, Michael – who was a senior in high school at the time – had been home under the watchful eye of the entire town of Leeds. He attended school as much as he could, but spent many hours either driving to Minneapolis or riding the train down, so we could be together as a family. We arrived home on Friday, January 25th and Hannah started back to school full days on Monday, January 28th. The school had to hire a para-professional to be with Hannah at all times. Her balance was unsteady, she suffered from severe short term memory loss and she could not even pick up a pencil and write to take notes. The para was a great help to Hannah and a great comfort to us – they worked with Hannah to get to class on time, know which books she needed to take to class, help her use the bathroom facilities and write down answers to questions as homework assignments came due.

The teachers and students at the Leeds School had several in-services before Hannah came back to school, so they would know how to help a student with a brain injury and so the kids would know what things would be like for Hannah. An IEP was set up for Hannah through the Special Education teacher at the school. OT, PT and speech services were given to Hannah at the school. She had to be given breaks between classes to rest. Her schedule was set up to allow time for rest periods – she usually had a class then study hall so she could have some down time before the next class. Still a year later she cannot do back-to-back classes and her schedule continues to allow for a study hall between classes for a mental break.

Over one year later, Hannah continues to go to Occupational Therapy and Speech therapy in Devils Lake twice per week. We make the 240 mile round trip once a week to Grand Forks where she sees a psychologist and a vision therapist. Hannah has been in bifocals since we got her home and had her eyes checked. There was damage to the ocular nerve back in the brain stem and does therapy to help strengthen this muscle. Hannah has trouble scheduling,

organizing, sequencing and reasoning. She has continued to show improvement in almost every aspect of her life. She just wants to be a "normal teenager again" and has worked extremely hard to get there. She has had reteach her brain to do all things we take for granted such as walking and talking. Hannah has had to learn many compensatory strategies and develop systems to help her navigate daily tasks that others do without thinking about.

Many wonderful opportunities have presented themselves this year. Not only has Hannah learned how to walk – she learned how to walk again in high heels. She made her physical therapists day when she walked into the hospital in high heels and was taller than he was! She was able to go to prom last year and there was not a dry eye in the room when she walked in looking as lovely as ever. This fall she competed in the Miss Teen USA ND pageant and walked the runway with confidence. Hannah and I have been able to share our story along with Rebecca Quinn from the Center for Rural Health as she has been giving TBI seminars around the state. Hannah has been able to stand up in front of crowds and talk with ease; she has many laughing in their seats. Hannah is on the cover of this month's "North Dakota Medicine Magazine" and is featured in a TBI article. Hannah is now a cheerleader for the Minnewaukan-Leeds Lions basketball team. It helps her with her short term memory, recall, coordination, rhythm and most importantly with friendships.

As a family, we have had the opportunity to meet many other individuals who have sustained TBI's. Meeting others who have gone through what we did really helped us and in turn, we hope that what we have gone through can help others.

TESTIMONY – PROTECTION AND ADVOCACY PROJECT
Senate Appropriations Committee, Hon. R. Holmberg, Chairman
Supplement to P&A Testimony Senate Human Services Comm.
SUMMARY OF AMENDMENTS TO SB 2198 IN SENATE HUMAN SERVICES
February 13, 2009

The amendments removed mention of a brain injury registry. The Department of Human Services, Department of Health, and advocates will try to accomplish some of these activities with existing data and within existing laws. We will report our progress in 2011.

The amendments restored language for extended employment services. Extended employment services are less intense, and begin after VR finishes working with an individual. The Legislative Council believes they inadvertently removed this language between drafts as the bill was prepared. The amendments also limit extended employment services to persons receiving case management.

All references to DOH were replaced with DHS because DHS is the lead agency on brain injury.

The appropriation was reduced markedly from "$2,634,864" to "$864,000." Most of this change reflects a different theory of how funding should be provided to existing programs when there are no changes in eligibility. The amendments leave the funding of existing DHS programs to the DHS appropriation, HB 1012. The Senate Human Services Committee made this change in consultation with the Human Resources Division of the House Appropriations Committee. The remainder of the appropriation amendment reflects trimming of various activities under the bill, such as informal support services.

3

TESTIMONY – PROTECTION AND ADVOCACY PROJECT
Senate Appropriations Committee, Hon. R. Holmberg, Chairman
Supplement to P&A Testimony Senate Human Services Comm.
EXTENDED EMPLOYMENT SERVICES IN SB 2198
February 13, 2009

Chairman Holmberg, and members of the Senate Appropriations Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A). P&A recommends your support of SB 2198.

Imagine you are driving home on icy roads. You are hurrying back to your family responsibilities and your regular career. You have driven in worse conditions, but tonight the unthinkable happens. You wake up in the hospital ten days later. Miraculous medical technology saved your life, but the blessing is mixed. You need to learn to speak, read, and walk again.

After weeks in the hospital, you spend six very productive months in a rehabilitation facility. You have indeed relearned to speak, read, and walk. You and your family are very proud of how you've struggled back. You and your spouse have spent all your savings and most of your retirement money supplementing your insurance coverage, but it's been worth it. You are eligible for Social Security Disability Income but have to wait two years to be eligible for Medicare. Medical bills are piling up due to extensive rehabilitation and maintenance. Your spouse can't live with the thought of giving up the house and you want to stay together.

Imagine your company kept a place for you. You try to return to work, but it just doesn't work out. You and your boss or partner try shifting responsibilities around but it's not practical to reinvent the company structure for one person. You have great skills remaining, but others are gone for now. You decide to ask Vocational Rehabilitation (VR, also called RCS) for help tapping your skills and learning new ones. However, VR tells you with regret they don't think you could hold a job without some ongoing support. Their rules won't let them start a case for you if the ongoing support you need to keep a job isn't available.

That is the biggest gap the appropriation in this bill attempts to bridge. All you want is to go back to work, earn money and take care of yourself and your family. You want to regain as much independence personally and financially as possible. You choose work!

Thank you very much for your consideration. Vickay Gross, a P&A employment advocate, and I would welcome any questions.

SB 2198 Budget Explanation

Services	Contractor or Temp Employees	Participants	Cost / person / month	Monthly Total	**Biennial Total**		per partic.	Notes
VR Extended	1	40	500.00	20000	**$480,000.00**		$12,000.00	
Informal Support Organization	1	200	31.25	6,250.00	**$150,000.00**		$750.00	
Public Awareness		9900	0.10	1000	**$24,000.00**		$2.42	
Day Services or Social/Recreation	0.25	10	200.00	2000	**$48,000.00**		$4,800.00	
Training & Quality Assurance	0.75	135	50.00	6750	**$162,000.00**		$1,200.00	
TOTAL	3				**$864,000.00**			

(1)

Mathern, Tim

From: Murry, Bruce D.
Sent: Monday, February 16, 2009 1:18 PM
To: Holmberg, Ray E.; Bowman, Bill L.; Christmann, Randel D.; Robinson, Larry J.; Mathern, Tim; Wardner, Rich P.; Kilzer, Ralph L.; Grindberg, Tony S.; Lindaas, Elroy N.; Fischer, Tom L.; Krauter, Aaron J.; Krebsbach, Karen K.; Seymour, Tom J.; Warner, John M.
Cc: Lee, Judy E.; Kelsch, RaeAnn G.; Mueller, Phil; Klemin, Lawrence R.; Rebecca Quinn; Larsen, Teresa A.
Subject: 2198 TBI in One Paragraph

Dear Senator Holmberg & Senate Appropriations Committee:

I tried to be succinct in Friday's hearing. I may have done so to a fault. I missed the mark in explaining what our current system does and what this bill proposes: Current TBI programs serve about 35 North Dakotans. These people qualify for nursing facility level of care, but chose more independent living. If they recover enough to work half time they often lose nursing facility eligibility. Limited help to keep a job it is not available if you recover beyond nursing facility level. People then tend to lose work, often followed by their independence. A return to residential services often follows. This revolving door is counterproductive. Extended employment support in the bill tries to create a step-down level of support people moving toward self sufficiency. The funding of informal brain injury services seeks to help people who can live & work independently without government help to continue to do so (about 1.5% of general population). For example a worker with brain injury might consult a nonprofit about tools to track work requests and stay on the job. The bill proposes limited funding of training and quality control efforts to increase the effectiveness of current and proposed TBI services. If so, more county agencies and local providers will have the expertise to help survivors of brain injury be more independent. Please contact me with any questions, or ask me to answer them for the Committee. Thank you very much for your consideration.

Sincerely,

Bruce Murry
Public Policy Advocate
ND Protection & Advocacy
(sent from a remote location)
(701) 328-2950 office
(701) 390-1000 (personal cell/mobile)
(701) 224-9341 (home)

CC: Sponsors, DHS, UND Ctr. Rural Health

#1

House Human Services Committee

March 9, 2009

Senator Tim Mathern

Chairman Weisz and Members of the Human Service Committee

My name is Senator Tim Mathern. I am a Fargo resident here to introduce SB 2198. Passage of this bill will give us more information about the prevalence of traumatic brain injury and expand services to individuals and families dealing with traumatic brain injury.

I served on a statewide committee this past interim and became convinced that we need to do more to address the specific need that persons with brain injuries have. Our past efforts often limited our services to persons of this population to services targeted to persons with intellectual disabilities or mental illness. This is often not appropriate. SB 2198 is the expression of the interim committee's work in the public policy aspect of their deliberations.

The services and costs in the original bill were much more extensive but the present version will make great strides in helping persons with a brain injury have employment and live independently instead of being institutionalized.

Thank you for the attention you will be giving to the many presenters coming before you. I ask for a Do Pass recommendation.

Thank you for your consideration.

#2

TESTIMONY – PROTECTION AND ADVOCACY PROJECT
House Human Services Committee,
Hon. Robin Weisz, Chairman
SUMMARY SB 2198 AND SENATE AMENDMENTS
March 9, 2009

Chairman Weisz, and members of the House Human Services Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A).

Current TBI programs serve about 35 North Dakotans. These people qualify for nursing facility level of care, but chose more independent living. If they recover enough to work half time, they often lose nursing facility eligibility. Limited help to keep a job it is not available if you recover beyond nursing facility level. People then tend to lose work, often followed by their independence. A return to residential services often follows. This revolving door is counterproductive. Extended employment support in the bill tries to create a step-down level of support so people can move toward self-sufficiency.

The funding of informal brain injury services seeks to help people who can live & work independently without government help to continue to do so (about 1.5% of general population). For example, a worker with brain injury might consult the contractor about tools to track work requests and stay on the job.

The bill proposes limited funding of training and quality control efforts to increase the effectiveness of current and proposed TBI services. If so, more county agencies and local providers will have the expertise to help survivors of brain injury be more independent.

The Senate removed mention of a brain injury registry from the bill, in consultation with stakeholders. The Department of Human Services (DHS), Department of Health (DOH), and advocates will try to accomplish some of these activities with existing data and within existing laws. We will report our progress in 2011.

The amendments restored language for extended employment services. Extended employment services are low intensity, "tune-up" on the job services. Extended services begin after DHS' Rehabilitation & Consultation Services (VR)

finishes working with an individual. DHS-VR cannot open a case without these services in place. The amendments also limit extended employment services to persons receiving some kind of case management to limit costs and administrative impact.

The Senate replaced all references to DOH with DHS because DHS is the lead agency on brain injury.

The Senate cut the appropriation by about 2/3, from $2,634,864 to $864,000. Most of this change reflects a different theory of how funding should be provided to existing programs when there are no changes in eligibility. The amendments leave the funding of existing DHS programs to the DHS appropriation, HB 1012. The Senate Human Services Committee made this change in consultation with the Human Resources Division of the House Appropriations Committee and the DHS. DHS stated they did not have to turn anyone away from the SPED and Medicaid personal care programs since the 2005 Session. The remainder of the appropriation amendment reflects trimming of various activities under the bill, such as informal support services.

PROTECTION AND ADVOCACY PROJECT
House Human Services Committee
Hon. Robin Weisz, Chairman
March 9, 2009

ATTACHMENT A – TABLE SUMMARIZING SB 2198

Issue/Need	Current Resources & Gaps	Solution Proposed SB 2198	Comments/Costs
Jobs	When people ready to work, services often withdrawn – they lose current brain injury services.	*Extended employment supports aimed below nursing facility level of care*	40 persons targeted for biennial total $480,000. Budget breakdown in Attachment B.
Informal Supports	ND among 3 states without Brain Injury Association	*One professional at private contractor similar to Alzheimer's Association or The Arc to provide ind. counsel & advoc.*	Est. cost $150,000 for biennium to serve 100 people & info to 1000.
Personal Cares	Few providers outside Morton & Barnes have expertise	*Existing SPED & Medicaid personal care services in HB 1012.*	Existing services developed through training, quality control efforts
Veterans with brain injuries	Veterans who've recovered beyond nurs. facil. level with VA no spec. services	*Access & suitability for veterans w/ TBI required*	See also BIA outreach, DHS training service providers.
Lead agency DHS	No partner agencies or specified duties	*National Guard, Dept.' Veterans Affairs, Dept. Public Instructionl, Dept.O' Health, specified partners*	Authority only -- No financial resources required
Severe Isolation if Unemployed w/o prospects	Persons physically lose elig. for TBI waiver but have no prospects of employment severely isolated & decline.	*Provide social and recreational resources for ten persons per month.*	$4,800 for each of 10 participants per biennium.
DHS Training, Public Ed, Quality Control	Few counties, vocat'l / care / health providers, schools, , etc. have TBI expertise.	*Resources to provide training, prevention educ., & measure program effectiveness*	$24,000 Public Educ. $162,000 Training, Quality Control, etc.

PROTECTION AND ADVOCACY PROJECT
House Human Services Committee
Hon. Robin Weisz, Chairman
March 9, 2009

Attachment B -- SB 2198 Budget Explanation

Services	Contractor or Temp Employees	Participants	Cost / person / month	Monthly Total	**Biennial Total**		per partic.	Notes
VR Extended	1	40	500.00	20000	**$480,000.00**		$12,000.00	
Informal Support Organization	1	200	31.25	6,250.00	**$150,000.00**		$750.00	
Public Awareness		9900	0.10	1000	**$24,000.00**		$2.42	
Day Services or Social/Recreation	0.25	10	200.00	2000	**$48,000.00**		$4,800.00	
Training & Quality Assurance	0.75	135	50.00	6750	**$162,000.00**		$1,200.00	
TOTAL	3				**$864,000.00**			

PROTECTION AND ADVOCACY PROJECT
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Attachment C -- SB 2198 Possible Funding Sources

Source	Biennial Incidence	Per Incident Revenue	Total Revenue			
Charit. Tax Credit	100	1000	100000			
Vehicular Fees¤	6000	10	60000			
Vehicular Offenses±	8000	50	400000			
SSA Empl. Incent.	10	1000	10000			
Recip Liab/Fee	280	25	7000			
Net General Fund			Remainder^			
		Total special $	$577,000.00			
		Estim. Net GF^	$287,000.00			
		Total	$864,000.00			
¤ATV registration, Personal Watercraft registration, perhaps endorsement for motor cycle w/o helmet & etc.¤						
±D.U.I., Boating U.I., Reckless driving, Drag racing, perhaps aggravated seatbelt violations & etc.±						

#2

March 5, 2009

My head is not "hard as rock." I am not "thickheaded". I do not "lack the education" for being a productive citizen of the community. I am an educated professional in my field of human services. It has been quite a struggle for me to get these college degrees.

The VR needs job coaches that have knowledge about working with a person who has head injuries. The colleges, other schools need teachers' aid, job coaches for employers that can help the person who has calculexia,(the disability of processing mathematics). It is the same as dyslexia only with numbers. Their aptitude test (Val par) they do for the job skills can be modified for the person with TBI. They do not know how difficult it is to pass that information from the brain, through their hands and fingers to mark the answers they know is correct. When the tests are over it is very discouraging to find out that the answers are wrong. This has been very frustrating for me, because I do know how to do these things and it gets marked wrong. On the dexterity, the ones with speed, I needed to do these slower but, the scores still got marked below average level, because in order for me to get the right answer, I had to move my hands slower. A couple of times I went for speed cause I knew I was going to score high on these. It turned to be a clumsy task that my fingers cramped up.

Starting from the age 15(1963) through 2007, I have had 15 serious closed head injuries. I have lost my age identity at the time of those injuries. After each injury, I kept wondering why things were not going right for me, why problems were always happening to me, why people were looking at me, why people did not hear what I was saying to them. Why I was always getting corrected, disagreed with, criticized for something I said or done when I knew I did it right. As you are reading this, this testimony may not make any sense to you. I am writing this as my mind is trying to explain the problems that we live with and the help we need to continue with our daily living. Even our writing skills are difficult to write so another person can read what I am trying to say. Again, what our words are in our brain, does not write the same thing on paper.

I ended up as a high school drop out. However, I did gradate from college with three different degrees. It was the longest, hardest years to endure. The instructors were so rude because I did not know the correct answer, because I did not write the best essay paper. "I was suppose to study, didn't I do my homework?" In college there were other students that where were able to get help having their subjects explained to them and tests. When I asked for the same type of help, I was told first I would need to fill out an application for a disability services, but

first I had to take some test to find out what kind of disability I had. Well, the decision the college instructors or disability personnel that gave me the tests said I did not have the learning disability for the type of help I was asking for. My school level had stopped at 9th grade, when I dropped out. I used to love doing Algebra classes, and my English classes. Well now I can't even do the beginning Algebra. There were college professors that said there was no such thing as head injuries. Still in my daily living, I have difficulty with my balance, thinking process, speaking skills, writing skills, and memory. Social services staff needs to be educated in recognizing, understanding and how to work with a person that has head injuries. Especially, helping the children of the parent that has had these injuries. My children had suffered emotional, physical abuse and the social services did not do anything to help my children. Domestic violence can cause brain injury, and counselors do not know how to recognize TBI and/or provide information about TBI to victims. There are judges, lawyers, doctors, nurses, chiropractors, law enforcement and correctional institution staff that do not know about TBI or believe there is such a thing. Police officers need to be taught about brain injury; several of our inmates have acquired the TBI's and are still receiving them. Once they are released from the institution they do not know what in the world they are suppose to do living away from the structured living they had inside the walls.

I can go on and on about the lack of education, the enormous emotional, living problems a person experiences with these injuries. Our brains have to work 6 to 8 times harder to function. This "silent epidemic" is in our communities and some are still ashamed to acknowledge it.

I am sharing a Personal Stories written by Lori Bray called Do You...? When I read this, I liked what it said about living with this.

Skipp Miller
Williston ND

Mister Chairman and members of the committee, my name is Lisa L. Anderson from Leeds, ND. I am here today to testify in favor of this bill, Senate Bill #2198. 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, 1:20 p.m. I received a call at work – your daughter has just been in a car accident and they are taking her the Rugby Hospital – get there as fast as you can. I left work and drove the 50 miles from Cando to Rugby. Hannah's injuries were too severe for the Rugby hospital to treat her – they were going to airlift her to Minot, but the plane was out on another call. They loaded her up in a second ambulance and left for Trinity Hospital in Minot where they were better equipped to deal with her fractures and injuries.

Hannah was eventually airlifted to Hennepin County Medical Center in Minneapolis as they are a Level 1 Trauma Center and have much experience with pediatric traumatic brain injury. Hannah was in a coma and remained in a coma for approximately 2 ½ weeks. She had multiple contusions and a fractured clavicle along with a fractured pelvis. Hannah was on life support for 3 weeks and we were not sure how severe her brain injuries were, although we knew there was bleeds all over her brain. The hospital provided a family room for us where we remained for 3 weeks. The first 2 weeks we sat by her bed not knowing if or when she would wake up. Eventually the doctors decided to start bringing her out of her medically induced coma – she would get "sedation holidays" as they called them because the physicians wanted to see if she would respond to any commands. The first 3 days there was nothing. The 4th day when asked to squeeze the doctors hand – she did ever so slightly. Within the next day or two, the doctor asked Hannah how many fingers and I holding up – he held up one and she held up one, he held up two and she held up two – there many tears as Dr. Karagu looked up at us and said "this just changed her whole prognosis".

Next it was time to wean Hannah from the respirator – another scary time in the ICU. Hannah's lungs were strong and seemed to be working well, even after having pneumonia while on the ventilator. First they turned down the machine and let Hannah practice breathing around the respirator for a few minutes, then for a few hours eventually she did this for 6-8 hours. Once it was determined she was strong enough they set out to remove the respirator. The respiratory therapist came in and removed the ventilator – turned it off and removed all tubes from Hannah's beautiful face. It was a scary 20 minutes. Hannah started off fine, but within minutes it was obvious she was in distress. She was the re-intubated and had to do more work with respiratory therapy to gain good lung function again. Two days later we tried it again, only this time with success – Hannah was breathing on her own and did so without any problems – a huge milestone after being on the ventilator for over 16 days.

Finally, she could begin receiving physical therapy and occupational therapy which mainly consisted of doing range of motion exercises to see where she was at as far as muscle tone. I will never forget the day that 3 therapists got Hannah up out of bed and she was like a limp rag doll – no muscle control what so ever. Someone had to literally hold her feet down on the floor and hold her knees in order for her to remain upright. Each day the therapists would come in, hold her body upright while the other one moved her feet in an attempt to start to retrain her brain how to walk again. Once Hannah was

medically stable, she was moved to a children's rehabilitation facility in St. Paul to begin her journey back. At this point, Hannah was unable to walk, sit up, talk, feed herself or do anything; she was like a newborn baby in a 15-year-old body.

While at the rehab facility, Hannah had a very intense daily schedule which included physical therapy, occupational therapy, speech therapy, recreational therapy, school and psychology along with all her medical issues. Hannah had to relearn everything – initially when she was tested the scores showed she was between 5-7 years old as far as her brain function. Every day for six weeks the therapists, nurses' doctors and teachers worked with her to improve skills and brain function. Her improvement was very rapid with such rigorous therapy and by the time we left rehab, Hannah was up to approximately a 12-year-old level of functioning.

Finally, on January 24, 2008, Hannah was discharged home to Leeds. We were finally leaving the Twin Cities after spending 10 weeks there and leaving our 17-year-old son back at home to work on his senior year of high school alone – we were coming home. As much progress as Hannah had made, we knew she had a lot more work ahead of her. She was able to walk on her own, but required a gait belt, so that we could assist her, she was very impulsive and did not have good judgment or reasoning skills yet at this point.

Monday, January 28, 2008 - Hannah returned to school – I was very frightened to leave her alone there, but she was not alone. The Leeds Public School was phenomenal. They had special in-services for the staff and for the kids before we came home to prepare everyone what it would be like for Hannah. They had to hire a para-professional to work one-on-one with our daughter as it was too much to expect her to go from class to class, remember what to bring with her to class, and she still could not write or even hold a pencil in her hand. The therapists from the Lake Region Special Education Department were at the Leeds school to evaluate Hannah and see how they best could help her with her educational needs. Occupational therapy provided different supports to help Hannah strengthen and use her left arm. She is left handed and her entire left side was affected by the accident. As I stated previously, she could not even hold a pencil. The para-professional would do all of Hannah's writing for her – Hannah would give verbal answers and the para would do all the writing. Each instructor that had Hannah gave her a printed out copy of the notes for their class along with a highlighter, which used to try and follow along and highlight things that she thought were important. We met with the special education department at the school to get Hannah's individual education program, or IEP set up. She has to have special accommodations when testing as the smallest noise will distract her. Hannah tests in a separate room where her tests were read aloud to her and she would verbalize the answer to her para.

Hannah attended speech, occupation and physical therapy three times a week in Devils Lake and also received these services at school through the Lake Region Special Ed. Her class schedule had to be re-evaluated as Hannah suffers from extreme exhaustion. She took a class then had a break, took another class then had a break – and so went her day. The school provided a place where she could rest when she needed it. The lunch room was a very noisy place and it was very over stimulating for Hannah. With her left sided weakness, she could not even carry her own lunch tray. Hannah also did not have good enough balance to get in and out from the lunch tables. The school provided another room for her to

eat in and some of her friends were allowed to eat lunch with her, in a room where the chairs pulled in and out from the table rather than the long benches that one had to step over to get into. The school also provided transportation for Hannah to get to school. We live across the street from the school, so this was not something we had thought of. They were going to send a school bus to pick her up, but she could not do stairs at all, let alone bus steps which are very high. They were going to send the mini bus but there were still steps. We finally figured out that they had a minivan and with some assistance, Hannah could get into the minivan without having to worry about steps and this worked out very well.

Hannah continued to improve with all the therapy and all the support that the school offered. She qualified for summer school. Through the Lake Region Special Education Department, Hannah attended summer school two days per week. It was not so much to help her catch up as to keep her moving forward and keep her from digressing. She worked on reading, comprehension, writing and math skills over the summer.

Hannah asked her doctors to consider letting her start her junior year of high school without a para-professional and they did not think she was ready, but she has proved them wrong. Not only has Hannah been able to handle school without any one-on-one support, but in a small school setting, she has flourished. The instructors there know what she is dealing with and what she has gone through, the kids will help her if she just asks for it. The school has made is possible for her to take part in extra-curricular activities, but some in a much different capacity. Last year she played volleyball, this year she went along with the team and videotaped. She is on the cheerleading squad, she plays in the band, and she sings in the choir and is in a special music group called the banner girls. The Leeds School system continues to be supportive and accommodating for Hannah and her needs following this very serious injury.

While we have found most of our support through the school system – I wonder, where do the people of North Dakota find support after their traumatic brain injury if they are not in the school system? When we were in Minnesota, we were given books, pamphlets and web sites to help educate my husband, my family and myself about TBI's. We were given a consumer guide for services available in the state of MN for people with head injuries. We were so very happy to be going home after our daughter's long hospitalization in MN that we did not even begin to imagine the road to recovery for Hannah and the difficulties that we would face once we were home.

I started researching the internet for the North Dakota TBI association only to find there was nothing. I could not call the MN Association as their phone numbers only worked in state. I almost panicked. We were 8 hours away from our TBI support system – it was frightening. Who would we look to for help when we had questions about Hannah's head injury? Every professional you asked questions of gave you different answers, no gave us anything consistent. We traveled to Bismarck to see the medical doctor who came once a month from the Gillette Children's Specialty Hospital to see patients. We traveled to Grand Forks once a week to see a psychologist who had dealt with head injury patients before. We traveled to Devils Lake three times per week to see OT, PT and speech therapists. We were referred to the Benson County Social Services to see if there were any programs that Hannah might be eligible for – we did not qualify. We were referred to the Lake Region Human Service Center for

neuropsych testing as someone mentioned Hannah might be eligible for a developmental disabilities program. All that did was leave us with another $900 bill to pay and no services were provided as she tested too high to qualify under the developmental disabilities program. It left us as parents very frustrated, but we were not willing to leave any stone unturned. We tried to follow through on every available lead if there was a program that could help our daughter; we wanted to know about it.

I have had to all but give up my job as office manager of a dental office, a job that I love, to be a caregiver to our daughter. My husband and I farm near Leeds and so Duane has his hands full with running the farm. What do people do who cannot give up one income to stay home and take care of their child, their spouse or their brain injured relative? How do people with brain injuries who are not able to live independently figure out ways to get help? How do they follow-up on services that may help them if they are not even able to remember they have appointments to go to?

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 groups. 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 independent taxpaying citizens.

By passing this bill, you will be providing much needed resources for the thousands of North Dakota citizens that have head injuries. We need to do outreach and education to everyone in the state. By passing this bill, you will provide support to everyone whose life has been changed by a head injury. We will have a place to turn to for help rather than every person having to do their own research and try and find help on their own.

If Hannah and I can take something terrible and make something good come out of it, then we have to say it was all worth it. If anything can be gained by what we have experienced in these past 15 months to help others who are less fortunate than us, then it was worth it. Thank you for listening to our story today and for considering this bill for all ND citizens with brain injuries – we are worth it.

#4

Good morning Chairman Weisz and members of the House Human Services Committee

My name is Mike Remboldt; I am the CEO of HIT Inc., a non-profit agency located in Mandan. HIT provides services to people with Developmental Disabilities, Infant Development services to children, services to people with Acquired Brain Injuries, services to low-income families through the Head Start program. Our service delivery area covers Western North Dakota, from Watford City to the South Dakota border.

I am here today to provide testimony on SB 2198, discuss some of the services available for people with traumatic brain injuries, and additional services services/funding needed to fill the gaps in these services.

Currently in North Dakota, there are only 3 residential programs for people with Brain Injuries.

- Dakota Alpha is a 20 bed skilled nursing facility in Mandan. 11 beds are designated as a 24 month heavy rehabilitation program and the remaining 9 beds are designated as long-term beds for people with severe behaviors that don't have any other alternatives in North Dakota

- Dakota Pointe is a 10 bed basic care facility in Mandan. The residents are unable to move directly to the community after rehabilitation and require some additional assistance during a transition period to give them the skills to move back into the community.

- Hi-Soaring Eagle Ranch is a basic care facility in Valley City, which is also transitional facility for people with brain injuries.

In addition these 3 residential programs, there are a few people living in their own residence that require QSP services (similar to ISLA in the DD program) to maintain their independence and continue living in the community.

HIT has several people with a brain injury in our services that have the desire to maintain a job in the community. They, with the assistance of a job developer and job coach, don't have any trouble finding a job that is gratifying to them and fulfills the needs of an employer by providing a valuable service.

The trouble begins when the job developing and job coaching monies run out. The traditional Supported Employment Program and Vocational Development programs are time limited in nature. Their purpose is to help someone find a job, provide supports to stabilize the relationship with the employer and back out of the equation. As I stated earlier, they are time limited programs. This is where the breakdown in services occurs.

I am not expert by any means about characteristics and behaviors of people with brain injuries, but I do know that someone with a brain injury needs ongoing support. A typical person with a TBI can remember high school or things that happened a long time ago, but ask them about this morning or yesterday and they get a frustrated look on their face. This carries into their vocation. They can maintain a job and be a contributing member of their local communities with ongoing vocational supports. There needs to be a funding source for ongoing vocational supports after the time limited Supported Employment and Vocational Development programs have concluded. People with brain injuries need the ongoing vocational support of an extended service program---like TBI extended services.

The other issue that I would like to address is the lack of information for the people with a traumatic brain injury and their families. Where do they go to find out about a brain injury and what types of services are available? How many people in North Dakota are diagnosed with an acquired or traumatic brain injury? These are all real questions and real concerns about the gap of information and services for North Dakota citizens with brain injuries. I know there is talk about creating a registry, and I am in favor of creating this list of people with brain injuries, but I ask you what good is a list of people that require services if the services are not available.

Please support SB 2198 and help enhance the information available to North Dakota citizens about the characteristics of a brain injury, types of services available, and how to access these services. However, more importantly, please help provide the money and programs for people in North Dakota with a brain injury that want to be an employed, contributing member of the communities in which they reside.

I would like to thank you for the time you allowed me to provide testimony and invite you to ask questions about the types of services HIT provides and the needed funding for ongoing supports of people with brain injuries in a competitive employment situation.

#5

Senate Bill 2198 A Bill Relating to Traumatic Brain Injury

March, 2009

House Human Services Committee
Rep. Robin Weisz, Chair

Chairman Weisz and Members of the Committee:

My name is Elaine Grasl and I am a member of District 47. I am here in support of Senate Bill 2198; a bill regarding traumatic brain injury. Brain injury–head injury is a subject about which I have testified in past sessions--our story may seem familiar.

Our cheerful, toddler son, who loved swimming and who swam so well at age 4, that instructors stopped to watch him, and who had just spent the larger part of his fourth year with short daily at home lessons learning the writing and sounding out of his ABCs and 123s, learning select word flash cards and beginning his special book. Shortly after the end of swimming season, at a boy scout breakfast, in a church community room, he fell face down onto a hard tile floor.

In the emergency room, the emphasis shifted mainly to his teeth, many of which were loosened and all askew. He was scheduled for dental surgery and we were given the usual instructions for head injury.

Days later, when we were able to resume his lessons, he could not perform what he had learned; it was harder for him to learn the second time. One day he asked me to carry him saying, "his legs were 'sleepy'." The next summer he could not swim. I'm not a doctor, but years later, after my own

experience with neck injury, I would say he was ALSO uncomplainingly dealing with "whiplash"–cervical spine injury. Years later, a specialist said, unofficially, that based on the symptoms that I had reported from that time, our son had incurred a significant brain injury.

I went from the parent who was tapped on the back and told , "What a well-behaved family you have" to "Can't you get that kid to sit still?!"

But worse, was what our child had to face.

Due to a warm, wonderful first grade teacher, he had a great start. Despite his intelligence, his school life became increasingly difficult especially after another injury occurred on the school playground. Because he had amnesia for the event, it was his school principal who ascertained what had happened. He was diagnosed with ADHD due to a head injury. Also affecting him were other significant events. In 1992, my mother, a great support for him and who, like me had an attitude to direct his energy towards positive activities, but wise enough to distinguish the usual childhood transgressions, passed away unexpectedly. In 1993, his older sister nearly died and became chronically disabled with a disorder that also affected her brain. All the kids were frightened after having been told that they could likewise be affected (but they were said to be okay).

He had always been an industrious little boy. A Pied Piper of sorts, he helped the neighborhood kids repair their bikes and built "forts". He loved

the outdoors and biking . However, he was also dealing with frustration and sadness–depression. Though he led his sixth grade class forward in a statewide reading contest, by the second half of the year (and probably before) he struggled to get up and go to school--we struggled together. His wonderful sixth grade teacher tried to advocate for the next year in junior high. It was a new beginning, we all thought.

But these were the beginnings of deeper and darker days. With increased age comes increased expectations–a certain developmental standard is assumed. Some skills could be met and exceeded, others such as organizational skills and focus, lagged behind. With time, I expected strengthened skills or self-instilled accommodations might appear, but his difficulties were not (then) widely understood. A ninth grade teacher described to me how our son would help others with their assignments. They would pass, but whe when it came to the tests, he was unable to recall how to proceed. A 7th grade teacher was extremely frustrated as he described an action which I later figured out was an accommodation to focus. (That was part of the problem, I was just learning, too.) He did not get a 504 plan until just before he left high school. He was refused a school evaluation for years. We had provided our own. I was told that doctors were just covering for him. Mike Ahman, had begun to work with the school, but with his credits just having been dropped again, my son gave up his dream to graduate with

his friends and eventually went on and achieved his GED with high total grades (math so, so). He had been called a faker (he had surgery for a congenital problem, later); we were both called liars; he was called worse. I have said that people's judgements likely caused more problems that the original head injury–the brain can be wonderfully resilient or unmerciful, dependent on the specifics of injury. Mistakes were made all around. I hoped with the harsh lessons (often undeserved) that were provided, would temper impulsivity and promote better reasoning skills to join with his intelligence, and fun loving, industrious nature. I just wanted him to stand on his own two feet.

There were those who were resolutely and stalwartly in his corner–including teachers, doctors–especially his pediatrician, family members, friends, neighbors, and later, employers. (He so appreciated his sixth grade teacher that he nominated him for the golden apple award and it was awarded.)

I learned tips and I garnered general tips from various individuals as time went on and I tried to provide them. It would have been wonderful for any of us to have been able to access a well known group which had credible, specific information, such as a brain injury association. As a parent, I just was not necessarily believed nor was our son. As you might guess, some believed that stronger discipline would make "it" all go away.

There are 1.4 million people diagnosed (and then those undiagnosed)

with brain injury every year in the U. S., and veterans with likewise unseen wounds who are returning after serving their/our country. As I feared some years ago, our soldiers are returning with brain injuries. Stronger discipline is not going to make "it" go away for them either. We should be a society who treats our people well. If many failed to see the needs of a small boy, and sought not to help, but to punish, will we be better prepared for those others? Will we see symptoms of depression, anxiety, anger, frustration, lack of reasoning skills, feelings of loss, substance abuse...and recognize the humanity...the value...the worthiness...perhaps the desire for an education or a job? These individuals deserve to return to a society where education, law enforcement, and other systems and society, in general does not make them the problem, but rather works together to support them to stand on their own two feet.

North Dakotans are good, fair people–let us learn together to do this.

Please support this bill.

Elaine Grasl
7314 Sunshine Lane
Bismarck, ND 58503-9134

District 47

#6

Testimony
Senate Bill 2198 – Department Human Services
House Human Services Committee
Representative Weisz, Chairman
March 9, 2009

Representative Weisz and members of the House Human Services Committee, I am Susan Wagner, LSW, Human Services Program Administrator, with the Division of Mental Health and Substance Abuse Services, for the Department of Human Services (DHS).

On behalf of the Department, I am not opposed to or in support of SB 2198, I am here to provide testimony about the history of services and activities related to individuals who have sustained a traumatic brain injury (TBI) in North Dakota.

Efforts to address the problem of TBI in North Dakota began in the 1980s with the formation of the Head Injury Association of North Dakota (HIAND). The Association's board of directors consisted of representatives from a mix of public and private entities whose concerns and interests spanned the spectrum of TBI from prevention to treatment and rehabilitation. The organization did obtain federal IRS 501c3 status and began accepting charitable donations. A grant from the Rocky Mountain Brain Injury Center further strengthened the organization and increased visibility.

In 1987, the HIAND introduced legislation that established TBI as a mandated reportable medical condition and required the North Dakota Department of Health (DoH) to establish a TBI registry. The legislation passed, mandating TBI as a reportable condition by a physician or

medical facility, and required the DoH to establish and maintain the registry. There was no fiscal note attached to establish and maintain the registry. DoH received a Center for Disease Control (CDC) surveillance and prevention capacity building grant that was used to establish the registry. A significant drawback to the system was the reliance on participating medical facilities to voluntarily complete the injury report card and forward to DoH. In most instances, the report cards were completed by emergency room departments and reflected only preliminary diagnoses, no treatment or discharge information.

In 1989, the HIAND introduced legislation that established the DHS as lead agency in North Dakota for the delivery of TBI services. This legislation also required DoH to provide DHS with names and addresses of individuals who were listed in the registry. DHS was then to forward to these individuals information on medical, rehabilitation, and social services that were available in North Dakota. A joint effort between DoH and DHS produced a brochure with service-related information.

The DoH maintained the registry until 1994, when the CDC funding ended. Due to the reliance on voluntary submission of the report cards, reporting compliance fell off significantly. In 1999, the TBI reporting and registry statute was repealed by the legislature at the request of DoH. During this same time, grant funding for the HIAND ended and the association became inactive.

The Indigenous People's Brain Injury Association (IPBIA) was established in 1994. The IPBIA was established for the benefit of all tribes in North Dakota and is comprised of individuals who have sustained a TBI, family members, and service providers. The IPBIA has become a recognized

leader in the field of Native American TBI issues and has hosted a national conference. The organization continues to exist today and hosts an annual conference.

On April 1, 1994, North Dakota received approval for a Medicaid waiver for TBI that enabled eligible individuals to choose between receiving care in an institutional care setting or in their home with the assistance of various community-based services. The TBI waiver was merged with the Aged and Disabled Waiver that was renamed the Home and Community-Based Services waiver. This was effective on March 31, 2006.

More than 3.17 million Americans live with a disability as a result of a TBI. Many of these individuals and their families are confronted with inadequate or unavailable TBI services and supports. Passage of the Traumatic Brain Injury Act of 1996 (P.L. 104-166) signaled a national recognition of the need to improve state TBI service systems. The Act authorized the Health Resources and Services Administration to award grants to states and territories for the purpose of planning and implementing needed health and related service systems changes.

North Dakota received a TBI planning grant in April 2003. The DoH selected the University of North Dakota School of Medicine's Center for Rural Health as a contractor to form the TBI Advisory Committee, conduct a statewide TBI needs assessment, and write a plan of action to address the needs of North Dakotans with TBI and their families. The advisory committee met regularly, the needs assessment was completed, and an action plan was developed. The action plan, designed to be executed during the three-year implementation phase of the TBI federal grant

program, set forth a number of intended outcomes and steps for achievement. Those outcomes are:

- TBI will have a presence in the state with accessible, available, appropriate, and affordable services and supports for individuals with TBI and their families;
- Individuals with TBI, family members, significant others, and providers of support and services to have timely information, resources, and education regarding TBI;
- Ensure a coordinated system for individuals with brain injuries and their families to access and receive services and supports;
- Increased quality and availability of key supports for individuals with TBI and their families; and
- Native American individuals with TBI and their families to have access to culturally appropriate TBI information, services, and supports.

In partnership with the University of North Dakota's School of Medicine Center for Rural Health, DHS applied for and was awarded a TBI Implementation Partnership Grant in April 2007. This is a three-year grant in the amount of $118,000 each year. The action plan developed as a result of the TBI planning grant laid the groundwork for this implementation grant. The goals of the grant are:

- To build a formal presence and infrastructure for the advancement of TBI focused issues;
- To provide timely information, resources, and education regarding TBI to individuals with TBI, family members, other caregivers, and service and support providers;
- To ensure a coordinated system to access and receive services and support for individuals with brain injuries and their families; and

- To improve access for American Indian individuals with TBI and their families to culturally appropriate information, services, and supports.

Progress on the goals is as follows:

- The Advisory Committee is established and active in planning and sustainability efforts;
- Partnerships have been developed with military support organizations in an ongoing effort to assess their needs. The project coordinator and state TBI program administrator serve on the Interservice Family Assistance Committee;
- Research has been completed on peer mentoring with Native American individuals who have sustained a TBI and preliminary discussion has been had about the most effective way to develop a project on each reservation in North Dakota;
- Seven educational presentations on TBI at various statewide conferences have been conducted. Plans are in place for presentations at the eight regional human service centers and the North Dakota State Hospital;
- A strategic plan for state government funding was developed;
- Resource packets for individuals who have sustained a TBI and their family members are in the development stage;
- Two spots on Good Health TV provide education and prevention of TBI to Native American individuals who are in the waiting room areas of the Indian Health Services clinics and hospitals in North Dakota;
- A resource library is in the development phase and will be operated out of the Prevention Resource Center, which is part of the Division of Mental Health and Substance Abuse Services;

- The state program administrator is working on a project to implement a screening tool at the regional human services;
- A statewide summit, "TBI – A Call To Action" was hosted by the advisory committee on October 13, 2008. Fifty five participants attended the summit. The culmination of the days work resulted in a policy subcommittee that has since met to develop fact sheets and plan the TBI Awareness days at the Capitol; and
- Grant funds were used to support 40 individuals to participate in the annual Indigenous Brain Injury Association Conference last fall.

With regard to Page 3, Section 7 of the Engrossed Senate Bill 2198: DHS understands that the functional eligibility requirements for personal care services (through Medicaid or Services Payments for the Elderly and Disabled [SPED]) are not intended to be changed by this bill; however, the bill does state: The DHS shall give priority under this section to individuals whose impairments are less severe or similar to those of individuals who are eligible for Medicaid waivers.

Personal Care Services, whether available through SPED or Medicaid, are available based on the functional and financial criteria noted in the attachment from Medical Services. Medicaid Personal Care is an entitlement and the number of people receiving the service cannot be capped. The preference language would not be needed for Medicaid Personal Care.

Personal Care Services under SPED could be limited, if adequate state funds are not available. SPED is 95% general funds and 5% county funds. The SPED program has not had to be capped since 2003; however, if it were to be capped in the future, it appears the language in section 7 would require the DHS to provide preference to clients who have

moderate or severe impairments as a result of a traumatic brain injury. This would require the DHS to potentially deny services to others who meet the functional eligibility requirements for SPED.

Please see the attached FACT SHEET and attachment from Medical Services.

That concludes my testimony. I will answer any questions you have at this time. Thank you.

LTC CONTINUUM FUNCTIONAL & FINANCIAL ELIGIBILITY REQUIREMENTS COMPARISON (1/2009)

North Dakota Department of Human Services

ExS[redacted]	MSP-Personal Care (Level A)	SPED	MSP-Personal Care (Level B)	Medicaid Waiver for HCBS (Elderly and Disabled)	PACE (Program of all Inclusive Care of the Elderly)	Nursing Home
Services • Adult Day Care • Adult Foster Care • Chore • Emergency Response System • Environmental Modification • Family Home Care • HCBS Case Management • Homemaker • Respite	**Service** • Personal Care Services	**Service** • Adult Day Care • Adult Foster Care • Chore • Emergency Response System • Environmental Modification • Family Home Care • HCBS Case Management • Homemaker • Respite • Personal Care Services	**Service** • Personal Care Services	**Service** • Adult Day Care • Adult Foster Care • Adult Residential • Chore & ERS Systems • Environmental Modification • HCBS Case Management • Homemaker • Non-Med Transportation • Respite • Specialized Equipment/Supplies • Supported Employment • Transitional Care • Extended Personal Care • Home Delivered Meals • Family Personal Care **Technology Dependent Medicaid Waiver** **Service** • Attendant Care Service	**Service** • All Medicare and Medicaid Services • Primary Medical Care • Meals • Nutritional Counseling • Home Health Care • Personal Care • Dentistry • Prescription Drugs • Social Services • Adult Day Care • Therapies • Transportation • Hospital Care • Hospital ER • Nursing Service • Nursing Home Care • Other services as determined by the team	**Service** 24 hour care, including; personal care, nursing care, restorative services, social service, recreational activities, room and board etc.
Personal Care Service: Assistance with activities of daily living such as bathing, dressing, toileting, transferring, eating, mobility and incontinence care. Assistance with instrumental activities of daily living may also be provided in conjunction with the tasks for activities of daily living. Personal Care Services allow individuals to live as independently as possible.						
Functional Eligibility Not severely impaired in ADLs: Toileting, Transferring, Eating **And** Impaired in 3 of the 4 following IADLs: • Meal Preparation • Housework • Laundry • Medication Assistance Or Have health, welfare, or safety needs, requiring supervision or structured environment	**Functional Eligibility** Impaired in 1 ADL **Or** Impaired in 3 of the 4 following IADL's • Meal Preparation • Housework • Laundry • Medication Assistance	**Functional Eligibility** Impaired in 4 ADLs, OR in at least 5 IADLs, totaling eight (8) or more points or if living alone totaling at least six (6) points **Or** If under age 18, meet **LOC** screening criteria **And** Impairments must have lasted or are expected to last 3 months or more	**Functional Eligibility** Impaired in 1 ADL **Or** Impaired in 3 of the following 4 IADL's • Meal Preparation • Housework • Laundry • Medication Assistance **And** Meet **LOC** screening criteria	**Functional Eligibility** Meet **LOC** screening criteria	**Functional Eligibility** Be 55 years of age or older **And** Be able to live safely in the community **And** Meet **LOC** screening criteria	**Functional Eligibility** Meet **LOC** screening criteria
Nursing Facility Level of Care Screening- **(LOC)** Eligibility may include a medical need, example: vent dependent, unstable medical condition, dementia; or an individual may qualify by needing assistance with 2 ADLs 60 % or more of the time. Complete criteria for LOC Screening - NDAC 75-02-02-09.						
Financial Eligibility Medicaid Eligible	**Financial Eligibility** Medicaid Eligible	**Financial Eligibility** Income & Asset Based Sliding Fee Scale Resources $50,000 or less	**Financial Eligibility** Medicaid Eligible	**Financial Eligibility** Medicaid Eligible	**Financial Eligibility** Medicaid and/or Medicare Eligible	**Financial Eligibility** Medicaid Eligible
Program Cap $1602.00 per month	**Program Cap** 480 units per month	**Program Cap** $1602.00 per month	**Program Cap** 960 units per month	**Program Cap** Limited to the highest monthly rate allowed to a nursing facility within the rate setting structure of the Dept.	**Program Cap** Managed care rate per/ member per/month	**Program Cap** Average rate: $5453.00 per/mo. Range $116.01-$415.56 per day

#7

Testimony
North Dakota Disabilities Advocacy Consortium
SB 2198
House Human Services Committee
Representative Robin Weisz, Chairman

Chairman Weisz and members of the House Human Services Committee, my name is James M. Moench, Executive Director of the North Dakota Disabilities Advocacy Consortium (NDDAC). The Consortium is made up of 24 member organizations concerned with addressing the issues that affect people with disabilities. (See attached list of members).

NDDAC supports the efforts finally recognize the devastating impact that a traumatic brain injury (TBI) has on an individual and their family. For too long, TBI has not been understood and those who suffered its debilitating effects have faced its consequences alone. In recognition that a great many ND soldiers and National Guard are coming home with some form of TBI, North Dakota must enhance its effort to address the issues caused by TBI. NDDAC believes the provision currently envisioned in engrossed Senate Bill 2198 give the state a good start in doing that long delayed task.

We urge your support of HB 1044

Thank you.

NORTH DAKOTA DISABILITIES ADVOCACY CONSORTIUM

2008-09 Membership

1. AARP
2. American People Self Advocacy Association
3. Autism Society of North Dakota
4. Experience Works, Inc.
5. Fair Housing of the Dakotas
6. Family Voices of North Dakota
7. Independence, Inc.
8. Mental Health America of North Dakota
9. Metro Area Transit – Fargo, ND
10. ND APSE: The Network on Employment
11. ND Association for the Disabled
12. ND Association of Community Facilities
13. ND Association of the Blind
14. ND Association of the Deaf
15. ND Center for Persons with Disabilities
16. ND Children's Caucus
17. ND Consumer & Family Network
18. ND Federation of Families for Children's Mental Health
19. ND IPAT Consumer Advisory Committee
20. Protection & Advocacy Project
21. Senior Health Insurance Counseling/Prescription Connection
22. The Arc of Bismarck
23. The Arc of Cass County
24. The Arc of North Dakota

3-02-09

Bruce Murry 4-27-08

SB 2198 BUDGET -- Senate

Services	FTE^	Participants	Mo. $ ea.	Mo. Total	Bienn. Total	Cost/partic.
VR Extended	0	40	500.00	20000	$480,000.00	$12,000.00
Informal Supp. Org.	0	200	31.25	6,250.00	$150,000.00	$750.00
Pub. Awareness		9585	0.10	1000	$24,000.00	$2.50
Social & Recreat.	0	10	200.00	2000	$48,000.00	$4,800.00
Training & Qual. A.	0	135	50.00	6750	$162,000.00	$1,200.00
TOTAL					$864,000.00	

SB 2198 BUDGET -- for Reps Pollert & Pietsch

Services	FTE^	Participants	Mo. $ ea.	Mo. Total	Bienn. Total	Cost/partic.
VR Extended√	0	15	357.50	5362.5	$128,700.00	$8,580.00
Informal Supp. Org.	0	200	27.50	5,500.00	$132,000.00	$660.00
Pub. Awareness		9585	0.03	250	$6,000.00	$0.63
Social & Recreat.	0	10	200.00	2000	$48,000.00	$4,800.00
Training & Qual. A.*	0	85	37.50	3187.5	$76,500.00	$900.00
TOTAL					$391,200.00	

^Senate, House, & proposed versions of SB 2198 contain only temporary or contractor employees, & no state FTE
Grey highlighted cells are variables the Conference Committee might adjust
√Job Coach 3.0 hrs/wk @ $27.50/hr, 52 weeks/yr; $27.50 is statewide average
* Training & Quality Assurance: Target Pop of 85 = Nurs. Facil Care - 25; Basic Care/Grp Home - 18; TBI ind. livin

NOTES

Earnings: $8 hr * 1/2 time * 2 years = $14,080 bienn.
Modeled after The Arc or Alzheimer's Assoc.
Partic. Assumes 1.5% ND population per CDC
Assumes 3 ea. Morton & Barnes, & 4 others
Aimed current & proposed service recip.

100.00%

NOTES

2009: 12 ppl; 2010:18 ppl; see below
consider one contractor employee w/ expertise
varies by target population; 1.5% of 639,000 residents
consider QSP $20/hr & 10 hrs/month
consider $25/hr * 1.5 hrs per mnth

45.28%

ıg - 17; & SPED/Pers. Care - 25