

2009 – 2010
Minnesota Statewide
Traumatic Brain Injury (TBI)
Needs and Resource Assessment

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This report is a summation of the surveys and Town Hall meetings held throughout the state of Minnesota during the months of April and May of 2009 which serves as an important component of Needs and Resource information for Minnesota interagency planning purposes. Periodic statewide TBI Needs and Resource Assessment and State TBI Planning efforts are requirements for State TBI Grantees.

A very special thank you goes to the more than four hundred persons with brain injury, family members, friends and professionals who took the time to respond to the survey, attend the meetings or forward their comments. Their experiences and challenges have created a collective vision for the future of brain injury services in Minnesota.

Acknowledgments

The Town Hall meetings were planned, developed and conducted by the Brain Injury Association of Minnesota, the Minnesota Departments of Human Services and Health (DHS and MDH), the DHS TBI Advisory Committee, and other members of the TBI Interagency Leadership Council along with community volunteers.

The Survey was planned and developed and conducted by the Brain Injury Association of Minnesota, the Minnesota Departments of Human Services and Health (DHS and MDH), the DHS TBI Advisory Committee and other members of the TBI Interagency Leadership Council.

The Survey was analyzed by The Brain Injury Association of Minnesota and the Minnesota Departments of Human Services and Health (DHS and MDH).

The purpose of a statewide TBI Needs & Resource Assessment is to inform the development of a required subsequent State TBI Action Plan, two of the four Core Components related to the State TBI Implementation Partnership Grant. The other two Core Components are a designated lead state agency (Minnesota Department of Human Services or DHS) and designated statewide TBI advisory council (DHS TBI Advisory Committee). The federal TBI Program at the Department of Health and Human Services (DHHS), Health Resources & Services Administration (HRSA) administers the State TBI Grant Program as well as the TBI Protection and Advocacy Program as authorized by the federal TBI Act. This Statewide Needs and Resources Assessment effort was supported by Minnesota's State Traumatic Brain Injury Implementation Partnership Grant (Grant #H21MC06770, HRSA, CFDA #:93.234) titled Traumatic Brain Injury in Minnesota Correctional Facilities.

Introduction

In May 2009, more than 400 Minnesotans shared their opinions about brain injury services with an array of state agencies and advocacy organizations. With staffing provided by the Brain Injury Association of Minnesota, the Minnesota Departments of Human Services and Health (DHS and MDH), the DHS TBI Advisory Committee, the Department of Employment and Economic Development, and other members of the TBI Interagency Leadership Council along with community volunteers, suggestions and criticisms were sought in order to identify service gaps and develop plans to address problem areas. They were able to do this through a combination of an online survey, a toll-free phone number, a dedicated voice mail box and a series of town hall style meetings held across the state. Meetings were held in St. Cloud, Minneapolis, Bemidji, Rochester, Mankato, Moorhead, Duluth, Marshall and St. Paul.

Overview

This town hall meeting and survey process was the first such project in ten years, the last having been undertaken in 1999 – 2000 resulting in the initial Minnesota State TBI Action Plan associated with the first Minnesota State TBI Grant. Other data and information have been considered by the DHS TBI Advisory Committee and the Minnesota TBI Interagency Leadership Council over time but no comprehensive statewide process has been undertaken in the interim. All together, 341 individuals completed the survey and 95 individuals attended the town hall meetings. Although the turnout for the town hall meetings was less than the 200 individuals who participated in 1999, the overall number of individuals participating statewide in some form was more than double.

Based on the data from this process, it is clear that there is still much work to be done. However, it is important to note that much has been accomplished in the ten years that have passed between these assessments to address the need for linking individuals with brain injury and family members to information, services, and supports as well as the need for capacity building and technical assistance for professionals and providers. Primary among these successes was the fact that Minnesota established a Resource Facilitation Program with our first three TBI State Grants (starting as a grant “Acute Care Discharge Model”). This program, which was established in 2003, is funded through legislation.

Other examples include the Minnesota Department of Education part time Statewide PI & TBI Consultant available to school personnel, family members, and health care providers; the incorporation of brain injury services into the Disability 2-1-1 System (Disability Link); the Minnesota Department of Employment and Economic Development holding collaborative multi-agency regional trainings for Workforce Center staff and community employment professionals to support the reintegration and return to employment for service members returning from Iraq. Further examples include the Minnesota Department of Human Services adding TBI specific on-line training for TBI Waiver county case managers and providers; and the Minnesota Department of Health making county specific TBI injury information available on-line. The Brain Injury Association of Minnesota continues to offer a wide range of information, training, services and supports for individuals, family members, professionals and providers. The most recent State TBI Implementation Partnership Grants have taken up efforts in the Minnesota Department of

Corrections system to screen and identify offenders with functional needs due to TBI, developing protocols for screening follow up and for Release Planning, as well as TBI training and capacity building for Minnesota Department of Corrections staff.

Town Hall Meetings

It can be challenging to analyze some of the qualitative data collected in town meeting style formats. At the meetings, participants, including individuals with brain injury, their family, friends and supporters as well as professionals and service providers, were encouraged to speak for five minutes about their perception of the quality of brain injury services and supports in Minnesota. Generally, individuals shared anecdotes without stating specific thoughts on services.

Surveys: Online and Hard Copy Options

More successful (numbers of respondents and depth of responses) was the paper/online survey offered to participants in the Town Hall meetings and to individuals on the Brain Injury Association of Minnesota mailing lists and web site. Surveys were also made available at the Brain Injury Association of Minnesota Annual Conference in April and an announcement was made during the conference encouraging attendees to participate. The survey consisted of 50 questions broken up into categories with a space for respondents to write in their own thoughts on brain injury services and supports in Minnesota. (See attached Survey document.)

Survey Results:

Demographics

Although brain injury is a disability that can affect all people, there are some distinct demographic results from Minnesota's respondents. The individuals with brain injury represented in this survey are primarily white (84%), middle-class individuals living alone or with a spouse. The largest group represented was between the ages of 50 and 59 (25.5%). The second largest age group of respondents was 40 to 49 (23.5%). There was also a strong response representing individuals between the ages of 30 to 39 (14.5%) and 22 to 29 (14.0%). These are the same people, according to the U.S. Census Bureau, who had the highest turnout rates in the 2008 elections.

Survey respondents were residents of Hennepin County (31%), St. Louis County (14%), Stearns County (7.5%), Dakota and Ramsey County (6% each), Washington County (4%) and Anoka County (3%).

While falls are currently the leading cause of brain injury in Minnesota, the largest group of respondents (38%) listed motor vehicle crashes as the cause of their brain injury. Second was falls (26.8% of respondents). Individuals who sustained their injury as a result of assault/abuse were third on the list with 13.4% of the total respondents.

Minnesotans with brain injury – and the current number stands at around 100,000 – represent 1.9 percent of the state's population. Most individuals with brain injury have family and supporters who work as their advocates and representatives and who have much at stake in the future of the state's healthcare and brain injury's place in that future.

Quality of Life

“Since I’ve advocated for myself, I have gradually built a better relationship with the police. Things went a lot better when I lived in a smaller city. I try to be steady as possible with the police but, when I’m in a crisis situation, my emotions can get too emotional. I can get confused, disoriented, and even have a seizure. Some police officers get this, others don’t. I had the Mayo clinic send a police chief a book on brain injury because the chief wasn’t getting it.”

Quality of life for individuals with brain injury is dependent on many different things: a person’s access to healthcare, their interaction with their community, the level of understanding on display by professionals and employers. The survey attempted to cover all avenues of quality of life. It began with access to services.

Many individuals, over half, make use of a social worker. They indicate a feeling of satisfaction that the professionals in their lives listen to and understand their needs, that they are supported in making decisions and that their overall access to services reduces the stress in their lives.

However, the comments made at town hall meetings and in the survey itself belie the feelings behind their answers. It is not, seemingly, the quality of care that is the issue, but their ability to access it.

Healthcare

Access to healthcare and the quality of healthcare were immediate concerns to those who attended the town hall meetings and those who took the survey.

Most individuals with health coverage had private insurance. However, families shared frustrations that their specific needs are not being addressed. Attendees at the town hall forums expressed disgust with a system which they erroneously perceive to require them to empty their savings accounts and sell family homes in order to qualify for basic services because their assets were judged “too high” to qualify.

Private insurance coverage is dependent on an individual’s income and assets. Several respondents expressed frustration with how their coverage interacted with Social Security. Of great concern is the amount of coverage a brain injury requires, since its effects are wide-ranging and encompass physical therapies, occupational therapies, counseling and – at times – regular personal care. One respondent reported being advised to divorce his wife in order to receive maximum help.

Also, once insurance runs out, families may have to quit jobs or reduce their hours in order to care for their loved ones. One family reported having to perform their child’s therapy themselves with the result that “Rachel is losing use of muscles, cognitive skills, and has health issues. We work full-time and take care of our daughter in the evenings, through the night and on the weekends. It would be much less stressful for our daughter and family if there were someone to help. I assume this will also go unnoticed which makes it extremely exhausting for us.”

Individuals called for better training of healthcare professionals regarding traumatic brain injury. One respondent said, “In my opinion, the most important gaps and barriers in identifying individuals with post-concussive/mild brain injury exist at the primary physician level. There are many people in the community that experience a post-concussive injury/mild brain injury that are never diagnosed. They fall thru the cracks - experiencing loss of employment, drug/alcohol abuse, failed relationships. Education of Primary Care Providers is necessary.”

Also, many individuals feel their opinion is not heard or that the very nature of their injury makes them, in the eyes of medical professionals, unreliable witnesses to their own health. Common comments included:

“The biggest difficulty that I have is the feeling that I need to "convince" people that my traumatic brain injury is real. I am constantly told how "lucky" I am that I do not "have to" work and that I "get to" stay home all the time,”

“My doctors tell me that nothing is wrong with me and yet I know that I am not the way I used to be,”

and

“TBI is only considered if there is an external force injury but these are the only people who truly understand the neurology involved and ABI kids are treated as emotionally disturbed.”

Of all respondents, 55 percent feel well represented by their supporters and feel that they have a say in the directions their lives are taking. They are represented by a social worker/ case manager or advocate who understands their brain injury. They feel listened to by professionals, are supported in making their own decisions and have services and supports that reduce their stress.

Transportation and Access to Healthcare

“There are huge gaps in all services out here in the Willmar area. I can’t find anyone who is an expert in TBI- I feel I have trained more doctors in the problems associated with a TBI than anyone has given to me. A two and a half hour drive to the Minneapolis area is impossible for some with brain injuries. Greater Minnesota needs some services out here.”

The above comment is characteristic of the comments related to transportation and access to healthcare. Individuals spoke at town hall meetings and in the surveys about their inability to reach services they need.

When discussing their child, one commenter said, “I cannot afford to leave work to drive him to or from a job and metro mobility is far too undependable to be able to get him there on time or pick him up on time.”

One provider summed up the issue by saying, “Access to services such as counseling, crisis and respite care, vocational supports, transportation and in-home supports are all barriers.”

But, the greatest need seems to be in Greater Minnesota. “I live in rural northern Minnesota where there are very little or no resources for people with TBI. We must travel long distances to get to a professional. Traveling is very hard on people with TBI. Why can't we have more services/resources in Northern Minnesota?”

The second issue raised regarding quality of life is with individuals’ income and living situations. Most individuals participating in the survey and town meetings indicated a decline in income, whether from out of pocket healthcare expenses, insurance premiums or loss of employment. Some pointed to a lack of occupational training in Minnesota for people with brain injury.

“My son is cognitively at a moderate to high function but has short term memory functioning and day programs for brain injury patients are much lower functioning so his day is spent at home.”

Employment

“There is a gap for those who have brain injuries but are still high functioning enough to work. I have been unable to find support groups on mentoring to assist me in this area. It's difficult also to find employment with specific limitations. People often don't believe you have them. Every time I've gone, they say I'm too high functioning for them to assist me. Yet, I have symptoms and concerns; clearly this is a gap.”

The above comment illustrates a common concern among individuals with brain injury: the lack of training opportunities for individuals with brain injury and the lack of understanding among employers for people with brain injury. Over 70 percent of respondents to the survey indicate that their employment has been affected as a result of their brain injury, with 42 percent indicating they are unemployed. It appears that the most common reason given for people being unemployed is that they cannot or are not allowed to perform the job they held prior to their injury.

“I have daily struggles with work and feel that my employer doesn't understand my brain injury and is looking for a reason to let me go.”

Individuals with brain injury indicate that they want help finding work, and those that received this service were satisfied with its outcomes. But, many others are in need of this service. Labor data suggests that individuals with brain injury in the workforce tend to hold their jobs for more than three years. What is imperative is the retraining of injured individuals to return to work and to assist them in locating appropriate jobs.

Those without work are increasingly dependent on Social Security, long-term disability or their spouse’s income. Comments at the meetings and in the survey indicate that this puts an

incredible stress on everyone involved and might be alleviated by helping the individual with a brain injury find gainful employment.

Level of Satisfaction with Services

“I have had to negotiate my own way through a maze of medical providers, etc. and have not gotten any help from anyone. Therefore, I have no idea whether the services and support available in Minnesota is adequate, but I would have to say that in my experience this is an extremely lonely process for me and my wife.”

Question 49 gave respondents a list of 35 services and asked them to rank their satisfaction with each one as “satisfied,” “dissatisfied,” “need but can’t access,” and “do not need/not applicable.”

In all, 181 individuals answered at least part of the question. No single service received responses from all of the 181. The most responded to service was “Alcohol/drug treatment; outpatient” with 179 responses; 150 of which were “do not need/not applicable.”

“There are many people in the community that experience a post-concussive injury/mild brain injury that are never diagnosed. They fall thru the cracks - experiencing loss of employment, drug/alcohol abuse, failed relationships.”

The category with the highest level of satisfaction – “Medical-General” – had 167 respondents, 30 of who answered “Do not need/Not applicable.”

The category with the highest level of dissatisfaction was “Educational Supports” with 35 of 176 respondents saying they were dissatisfied. However, 42 of those 176 responded that they were satisfied. It should be noted that in none of the categories, did “dissatisfied” reach a higher percentage of respondents than “satisfied.”

“There is little to no educational materials, or trainings regarding TBI and the Native American populations that I am aware of at least, when working with people who have had head or brain trauma - lot of times they do not acknowledge or disregard injury as reasons for not being able to get things accomplished - stigma of not being normal somehow and the clients never speak up about experiences or things they may have noticed in their personal lives since the injuries - keep the effects secret almost unless it has a physical symptom to bring them to care.”

The category with the greatest number of respondents indicating that they needed but could not access a service was “support groups.” Support groups also receive a 50 in satisfied and a 21 in dissatisfied out of 171 respondents.

“About a year ago I joined a TBI support group and learned a lot of things that I do are because of TBI, just by talking with others. I am so glad that I am in a support group with others to find out that I am not the only one who thinks or does things the way I do.”

“Each county in Minnesota should have access to classes and support groups for people with brain injury. Most people do not have transportation to go to the Cities for classes. Please make it accessible to have services in the counties - people live in like Stearns County.”

Conclusions

The general feeling from the surveys and the town hall meetings – from individuals with brain injury as well as from professionals – is that while the services in Minnesota are generally of a high quality, too often those who need access find it most difficult to access services.

In 1999, Minnesota’s needs assessment concluded with the following comments, which seem as poignant and relevant today.

Persons with brain injury, their family and friends are working hard to improve their self-sufficiency, community integration, and overall quality of life. Professionals are working very hard to assist them in this journey. Unfortunately, consumers and professionals alike spend long hours working within a system which they feel has a lot of room for improvement. They face obstacles related to public awareness, the structure of brain injury services, a lack of professional training, and an inconsistent outreach system. They grapple with problems in regard to employment, education, transportation, housing, health care, continuing care, and recreational needs. They are forced to struggle to obtain funding for resources that they desperately need.

Survey respondents and town hall meeting participants throughout Minnesota spoke about the strengths and weaknesses that they see in the brain injury community. They expect equal access to funding and services. They expect a high level of awareness, training and competency for professionals who work with persons with brain injury. They expect that not one person with a brain injury should fall through the cracks.

Persons with brain injury expect to become as fully integrated into society and self-sufficient as possible. As a society, it is our responsibility to make these goals a reality.

Reflections & Lessons Learned for future TBI Needs & Resource Assessments:

Town Hall Meetings

The meetings tended to become forums in which to criticize the Brain Injury Association of Minnesota, as opposed to discussing and evaluating services directly offered by state or county governments.

Why might the town hall forums not have worked as well as possible in eliciting broad participation and content feedback? Several possibilities exist:

- The meetings were principally staffed by Brain Injury Association of Minnesota employees and volunteers, leading to the impression that the events were Brain Injury Association of Minnesota events and therefore should reflect the services offered by the Association.

- Meetings were held during the late afternoon and early evening with the idea that professionals would attend during the day and individuals and family members would attend in the evening. However, while the events were designed for attendees to drop in at their convenience, more than one participant indicated that they believed full attendance was mandatory. This perception may have led potential participants to forgo the meetings, believing that they would not be able to attend the entire session. For subsequent meetings, the timing and length of the meetings should be reconsidered.
- Should town hall meetings be considered in the future, the process that was developed for the first round of TBI Town Hall meetings in 1994 (pre-TBI Grant) should be considered as they were enormously successful. That series of meetings was planned by the DHS TBI Advisory Committee and facilitated by one highly experienced and skilled facilitator from the brain injury community who used certain consistent topics to gather feedback on as well as open forum time to allow for other topics and personal stories. The facilitator also addressed the toll-free phone questions and those submitted by mail. Meetings were attended by representatives from the DHS TBI Advisory Committee who volunteered their participation and could field some questions and offer meeting support. Much advance outreach was conducted through the DHS TBI Advisory Committee as well as the Brain Injury Association of Minnesota and efforts were made to reach out to persons not associated with the Brain Injury Association of Minnesota and to some under served communities.

Surveys

- In the future, increased effort should be made to reach out to persons with brain injury and family members, providers, and others not associated with the Brain Injury Association of Minnesota; to underserved communities, and to populations identified as high-risk populations.

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1) Which one of these groups best describes your relationship to brain injury?

Answer Options	Response Percent	Response Count
I am a person with a brain injury (If you are assisting	41.3%	137
My spouse has a brain injury (please skip to question #	3.3%	11
My sibling has a brain injury (please skip to question	3.0%	10
My parent has a brain injury (please skip to question	0.9%	3
My child has a brain injury (please skip to question #6)	8.4%	28
My significant other has a brain injury (please skip to	0.3%	1
I am a person assisting / caregiver (please skip to	4.5%	15
I am a provider/professional (please skip to question #	34.9%	116
Other (please specify)	3.3%	11
<i>answered question</i>		332
<i>skipped question</i>		7

Number Other (please specify)

- 1 I have slight brain injury from car accident/drug use
- 2 State Rehabilitation Council
- 3 Yellow Medicine County Veteran Service officer

I had a minor concussion in 2006, but you won't take me off your mailing list, even though I have asked you to on multiple occasions. I am not brain-injured, and your repeated use of tax dollars to pester me is a prime example of

- 4 government funding being used for wrongheaded purposes.
- 5 aunt to person with brain injury

- 6 I am a person, who has experienced multiple brain injuries, both in childhood, and adulthood
- 7 i live with others with brain injurys
- 8 Beat in the head
- 9 FDS
- 10 No Comment
- 11 It's ME

Online 2009 Minnesota Needs and Resources Assessment for Individuals with Brain Injuries

2) Which of these best describes where you (person with the brain injury) currently live?

Answer Options	Response Percent	Response Count
House/apartment/college dorm	78.1%	121
Group home/foster care	14.8%	23
Nursing home	0.6%	1
Assisted living	4.5%	7
Rehabilitation facility	0.6%	1
Hospital	1.3%	2
Other (please specify)		16
<i>answered question</i>		155
<i>skipped question</i>		184

Number Other (please specify)

- 1 Reservation
- 2 none-I do not have a brain injury
- 3 he lives with me (mom)
- 4 I help veterans who live in their homes
- 5 currently in a pvt home, but transient and borderline homeless
- 6 at my residence
- 7 loosing home unable to work
- 8 handicapped, accessible home
- 9 18 years post initial injury, I am the full time mother of four and an assisant in the office of my husband's farm.
- 10 my sister and I live and work together
- 11 professional in a rehabilitation setting
- 12 pening homelessness
- 13 None
- 14 With My husband in our home
- 15 Home with mom (myself) Stepdad, brother Tony. Work takes care off scott 4 days a week.
- 16 I live at Marrie T. Facility

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3) How do you (person with the brain injury) categorize yourself? Please check all that apply.

Answer Options	Response Percent	Response Count
White	84.1%	132
Black or African American	4.5%	7
American Indian and Alaska Native	5.1%	8
Asian	2.5%	4
Native Hawaiian and Other Pacific Islander	1.3%	2
Two or more races	5.7%	9
Some other race (please specify)		9
<i>answered question</i>		157
<i>skipped question</i>		182

Number Some other race (please specify)

- 1 unknown mix
- 2 This is an irrelevant question.
- 3 European American
- 4 Race is a sociological construct
- 5 human being of rich heritage
- 6 Middle Eastern
- 7 German, Scottish, Irish
- 8 Irish American
- 9 Hispanic

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4) If you are a person with a brain injury, with whom do you live? (Please check all that apply.) If you are not an individual with a brain injury, please

Answer Options	Response Percent	Response Count
I live on my own	36.2%	55
I live with my spouse	34.9%	53
I live with minor children	11.8%	18
I live with a sibling	2.6%	4
I live with a parent	9.9%	15
I live with adult children	5.3%	8
I live with my significant other	4.6%	7
I live with my caregiver/person assisting	8.6%	13
Not applicable	8.6%	13
Other (please specify)		15
<i>answered question</i>		152
<i>skipped question</i>		187

Number	Other (please specify)
1	reservation
2	with roomates
3	Adult Foster Home.
4	a group home with others who have pysical challenges.
5	Live with a friend
6	Independent sobor house
7	Friends
8	group home
9	With significant other and minor child
10	group home with other adults with TBI
11	group home with other TBI adults
12	I live in a roup home
13	I live in a group home. Marrie T. Facility
14	Also Serving animal,Dog
15	Group Home

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6) How did the brain injury occur? Please check all that apply.

Answer Options	Response Percent	Response Count
Motor vehicle crash	38.0%	68
Motorcycle crash	7.3%	13
Fall	26.8%	48
Stroke/aneurysm	9.5%	17
Assault/abuse	13.4%	24
Pedestrian (hit by motor vehicle, motorcycle, bike, etc.)	5.6%	10
Work accident	6.1%	11
Tumor	2.2%	4
Bicycle crash	3.4%	6
Sports related	4.5%	8
Other (please specify)		40
<i>answered question</i>		179
<i>skipped question</i>		160

Number	Other (please specify)
1	I have seen my brain scan
2	Suicide Overdose
3	deer came through my windshield directly into my head
4	Skate Boarding Accident resulting in TBI/Stroke
5	cardiac arrest caused by a med overdose
6	Fetal Alcohol - Due to birth mother drinking
7	Road side explosions
8	accident during delivery at home
9	absess
10	brain hemorage/ than accident right after
11	Two TBIs, both riding bicycle in collision with moving vehicle
12	Snowmobile crash
13	Friend ran over him with a 4 wheeler

- 14 Diving off of a snowmobile & head butting a pine tree at 25 MPH
- 15 cavernous malformation
- 16 I was born with the umbilical cord around my neck.
- 17 Sledding Accident hit a parked car
- 18 Anoxic Brain Injury (under water up to 10 minutes)
- 19 hit my head on bar
- 20 encephalitis
- 21 well i was born with it
- 22 School Shooting
- 23 I don't really know
- 24 Chemical Fumes
- 25 Hit by a gate, head crashed into glass hit in the head by client.
- 26 ATV rolled without a helmet on
- 27 Seizure
- 28 Fight
- 29 Surgery
- 30 Lack Of Oxygen at birth
- 31 Snow Boarding
- 32 hit in the head during robbery
- 33 Drug use huffing ect.
- 34 Hit by a gate, head crashed into glass, hit in head by client
- 35 Black out/ Fainting spells. I have Fainting Spells
- 36 Chemicals/Fumes
- 37 I was hit by a car while running
- 38 Stroke caused by high blood pressure
- 39 2 Accidents at theater: 1996, 2005
- 40 Travel of studies in the Andes in peru

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7) Please check all categories that currently apply to you (person with the brain injury).

Answer Options	Now	Before my brain injury	Response Count
A. Homeless	9	3	11
B. Offenders/Ex-offenders	8	5	12
C. Recipient of alcohol/drug abuse services	22	10	26
D. Recipient of mental health services	64	15	68
E. Victim of domestic violence	7	9	14
F. Not applicable	72	52	74
G. Other	22	3	22
Other (please specify)			33
<i>answered question</i>			164
<i>skipped question</i>			175

Number	Other (please specify)
1	I attend AA meetings
2	BEHAVIORAL SERVICES , ils services,day program
3	he has a TBI waiver and receives in home support services Issues in school with learning, can make or keep friends, no cause and effect, at risk of being manipulated by friends or others
4	etc.
5	I use mental health services for the vets, alcohol and OIF services at St. Cloud
6	Most people think I'm Drunk, when I haven't been drinking
7	denied access to health care currently, medical facilities will not even accommodate working memory deficit...
8	arrested for attacking a police officer - impulse control issue.
9	none
10	E. before and during. D. during and after Became pregnant and was verbally and emotionally abused by babys father who she met after TBI dx. She is now 5 months
11	pregnant so it is all recent.
12	I was none of the above. I live alone now and before my brain injury as a professional adult.
13	seeing therapist, in AA, pending SSDI

- 14 debt, depression, poor choices,
- 15 had to file bankruptcy, having trouble getting meds
- 16 I am currently in DBT at courage center. I also receive ARMHS' and ILS services
- 17 Living in health compromised circumstances-- Now
- 18 nothing has changed for me. owned my home before and now
- 19 Speech Services
- 20 initial brain injury occurred in infancy, so there is no before my brain injury
- 21 I was date raped within a year after my brain injury
- 22 I had a freak accident when I was a child and maybe two I don't remember!
- 23 VA
- 24 unsure of the meaning of the question thought

- 25 Recipient of outpatient brain rehabilitation services- namely neuropsychological testing and counseling sessions
- 26 Assisted living
- 27 Siting high
- 28 Mood swings, Inner anger
- 29 VA
- 30 Work Comp
- 31 Faster Home
- 32 Currently attending crp at courage center trying to get better
- 33 TBI- recovery programs PT/ OT/ SLP/ ILS Executive function compensation strategies

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8) How old are you (person with the brain injury) now?

Answer Options	Response Percent	Response Count
Birth-2	0.0%	0
3-5	0.5%	1
6-11	1.0%	2
12-18	4.0%	8
19-21	3.5%	7
22-29	14.0%	28
30-39	14.5%	29
40-49	23.5%	47
50-59	25.5%	51
60-69	8.0%	16
Over 70	5.5%	11
<i>answered question</i>		200
<i>skipped question</i>		139

9) Number of years you (person with the brain injury) have been living with a

Answer Options	Response Percent	Response Count
Less than 1 year	3.6%	7
1 year	6.2%	12
2 years	12.4%	24
3-5 years	20.2%	39
6-10 years	17.6%	34
11-20 years	21.8%	42
Over 20 years	18.1%	35
<i>answered question</i>		193
<i>skipped question</i>		146

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10) How long did it take for your brain injury to be identified/diagnosed?

Answer Options	Response Percent	Response Count
Immediately	63.4%	123
Under 6 months	13.9%	27
6 months - 1 year	4.1%	8
More than 1 year - 2 years	4.6%	9
More than 2 years - 5 years	2.1%	4
More than 5 years - 10 years	5.7%	11
Over 10 years	6.2%	12
<i>answered question</i>		194
<i>skipped question</i>		145

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11) Please check all of the types of health care coverage that apply to you (person with the brain injury).

Answer Options	Response Percent	Response Count
Legal Settlement	11.8%	23
Managed Care	7.2%	14
Medicaid/Medical Assistance/MA/Waiver	33.3%	65
Medicare	30.8%	60
Minnesota Care/General Assistance Medical Care	10.3%	20
Private Insurance	41.5%	81
VA/TriCare	4.6%	9
Workers Comp	5.1%	10
Chemical Dependency Treatment Fund/County	6.7%	13
I have no health insurance	6.2%	12
Unsure	5.6%	11
Other (please specify)		20
<i>answered question</i>		195
<i>skipped question</i>		144

Number	Other (please specify)
1	Medica
2	Insurance through my employer
3	short term disability (offered through employer)
4	county will not assess, respond to questions, despite crisis
5	Blue Cross/Blue Sheild
6	Legal settlement at one time,MA at one time
7	husbands insurance-blue cross through work
8	spouse works and carries health care cov through job
9	ssd has not kick in till aug/sept2008- NO HELP from state of MN
10	auto insurance-MINE
11	ONE battle after anothe with Insurance companies for many injuries
12	Medica

- 13 Medica, Blue cross Blue Shield
- 14 Medicaid/ GAMC is only for 6 months. Social Security
- 15 Auto Insurace
- 16 Blue Cross
- 17 MA
- 18 2 INS. Also
- 19 SSI just went through, that's gonig to change health insurance
- 20 MCHA

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12) I have a social worker/case manager/advocate.

Answer Options	Response Percent	Response Count
Agree	50.3%	98
Disagree	22.6%	44
Not applicable	27.2%	53
<i>answered question</i>		195
<i>skipped question</i>		144

13) I feel that professionals listen to my needs.

Answer Options	Response Percent	Response Count
Agree	61.9%	122
Disagree	24.4%	48
Not applicable	13.7%	27
<i>answered question</i>		197
<i>skipped question</i>		142

14) My service provider understands my brain injury.

Answer Options	Response Percent	Response Count
Agree	52.8%	102
Disagree	20.2%	39
Not applicable	26.9%	52
<i>answered question</i>		193
<i>skipped question</i>		146

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15) I am supported in making my own decisions.

Answer Options	Response Percent	Response Count
Agree	67.5%	131
Disagree	14.4%	28
Not applicable	18.0%	35
<i>answered question</i>		194
<i>skipped question</i>		145

16) My services/supports reduce my stress.

Answer Options	Response Percent	Response Count
Agree	51.0%	100
Disagree	21.4%	42
Not applicable	27.6%	54
<i>answered question</i>		196
<i>skipped question</i>		143

17) I get the help I need to live where I want to live.

Answer Options	Response Percent	Response Count
Agree	51.0%	101
Disagree	25.3%	50
Not applicable	23.7%	47
<i>answered question</i>		198
<i>skipped question</i>		141

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18) My services/supports assist me in living a more independent and productive life.

Answer Options	Response Percent	Response Count
Agree	54.4%	106
Disagree	16.4%	32
Not applicable	29.2%	57
<i>answered question</i>		195
<i>skipped question</i>		144

19) I have enough information and assistance to make my choices.

Answer Options	Response Percent	Response Count
Agree	57.9%	113
Disagree	24.6%	48
Not applicable	17.4%	34
<i>answered question</i>		195
<i>skipped question</i>		144

20) I have a clear choice among meaningful services/supports.

Answer Options	Response Percent	Response Count
Agree	46.9%	92
Disagree	32.1%	63
Not applicable	20.9%	41
<i>answered question</i>		196
<i>skipped question</i>		143

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21) I have multiple options for services/supports.

Answer Options	Response Percent	Response Count
Agree	43.7%	86
Disagree	35.5%	70
Not applicable	20.8%	41
<i>answered question</i>		197
<i>skipped question</i>		142

22) My services/supports are tailored to meet my individual needs/goals.

Answer Options	Response Percent	Response Count
Agree	51.0%	100
Disagree	25.5%	50
Not applicable	23.5%	46
<i>answered question</i>		196
<i>skipped question</i>		143

23) I have a say in HOW I receive services/supports.

Answer Options	Response Percent	Response Count
Agree	53.0%	105
Disagree	24.2%	48
Not applicable	22.7%	45
<i>answered question</i>		198
<i>skipped question</i>		141

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24) I have a say in WHEN I receive services/supports.

Answer Options	Response Percent	Response Count
Agree	45.8%	88
Disagree	30.2%	58
Not applicable	24.0%	46
<i>answered question</i>		192
<i>skipped question</i>		147

25) My services/supports are flexible and work around my needs and

Answer Options	Response Percent	Response Count
Agree	52.8%	103
Disagree	22.1%	43
Not applicable	25.1%	49
<i>answered question</i>		195
<i>skipped question</i>		144

26) I have a say in WHO provides my services/supports.

Answer Options	Response Percent	Response Count
Agree	48.2%	93
Disagree	28.0%	54
Not applicable	23.8%	46
<i>answered question</i>		193
<i>skipped question</i>		146

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27) I have a say in my goals.

Answer Options	Response Percent	Response Count
Agree	72.8%	142
Disagree	9.7%	19
Not applicable	17.4%	34
<i>answered question</i>		195
<i>skipped question</i>		144

28) My services/supports are respectful of my dignity.

Answer Options	Response Percent	Response Count
Agree	67.0%	128
Disagree	10.5%	20
Not applicable	22.5%	43
<i>answered question</i>		191
<i>skipped question</i>		148

29) I am included in all decisions that involve me.

Answer Options	Response Percent	Response Count
Agree	63.0%	121
Disagree	24.5%	47
Not applicable	12.5%	24
<i>answered question</i>		192
<i>skipped question</i>		147

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30) I have the skills and information I need to advocate for myself and my needs.

Answer Options	Response Percent	Response Count
Agree	54.8%	103
Disagree	36.7%	69
Not applicable	8.5%	16
<i>answered question</i>		188
<i>skipped question</i>		151

31) My income has been reduced as a result of my brain injury.

Answer Options	Response Percent	Response Count
Agree	68.3%	127
Disagree	14.5%	27
Not applicable	17.2%	32
<i>answered question</i>		186
<i>skipped question</i>		153

32) My emotional/psychological health has been harmed as a result of my brain injury.

Answer Options	Response Percent	Response Count
Agree	80.4%	152
Disagree	13.2%	25
Not applicable	6.3%	12
<i>answered question</i>		189
<i>skipped question</i>		150

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33) My health has been harmed as a result of my brain injury.

Answer Options	Response Percent	Response Count
Agree	68.6%	129
Disagree	23.4%	44
Not applicable	8.0%	15
<i>answered question</i>		188
<i>skipped question</i>		151

34) My living situation has become worse as a result of my brain injury.

Answer Options	Response Percent	Response Count
Agree	50.0%	96
Disagree	31.8%	61
Not applicable	18.2%	35
<i>answered question</i>		192
<i>skipped question</i>		147

35) My marriage has been harmed by my brain injury.

Answer Options	Response Percent	Response Count
Agree	25.8%	49
Disagree	15.3%	29
Not applicable	58.9%	112
<i>answered question</i>		190
<i>skipped question</i>		149

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36) My parent's marriage has been harmed by my brain injury.

Answer Options	Response Percent	Response Count
Agree	14.8%	28
Disagree	32.3%	61
Not applicable	52.9%	100
<i>answered question</i>		189
<i>skipped question</i>		150

37) My personal/intimate relationships have been harmed by my brain injury.

Answer Options	Response Percent	Response Count
Agree	68.6%	131
Disagree	15.7%	30
Not applicable	15.7%	30
<i>answered question</i>		191
<i>skipped question</i>		148

38) My alcohol/drug use has changed as a result of my brain injury.

Answer Options	Response Percent	Response Count
Not applicable	44.8%	86
Use has increased	10.9%	21
Use has decreased	24.5%	47
No change	19.8%	38
<i>answered question</i>		192
<i>skipped question</i>		147

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39) Have you worked from time to time since you were injured?

Answer Options	Response Percent	Response Count
Yes	64.0%	119
No	36.0%	67
<i>answered question</i>		186
<i>skipped question</i>		153

40) Have you used vocational rehabilitation?

Answer Options	Response Percent	Response Count
Yes	40.3%	75
No	59.7%	111
<i>answered question</i>		186
<i>skipped question</i>		153

41) My employment has changed as a result of my brain injury.

Answer Options	Response Percent	Response Count
Agree	72.2%	135
Disagree	11.8%	22
Not applicable	16.0%	30
<i>answered question</i>		187
<i>skipped question</i>		152

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42) Which of these best describes your current employment status:

Answer Options	Yes	No	Response Count
Volunteer	43	52	95
Unemployed	80	40	120
Employed part-time	43	57	100
Employed full-time	32	59	91
Supported employment	14	67	81
Not applicable	20	36	56
<i>answered question</i>			191
<i>skipped question</i>			148

43) If you are not working, which reason applies?

Answer Options	Response Percent	Response Count
Can't or not allowed to perform the job I held prior to	27.8%	49
Can't perform any job	15.3%	27
Can't find work	6.3%	11
Lack of transportation	1.1%	2
I need help in finding a job	9.7%	17
Not applicable	39.8%	70
<i>answered question</i>		176
<i>skipped question</i>		163

44) If you are looking for a job, are you receiving assistance in finding a job?

Answer Options	Response Percent	Response Count
I do not need this service	60.5%	92
I receive this service and am satisfied	8.6%	13
I receive this service but am dissatisfied	7.2%	11
I need this service	23.7%	36
<i>answered question</i>		152
<i>skipped question</i>		187

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45) If you have a job, did you receive assistance in finding your job?		
Answer Options	Response Percent	Response Count
I did not need this service	61.8%	89
I received this service and was satisfied	11.8%	17
I received this service but was dissatisfied	4.2%	6
I need this service	22.2%	32
<i>answered question</i>		144
<i>skipped question</i>		195

46) Are you or did you receive assistance in keeping your job?		
Answer Options	Response Percent	Response Count
I do not need this service	57.9%	88
I receive this service and am satisfied	11.8%	18
I receive this service but am dissatisfied	5.9%	9
I need this service	24.3%	37
<i>answered question</i>		152
<i>skipped question</i>		187

47) What is the longest you have held a job since you were injured?		
Answer Options	Response Percent	Response Count
Not applicable	34.6%	63
Less than one month	3.3%	6
1-3 months	7.1%	13
4-6 months	3.3%	6
7-9 months	3.3%	6
10-12 months	5.5%	10
More than 1 year to 3 years	18.7%	34
More than 3 years	24.2%	44
<i>answered question</i>		182
<i>skipped question</i>		157

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48) If you are not working, what is your source(s) of income?

Answer Options	Response Percent	Response Count
First	99.1%	116
Second	55.6%	65
Third	17.9%	21
<i>answered question</i>		117
<i>skipped question</i>		222

Number	First	Second	Third
1	MA		
2	student in school -child		
3	SSDI	TBI Waiver	
4	SSI		
5	retirement/ disability	social security	
6	disability from job	SSDI	
7	Mother	County assistanc none	
8	mother-mother's income is reduced due to caring for son with brain injury		
9	Social Security		
10	Social Security	SSDI	
11	VA Benefits		
12	Parents, as I am 11 years old		
13	SSD	SSI	Parents
14	Social Security Disability	Long Term Disability Ins	
15	disability income		
16	disability insurance	spouse's income	
17	social security	barter/charity	
18	Husband's Income	Assistance from my parents	
19	Social Security Disability	Long Term Disability Insurance	
20	social security	retirement	investments
21	Social Security Disability	SSI	MSA

22	social security disability	long term disability
23	social security/retirement benefits from employment	
24	Social Security Disability	Long Term Disability
25	husband	my part-time job
26	SSI Disability	Food Stamps
27	Section 8 housing	Freelance work Energy Assistance
28	SS	savings
29	Social Security Disability Payment	
30	funds from a casino	
31	Social Security Disability	Long-term disab Spouse's income + interest on savings
32	Workmans Comp	
33	parents	nothing - dr took off work and work comp wont pay
34	Unemployment	
35	beg	borrow steal
36	SSI Disability	Spouse
37	S.S.D.I	
38	Private insurance	Medicare
39	medical assistance	
40	ssd	Wife
41	ssdi	none none
42	SSI	MA
43	Unemployment Ins. following layoff	Wife's income
44	Social Security Disability	
45	Social Secutirty Dissibility Income	
46	SSDI	retirementPension
47	SSDI	Parents
48	Savings	Sporadic work
49	Parents	
50	unemployment	none none
51	Pension	Social Security Investments
52	ssi	
53	Social Security Disability	personal investment income
54	spouse's retirement and income	my savings we do without
55	social securiyt	
56	social security	a job a job
57	spouse's income	investment income (I'm retired)

58	Annuity			
59	social security disability		Michigan teacher retirement	
60	SSI			
61	social security			
62			Retired	
63	SSDI		Workmans Comp settlement not R/T TBI	
64	ssI			
65	SSI			
66	5.5 Woked in Past		Past \$ owed to r outside help	
67	Unemployment		help from family	
68	retirement pension		spouse pension	
69	I physically would collapes with each effort that i made to return to work and schoolbut I REALLY TRIED			
70	Social Security			
71	SSDI		CADI wavier	
72	Disabililty from S.S		G.A.M.A	Medicare/ rule25
73	SSI			
74	ME			
75	none			
76	USAF retirement benefits		social security	
77	social security			
78	SSI			
79	SSDI			
80	SSI			
81	SSI			
82	SSI		WIC	my dad
83		0	0	0
84	SSI			
85	Disability		Sec. 8 assistanc	food assistance
86	SSI			
87	TBI		SS	
88	severance pay			
89	settlement			
90	Parents			
91	Social security			

92	SS Disability	
93	Social Security Disability income	
94	SSSDI	Part-time job NH
95	SSI Disability	Disability Insurance
96	Social Security Disability	teacher ret disability
97	Social	Own Business
98	Unemployment	Help From Family
99	Social Security	Spouse Income
100	S>S (worked in past)	Past \$ owed to r outside help
101	SSI	
102	Workers Comp	SST
103	Social Security	Retired
104	SSI	Retirement
105	employment	
106	S.S	
107	Work Comp since his accident	
108	Long term Disability	
109	MA	
110	S.S	Parents
111	SSDI	
112	N/A not working	
113	Social Security	Do odd jobs fix cars
114	Workers comp lost wages	permency rating lunds job= 12 hours
115	SSI	Family
116	Workman's comp	
117	Savings	Debt

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49) If you are a person with a brain injury, which choice best describes your level of satisfaction with the following services?

Answer Options	Satisfied	Dissatisfied	Need but can't access	Do not need / not applicable	Response Count
20. Medical - general	111	12	14	30	167
21. Medical - specific to brain injury	81	32	17	38	168
07. Dental	86	24	15	53	178
33. Support group	52	21	31	67	171
24. OT (occupational therapy)	54	20	15	78	167
29. PT (physical therapy)	66	16	13	75	170
05. Case management	67	28	23	58	176
17. Individual counseling	73	16	20	64	173
32. Speech therapy	55	7	13	88	163
22. Neuropsychology	64	26	21	58	169
35. Vision care as a result of injury	50	20	15	83	168
06. Cognitive rehabilitation	63	23	30	60	176
34. Transportation	58	26	18	65	167
19. Legal counsel related to injury	35	19	15	98	167
14. Home care support	51	12	15	96	174
30. Recreation	62	23	18	66	169
03. Assistive technology	25	12	26	110	173
18. Inpatient rehabilitation	38	12	8	110	168
25. Outpatient rehabilitation	56	19	17	79	171
23. Nursing	66	7	6	87	166
26. Parenting support	30	10	12	117	169
16. Housing assistance	33	10	15	109	167
04. Behavioral supports	61	14	19	80	174
10. Family counseling	27	20	17	108	172
15. Home modifications	31	12	8	120	171
31. Respite care	18	9	4	132	163
08. Educational supports	42	35	23	76	176
02. Alcohol/drug treatment; residential	13	3	2	158	176

01. Alcohol/drug treatment; outpatient	23	5	1	150	179
09. Emergency shelter	25	6	4	136	171
12. Group counseling	28	21	15	104	168
11. Financial assistance	48	23	27	72	170
13. Health care coverage	98	14	13	51	176
28. Psychological services	72	16	18	61	167
27. Psychiatric services	56	17	13	80	166
<i>answered question</i>					181
<i>skipped question</i>					158

50) Comments available for viewing online at www.braininjurymn.org

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50) Thank you for taking the time to share your comments, needs and opinions with us. If there are thoughts that you were not able to express in this survey, we ask that you please take a few moments and express those thoughts in the box below. We welcome comments about what you feel to be the most important services/supports/resources. Where do you feel the most important gaps and barriers exist? Where do you feel good progress has been made in Minnesota brain injury services and supports?

Answer Options	Response Count
	93
<i>answered question</i>	93
<i>skipped question</i>	246

Number	Response Text
1	Gaps and barriers for children in the school system and medical system.
2	I think that many individuals are not identified. My brain injury exacerbated my anxiety and depression and ultimately my chemical misuse (addiction to pills).
3	I sm just re-starting OT and PT - Unable to access residential pain clinic services - Overall my services and support are great.
4	The social/emotional ramifications of a brain injury are not being addressed.(2) The children of parents with brain injury are not being addressed at all and are left out of the picture throughout treatment. The divorce rate of couples experiencing brain injury needsto be addressed and dealt with because of the impact it is having on our children.
5	i have received excellent support from the local independant living agency. the independant living specialist, erin fontaine, is outstanding.
6	Please stop telling us about support groups if they don't exist!
7	I feel that people are not trained in acquired brain injury well. Even the services we receive from TBI waiver has resulted in 2 of 3 ILS staff quitting within the first month. People do not understand the medically induced behavioral problems and inappropriate responses only serve to increase the issues including low self-esteem (both in the private service professionals and within the educational system). Huge area of need is for ABI to be treated by TBI professionals in the school setting. TBI is only considered if there is an external force injury but these are the only people who truly understand the neurology involved and ABI kids are treated as emotionally disturbed
8	The significant change is having a case worker and a living skills person with a background and understanding of brain injured persons.
9	Each County in MN. should have access to classes and support groups for people with Brain Injury..most people do not have transportation to go to the Cities for classes..Please make it assessable to have services in the Counties people live in like Stearns County..Thank You for your Survey to us..

I have just recently learned that I have TBI. I have lived with TBI without knowing it. All my life I thought I was dumb or just plain stupid until I learned that there is a reason why I learn differently. I am a parent of 2 grown children, 1 has Down Syndrome and 1 has MS. I feel that because of my disability that I was able to help my children advance in their lives. About a year ago I joined a TBI support group and learned a lot of things that I do are because of TBI just talking with others. I am so glad that I am in a

10 support group with others to find out that I am not the only one who thinks or does things the way I do.

I believe we need to manage stroke survivors differently. Permitting them to sleep at will, to be removed from too-much-stimulation at will, and to regain cognitive capacities at their own unique pace -- this philosophy or approach is the way in which to

11 manage stroke survivors so that many more recover to live a nearly normal life.

I am a parent of two children with FASD. I would really like to see the Brain Association in MN take the first steps in adding FASD to the list of Traumatic Brain Injuries. I can't understand why nine months in an alcohol bath is not "blunt" force trauma. I do not wish to be disrespectful to others who have suffered a TBI, however I would like to see my children be able to access some of the services that fall under the TBI, for their own TBI. □

12 Thanks you for listening

13 TBIs are not just in the metro area of MN. Outreach needs to be made to rural MN.

THE DOCTORS, NURSES OT PT, AND SPEECH THERAPIST WERE ALLAWESOME!! □

14 THE NEEDS OF THE PATIENT CAME FIRST AT MAYO CLINIC.

The biggest difficulty that I have is the feeling that I need to "convince" people that my traumatic brain injury is real. I am constantly told how "lucky" I am that I do not "have to" work and that I "get to" stay home all the time. This is tremendously stressful and difficult to accept. This reflects a lack of understanding about this hidden injury. I have had to negotiate my own way through a maze of medical providers, etc. and have not gotten any help from anyone. Therefore, I have no idea whether the services and support available in Minnesota is adequate, but I would have to say that in my experience this is an extremely lonely process for me and my wife. Only now, over a year after my accident, am I starting to get some cognitive help that I have long needed. If my experience is typical, the most important gap is in provider understanding of the problems of brain injury and coordination of resources. I am fortunate in that I have good insurance that has helped to pay some of the expenses, but much of

15 the medical care that I have received has, in all candor, been a complete waste of time.

Vision care is huge area missing in MN as is accessing brain injury care and having primary care physicians recognize brain injury

16 symptoms and the need for referrals for brain injury evaluations.

Since my husband was moved from a care facility to a group home his level of care has increased tremendously. However the needs of the family are not taken into consideration when assessing the county spend downs. Currently we are in danger of losing our family home because the county is taking all but \$89 of his monthly disability income. This is a huge gap that affects the

17 amount of time I am now able to devote to being with him.

18 I fell several years ago, breking a nerve in my Rt Cheek, Dr said to let it heal, it hasn't.

The support groups I can find are mainly just people who have had or are living with a person who has a head injury. I don't find
19 any groups where there are survivors such as myself to relate to and gain advice from.

20 From my perspective, this survey is a waste of tax dollars.

21 Contact from brain injury association was appreciated. I feel that presently I am fully recovered

22 Living in a rural setting makes accessing things like transportation to do much of anything.

I experienced progressive deterioration as a result of multiple brain injuries. Two childhood injuries were not reported and not diagnosed/misdiagnosed. The results were clear: I was having seizures and could no longer work at grade level in academics, became physically uncoordinated, and organization of thought and speech was increasingly difficult and it appears that I may have become increasingly dependant on others to organize my environment and experienced stress intolerance, additional symptoms and emotional disequilibrium. As an adult woman in an abusive relationship, I experienced two more head traumas that were severe and life changing, still untreated and minimized, finally after a pedestrian and traffic accident, I could no longer function around strong odors, varying light conditions, with background noise or organize well enough to assume leadership positions. My life and the lives of our children changed financially, emotionally, relationally. I lost job because I could not assess my reality effectively and
23 did not have the words or the self-advocacy skills (still don't) to explain to bosses or get accommodations. I only wish I had been diagnosed

I had an employment worker who was familiar with TBI. On my own, I found a job that I kept for 2 1/2 years. I got laid off last month. I wrote a letter to the employment Dept. Mgr., asking if there is anyone available to help me, who is familiar with TBI. I knew this Mgr. and thought he could at least have responded and told me 'get in line.' I got no response at all. I can only work part time, due to TBI fatigue. I need a job. I need help. □

24 Separate issue: my Section 8 is great!

25 giving me information now, where I need to go or do.

Our daughter is in high school and since she is receiving some PT, OT and Speech therapy at school, she is not able to receive other outpatient therapy, which would be so good for her since her injury was over a year ago, but not yet two years. I would like
26 to see more therapy before it gets too long since her accident.

One of the most important things I think a person with a brain injury should have is a therapist or psychologist to talk to. It's very hard coping with everything, especially memory issues. I was put on an antidepressant a few months after the accident. It got really tough for me. I had troubles with small things like finding my vehicle at a mall, remembering where I put my glasses while I had double vision for quite sometime after the car accident. I just think it's important to have a therapist to talk to when going through all of the changes so a person doesn't feel so alone. Because nobody knows how it feels unless they've been through it.

27 thank you

I know that for awhile I would get calls from a support person, but after awhile that ended. It would be nice to have a person to call and ask questions of and get support about education, counseling and general knowledge things. One person assigned to me that when I would call would not have to pull files and research my situation. Someone to call to help me to understand the issues I run
28 into from time to time.

We lived in Little Rock, Arkansas at the time of my husband's two TBIs (2003 and 2004) so all services/supports mentioned were received in Arkansas until June 2008. Since our move to MN, we have accessed PT, individual + joint mental health counseling, and
29 regular medical care.

There is nothing in the St.Cloud AREA OTHER THAN CENTRA CARE. NO OPTIONS YOU HAVE TO TAKE WHO THEY GIVE YOU NO MATTER HOW RUDE OR BUSY THEY ARE. THERE IS NO INFO ON BRAIN INJURIES HERE, NO CLASSES UNLESS YOU HAVE THE ABILITY TO GO TO THE CITIES!!! VERY UNFAIR AND A TERRIBLE INJURY TO HAVE AS YOU CANT GET INFO OR HELP IN ANY
30 KIND OF A TIMELY MANNER.

Once I learned to self advocate the services and help I received improved, but it took 5-6 years for me to reach that point and I
31 continue to learn each day.

The police did not thoroughly investigate the crime in which the injury was sustained. I could really use some legal and financial
32 help! Can't work and now I'm loosing my house because of that !

There are huge gabs in all services out here in the Willmar area. i cant find anyone who is an expert in TBI's- i feel i have trained more DR. in the problems associated with a TBI than anyone has given to me. A 2 1/2 hour drive to the MPLS area is impossible for
33 some with brain injuries. Greater MN needs some services out here.

34 Gaps are in the 'extreme' NW portion of the state...Moorhead is not 'extreme' NW MN

35 Alot of trouble with transportation. No city buses in our area. \$40 per day for a cab to and from work !

Our daughter had NO after care, she lost her job with benefits because of brain injury. She has never received any health insurance, social security or disabilty as a result of her brain injury.□

Nobody ever contacted us and I had no idea where to look for help for her or what options were out there. My husband and I supported her for 3 years after accident and were drained, emotionally and finacially. I would think that the health care provider
36 would have given us info on what help was out there for her and us. We feel let down by our state and health care providers.

37 I feel things spinning out of control, I need help□

lots of progress has been made in more services for TBI in out-state MN, but there is need for more, ie housing & services tailored
38 to individual needs. We have been working with this since 1977.

39 Can't not aford the meds that range from \$200-400 every 30days with some kind of help

40 Why is there no public meeting scheduled in Duluth related to this?

41 My son and I were very lucky following a car accident in July '07 and both of us recovered quickly from our level II head trauma. It

42 Memory loss so for test had to keep scrolling up for headings for each category.

43 My biggest problem is making decisions. Mine turn out to cost me money. I have tried to get assistance and have ben tuned down,

The Brain Injury Association of Minnesota has been and still has been greatly helpful to me in my ongoing recovery. The support of the mentor program helped me through a very difficult time in my recovery. When your whole world gets turned up side down with just one missed step nothing is ever the same again. From learning to talk, walk, eat, write and communicate your need to others is a long a difficult journey. Then when you suffer yet another stroke and have to start all over again it takes even longer the second time through. It is as if your spirit has been broken and your hope for a more normal life vanishes any attempt to look into the future seem hopeless. The only saving grace is the amount of special services you are able to obtain. With more and more services being cut I can't help but feel like I'm some sort of low life of society. This is wrong in so many ways, what ever happened to quality of life? Were is affordable handicapped housing for low income disabled US citizens? Why are we not allowed access to
44 on going pool therapy or on going physical therapy that helps our bodies to stay more limber and stronger so as to not increase the ;

A huge gap for us is the lack of services available to us because we DON'T have medicaid. The Brain Injury Assoc. was unable to assist me when I needed home care, repite care, nor did I ever get a case worker to help me because I didn't have medicaid. Right now with the economic times I cannot let my son start vocational rehab because I cannot afford to leave work to drive him to or from a job and metro mobility is far too undependable to be able to get him there on time or pick him up on time. My son is cognitively at a moderate to high function but has short term memorty functioning and day programs for brain injury patients are much lower functioning so his day is spent at home. There needs to be service to help us get these folks back into social society. I would at least like to see him volunteering, but again, I have no way of getting him there. Without a case worker, I have been left to find services for him . The support groups he has gone to are not enjoyable because he says all they do is complain, and he
45 gets tired of hearing it. I have tried very hard to keep him off medicaid so those who can't affort to do that can get the medicaid, bu

I have found the support that my daughter has treceived from both Mayo the MN BIA and PACER to be GREAT. I have nothing but
46 high marks for everyone that has been involved in my daughter care and recovery.

47 I recovered with a bit of therapy and other than new dents in my skull, I don't notice any residual harm.

I was provided with speech therapy after my injury, but I was 24 then, and there was nothing for young people .. support or services or anything. Now, I am about to lose my job because I do not have effective documentation about my disability. All tests
48 are 17 years old. I really need help now, but I appear to function fine, so there is not yelp.

Assumption is that insurance takes care of problems my experience is that it does not, often conflict between insurance carriers- autoVs health who/what responsible for: attempts to move brain injury into mental illness, then health insurance as auto covers only body injury! No insurance-on paper or otherwise-covers all needs in brain injury-magnitude is so great no individual/family is equipped to deal with. Medical advice was to get divorced to maximize help, otherwise view was that spouse could take care of me. forced to move from home of 24 years-no help with accessible construction. Increased expenses, taxes,... decreased living space, mobility-ie. ranch style vs.2 story, 4" doorways/hallways, ramping, grading... , decreased access to work space. Increased need for help-if you cannot do the entire chore, you cannot do the chore, decreased ability to learn and grow, keep up with ever/ rapidly changing, technical world-we value head in our country, often above all else, decreased ability to manage resources, increased need for on-going- often maintenance type health care, often not covered by health insurance, now separate deductible for mental h

I would like to see more and better public transportaion available that can transport me to, from, between, across, and within more than one and beyond my own county.□

Due to my brain injury, the signals from my two eyes are not combined; thus I have double vision. This makes it difficult to drive at night. I also have trouble making the quick decisions to drive safely in heavy traffic. I cannot drive in any city bigger than New Ulm: 14,000.□

□

Good progress has been made in the information and support services for brain injury offered by many, especially by the Brain Injury Association of MN. Unfortunately this is due to the fact that there are ever more brain injuries. The information and services they provide are very important! I am thankful that they have been able to grow and pray that they continue to keep up as a leader and advocate with all of the changes in disability services.□

□

I would also like to see failure to wear a seatbelt in a moving car as a primary offense. Had I not been wearing my seatbelt during my accident in 1992, I surely would have lost my life or my injuries would have been severly worsened. The wearing seatbelts by all

I live in rural northern MN where there are very little or no resources for people with TBI. We must travel long distances to get to a professional. Traveling is very hard on people with TBI's. Why can't we have more services/resources in Northern MN?

Doctors up noth here don,t even no what to do with my head injury, I look and sound normal but inside i am all messed up memory problems emotioanl cj=hanges am not the same I am not a good self starter anymore i daydream and drift off from chores

It would be nice to have a support group for individuals with mild TBI

I'am upset because where I live there is nothing for me here as a brain injured person.

2005 Dec 23 fell on the ice and hit the back side of my head, I don't remember the amount. 2 blood clots one of the cells of my brain. The other clot was in my forehead. 4 days in the hospital. I lost my sense of smell. My hand and left leg was always in pain. at
55 my age you learn to live with it

56 I now am finally starting to get the help that I've asked for. Everyone was trying to label my problem on my severe ADD

57 Many PLACES

There is a gap for those that have brain injuries, but are still high functioning enough to work. I have been unable to find support
58 groups or mentoring to assist me in this area.

I was in a car accident 3/20/02 and besides my stay at the hospital and some PT and OT back home after I was released I have had no one help me with any of my concerns or no one to talk to that has been in my situation. However I found my future
59 husband and he has been through this except he has gotten help. I have not. KAYLA

As the sister of someone with a brain injury who has a spouse to care for him I am too far removed for most of these questions. However, I helped a lot providing research, etc., on care options. One observation -- there is a huge service gap between acute care and getting home or to a community setting for people with serious injury. In our case, hospital social workers rushed our decisions and did not provide enough information to make informed choices. Bethesda was the only option at a certain stage of recovery and was not a good fit. I work "in the system" so I had access to numerous experts but still really struggled with advising my sister in law. 10 months out from a serious aneurism my brother is home with some community supports -- a huge victory! I am
60 grateful to the state of Minnesota and the public policy people at DHS for providing care second to none for people with disabilities.

I am an individual with a post-concussive/mild brain injury as a result of 2 motor vehicle accidents within a 3 month period of time. I work in the health care industry. In my opinion, the most important gaps and barriers in identifying individuals with post-concussive/mild brain injury exist at the primary physician level. I went to see my primary physician the day after the 1st accident. He ordered PT for whiplash injury. 3 weeks later, my PT recommended that I return to my primary care physical because of my complaints about short-term memory issues. I returned to see my primary physician. I reported to him issues with memory, organizational issues at work, word finding issues, getting lost driving in familiar areas to name a few. He did not offer any outside support for me or any testing. One of his entries he wrote in my medical record: "patient's symptoms could be brain injury or depression - choose to treat depression as this is a more treatable diagnosis." (At a later time, I was able to access/read my
61 medical record as a result of litigation.) Over the course of 3 months, my symptoms did begin to clear. I was not back to what I would

I wish police and judges understood brain injury and predators more. I have been targeted repeatedly by a predator since the brain injury. Female police officers have sometimes been easier to deal with, not always. Some male police officers have been understanding, some very mean and not understanding. I wish there were more consistency. Since I've advocated for myself, I have gradually built a better relationship with the police. Things went a lot better when I lived in a smaller city. Some police officers are more tolerant with someone with brain injury. Some police officers have a bad attitude and think that the person with brain injury is an emotional wacko. I try to be steady as possible with the police, but when I'm in a crisis situation, my emotions can get too emotional. I can get confused, disoriented, and even have a seizure. Some police officers get this, others don't. But at least things have improved. I had the Mayo Clinic send a police chief a book on brain injury because the chief wasn't getting it. But I'm grateful that things have improved. Getting a judge to listen about brain injury is a whole different story. One judge refused to sign a restraining

62

My adult daughter has a severe brain injury. We have struggled from day one to get her the right care and help in many areas. Because our daughter cannot speak or walk, medical staff assumes she cannot understand. She understands! She continues to improve but still needs complete care including a feeding tube. She has the drive and support of her family to succeed but we cannot do it without the proper services and equipment. At this point, family is doing all therapy with no equipment as insurance has discontinued therapy months ago. We have been waiting for home modifications for 6 months. Rachel has had to have bed baths and is homebound because of the neglect of our system. We have been waiting for a decision on an appeal for a home elevator from a judge in the MN Dept of Human Resources for 5 months. He told us it would take 1-2 months for a decision and then lied to me a few months ago about looking at it that week and giving us a decision within a few days. This is unacceptable. Our county CADI waiver office is withholding any other improvements to our house until his decision. Therefore, Rachel gets bed baths, can only access one level inside the house, and we have been living on plywood and chipboard for 7 months. Because of the lack of efficiency or

63

64 NONE

65 How Do I get my self respect back?

Would like more help in getting head injured or disabled to socialize - like day at zoo, state fair, other MN attractions. Maybe even volunteering at BIAM more as means to get together. I love writing and if someone could help set up writing group at my building party room or SDale library. Set up a data base to hitch rides with someone locally so provide names in each person's living area they could call on to meet at activity.

66

After the injury I received an invitation from the state for Brain Injury assistance which I declined. After about a week later I was regretting that decision as anger issues surfaced. Also the ability to perform at pre-injury levels in advanced math and chemistry created problems in school. It would have helped if the school could have been supportive or at least interested in helping with the problem. If we would have gotten the state involved I was concerned there would be a stigma attached to my son's record. So I watched my A & B student drop to C's & D's. When speaking with school officials they were not concerned with the drop of grades due to the injury. I think a memo sent to schools from the state for the children who have suffered a head/brain injury would be help-full.

I still see double and would like more support. I would like to have more cognitive abilities. I want to walk without a cane (walk normally).

I didn't have a problem before my brain injury. It played a major part in my alcohol use. I can't hold a job where I need memory and I can't drive to work.

Understand that brain injury is separate from mental health.

I didn't know there were any services available to me.

It's imperative that victims of TBI have direction after their injury; I endured tremendous hardship after I left the hospital specifically because my insight was so poor, and the resources for further rehabilitation weren't adequately stressed, nor was their importance emphasized.

-very happy to be apart of the survey- I believe legislative it's on hold for professionals. hone bill wasnt able to be stopped, due to in his name so bill was not stopped for 6 months and to be paid. only shut off when final not paid. Legally if a person is unable when in their name, brain injured family is not able to sign if person is and Adult. Doctors should be able to give the rights to someone- ASAP. Bills pile up and the late fees.

Good support for people with brain injuries, but there is room for improvement with advocacy of those with TBI. It's nice to have a good support group.

People living outside the cities are still lacking in services and supports

I believe the state of Minnesota is in the statue age when it comes to workers comp! example a man loses a arm at work in Minnesota the most he can collect is \$50,000 if he works for the railroad is a million!!! how long is \$50,000 going to last this person in Minnesota. Minnesota get a life.

There is a gap for those who have brain injuries but are still high functioning enough to work. I have been unable to find support groups on mentoring to assist me in this area. It's difficult also to find employment with specific limitations. People often don't believe you have them. Every since I've gone to say I'm too high functioning for them to assist me. yet , I have symptoms and concerns clearly this is a gap. I think you do a excellent job helping several brain injured and handicapped and love made great strides political, but have left a huge number of us hanging. this sentiment has been echoed by you. The sentiment is returned by you, own and employees and volunteer.

76

77 Many paces

More vocational- no access JMD > personal care short coming. good relationship with BIAMN. Look to start a web busy but need tools to start. □

We need more advocacy in northern MN Cass. Co □

78 took 2 1/2 years to figure out system not accessible in northern Minnesota

I want to do transportation by my self but they won't let me. I'm kaley and my TBI happened on 9/16/07. I am still going through a lot because I have been diagnosed with the disease multiple sclerosis. but with the TBI in the programs I am in at school, I am the only one with TBI. They just don't know anything about it either. I don't think they know anything about it either. I had to have my program changed many times with my case manager. She is going to try and find me a group to go to with people who have TBI. I also see a psychologist with TBI. I like talking with him because he knows what I'm going through. He is leaving common link so I won't be able to talk to him anymore. It makes me mad because I can't talk to someone with the same problems. I get mad easily and I scream and swear. some things I want to do, like drive they won't let me do because of my seizures. I want just to be myself with out telling anything. My accident happened when I was 17. It will be two years in September. With all the bones that

79 were fractured they put me fake bones in. one by my eye and ears right in the middle dissolved. its like my skin sank in. Just some stuff

80 I went through quite a bit of therapy the first 6 months and felt I have to get back to work.

2005 Dec 23, I fell on the ice and hit the back right side of my head. I don't remember the ambulance or the helicopter ride to the hospital. 2 blood clots one almost on brain cell the other in my forehead. I spent four days in the hospital and a couple of months in recovery at home. I lost my sense of smell my left arm, and, and leg are painful sometimes. at my age you learn to live life with it. I'm still on the right side of the grass. □

□

81

Thanks EE Sce

More focus needs to be put on the needs of the brain injured person and helping them through the medical system. My medical provider was not helpful and seemed disrespectful. I would have welcomed information on how to change medical providers and support through this process. I was so frightened I was going to lose my job because I couldn't remember stuff at first. Early help to help me decide on a return to work plan and to support me in learning ways to help me remember and deal with job

82 responsibilities would have been so helpful.

I have asked for many services and have not received anything. Counties and other entities have all turned me down. My doctors tell me that nothing is wrong with me and yet I know that I am not the way I used to be. I feel that I have nerve damage and other issues related to the injury that doctors don't acknowledge. I have daily struggles with work and feel that my employer doesn't understand my brain injury and is looking for a reason to let me go. I am very frustrated that neurologists really don't understand me or my brain injury and that concerns me. All the doctors kept telling me was that I am depressed and they all wanted to put me on anti-depressants. I don't like to take drugs unless I really have to. My doctors say I am not complying with

83 the care and that I have an underlying behavioral disorder. This really upsets me.

84 Although this survey is a good idea, I could use some work.

Bemiji does little I feel with brain injury rehab. I feel criteria needs to be raised as people's brains do at times change. Scott learned to talk, eat, use the toilet. he has problems with initiating conversation so he was cut off of speech therapy, after two weeks he doesn't walk, but no PT really tried to walk with him. there are gait trainers, but nobody tried. We will try as his family to push, but so far no luck. I know the Brain Injury Association is a push and help for passing laws to help these situations. I would like to hear more about the research, and help for folks out of brain injury 3- years. we will help too if you need anything.

Robyn Hoem 218-444-8688

85 WE enjoyed the Bemiji MN town hall meeting. we need support group better outpatient therapy assistive tech. we would like to be on a list for progesterone research.

I am not sure if applicable but I need help in short term memory retention. It has improved somewhat but people I associate with is also affecting my personality, my day to day activity. I find myself attempting to cover when I don't remember a recent event. Thank

86 you.

My son has been in several group homes and in my opinion they have all been sub standard !!!!

He was being treated for MS until a month ago and now is being treated for Parkinsons ??? He is a charge of Dakota county and Thomas Allen Consultants and in my opinion neither do a very good job. It seems to me that they just stick them in a home and forget about them. He has been in a home (Saganaw home--North of Cloquet) since October of 2008 and has never meet his guardian.

My wife and I are trying to become his guardians but the deeper we get into the system the more we realize the politics involved all
87 of the parties involved(Counties, social workers and their companys and att'ys....seems to me they are all in bed together.

88 Residential Rehab Program

My brain injury did not have most of the common effects on my performance/abilities/cognitive abilities. However, it did have significant effects on my general socializing. I had proplems switching enviroments (going between family, friends, and colleagues). This only had a detrimental effect at work. Judging appropriateness or how much information to disclose was a definate barrier.

I was fortunate to have a very flexable employer and a couple of very good mentors.

While I'm not sure how there is any effective was to "teach" this judgement skill, I do know that it was a material matter with regards to my injury.

Thank you,

Justin D. Sundberg

89 JDSundberg@stthomas.edu

I am a person with brain injury. the courage center has been helping me for the last 8 or 10 months. The Courage Center is a great
90 Help.

very difficult= family out east and I live here, without their assistance or coordinated care. □

Cognitive therapy stopped " good enough" (average?) but didn't push pre imaging abilities.□

Workers comp adjusters interfere/ don't understand TBI. try to deny service I would have not gotten without lawyer and workers Comp mediator. huge gap= NO Personal Health Care. "earn" too much money because of comp lost wages, lost insurance since injury, wish i'd been advised to apply for social security or MN health options. a couple of years ago, and didn't have worry of no personal insurance. Progress= conferences for professionals and providers and persons with BIS. combined conferences more

91 helpful than splitting professional from others.

92 Many questions are hard to answer when I have service providers that I am satisfied with and some that I am dissatisfied with ,

PT has been supportive, yet sometimes finding an accessible drinking fountain has been nearly impossible because courage center
93 doesn't have enough fountains 4 w/c users.

Online 2009 Minnesota Needs and Resources Assessment for Individuals with Brain Injuries

51) County or counties in which your organization physically provides services.

County									
Aitkin	Anoka	Becker	Beltrami	Benton	Big Stone	Blue Earth	Brown	Carlton	Carver
3	20	4	8	9	0	2	0	4	2
Cass	Chippewa	Chisago	Clay	Clearwater	Cook	Cottonwood	Crow Wing	Dakota	Dodge
2	1	2	2	2	1	0	2	25	0
Douglas	Faribault	Fillmore	Freeborn	Goodhue	Grant	Hennepin	Houston	Hubbard	Isanti
0	0	1	0	1	0	69	0	1	1
Itasca	Jackson	Kanabec	Kandiyohi	Kittson	Koochiching	Lac Qui Parle	Lake	Lake of the Woods	Le Sueur
2	0	0	3	1	2	0	5	0	0
Lincoln	Lyon	Mahnomen	Marshall	Martin	McLeod	Meeker	Mille Lacs	Morrison	Mower
1	3	1	2	0	0	0	2	3	0
Murray	Nicollet	Nobles	Norman	Olmsted	Otter Tail	Pennington	Pine	Pipestone	Polk
1	1	1	0	9	2	1	1	2	2
Pope	Ramsey	Red Lake	Redwood	Renville	Rice	Rock	Roseau	St. Louis	Scott
0	30	0	1	0	1	6	0	18	2
Sherburne	Sibley	Stearns	Steele	Stevens	Swift	Todd	Traverse	Wabasha	Wadena
3	1	13	0	1	0	1	0	0	1
Waseca	Washington	Watsonwan	Wilkin	Winona	Wright	Yellow Medicine	Response Count		
0	10	0	1	1	2	3	61		

Question Totals

answered question 143

skipped question 196

Online 2009 Minnesota Needs and Resources Assessment for Individuals with Brain Injuries

52) Which of these services does your organization provide?

Answer Options	Yes	No	Response Count
22. Medical - general	45	61	106
23. Medical - specific to brain injury	46	57	103
08. Dental	22	74	96
35. Support group	58	45	103
26. OT (occupational therapy)	48	60	108
31. PT (physical therapy)	51	55	106
06. Case management	79	35	114
19. Individual counseling	59	49	108
34. Speech therapy	45	61	106
24. Neuropsychology	44	61	105
37. Vision care as a result of injury	22	73	95
07. Cognitive training	86	40	126
36. Transportation	64	44	108
21. Legal counsel related to injury	10	83	93
16. Home care support	63	43	106
32. Recreation	86	30	116
04. Assistive technology	62	44	106
20. Inpatient rehabilitation	39	61	100
27. Outpatient rehabilitation	48	60	108
25. Nursing	67	48	115
28. Parenting support	39	57	96
30. Psychological services	55	56	111
29. Psychiatric services	44	60	104
18. Housing assistance	50	55	105
05. Behavioral supports	100	27	127
12. Family counseling	37	64	101
17. Home modifications	34	62	96
33. Respite care	31	70	101

09. Educational supports	74	37	111
01. Advocacy	110	15	125
03. Alcohol/drug treatment; residential	19	79	98
02. Alcohol/drug treatment; outpatient	35	68	103
10. Emergency shelter	15	79	94
14. Group counseling	42	59	101
13. Financial assistance	32	64	96
15. Health care coverage	25	69	94
11. Employment services	61	45	106
	<i>answered question</i>		153
	<i>skipped question</i>		186

Online 2009 Minnesota Needs and Resources Assessment for Individuals with Brain Injuries

53) Thank you for taking the time to share your comments, needs and opinions with us. If there are thoughts that you were not able to express in this survey, we ask that you please take a few moments and express those thoughts in the box below. What

Answer Options	Response Count
	53
<i>answered question</i>	53
<i>skipped question</i>	286

Number	Response Text
1	Hard to find vocational services appropriate for individuals with BI
2	There is a need for more environments where individuals with BI can be supported differently than individuals with ID.
3	There is little to no educational materials, or trainings regarding TBI and the Native American populations that I am not aware of at least, when working with people who have had head or brain trauma - lot of times they do not acknowledge or disregard injury as reasons for not being able to get things accomplished - stigma of not being normal somehow and the clients never speak up about experiences or things they may have noticed in thier personal lives since the injuries - keep the effects secret almost unless it has a physical symptom to bring them to care.
4	There are few if any services in Out state Minnesota - the gaps are widening with the budget deficit.
5	One of the most important barriers that I see working with clients with TBI is the lack of supportive employment options in an environment where staff are trained to work with individuals with brain injury. Another major gap I see is in the transition from a group home setting into their own apt. or home. More apts with services available are needed to offer a transitional step to living more independently.
6	An important area that I feel is under-addressed is the connection between brain injuries and abuse whether the injury is a result of abuse or the abuser is taking advantage of someone with a brain injury. While I understand there are resources available on this topic and is becoming more widely recognized and discussed, I feel that greater funding sources need to be in place in order to provide resources to create awareness and support for victims of abuse.
7	Need more funding!!
8	Greater MN lacks in qualified TBI providers and behavioral services for individuals with TBI.

As a professional with a TBI, it is encouraging how well we are networking to provide services. MN is make great progress there. Our gaps involve funding for housing, medications that are affordable, day programming and structure, more vocational opportunities and family support such as family weekends and other resources. It is encouraging to see more housing with supports type providers decide to work with individuals with brain injury. We need to continue to make monies available to help people stay in the community. We also need more monies available for day type programs. People need SOBER fun. It would also be nice to have more mental health counselors be educated about adjustment to brain injury and understand the grief cycle
9 around it. Thank you for helping individuals with brain injury.

Private insurance often excludes coverage for cognitive rehabilitation. If the state Medicaid funding is reduced, services will be very limited for people with brain injury. Advocacy for these concerns is critical. Transportation is challenging if someone does not live within Hennepin county or if has to travel outside of Hennepin county. good progress has been made in provided resource
10 facilitation.

It would be great to have training seminars to educate psychologists and counselors on how to do therapy/counseling with persons having sustained a brain injury. We have lots of great psychologists in Blue Earth County, but only 3 of us are qualified in providing
11 TBI services. Thanks!

Access to services such as counseling, crisis and respite care, vocational supports, transportation and in-home supports are all barriers. People with brain injury who are homeless, in correctional facilities and have dual diagnosis are much underserved. Minnesota was making great progress with the TBI waivers until all of the funding cuts. Waivers keep people out of long term care facilities which cost the system huge amount of funds. Today, collaborative efforts are key, keep the Interagency Leadership
12 Council working together so state entities and the Brain Injury Association are communicating and strategizing together.

13 We need more services in northern minnesota regarding brain injury assistance both acute and rehab.

14 we need more education in the swmn area not in the cities

Again, having TBI myself, I can help others better. It is a "been there, done that" situation and that makes consumers comfortable
15 talking with me.

Having a good case manager is key. Social workers need to responded to the needs of the injured and their family and be
16 educated how to meed those needs and respective of those needs.

The system is confusing and difficult to navigate for staying eligible, medical support, and integrating services. Families are
17 understandably struggling.

Advocacy has improved a lot, the BIA of MN is an excellent resource in many aspects.□

The Medicaid program, although providing many needed services, is too long in process for eligibility and delays folks from returning to the community costing thousands more \$ than necessary□

More accessible, affordable and appropriate housing is needed for oversight needs regarding cognition especially when AFC is not required but safety is a concern and PCA doesn't provide enough oversight time□

TRANSPORTATION□

Insurance companies need to be more responsible for in home service needs and before that to pay for in patient rehab to help folks get ready to move to the community. Too frequently cut off payment for lack of progress or too much physical progress while cognition is still being addressed□

Vision and cognition is hard to get addressed□

18 Rural communities lack services in the above areas

The biggest gap I see is in treating the whole family. Family support is important and cannot be effective when financial burdens

19 become too much to bare.

The largest gap that I see is training and outreach to agencies and individuals who do not live in or near the Twin Cities area.

Training from BIA is too expensive to get in outer areas of the state and on-line/videos/video conferences are not available to even

20 attempt to bridge the gap.

One area of need that I see is Parent Supports for parents who have brain injury and need respite for children who do not have disabilities. Currently we are only able to get respite for them if they have a disabled child. There are also no current group homes that take parents and children; If the adult has an injury and would like support in learning how to parent again.□

□

21 I would also like to see more support groups for teens with brain injury.

Services for brain injury are focused on the medical model in which a person receives care based upon a medical illness. Typically, medication is used as a means of medical intervention and there is less emphasis on individual psychotherapy, cognitive rehabilitation or cognitive training. We have more facilities available for housing, but no means to manage behavior other than behavioral management and medication. There is no published study showing the effectiveness for any of the antidepressants or anti-anxiety medications for persons with a TBI, but yet nurse practitioners and physicians prescribe these routinely. In contrast, there are several published review studies that show the effectiveness of cognitive rehabilitation and cognitive training for TBI. But cognitive rehabilitation is not considered routine and MD's and Nurse Practitioners will prescribe these medications and waste valuable resources. There needs to be less money spent on medication and more money spent on cognitive training, cognitive rehabilitation, training staff in group homes, and less emphasis on medication for treatment.□

□

22 Finally, a statewide program to educate, evaluate, manage, and treat persons in high sports who sustain a concussion would be help

There are still many individuals with a brain injury who reside in a nursing homes who desire to live in the community where care and support can be delivered in a more individualized manner. There are quality providers with years of residential experience who want to provide services for these individuals and they are not allowed to expand their businesses under the current county contracting arrangements. □

23 I believe that there should be much more emphasis on brain injury prevention. Just one idea; we need a state wide campaign on use of helmets for bike and motorcycle riders. Helmets should be free or very inexpensive wherever bikes or motorcycles are sold.

24 I received good medical attention immediately after my fall. I feel that was was valuable in my recovery.

I have worked as a case manager for persons with TBI. Their services are usually in the waiver category. In investigating several MR diagnosis some of the injuries happened shortly after or during birth. Many of my clients who deemed MR actually have injuries which fall into this time frame. (With doctor documentation to verify.) Many have developmental stages which fall into the "normal" range . Most socialization skills which also fall into the normal range. It is the social and emotional needs of these persons who have carried these mis-diagnosis, then thusly, worked with the wrong the interventions and interventionists who have been hurt. When observing and questioning these individuals they report how they have never fit in with "those" people all their lives. They end up in group homes with persons who are MR in the mild, moderate, and severe categories. Persons with TBI then report they are very lonely and, in some cases, think of or have attempted suicide. □

25 I found it very difficult, from the counties, to change their waivers into a TBI rather than the MR. Services for persons with TBIs have been increasing their skills, educational and social levels for years. My question is why, if an investigation and the accompanied

26 We don't directly provide many of the services listed above, but we provide access to them by seeking out the vendor, making appointments, providing transportation etc.

27 One of the gaps in service is Day Programs for Adults with TBI in The Northeast. Also children with TBI and behaviors that need treatment or longer-term subacute rehab is also not available.

28 It took me a long time 1yr and 1/2 to get services, none was provided to my husband or family to know what is happening with Mom

29 We also have crisis beds available with behavioral support and completion of functional behavioral assessments.

30 I personally need some legal and financial help

One important area that is not being addressed is transportation for individuals with brain injuries. The current system of Metro Mobility and MNET are not always solutions for our clients to get to appointments and/or out into the community. Many clients do not even get Metro Mobility tickets, and don't have enough money to pay for the ride. Many times the rides are not able to get them to appointment/places at the appropriate times. Some clients have to arrive hours earlier than needed. In addition, they have to call so far in advance it is tough for many of them to remember due to the fact their memory is impaired. A system where they can call with less time in advance would be helpful. More funding to provide tickets to clients so they can use this transportation to get out into the community would be helpful. Another area is housing. There is very limited places for a person with a brain injury to go. Group homes may not know how to work with a person with a brain injury or don't have staff to assist them properly. Apartments are tough to come by that are clean and affordable for our clients.

31

1. A continued concern is for people diagnosed with mild brain injury or concussion in an Emergency Room and discharged with little or no information and no follow up. The Mayo Model of providing follow up over a 3 month period makes sense, so individuals can be referred for appropriate services in a timely way when symptoms do not fully resolve. 2. After sustaining a brain injury, individuals need to put forth tremendous effort to address physical, cognitive and behavioral challenges. This is often a period when financial circumstances are overwhelming. We need some sort of short gap funding to address basic needs while they are awaiting WC claims, insurance settlements or SSA benefits. The toll of an individuals economic crisis is enormous, impacting their relationships and their rehabilitation. 3. The waiver programs offer a lot of positive supports for individuals. One concern is that , while outcome driven models are part of our world reality, support, education and oversight is needed to ensure professionals are measuring what is of value to each individual. Another waiver concerns is that tremendous energy is put into accessing the appropri

32

The major gap for us is having a facility to discharge patients to that still have acute medical needs and also have behavior problems. No one seems to "get" brain injury, or want to deal with the concerns and staffing requirements needed to deal with the cognitive and behavioral problems.

We are fortunate that MN has MNCare and GAMC or more patients would be "stuck" in acute care.

We need the SMRT process changed to eliminate the 3 month waiting period for TBI and stroke!

We are very concerned about the proposal at the state level to not pay for or limit PT, OT and Speech services post-brain injury. The key window for recovery is right after the injury, these services are essential to a good recovery.

33 I am thankful the stimulus package has saved programs but am still concerned about the proposed limits in the benefits packages.

34 We definitely have a need for more accessible services in Northern Minnesota, such as education and training sessions for example.

To obtain more brain injury support groups for those who have lost their former friends and need something or someone to talk to
35 on a regular basis, I see a lot of survivors that are very lonely and bored.

As a person with a brain injury, I feel we can use a brain injury center here in Beltrami County. My family could not afford to live in
36 any other county to meet my needs, where there is more support.

We support rehabilitative services in the home, but informally, not in a professional manner. We give our individuals a high quality of
37 care and support them in many different aspects of everyday life.

38 Minnesota has a great number of adult foster care but needs more for individuals with TBI.

I work in Independent Living Skills. While there is a need for this type of work, I see a need also for something between ILS and
39 PCA.

I am a person with a brain injury, I didn't realize at first that this was for Providers. The title of the page blended with the
40 information at the top of my screen - This happened to me previously during this survey. It would have helped if the page opened
as a Word Document.

41 Please feel free to contact me

38. ILS

42 39. Residential support Services.

- We also provide Residential support service-.

43 no

44 Easier access to funding or more community management, access to more housing.

Minnesota has a great number of adult foster care, but needs more number LS for individuals with TBI. The foster care is also
45 concentrated in Duluth, rural areas have fewer options.

Availability waivers.

46 concerns foster care moratorium. What services are available. Transportation. Dental psychiatry in Duluth

47 It was good to share and meet other professionals!!!

Gaps and Barriers : Post active services, behavioral education for family caregivers, behavior/grieving v. mental illness awareness, required minimal training for direct support staff/ certificate program with required courses and hours of supervision (and legislative fund for it!), vocational options outside of LTCC budget, therapeutic Rec Paid for by insurance, more in home therapeutic providers (ie. SPL, MI, CTRs, VOL, OT, and PT), transition case managers required to have Brain injury training if supporting students with brain injury. There is a lack of behavior hospital care (there is only two in the state).□

Progress: More awareness, stability of BIA MN a advocacy organization, now on radar screen for corrections and CO and MI providers still need training (apply info to system change and empathy)□

Potential: More prevention awareness with sports and other areas.□

Strategy: require brain injury education with all drivers ed classes (i.e. parents night!)□

48 require a trained specialist in a school district if a certain number know and identify students with brain injury. Brain injury association of MN in collaboration with providers (residential, home health, PCA. formulate a certificate for serving pwBI. (BIS from

Gaps/Barriers: Availability of waivers□

Concerns of foster care moratorium/ what services available and will all those find them.□

transportation (flexibility, outside city limits)□

dental□

psychiatry in Duluth- Many providers in the area strain current psychiatric services.□

Good progress: Locally communicated more openly with police throughpouts area brain injury round table and lakes area fostercare provider group.□

49 Locally provider are coming together for training/ resources showing.

50 We support many rehabilitative services in the home but informally, not in a professional manner. we give our individuals a high quality of care and support them in many different aspects of everyday life.

1. Direct care staff training on individual rights- right to choice- where to live, where to work, free association, treat and respect.

2. Transportation- Statewide public transportation options.

3. Quality Assurance need to ensure " person centered" services

51 4. Need to improve services to connect people with brain injury to community- purpose filled life!

Gaps: employment and advocacy.

Progress: Brain Injury Association of MN, who do comprehensive work, check with me every few months, (I facilitates support group) (TBI Club) every first sunday of the month, 2pm 1011 Washington AVE. S , Minneapolis,MN 55415

52 Potential: in wilderness inquiry's work providing people where support, respect.

53 No