2017 Missouri Traumatic Brain Injury Needs Assessment Report

Report on the TBI Survivor / Family Needs Assessment Survey and the Professional Service Provider Needs Assessment Survey

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- Andrea D. Buening, Chair of Advisory Committee, Person with a brain injury
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Executive Summary

The Missouri Traumatic Brain Injury (TBI) Needs Assessment is supported through the Missouri TBI Implementation Partnership project. The overall goal of this project is ***"to provide individuals with traumatic brain injuries and their families with improved access to comprehensive, multidisciplinary, coordinated, and easily accessible systems of care."*** Historically the State of Missouri has conducted needs assessments every five years to inform the development of a Missouri Five Year Plan, which guides the provision of services and supports for individuals with TBI and their families. As a part of this project, an intensive needs assessment was completed ten years ago that involved interviews and focus groups with survivors, their families, and the professionals that serve them. A needs assessment conducted approximately five years ago was designed to build upon the earlier effort through surveys focused on survivors, their families, and the professionals who serve them. The current needs assessment, conducted with survivors of TBI, their family members, and professionals, builds upon these previous efforts and provides updated information on current needs of, and service availability to, the Missouri TBI community. Results will again be used to inform the development of a Missouri Five Year Plan.

Background

In Missouri, the number of TBIs treated in emergency rooms and hospitals is tracked by the Missouri Information for Community Assessment (MICA). This data shows that between around 15,000 people are treated for traumatic brain injury each year in Missouri. In 2014, a total of 16,839 people who had a skull fracture or intracranial injuries visited an emergency room. Of these, 4,824 (29%) received inpatient hospitalization. Many more people who sustain a TBI go untreated, seek care in another medical setting, or are misdiagnosed. While there is no

estimate for unreported TBIs in Missouri, some estimate the national figure to be as high as 3 million annually.

Methodology

The research team at the University of Missouri—Kansas City Institute for Human Development (UMKC-IHD) collected survey data from multiple sources to determine the mental and behavioral health needs of Missouri's TBI survivors, their families, and service professionals. The Missouri TBI Survivor and Family Needs Assessment included 49 questions regarding TBI survivors' demographics, perceived needs, satisfaction regarding the services they received/are receiving as well as the barriers they are facing. Links to the online version and paper copies were disseminated throughout the state by support coordinators and service provider organizations.

The Missouri TBI Professional Needs Assessment included 45 questions about professional affiliation, services provided, knowledge, training needs and perception of barriers and gaps in service related to TBI. The web link to the electronic questionnaire was distributed to a wide group of professionals including medical personnel, school nurses, educators, veteran service personnel, vocational rehabilitation staff and a number of general community groups such as first responders and law enforcement personnel.

Key Findings

TBI Survivor and Family Member Needs Assessment Survey

- The majority of individuals with TBI (63.0%) were diagnosed within the first week of injury—51.8% were diagnosed in the same day as the injury.
- There were marked increases in which of the following health conditions TBI survivors experienced from before to after the TBI occurred: cognitive (9.1% vs. 82.6%), physical

(9.8% vs. 63.0%), behavior change (11.2% vs. 60.1%), language (7.2% vs. 54.7%), depression (24.3% vs. 65.9%), and chronic pain (12.3% vs. 54.0%)

- Most respondents reported that the following areas of their lives got worse after their TBI: psychological status (87.2%), income (85.9%), general health (85.3%), employment (83.7%), interpersonal / social (80.8%), marriage (76.2%), education (66.7%), and living situation (59.3%)
- Over half of respondents (54.7%) reported that they want to live in a different place from where they are currently living. Of those, 51.0% wanted to live "independently without assistance" or "in own apartment/home with outside assistance" and about 48% wanted to live with family.
- Over a quarter of respondents (27.5%) identified insufficient financial resources as a barrier to their desired living situation, followed by lack of employment (15.6%) and need help coordinating and planning for services (11.2%).
- When asked, "Did anyone provide you with information or advise you about services available for people with traumatic brain injury?" less than half of the survivors (44.6%) reported that information had been provided.
- Almost 85% of TBI survivors received emergency room care at the time of injury and reported that they were generally satisfied with these services
- Among the 186 people who received hospital admission at the time of injury, about half (58.1%) reported that they received discharge planning services before they left. The average level of satisfaction with the discharge planning service is 3.2, which is between satisfied and very satisfied
- The average satisfactory rating for Medical and Hospital Services was "*Satisfied*".

- The average satisfactory rating for Acute Rehab services was almost "*Very Satisfied*".
- The average satisfactory rating for Community Services and Supports was almost "*Very Satisfied*".
- There is a statistically significant increase in satisfaction level with home health from year 2011 to year 2017.
- There is a statistically significant increase in satisfaction levels with financial management, legal services, and housing assistance from year 2011 to year 2017.
- Over half of the respondents (n=181, 65.6%) reported that they have met professionals providing services related to TBI who need to learn more about TBI.
    - ✓ The most frequently identified professionals who need to learn more about TBI include teachers (76.8%), law enforcement personnel (72.4%), and principals (70.2%).
    - ✓ Most of these respondents (82.3%) indicated that professionals need more general knowledge about TBI. Respondents also indicated that professionals need additional training or information on managing cognitive changes (76.2%), specific knowledge about needs (76.2%), and additional information on available services for TBI (76.2%).

Professional Needs Assessment Survey

- Most professionals reported having either minimal (44.3%) to moderate (41.3%) knowledge of available supports and services for individuals with TBI and their families, whereas fewer than 10% reported having a great deal of knowledge on the subject.
- Over half of respondents (58.3%) served 20 or fewer individuals with TBI in the last five years.

- There was a significant increase in the mean rating of service adequacy from five years ago to today for the following services:
    - ✓ Urgent care
    - ✓ Doctor's office service
    - ✓ Hospital discharge planning
    - ✓ Acute rehab services (inpatient/outpatient rehab, and home health)
    - ✓ Service coordination
    - ✓ Mental health counseling
    - ✓ Information and referral
- Mean service adequacy ratings of respite service are significantly lower in 2017 than 2012.
- Adequacy in discharge planning and continuing education have had a statistically significant increase since 2007.
- Adequacy in inpatient rehab is significantly lower in 2017 than it was 10 years ago.

The findings of this needs assessment are not definitive; they suggest areas to explore in greater depth regarding TBI and survivors' needs for resources and support. The findings could be considered when improving policies and strengthening programs throughout Missouri.

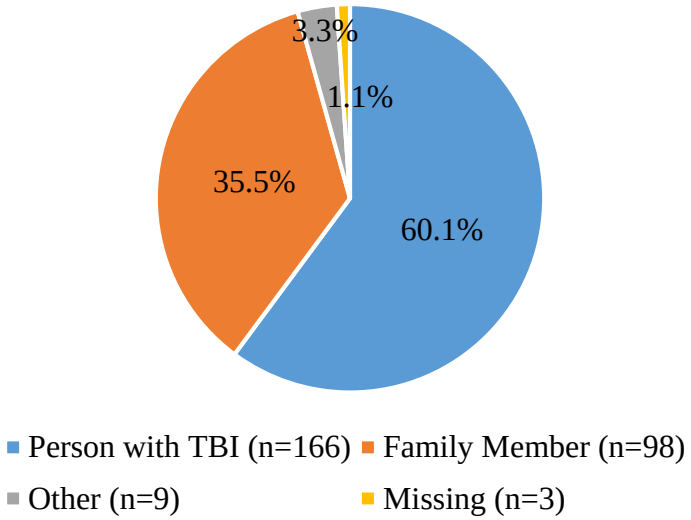
Part I: Survivor and Family Survey Results

The goal of the Missouri TBI Survivor and Family Needs Assessment is to systematically identify needs and measure the gaps between current conditions and desired conditions through participation of TBI survivors and their family members. The survey included 49 questions regarding TBI survivors' demographics, perceived needs, satisfaction regarding the services they received/are receiving as well as the barriers they are facing. This needs assessment survey was distributed to TBI survivors and their family members through a variety of channels, where links to the online version and paper copies were disseminated throughout the state by support coordinators and service provider organizations. The survey was anonymous and took approximately 15 minutes to complete. Respondents had the option to start the survey and stop, and then continue the survey at another time. They could also opt to not complete the survey if they wished.

Demographics

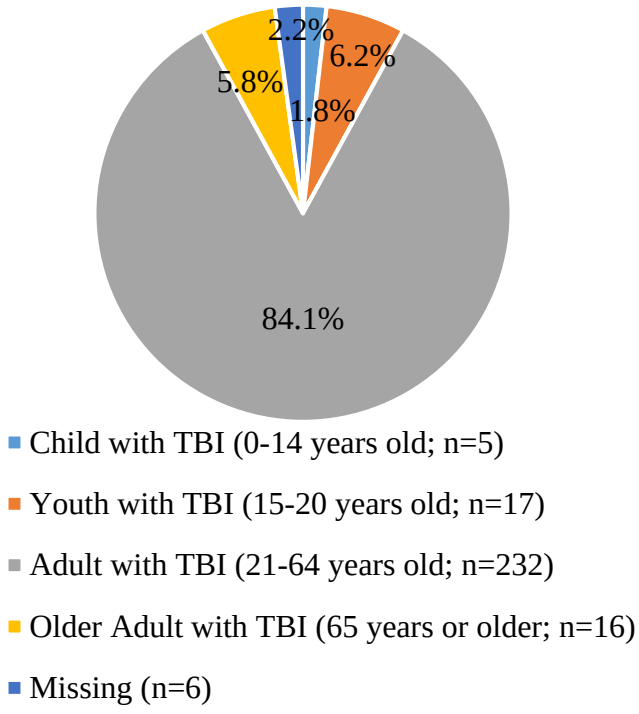
This section displays the demographic profile of the TBI survivor and family survey participants, including age, race, date and severity of injury, zip code, and military affiliation. A total of 276 participants completed the online TBI Survivor and Family Member Survey. Over 60% of respondents identified as a person with a TBI (Figure 1.1).

Figure 1.1. Survey Respondents



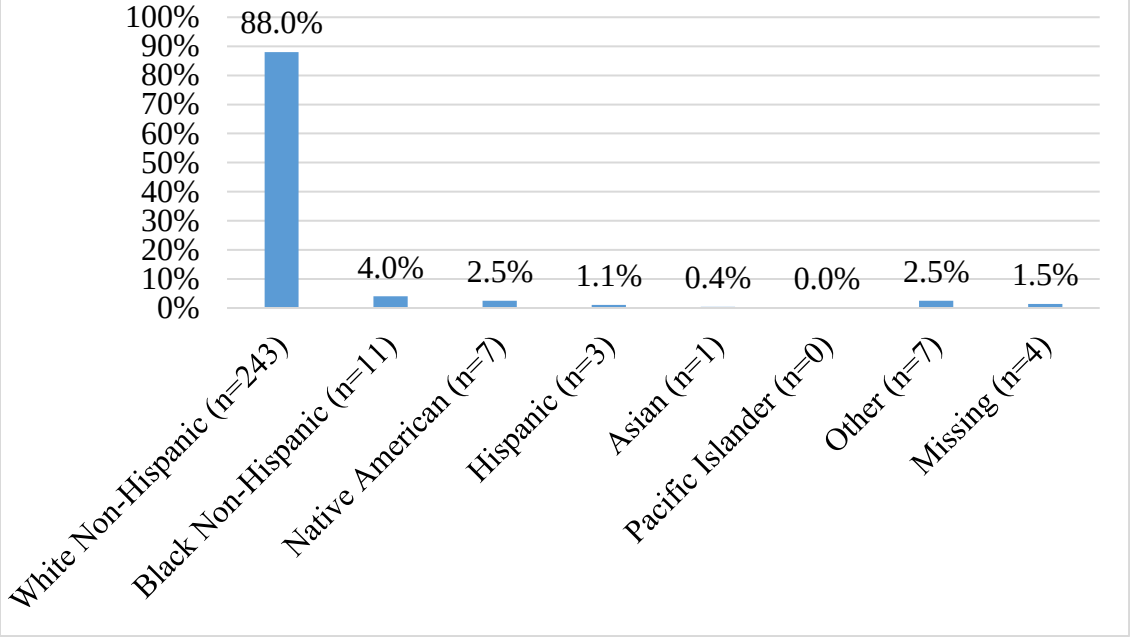
The majority of TBI survivors represented in the survey are between the ages of 21 and 64 years old (84.1%), followed by youth ages 15 to 20 years old (6.2%), older adults with TBI (5.8%), and children with a TBI (2.2%; Figure 1.2).

Figure 1.2. TBI Survivor Age



There were slightly more male than female respondents (57.6% vs. 41.3%, missing=1.1%). The majority of survey respondents identified as white, non-Hispanic (88.0%), followed by black, non-Hispanic (4.0%) and Native American (2.5%; Figure 1.3).

Figure 1.3. TBI Survivor Race / Ethnicity



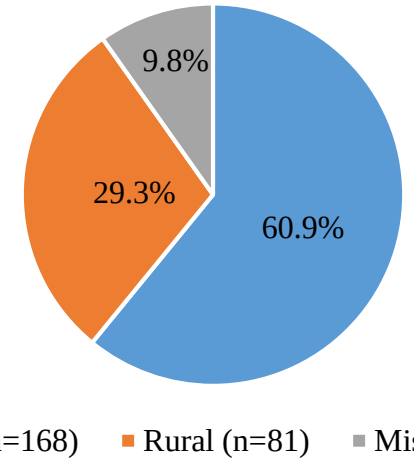
Most of these TBI survivors reported that they were "never a military service member" (85.5%; Table 1.1).

Table 1.1. TBI Survivor Military Service

Military service member	**n**	**%**
Never a military service member	236	85.5
Former military service member	33	12.0
Current military service member	0	0.0
Missing	7	2.5

TBI survivors represented 146 zip codes in 55 Missouri counties. Also, there were six participants from Kansas, four from Illinois, and two from Iowa. Missouri counties were categorized into urban and rural using the Census Bureau criteria that are used by Missouri Information for Community Assessment (MICA). Urban counties are defined as those with a population density over 150 persons per square mile, plus any county that contained at least part of the central city of a Census-defined Metropolitan Statistical Area (MSA). Using this definition, 11 Missouri counties were classified as urban. The remaining 44 counties in Missouri were considered rural. Approximately 61% of TBI survivors reportedly reside in urban areas (Figure 1.4).

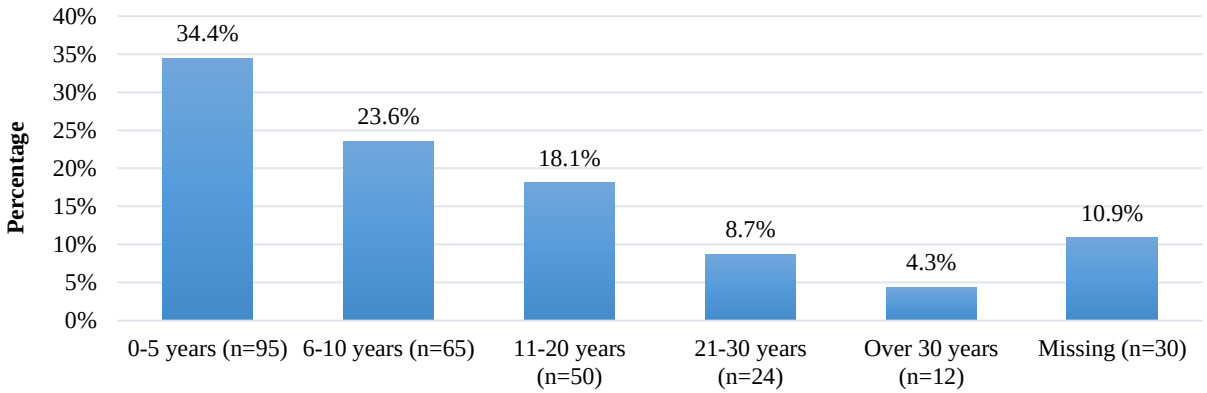
Figure 1.4. TBI Survivor Zip Code Distribution



TBI and Other Health Conditions

Figure 1.5 shows the recency of traumatic brain injuries, which occurred between 1962 and 2017.

Figure 1.5. Time Since Injury

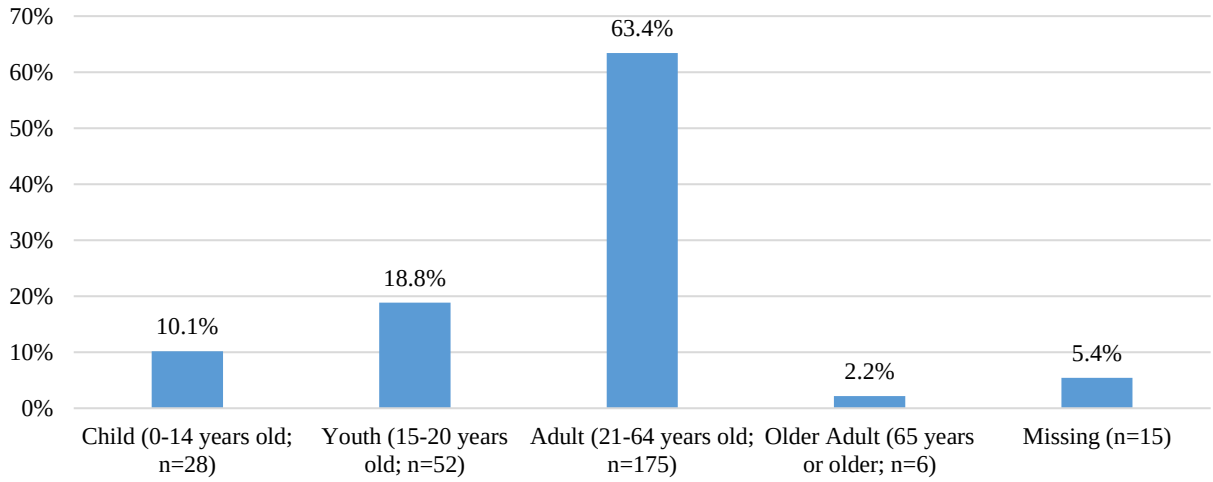


The years were divided into five groups with injuries occurring:

- 0 to 5 years ago
- 6 to 10 years ago
- 11 to 20 years ago
- 21 to 30 years ago
- Over 30 years ago

Over half of the TBI survivors represented in this survey (58.0%) experienced a TBI 10 or fewer years ago. In terms of age, Figure 1.6 shows the approximate age of the TBI survivor at the time of the injury.

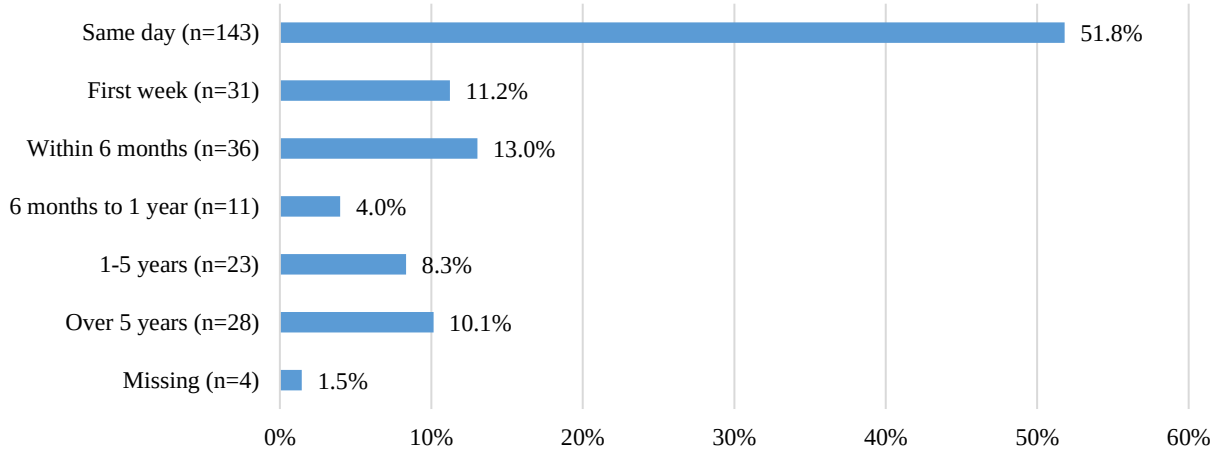
Figure 1.6. Age at the Time of Traumatic Brain Injury



Over half of the survivors reported experiencing the injury in adulthood (63.4%), followed by youth (18.8%), childhood (10.1%), and older adulthood (2.2%).

Figure 1.7 displays about how long after the injury the survivors were diagnosed with TBI.

Figure 1.7. Diagnosed with TBI After Injury



Slightly over half of the TBI survivors (51.8%) reported that they were diagnosed with TBI the same day as the injury. Table 1.2 shows disabilities or significant health conditions that survivors had *before* the TBI as compared to those that developed *after* the TBI.

Table 1.2. TBI Survivors Health Conditions Before and After Injury					
	Before		**After**		
	n	**%**	**n**	**%**	**% Change**
Cognitive	25	9.1%	228	82.6%	73.6%
Physical	27	9.8%	174	63.0%	53.3%
Behavior change	31	11.2%	166	60.1%	48.9%
Language	20	7.2%	151	54.7%	47.5%
Depression	67	24.3%	182	65.9%	41.7%
Chronic pain	34	12.3%	149	54.0%	41.7%
Sensory	26	9.4%	138	50.0%	40.6%
Sleep disorder	36	13.0%	139	50.4%	37.3%
Other mental health	51	18.5%	126	45.7%	27.2%
PTSD	26	9.4%	93	33.7%	24.3%
Seizure disorder	10	3.6%	64	23.2%	19.6%
Diabetes	9	3.3%	18	6.5%	3.3%
Alcohol use abuse	29	10.5%	31	11.2%	0.7%
Drugs use disorder	19	6.9%	21	7.6%	0.7%
Other	22	8.0%	30	10.9%	2.9%

The percentage of TBI survivors experiencing each of the identified health conditions increased from before their TBI occurred to after the TBI. Most notably, there were marked increases in the following health conditions from before to after the TBI occurred: cognitive (9.1% vs. 82.6%), physical (9.8% vs. 63.0%), behavior change (11.2% vs. 60.1%), language (7.2% vs. 54.7%), depression (24.3% vs. 65.9%), and chronic pain (12.3% vs. 54.0%).

Impact of TBI

Respondents were also asked to rate the impact the TBI had on various aspects of their lives by indicating whether each area got better, got worse, or stayed the same. Table 1.3

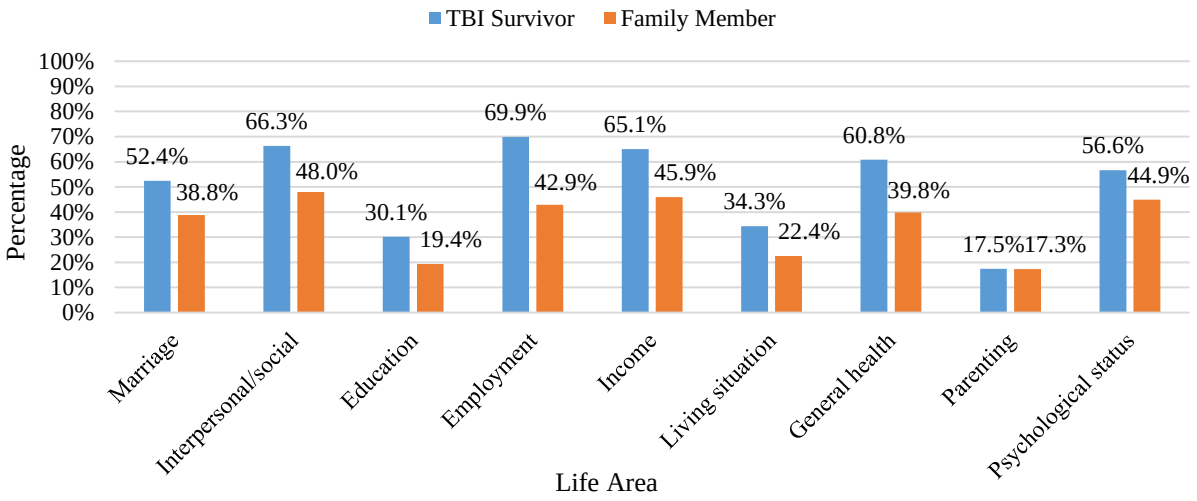
displays the life areas and corresponding responses. Over 80% of respondents reported that the following areas of their life got worse: psychological status (87.2%), income (85.9%), general health (85.3%), employment (83.7%), and interpersonal / social (80.8%).

Table 1.3. Areas of life affected by TBI in percentage

	n (%)	No Change	Better	Worse
Marriage	172 (62.3)	10.5	5.2	76.2
Interpersonal/social	203 (73.6)	6.4	4.4	80.8
Education	108 (39.1)	23.1	5.6	66.7
Employment	196 (71.0)	5.6	2.0	83.7
Income	185 (67.0)	5.4	3.2	85.9
Living situation	140 (50.7)	21.4	8.6	59.3
General health	170 (61.6)	7.1	0.6	85.3
Parenting	98 (35.5)	29.6	4.1	48.0
Psychological status	164 (59.4)	4.3	0.6	87.2

Areas that Got Worse: Figure 1.8 further shows the negative impact of select areas as perceived by TBI survivors and family members. Almost 70% of TBI survivors reported that their employment situation got worse as a results of their TBI, whereas about 43% of family members reported that this area of their life was negatively impacted. Over half of the TBI survivors also reported that their interpersonal/social life (66.3%), income (65.1%), health (60.8%), psychological status (56.6%), and marriage (52.4%) got worse as a result of their TBI.

Figure 1.8. Negative Impact of TBI on Survivors and Families

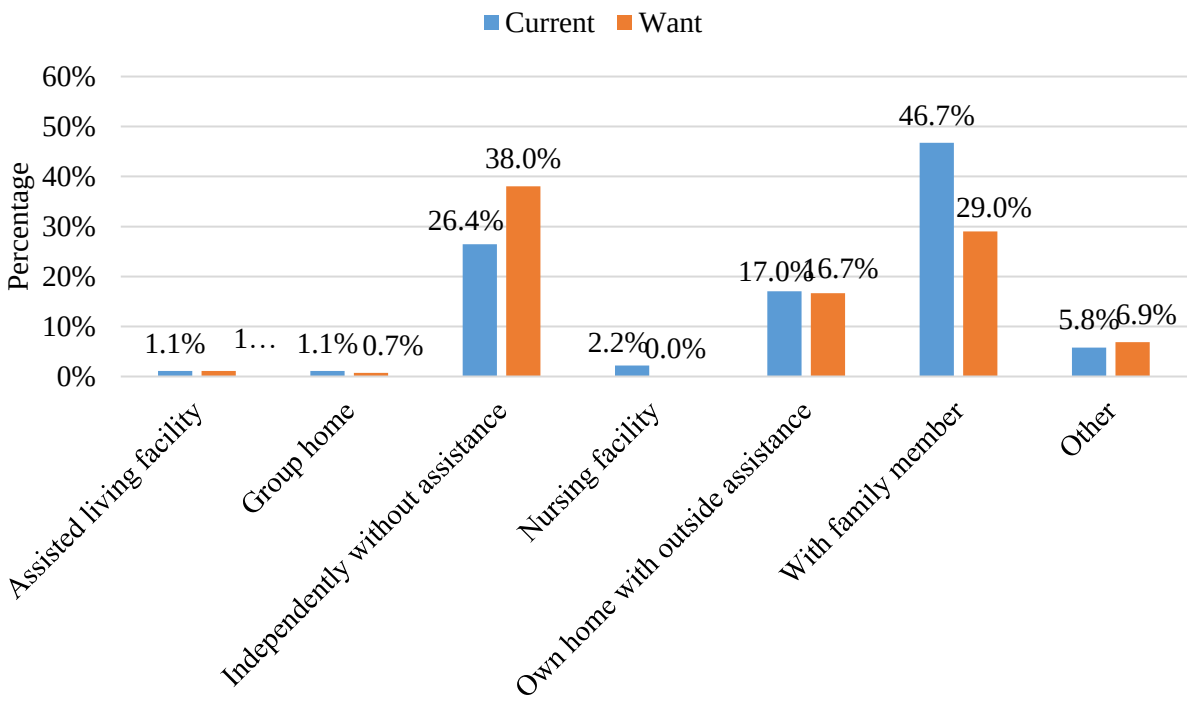


Data were collected about the living situation of TBI survivors in order to assess how to better support people to live in the setting of their choice. Specifically, this data includes information on where survivors currently live, where they would like to live, and any barriers they face regarding their living situation. Table 1.4 and Figure 1.9 display information on where TBI survivors are currently living versus where they would like to be living.

Table 1.4. Frequency of living situations

Living Options	Currently Living		Desired Living	
	n	%	n	%
Assisted living facility	3	1.1	3	1.1
Group home	3	1.1	2	0.7
Independently without assistance	73	26.4	105	38.0
Nursing facility	6	2.2	0	0.0
Own home with outside assistance	47	17.0	46	16.7
With family member	130	47.1	80	29.0
Other	16	5.8	19	6.9

Figure 1.9. Living Situation Affected by TBI

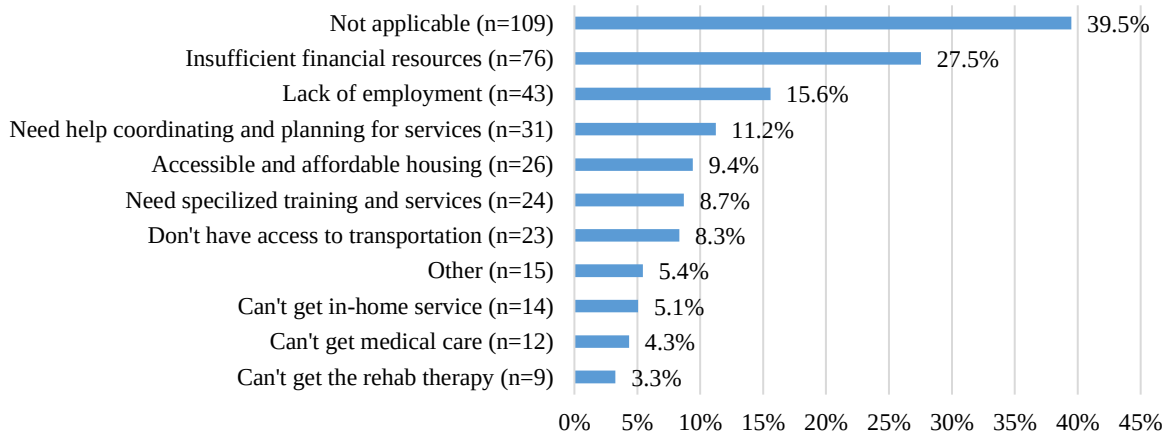


Among the 276 responses, 151 (54.7%) wanted to live in a different place from where they are currently living, 89 (32.3%) were living where they want to live, and 36 (13.0%) did not indicate where they want to live specifically or skipped this question. Among those who were not living where they want to live (*n*=151), the majority (51.0%) were currently living with family, while almost 40% are living independently with no assistance.

When asked where the survivor of TBI would live if they had the choice, "independently with no assistance" and "in own apartment/home with outside assistance" together make up approximately 51.0% (*n*=77) of these responses, and about 48% would like to live with family members. Participants were also asked why they were not living where they want to; Figure 1.10 shows these barriers or challenges reported by respondents. Over a quarter of respondents (27.5%) identified insufficient financial resources as a barrier to their desired living situation,

followed by lack of employment (15.6%) and need help coordinating and planning for services (11.2%).

Figure 1.10. Barriers to Desired Living Situations



Among the six identified TBI survivors who are currently living in a nursing facility (shown in Table 1.4), two have been living there for over five years, and half moved from home to nursing facility. The reasons given for admission to the nursing facility include:

- Behavior issues (*n*=2)
- Couldn’t get in-home services (*n*=2)
- Couldn’t get the medical care I need (*n*=1)
- Lack of needed specialized training and services (*n*=1)
- Special care (e.g. was in a coma, needed to learn to walk) (*n*=1)

Three of the six respondents living in a nursing facility would like to return to the community. The barriers they identified that are preventing them from moving include:

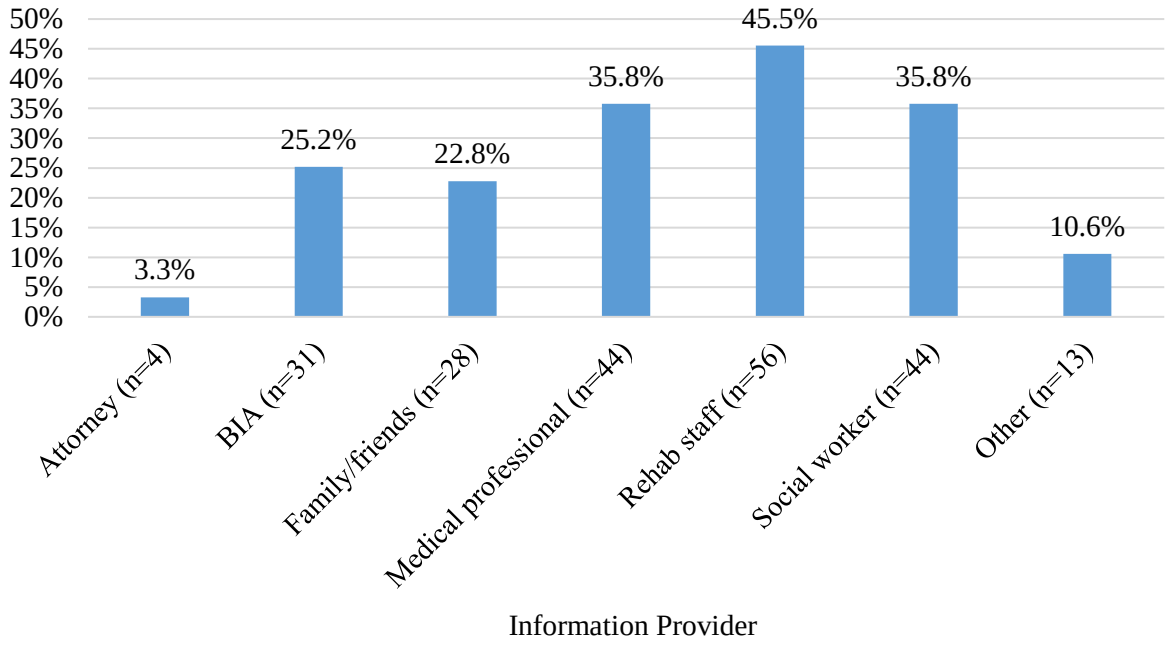
- Lack of access to transportation (*n*=3)
- Lack of help coordinating and planning for services (*n*=3)
- Insufficient financial resources (*n*=2)

- Lack of access to accessible and affordable housing (*n*=2)
- Lack of employment (*n*=2)
- Lack of needed specialized training and services (*n*=2)

Services and Supports

Respondents were asked, "Did anyone provide you with information or advise you about services available for people with traumatic brain injury?" Less than half of the survivors (44.6%) reported that information had been provided. For those who were provided information (n=123), about half (55.3%) reported that the information was provided before leaving the hospital or doctor's office. Figure 1.11 shows the roles of the person who provided information. Almost 46% or respondents reported that information on TBI was provided by rehabilitation staff, followed by social worker (35.8%), medical professional (35.8%), and the Brain Injury Association (BIA; 25.2%).

Figure 1.11. Roles of Person Provided Information (n = 123)



The survey participants were asked to identify the services they are currently receiving, those they received in the past, the services they needed but did not receive, and those they felt they did not need. The service areas addressed include:

- Medical and hospital services (e.g. emergency room, doctors office, and hospital)
- Acute rehabilitation services (e.g. inpatient/outpatient rehabilitation, and home health services)
- Community services (e.g. housing, employment, recreation, and counseling)

Medical and hospital services. TBI survivors and their family members were also asked about the medical and hospital services the survivors received at the time of injury. For each service they received, respondents were asked to rate their satisfaction level:

- 1 = Very Dissatisfied
- 2 = Dissatisfied
- 3 = Satisfied
- 4 = Very Satisfied

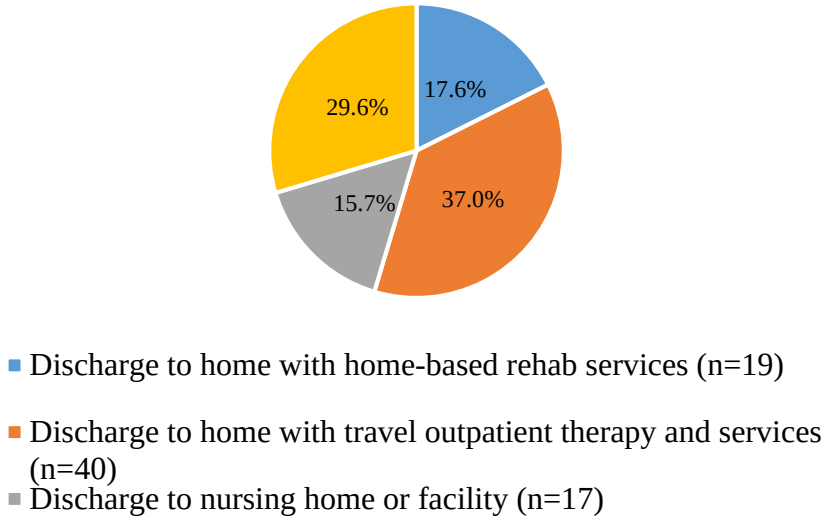
Table 1.5 shows the number of TBI survivors who received each medical service and the average satisfaction rating with each service. Almost 85% of TBI survivors received emergency room care at the time of injury and reported that they were generally satisfied with these services (*M*=3.0, *SD*=1.1)

Table 1.5. Satisfaction with medical and hospital services received

	n	**%**	**Mean**	**SD**
Emergency room care	234	84.8	3.0	1.1
Hospital admission	186	67.4	3.2	1.0
Doctor's office service	70	25.4	2.9	1.2
Urgent Care/walk-in services	37	13.4	3.1	1.1

Among the 186 people who received hospital admission at the time of injury, about half (58.1%) reported that they received discharge planning services before they left. Figure 1.12

Figure 1.12. Type of Discharge Plans (n = 108)



shows the type of discharge plans, where about 37% of respondents were discharged to home with travel outpatient therapy and services and 30% were discharged to a residential brain injury rehabilitation program. The average level of satisfaction with the discharge planning service is 3.2, which is between satisfied and very satisfied.

Acute rehabilitation and community services. Participants were also asked about community-based services received after the injury. For each service, they indicated whether they were currently receiving it, received it in the past, needed but did not receive it, or did not need it. The types of services received, currently or in the past, are presented in Table 1.6. Table 1.7 shows only those who are currently receiving services or have received services in the past and indicates the respondents rating of these services. For each service they received, respondents were asked to rate their satisfaction level:

- 1 = Very Dissatisfied

- 2 = Dissatisfied
- 3 = Satisfied
- 4 = Very Satisfied

Over half of respondents reported that they received outpatient (60.1%) and inpatient (53.6%) rehabilitation services, with mean satisfaction ratings of 3.78 and 3.99, respectively.

Table 1.6. Types of Services Received								
	Currently receiving services		**Received in the past**		**Needed but did not receive**		**Did not need**	
Acute Rehabilitation Services								
Inpatient rehab	7	2.5%	141	51.1%	50	18.1%	53	19.2%
Home health	21	7.6%	46	16.7%	55	19.9%	113	40.9%
Outpatient rehab	39	14.1%	127	46.0%	50	18.1%	33	12.0%
Community Services and Supports								
Employment services	27	9.8%	60	21.7%	57	20.7%	96	34.8%
In-home services	40	14.5%	30	10.9%	46	16.7%	131	47.5%
Transportation	21	7.6%	27	9.8%	54	19.6%	142	51.4%
Service coordination	80	29.0%	38	13.8%	68	24.6%	66	23.9%
Treatment for substance use disorder	4	1.4%	24	8.7%	16	5.8%	205	74.3%
Mental health counseling	72	26.1%	69	25.0%	45	16.3%	67	24.3%
Use of assistive technology	35	12.7%	46	16.7%	18	6.5%	151	54.7%
Respite	9	3.3%	11	4.0%	28	10.1%	193	69.9%
TBI support groups	67	24.3%	50	18.1%	79	28.6%	52	18.8%
Assistance with financial management	31	11.2%	22	8.0%	80	29.0%	113	40.9%
Recreation services	18	6.5%	25	9.1%	85	30.8%	110	39.9%
Legal services	18	6.5%	43	15.6%	63	22.8%	120	43.5%
Section 8 or other housing assistance	17	6.2%	12	4.3%	41	14.9%	173	62.7%

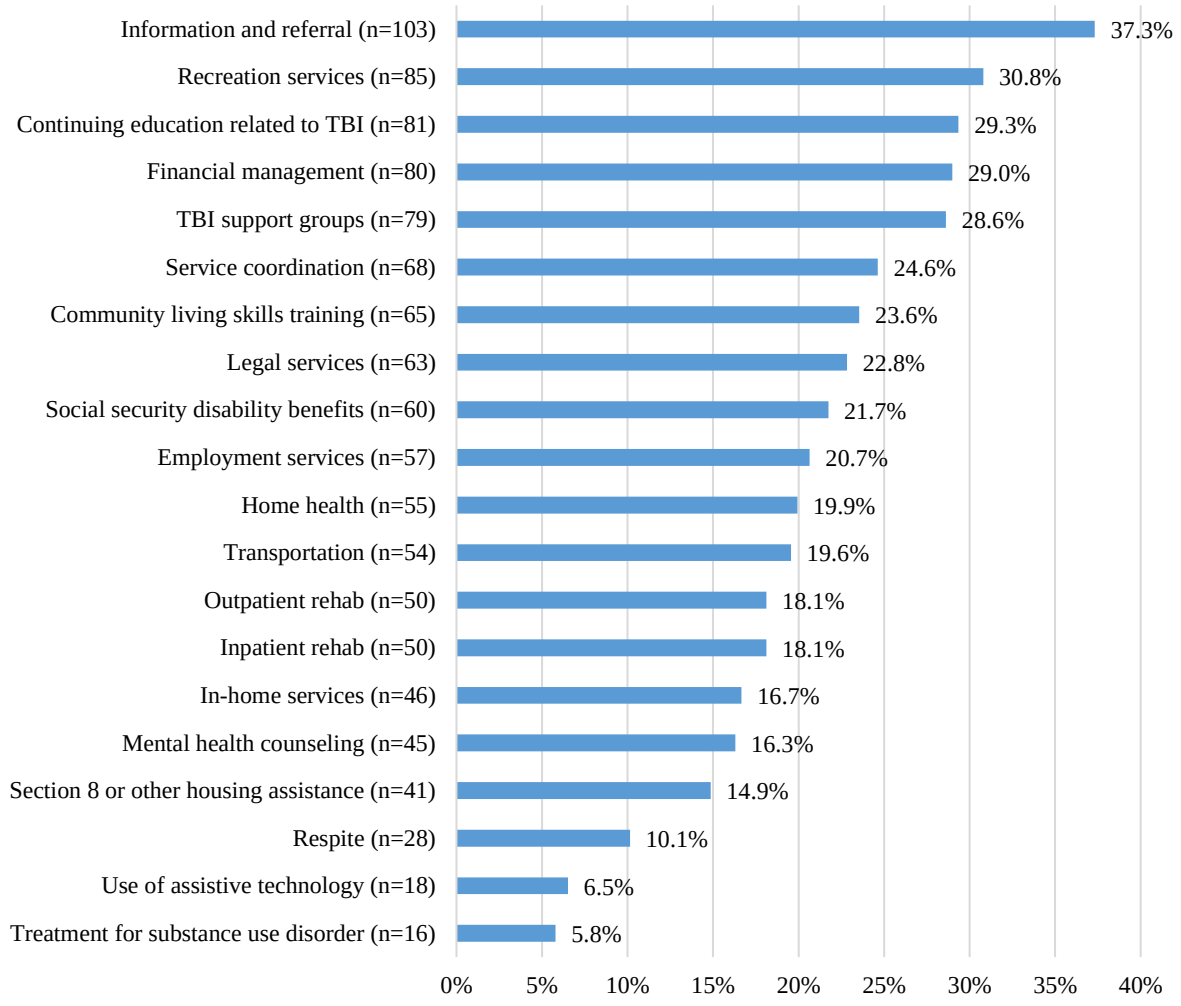
Table 1.6. Types of Services Received								
	Currently receiving services		**Received in the past**		**Needed but did not receive**		**Did not need**	
Assistance applying for social security disability benefits	41	14.9%	65	23.6%	60	21.7%	82	29.7%
Continuing education related to TBI	49	17.8%	48	17.4%	81	29.3%	70	25.4%
Community living skills training	21	7.6%	33	12.0%	65	23.6%	122	44.2%
Information and referral	48	17.4%	51	18.5%	103	37.3%	42	15.2%

Table 1.7. Ratings of Services Received				
	Currently Receiving or Received in the Past		**Mean**	**SD**
Acute Rehabilitation Services				
Inpatient rehab	148	53.6%	3.99	1.2
Home health	67	24.3%	3.47	1.2
Outpatient rehab	166	60.1%	3.78	1.2
Community Services and Supports				
Employment services	87	31.5%	3.38	1.1
In-home services	70	25.4%	3.69	1.1
Transportation	48	17.4%	3.75	1.1
Service coordination	118	42.8%	3.91	1.2
Treatment for substance use disorder	28	10.1%	3.38	1.1
Mental health counseling	141	51.1%	3.65	1.2
Use of assistive technology	81	29.3%	3.69	1.2
Respite	20	7.2%	3.84	1.3
TBI support groups	117	42.4%	3.82	1.2
Assistance with financial management	53	19.2%	3.38	1.2
Recreation services	43	15.6%	4.00	1.4
Legal services	61	22.1%	3.79	1.2
Section 8 or other housing assistance	29	10.5%	3.57	1.2
Assistance applying for Soc. Sec. disability benefits	106	38.4%	3.83	1.2
Continuing education related to TBI	97	35.1%	3.58	1.2
Community living skills training	54	19.6%	3.70	1.2
Information and referral	99	35.9%	3.74	1.2

Figure 1.13 shows the acute rehabilitation and community services that respondents reported as “needed but not received.” The greatest reported need is for information and referral

(37.3%), followed by recreation services (30.8%), continuing education related to TBI (29.3%), and financial management (29.0%).

Figure 1.13. Services Needed but not Received (n = 276)



Service satisfaction comparison: 2011 vs. 2017. Figures 1.14-1.16 shows a comparison of service satisfaction ratings from the 2011 needs assessment and service satisfaction ratings in 2017. Table 1.8 indicates the statistical significance of the differences in service satisfaction ratings from 2011 to 2017. Satisfaction ratings of urgent care/walk-in services and discharge plan services slightly increase from 2011 to 2017, though these differences are not statistically significant (Figure 1.14). Satisfaction ratings for emergency room care, doctor's office services,

and hospital admission services slightly decreased from 2011 to 2017, though these differences are not statistically significant (Figure 1.14). Satisfaction ratings for the three acute rehabilitation services are higher in 2017 than in 2011, however only the ratings difference for home health services ratings is statistically significant (Figure 1.15). Similarly, satisfaction ratings for the 17 community services are higher in 2017 than in 2011, however only the ratings difference for financial management services, legal services, and section 8/housing assistance services ratings is statistically significant (Figure 1.16).

Figure 1.14. Medical Service Satisfactory Level across Years

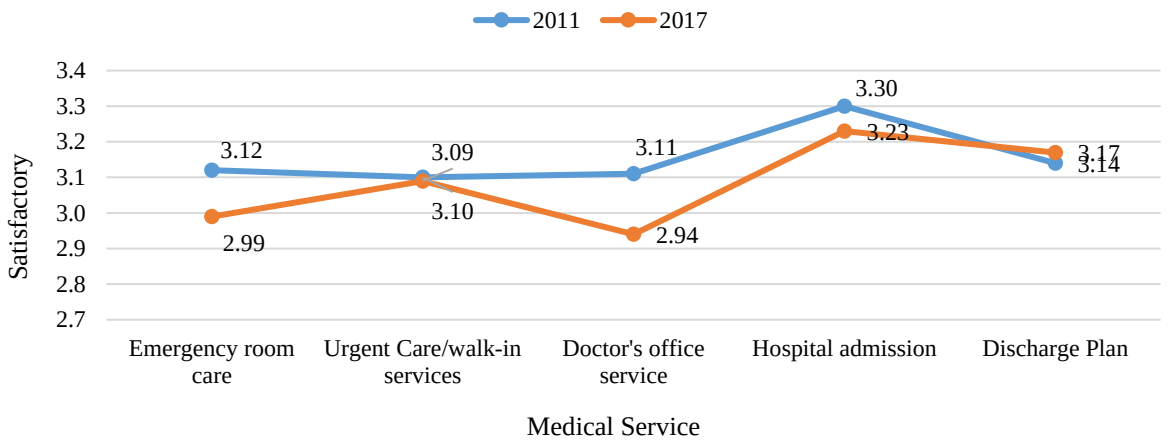


Figure 1.15. Acute Rehabilitation Service Satisfactory Level across Years

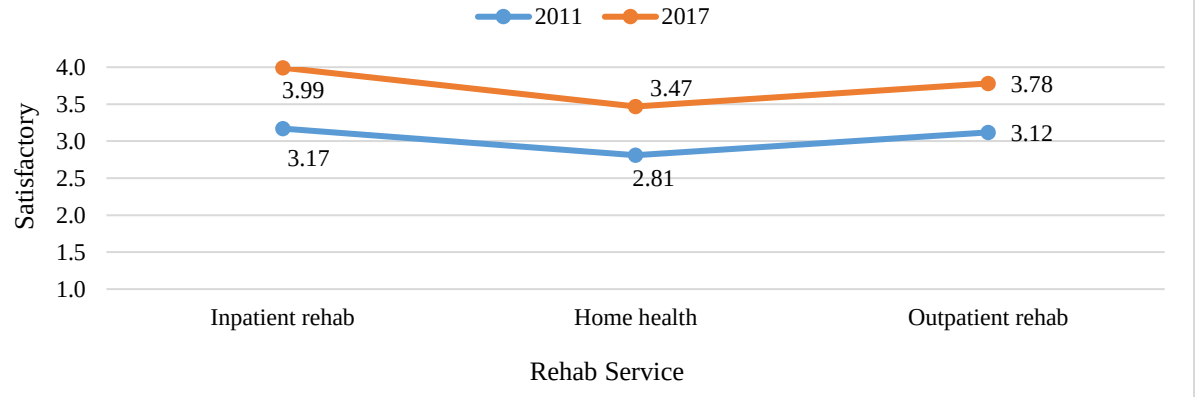


Figure 1.16. Community Service Satisfactory Level across Years

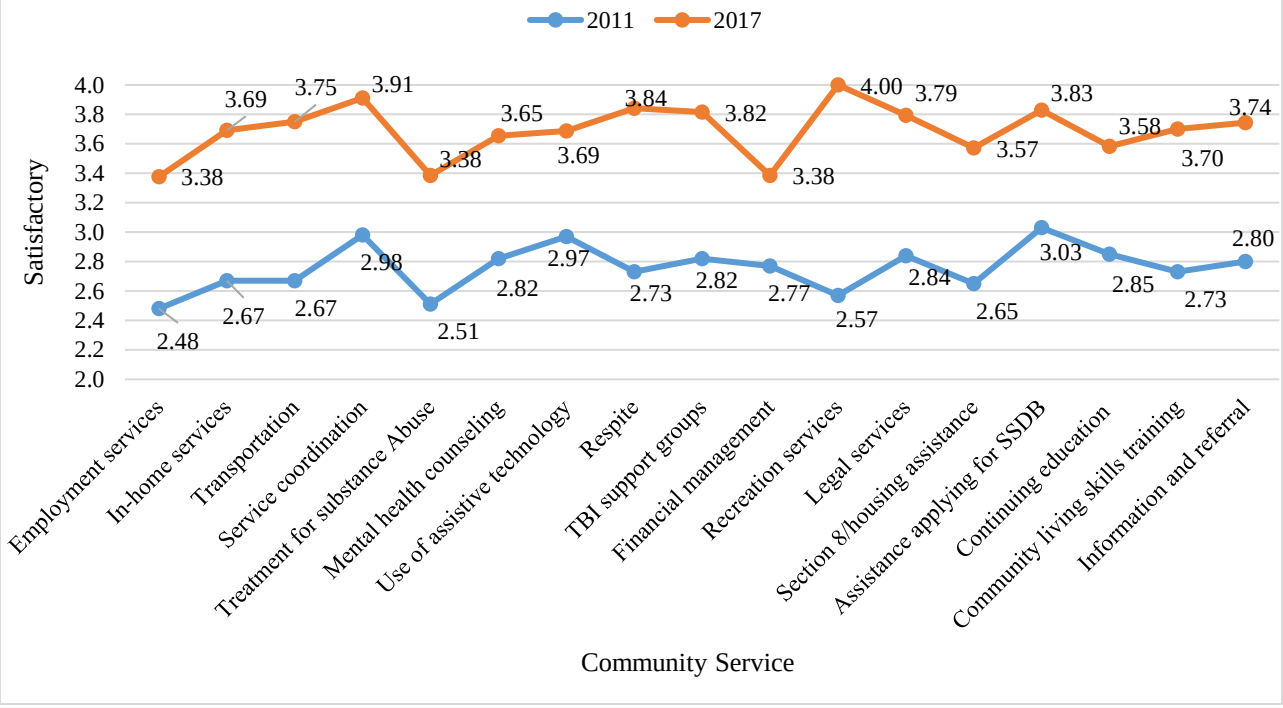


Table 1.8. Year comparison in services

	2011		2017		2017-2011
	n	**Mean**	**n**	**Mean**	**Mean Difference**
Medical/Hospital Services					
Emergency room care	219	3.12	221	2.99	-0.13
Urgent Care/walk-in services	52	3.10	34	3.09	-0.01
Doctor's office service	85	3.11	66	2.94	-0.17
Hospital admission	198	3.30	178	3.23	-0.07
Discharge Plan	160	3.14	109	3.17	0.03
Acute Rehabilitation Services					
Inpatient rehab	190	3.17	142	3.99	0.82
Home health	91	2.81	64	3.47	0.66*
Outpatient rehab	191	3.12	136	3.78	0.66

Table 1.8. Year comparison in services					
	2011		2017		2017-2011
	n	Mean	n	Mean	Mean Difference
Community Services and Supports					
Employment services	128	2.48	85	3.38	0.90
In-home services	80	2.67	68	3.69	1.02
Transportation	100	2.67	44	3.75	1.08
Service coordination	163	2.98	112	3.91	0.93
Treatment for substance Abuse	43	2.51	26	3.38	0.87
Mental health counseling	146	2.82	136	3.65	0.83
Use of assistive technology	96	2.97	77	3.69	0.72
Respite	34	2.73	19	3.84	1.11
TBI support groups	128	2.82	114	3.82	1.00
Financial management	73	2.77	52	3.38	0.61*
Recreation services	68	2.57	2	4.00	1.43
Legal services	76	2.84	58	3.79	0.95*
Section 8/housing assistance	46	2.65	28	3.57	0.92*
Assistance applying for SSDB	126	3.03	99	3.83	0.80
Continuing education	102	2.85	89	3.58	0.73
Community living skills training	85	2.73	50	3.70	0.97
Information and referral	120	2.80	90	3.74	0.94
*p <.05					

Hypothesis Testing – Do participants' characteristics affect their responses?

Hypothesis testing was conducted to assess whether satisfaction ratings differ by respondents' characteristics. One-way Analysis of Variance (ANOVA) indicated that satisfaction ratings provided by respondents do not differ by age, gender, race, region (rural or urban), or

length of time in TBI. However, satisfaction ratings do differ by who completed the survey and the age at the time of injury.

Do satisfaction ratings differ by who completed the survey (Survivor vs. Family)? Yes. The *Levene's F* test revealed that the homogeneity of variance assumption was met (p = .32; Table 1.9). The one-way ANOVA indicated a statistically significant (at a .05 significant level) group difference, $F(2, 86) = 4.20$, p = .02. In other words, TBI survivors rated their satisfaction with information and referral services significantly higher than family respondents (M=4.0 vs. M=3.3).

Table 1.9. Ratings to services by who completed the survey

	Survivor		Family		Mean Difference
	n	**Mean**	**n**	**Mean**	
Info & Referral	58	4.0	30	3.3	0.7*

*p <.05

Do satisfaction ratings differ by the age at the time of injury (Child, Youth, Adult, and Older Adult)? Yes. The *Levene's* F test revealed that the homogeneity of variance assumption was met (p = .56; Table 1.10). The one-way ANOVA indicated a statistically significant (at a .05 significant level) group difference, F(3, 207) = 3.02, p = .03. In other words, respondents representing youth ages 0 to 14 rated their satisfaction with emergency room care significantly higher than adults ages 21 to 64 (M=3.4 vs. M=2.8).

Table 1.10. Ratings to services by age at the time of injury

	Youth (0-14 years)		Adult (21-64 years)		Mean Difference
	n	**Mean**	**n**	**Mean**	
ER Care	46	3.4	138	2.8	0.5*

*p <.05

Additional Needs

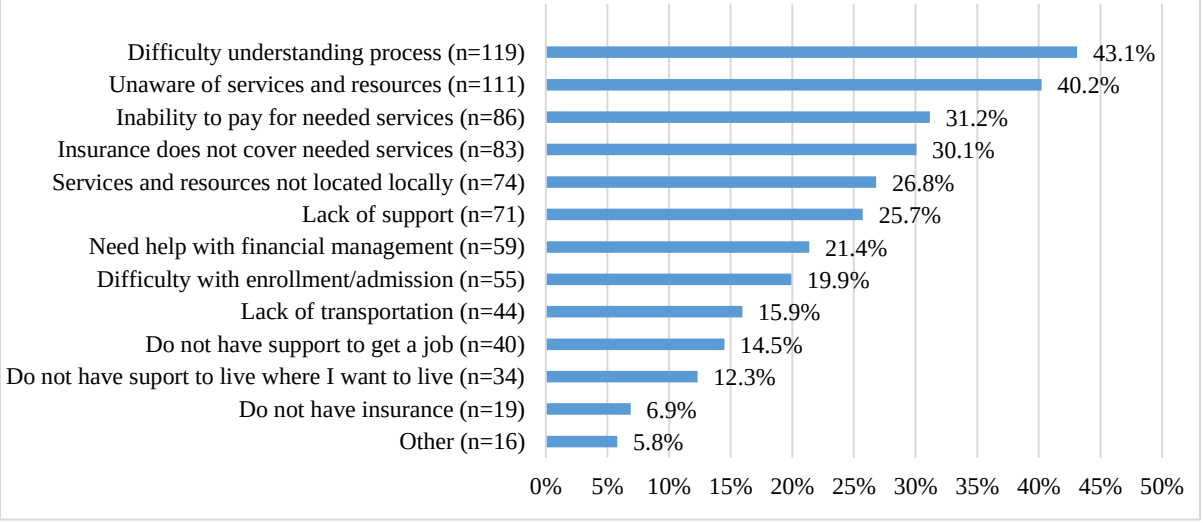
To further explore issues that may not have been covered in the needs assessment survey, respondents were asked, “Do you have any other comments about services that you need or that you have had trouble getting?” There were 130 responses to this question, and the key issues identified by respondents are listed as below:

- Support and service in more life aspects (*n* = 20)
- Insurance coverage/waiver and financial issues (*n* = 17)
- Proper medical care, timely rehab, and long-term therapy (*n* = 14)
- Resources and referral about TBI (*n* = 11)
- Timely TBI diagnosis or identification (*n* = 11)
- Housing (*n* = 5)
- Transportation (*n* = 3)

Barriers

Figure 1.17 displays the problems participants reported having in getting the services they need related to TBI. Respondents were given a list of response options, the most common response was difficulty understanding the process (43.1%), followed by being unaware of available services and resources (40.2%), and inability to pay for needed services (31.2%).

Figure 1.17. Problems in Getting the Services Needed



Services working well

When asked what services and supports respondents think work well for people with TBI and their families in MO, 145 (52.5%) provided comments. The services that are most frequently reported as working well are listed below:

- TBI support groups (*n* = 14)
- Medical care, respite, other support (*n* = 13)
- Service Coordination/case management (*n* = 13)
- Vocational rehab, other rehab (n = 13)
- BIA and facility resources (*n* = 9)
- Service in general (n = 7)
- Education on TBI (*n* = 6)
- Independent living, housing (*n* = 5)
- Therapy (e.g. speech, behavior) (*n* = 5)

Improvement for Professionals

Respondents were asked a series of questions regarding the knowledge and capacity of professionals who provided services related to TBI. Over half of the respondents (n=181, 65.6%) reported that they have met professionals providing services related to TBI who need to learn more about TBI. Table 1.11 displays the medical/hospital personnel, community service providers and professionals, educator/school personnel, and rehabilitation personnel identified by respondents as those needing to learn more about TBI. The most frequently identified professionals who need to learn more about TBI include teachers (76.8%), law enforcement personnel (72.4%), and principals (70.2%).

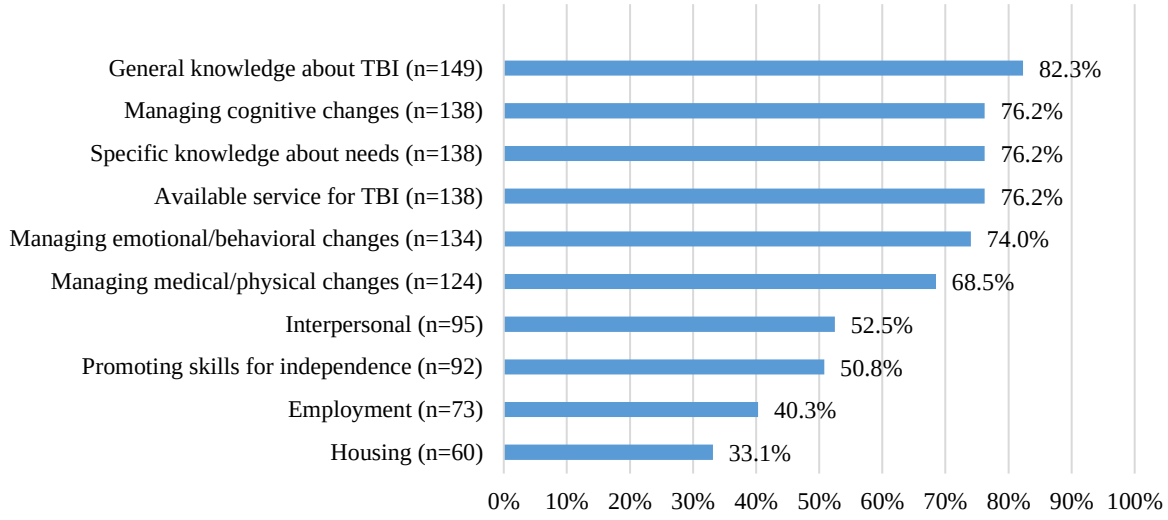
Table 1.11. Frequency of professionals needing to learn more about TBI (*n*=181)

	n	**%**
Medical/Hospital Personnel		
Family medical provider	99	54.7
Emergency room medical provider	85	47.0
Nurse	81	44.8
Discharge planner	79	43.6
Psychologists/neuropsychologists	77	42.5
Other	29	16.0
Community Service Providers & Professionals		
Law enforcement personnel	131	72.4
Social worker	117	64.6
Mental health professional	111	61.3
Vocational rehab personnel	103	56.9
Attorney	97	53.6
First responders	96	53.0
In home care provider	93	51.4

Table 1.11. Frequency of professionals needing to learn more about TBI (*n*=181)		
	n	**%**
Adult brain injury program provider	86	47.5
Other	35	19.3
Educator/School Personnel		
Teacher	139	76.8
Principal	127	70.2
School nurse	121	66.9
Coach	118	65.2
Other	31	17.1
Rehabilitation Personnel		
Administrator	113	62.4
Physical therapist	107	59.1
Occupational therapist	104	57.5
Speech therapist	95	52.5
Other	16	8.8

In addition to identifying professionals, survey respondents were asked what additional training or information professionals needed to improve their capacity to serve individuals with TBI. Figure 1.18 shows that most respondents (82.3%) indicated that professionals need more general knowledge about TBI. Respondents also indicated that professionals need additional training or information on managing cognitive changes (76.2%), specific knowledge about needs (76.2%), and additional information on available services for TBI (76.2%).

Figure 1.18. Areas of Improvement for Professionals (n = 276)



Improvement to statewide services

Respondents were asked "what do you feel needs to be done to improve statewide services and supports for people with TBI and their families?" There were 161 respondents (58.3%) who provided feedback. Responses were categorized as follows:

- TBI education to general public, medical professionals, and service providers (*n* = 45)
- TBI support (e.g. in-home respite, support groups, people first support) (*n* = 26)
- Easy access to resources and TBI programs (*n* = 13)
- Funding (e.g. no funding cut) (*n* = 11)
- Medical care, rehab, and therapy (*n* = 8)
- Timely service (e.g. diagnosis, referral, support) (*n* = 6)
- TBI case management or social worker (*n* = 5)
- Employment opportunity (*n* = 4)
- Financial issues (*n* = 4)
- Housing and independent living (*n* = 4)

Part II: Professional Survey Results

The goal of the Missouri TBI Professional Needs Assessment was to systematically identify needs and measure the gaps between current conditions and desired conditions through participation of professionals who may provide supports and services to survivors of TBI. This survey questionnaire included 45 questions regarding professional affiliation, services provided, knowledge, training needs and perception of barriers and gaps in service. The web link to the electronic questionnaire was distributed to a wide group of professionals including medical personnel, school nurses, educators, veteran service personnel, vocational rehabilitation staff and a number of general community groups such as first responders and law enforcement personnel. The survey was anonymous and took approximately 15 minutes to complete. Respondents had the option to start the survey and stop, and then continue the survey at another time. They could also opt to not complete the survey if they wished.

Profile of Professionals

The valid sample size for the professional needs assessment survey is 1,070, after removing duplicate responses. Figure 2.1 displays the professional role or position of survey respondents. Table 2.1 elaborates on these roles. Almost 40% of respondents identified as medical personnel, followed by educator (25.5%) and rehabilitation personnel (23.2%; Figure 2.1). Notably, most educators/school personnel identified as school nurses (82.4%; Table 2.1).

Figure 2.1. Professional Role

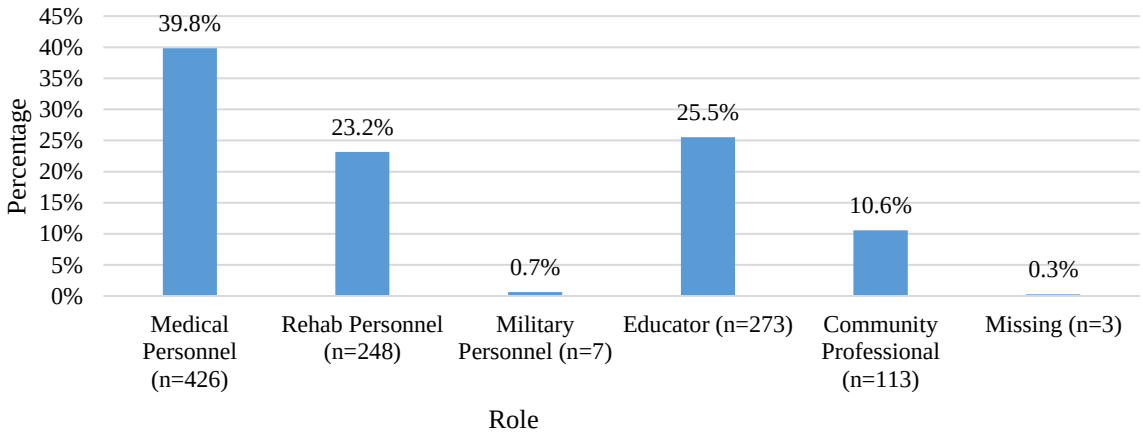


Table 2.1. The profile of professional affiliation

	n	%
Medical/Hospital Personnel (n = 425)		
Other physician	126	29.6
Nurse	116	27.3
Primary care physician	56	13.2
Other	39	9.2
Emergency room physician	33	7.8
Physician assistant	22	5.2
Advanced nurse practitioner	11	2.6
Psychologist	11	2.6
Licensed athletic trainer	8	1.9
Discharge planner	2	0.5
Nurse practitioner	1	0.2
Rehabilitation Personnel (n = 248)		
Occupational therapist	72	29.0
Physical therapist	71	28.6
Speech therapist	67	27.0
Other	26	10.5
Administrator	12	4.8

Military Service Personnel (n = 7)		
Educator/School Personnel (n = 273)		
School nurse	225	82.4
Other	35	12.8
Teacher	6	2.2
Administrator	5	1.8
Coach/director	2	0.7
Community Service Providers & Professionals (n = 113)		
Other advocate	35	31.0
Social worker	21	18.6
Adult brain injury program provider	16	14.2
Vocational rehab personnel	15	13.3
Caseworker	12	10.6
Mental health professional	9	8.0
Department of corrections personnel	2	1.8
In home care provider	2	1.8
Attorney	1	0.9
First responder	0	0.0
Law enforcement personnel	0	0.0
Youth club coach	0	0.0
Note. Percentages were calculated with missing responses excluded		

Respondents were asked how long they have been in their current position. The average length of time is 9.7 years, with a range from 1 month to 48 years. Most professionals reported that they serve others in addition to people with TBI (94.5%) versus serving only people with TBI (2.4%; missing = 3.1%). The estimated number of individuals with TBI professionals reported serving in the last five years (2011 to 2017) is shown in Figure 2.2. Over half of respondents (58.3%) served 20 or fewer individuals with TBI in the last five years.

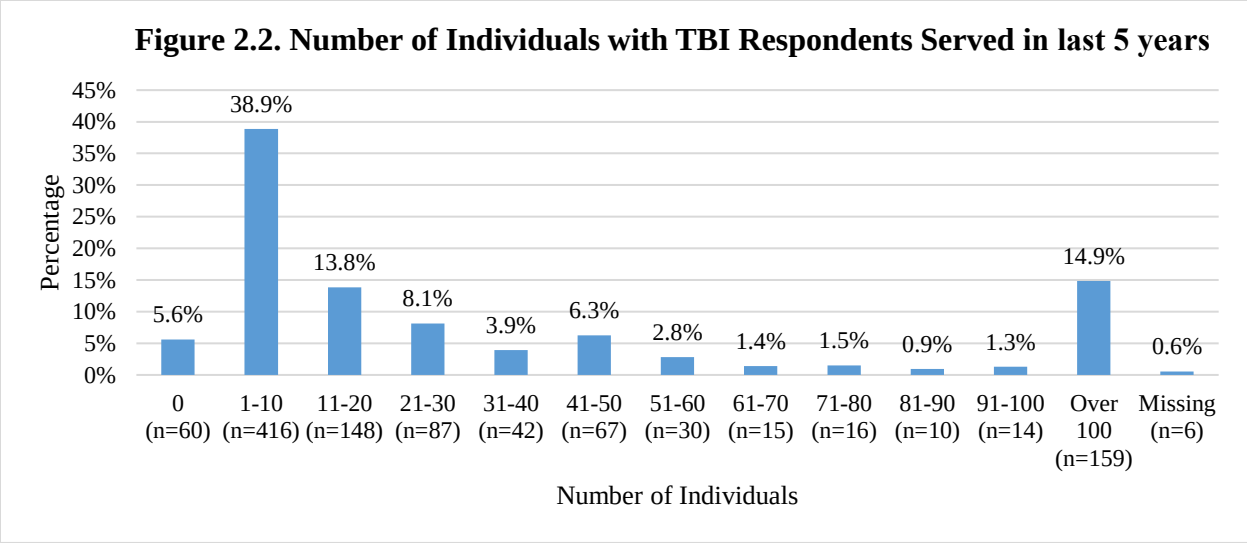
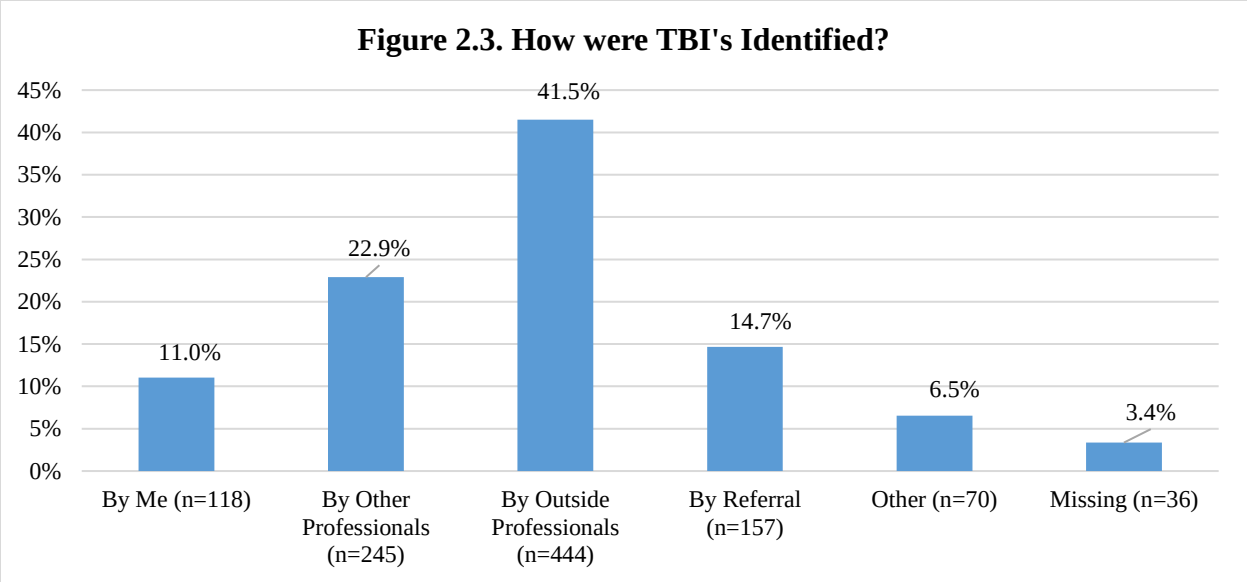


Figure 2.3 shows that almost 42% of TBIs were identified by outside professionals, followed by other professional within the organization (22.9%), and by referral sources (14.7%).



Professional were also asked to rate their knowledge of available services and supports for individuals with TBI and their families, given the following response options: a great deal of knowledge, moderate knowledge, minimal knowledge, and no knowledge. Figure 2.4 shows that most professionals reported having minimal (44.3%) to moderate (41.3%) knowledge of

available supports and services, whereas fewer than 10% reported having a great deal of knowledge on the subject.

Figure 2.4. Knowledge Rating of Available Services and Supports

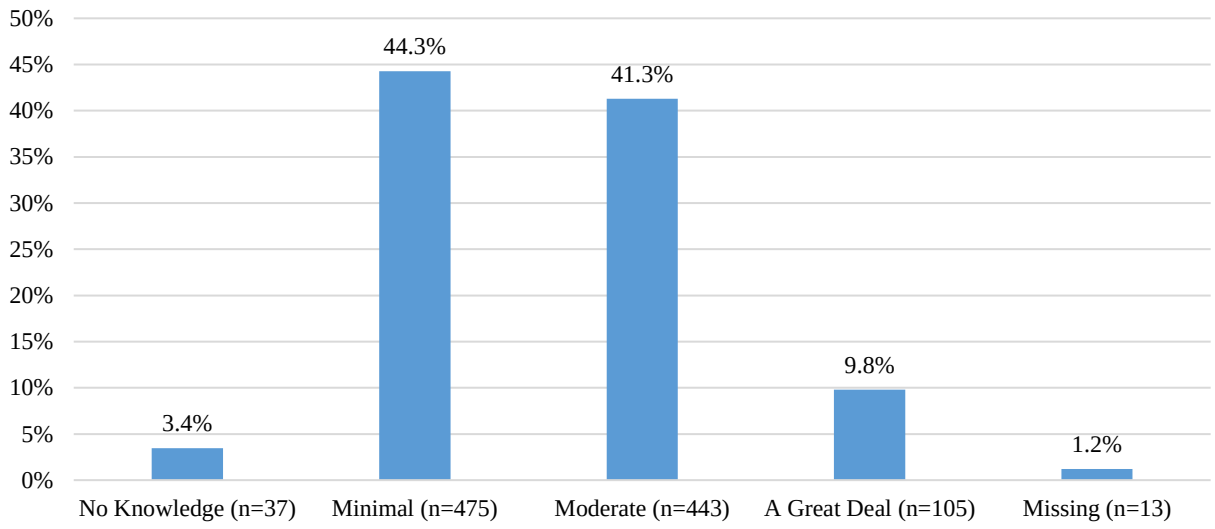
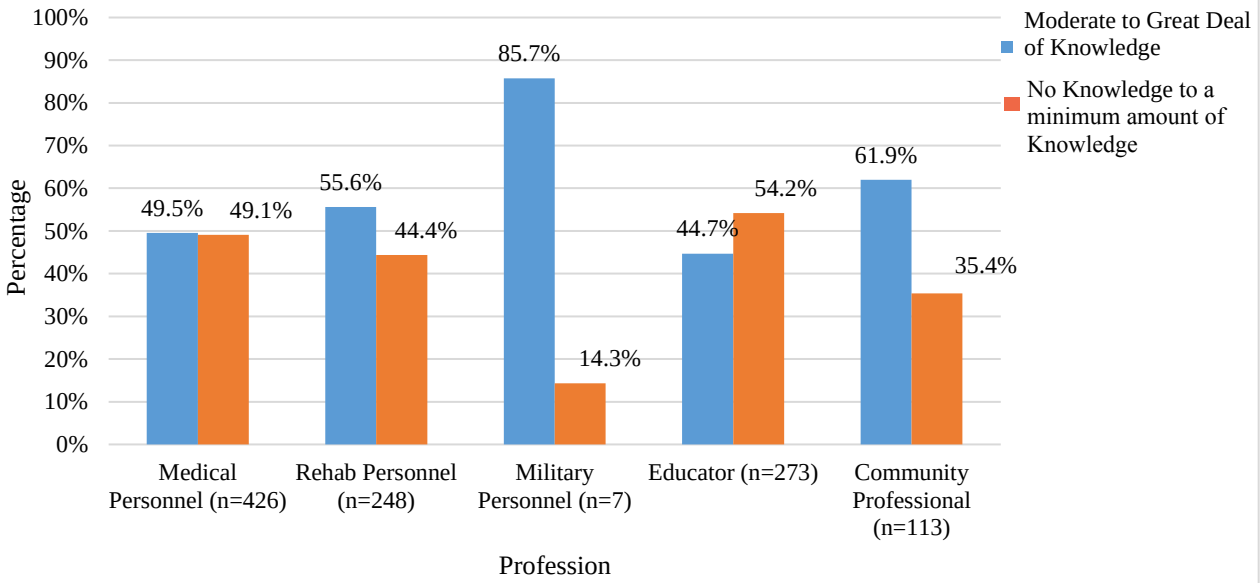


Figure 2.5 shows the knowledge rating by profession for those respondents who both provided their knowledge ratings and reported their profession or role (n=1020), combining no knowledge to a minimum amount of knowledge and moderate knowledge and a great deal of knowledge. Most military personnel (85.7%) and community professionals (61.9%) report having moderate to a great deal of knowledge.

Figure 2.5. Knowledge Ratings by Profession (n = 1020)



Services and Supports

Respondents with at least moderate knowledge were asked to rate the adequacy of the services and supports that currently exist in Missouri. Specifically, these respondents were asked to rate how adequate the service areas were five years ago and currently. Respondents were asked that in rating adequacy, they consider accessibility, quality, and appropriateness of service. The rating scale is listed as below:

- 0 = Don't Know
- 1 = Very Inadequate
- 2 = Somewhat Inadequate
- 3 = Somewhat Adequate
- 4 = Very Adequate

Table 2.2 displays the comparison of service adequacy ratings currently to five years ago. There was a significant increase in the mean rating of service adequacy from five years ago to

today for the following services: urgent care / walk-in services, doctor's office services, hospital discharge planning, inpatient rehabilitation, home health services, outpatient rehabilitation, service coordination, mental health counseling, and information and referral.

Table 2.2. Comparison of service adequacy ratings: Currently and five years ago									
	Currently				**Five Years Ago**				
	n	**%**	**Mean**	**SD**	**n**	**%**	**Mean**	**SD**	**Mean Diff.**
Medical/Hospital Services									
Emergency room care	450	82.1	2.8	1.4	384	70.1	2.1	1.5	0.7
Urgent Care/walk-in services	403	73.5	2.3	1.5	349	63.7	1.7	1.4	0.6**
Doctor's office service	430	78.5	2.5	1.4	368	67.2	2.0	1.5	0.6**
Hospital inpatient services	440	80.3	2.8	1.5	382	69.7	2.3	1.6	0.6
Hospital discharge planning	434	79.2	2.5	1.4	380	69.3	2.0	1.5	0.5**
Acute Rehabilitation Services									
Inpatient rehab	417	76.1	2.6	1.6	364	66.4	2.1	1.6	0.5**
Home health	361	65.9	1.9	1.5	318	58.0	1.6	1.5	0.4**
Outpatient rehab	424	77.4	2.5	1.5	367	67.0	2.0	1.5	0.5**
Community Services and Supports									
Employment services	310	56.6	1.5	1.5	271	49.5	1.2	1.3	0.3
In-home services	325	59.3	1.7	1.5	279	50.9	1.3	1.4	0.4
Transportation	337	61.5	1.6	1.4	290	52.9	1.2	1.3	0.4
Service coordination	373	68.1	2.0	1.5	324	59.1	1.6	1.5	0.5**
Treatment for substance use disorder	340	62.0	1.5	1.4	300	54.7	1.2	1.2	0.3
Mental health counseling	407	74.3	1.9	1.4	363	66.2	1.5	1.3	0.4**
Use of assistive technology	345	63.0	1.8	1.5	301	54.9	1.4	1.4	0.4
Respite	277	50.5	1.2	1.4	241	44.0	1.0	1.2	0.3
TBI support groups	329	60.0	1.7	1.5	283	51.6	1.3	1.3	0.5
Assistance with financial management	260	47.4	1.1	1.3	220	40.1	0.9	1.1	0.3
Recreation services	278	50.7	1.3	1.4	240	43.8	1.0	1.2	0.3

Table 2.2. Comparison of service adequacy ratings: Currently and five years ago									
	Currently				Five Years Ago				Mean Diff.
	n	%	Mean	SD	n	%	Mean	SD	
Legal services	224	40.9	1.0	1.3	197	35.9	0.8	1.2	0.2
Section 8 or other housing assistance	207	37.8	0.8	1.2	179	32.7	0.7	1.0	0.2
Assistance applying for social security disability benefits	259	47.3	1.3	1.5	230	42.0	1.1	1.3	0.2
Continuing education related to TBI	386	70.4	2.0	1.5	334	60.9	1.5	1.3	0.5
Community living skills training	291	53.1	1.4	1.5	250	45.6	1.1	1.3	0.3
Information and referral	368	67.2	2.0	1.5	321	58.6	1.6	1.4	0.5**
*$p < .05$, **$p < .001$									

Respondents were asked, “In regards to needed services and supports, what do you think is working well for individuals with TBI and their families?” A total of 376 (35.1%) respondents provided valid answers (“NA”, “don’t know”, and “unsure” responses were excluded), key topics have been categorized and are listed below:

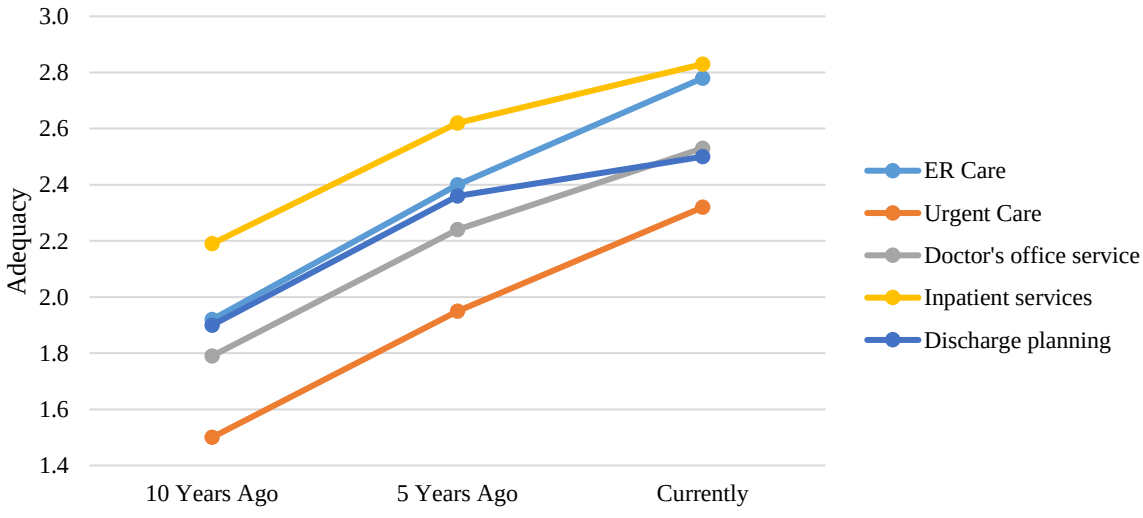
- TBI education and awareness (*n* = 45)
- Acute care, rehab (*n* = 44)
- Information, resources, and referral (*n* = 35)
- Service coordination/case management (*n* = 27)
- Medical care (*n* = 19)
- Continued therapy, support, and counseling (*n* = 16)
- Support groups (*n* = 12)
- Service in general (*n* = 9)
- Timely diagnosis and treatment (*n* = 8)

- Access to service (n = 5)

Service adequacy ratings comparison over time

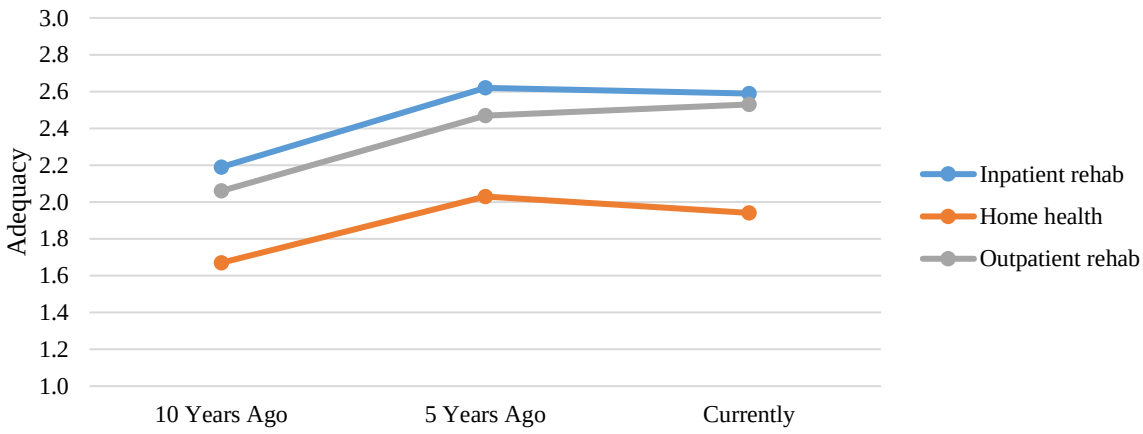
For the purpose of investigating if the services adequacy ratings have changed across the years (2007, 2011, 2017), the ratings in the current survey were compared to the ratings from the previous needs assessment survey conducted in 2011. The ratings provided as "currently" in the survey of 2011 are assumed to be more accurate than the ratings provided as "five years ago" in the survey of 2017, and thus are used in place of "five years ago" ratings in the results below. This is because respondents gave ratings of service adequacy in 2011 as they were experiencing the services conditions, rather than recalling them several years later for the current survey. Figures 2.6 and 2.7 show the medical / hospital services adequacy ratings and acute rehabilitation services adequacy ratings, respectively, over time. Table 2.3 displays the means, the mean difference, and whether the mean difference is significant for the service adequacy ratings over time. With regard to medical / hospital services, professionals' ratings of the adequacy of discharge planning services significantly increased from 2007 to 2011, from 2011 to 2017, and from 2007 to 2017 (Figure 2.6 and Table 2.3).

Figure 2.6. Medical/hospital services adequacy over time



With regard to acute rehabilitation services, professionals' ratings of the adequacy of inpatient rehabilitation services significantly increased from 2007 to 2011, but decreased from 2007 to 2017 (Figure 2.7 and Table 2.3).

Figure 2.7. Acute rehab services adequacy over time



Professionals' overall average ratings of the adequacy of acute rehabilitation services also significantly increased from 2007 to 2011 and from 2007 to 2017 (Table 2.3). With respect to community services and supports, professionals' ratings of the adequacy of respite services significantly decreased from 2011 to 2017 and ratings for continuing education significantly increased from 2007 to 2011 and from 2007 to 2017 (Table 2.3).

Table 2.3. Service adequacy ratings over time

	10 Years Ago (2007)		**5 Years Ago (2011)**		**Currently (2017)**		**2011-2007**	**2017-2007**	**2017-2011**
	n	***M***	***n***	***M***	***n***	***M***	**Mean Difference**		
Medical Services									
ER Care	206	1.9	207	2.4	540	2.8	0.5	0.9	0.4
Urgent Care	202	1.5	210	2.0	533	2.3	0.5	0.8	0.4
Doctor's office service	206	1.8	209	2.2	532	2.5	0.5	0.7	0.3
Inpatient services	204	2.2	206	2.6	536	2.8	0.4	0.6	0.2
Discharge planning	204	1.9	211	2.4	537	2.5	0.5**	0.6**	0.1**
Overall	199	1.9	200	2.3	543	2.6	0.5	0.7	0.3

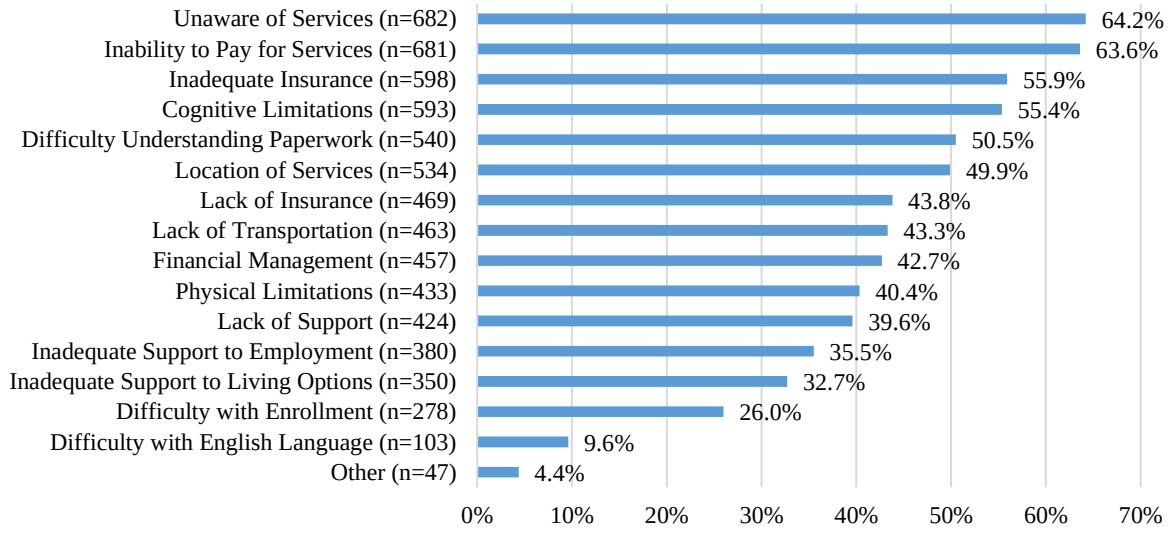
Table 2.3. Service adequacy ratings over time									
	10 Years Ago (2007)		5 Years Ago (2011)		Currently (2017)		2011-2007	2017-2007	2017-2011
	n	*M*	*n*	*M*	*n*	*M*	Mean Difference		
Acute Rehab Services									
Inpatient rehab	202	2.2	207	2.6	535	2.1	0.4*	-0.1**	-0.6
Home health	202	1.7	207	2.0	536	1.6	0.4	-0.1	-0.5
Outpatient rehab	204	2.1	208	2.5	537	2	0.4	0.0	-0.5
Overall	200	2.0	2.6	2.4	539	2.4	0.4*	0.4**	0.0
Community Services and Supports									
Employment services	188	1.5	192	1.9	530	1.6	0.4	0.1	-0.4
In-home services	191	1.7	192	2.0	532	1.7	0.3	0.0	-0.3
Transportation	187	1.7	190	2.0	532	1.6	0.3	-0.1	-0.4
Service coordination	189	1.9	190	2.4	532	2.0	0.5	0.1	-0.4
Substance Abuse	187	1.5	189	1.9	536	1.5	0.3	0.0	-0.4
Mental health	189	1.8	192	2.2	533	1.9	0.4	0.1	-0.3
Assistive tech	190	1.8	189	2.4	533	1.8	0.6	0.0	-0.6
Respite	188	1.3	191	1.5	531	1.2	0.2	-0.1	-0.3*
Support groups	187	1.6	189	2.1	533	1.7	0.5	0.1	-0.4
Financial management	186	1.2	190	1.5	534	1.1	0.3	-0.1	-0.4
Recreation services	188	1.2	192	1.5	525	1.3	0.3	0.1	-0.2
Legal services	188	1.0	190	1.3	531	1.0	0.2	0.0	-0.3
Section 8 /Housing	183	1.1	188	1.3	529	0.8	0.2	-0.3	-0.4
Assistance for SSDB	188	1.7	189	2.0	531	1.3	0.3	-0.4	-0.8
Continuing education	183	1.6	188	2.0	530	2.0	0.5*	0.5**	0.0
Community living	183	1.5	190	1.8	530	1.4	0.3	0.0	-0.3
Info & referral	186	1.7	189	2.3	524	2.0	0.6	0.3	-0.3
Overall	153	1.5	166	1.9	541	1.5	0.4	0.0	0.0

*$p < .05$, **$p < .001$

Barriers to Accessing Services

Professionals were asked to indicate the barriers individuals with TBI and their families face in accessing services and supports (multiple selections were accepted). Figure 2.8 indicates that the most frequently identified barriers to services include unaware of services (64.2%), inability to pay for services (63.6%), inadequate insurance (55.9%), cognitive limitations (55.4%), and difficulty understanding paperwork (50.5%).

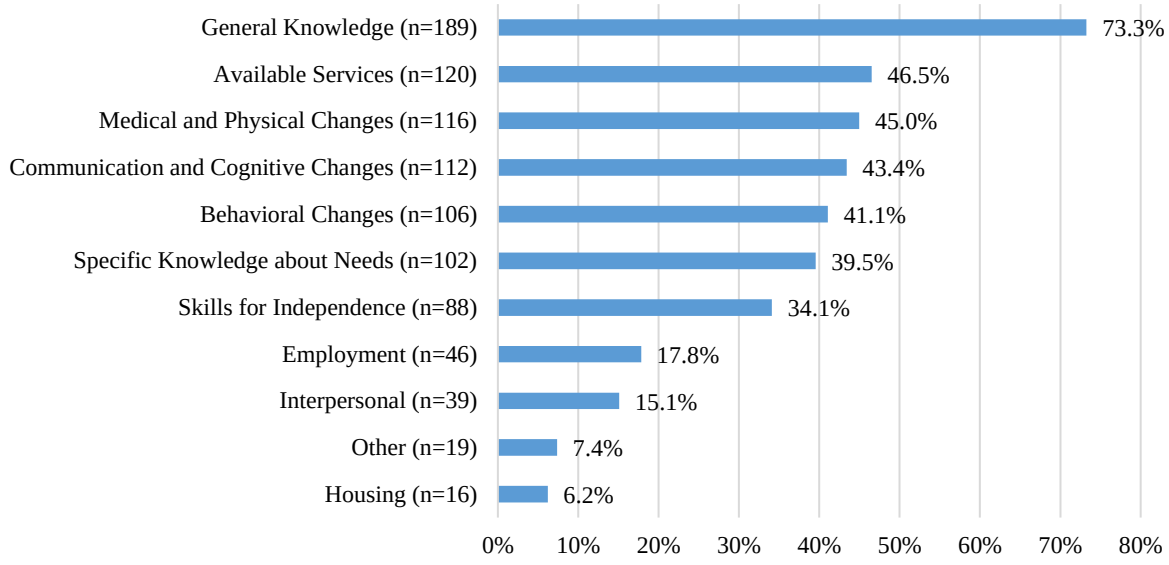
Figure 2.8. Barriers in Accessing Services and Supports (n = 1070)



TBI Training for Professionals and the Community

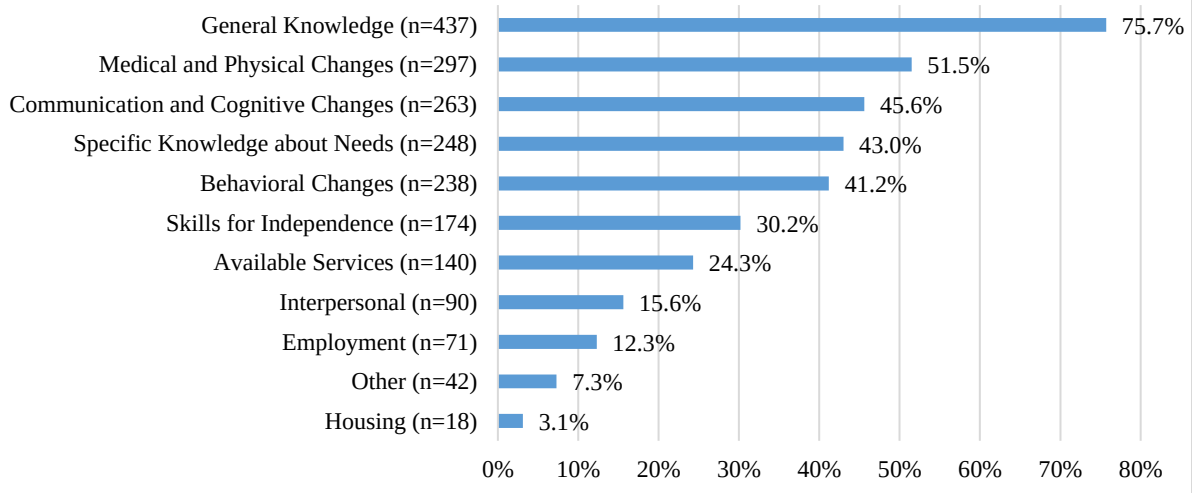
Less than one quarter of professionals (24.1%) reported that their organization provides education or training to the community on TBI. Figure 2.9 shows the types of TBI trainings that these professionals reported their organizations provide. The most frequently provided TBI support or service provided to the community is general knowledge (73.3%), followed by available services and supports for individuals with TBI and their families (46.5%).

Figure 2.9. Type of TBI Training Provided to Community (n = 258)



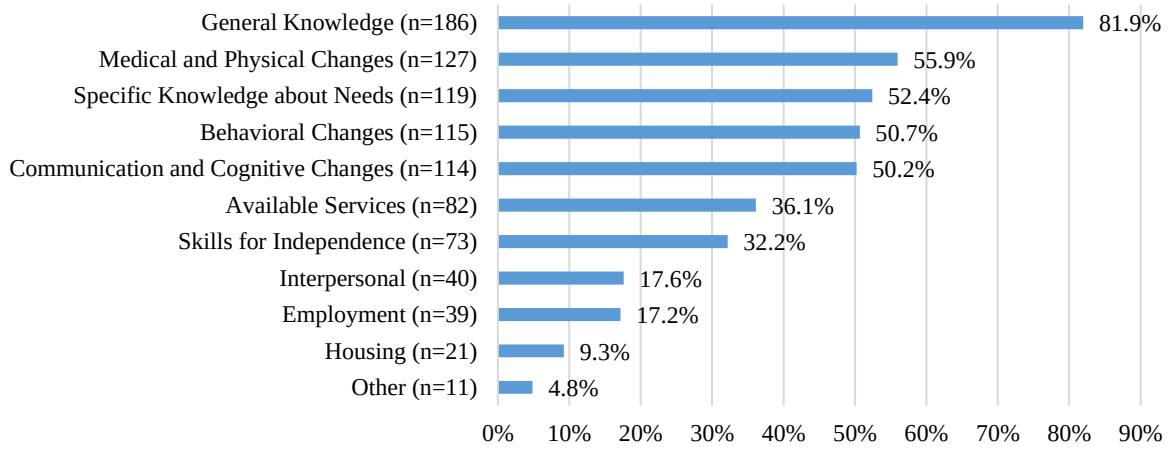
When professionals were also asked if TBI training was part of their professional training, just over half of the professionals (53.9%) responded affirmatively. Figure 2.10 shows that the most frequently identified type of training received was general knowledge about TBI (e.g. causes, types; 75.7%), followed by trainings on medical and physical changes (51.5%).

Figure 2.10. Types of Training Received as Professional Training (n = 577)



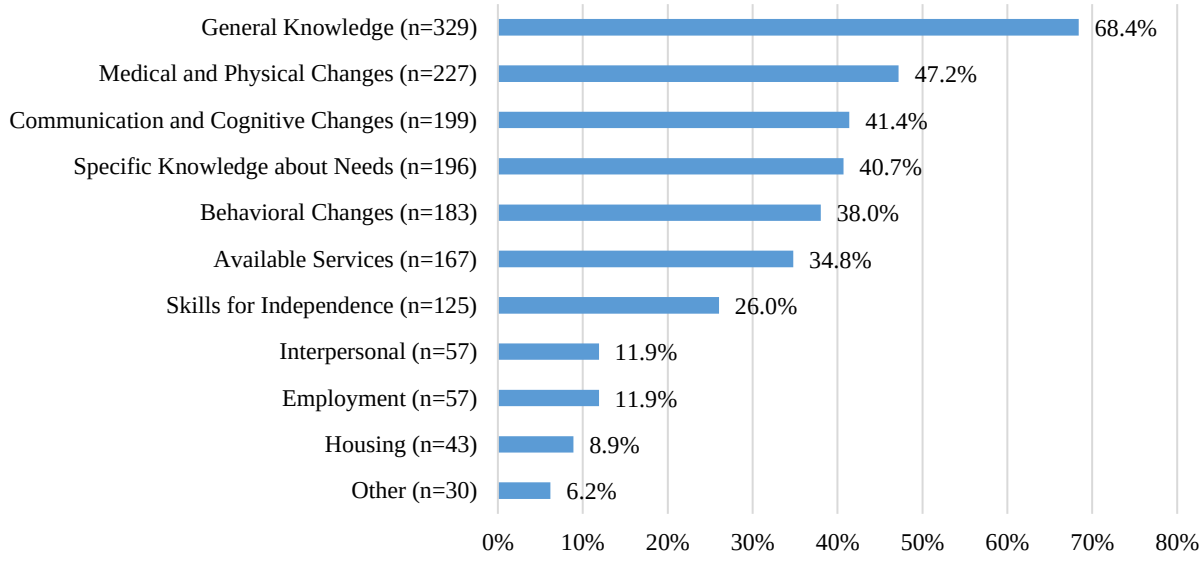
Professionals were also asked whether their organization currently offers TBI training and information to staff (not from outside source). Less than one quarter (21.2%) of professionals responded affirmatively. Most of these respondents (81.9%) indicated that general knowledge trainings are provided from within the organization (Figure 2.11).

Figure 2.11. Types of Training from Internal Sources (n = 227)



Half of respondents further reported that they or other staff within their organization access training or information regarding TBI from external sources. The most frequently reported type of training accessed from external sources includes general knowledge about TBI (68.4%; Figure 2.12).

Figure 2.12. Types of Training Access from External Sources (n = 481)



A total of 303 (28.3%) professionals provided comments on additional training or information they need to improve their capacity to serve people with TBI and their families. The most frequently mentioned comments were categorized into broader topic areas and are listed below:

- More trainings about available resources and services specific to TBI (*n* = 92)
- Any more education or training on TBI (*n* = 49)
- General knowledge about health conditions of people with TBI and what they need (*n* = 31)
- Best practice in acute care for TBI (*n* = 10)
- Update treatment, resources, services for TBI (*n* = 5)

Professionals were also asked "What is your preferred method through which to obtain additional training and information?" and were given the following rating scale:

- 1 = Very low preference
- 2 = Low preference

- 3 = High preference
- 4 = Very high preference

Table 2.4 displays professionals' mean preference ratings related to methods of obtaining training. Professionals indicated a high to very high preferences for online training (M=3.1, SD=1.0) and in-service training (M=3.0, SD=1.0).

Table 2.4. Preferred Method to Obtain Training

	n	%	Mean	SD
Online training	1015	94.9	3.1	1.0
In-service training	1017	95.0	3.0	1.0
State conference	972	90.8	2.2	1.0
Regional training	970	90.7	2.4	1.1
Through professional organization	982	91.8	2.9	1.0

A total of 189 (17.7%) respondents provided additional comments regarding how to improve statewide services and supports for individuals with TBI and their families. Their responses have been categorized in to topic areas and are listed below:

- Make known the available resources, supports to providers, individuals with TBI and their families (*n* = 39)
- Other TBI services (e.g. identification/diagnosis, long-term care plan) (*n* = 24)
- Continuing education on TBI (*n* = 21)
- Funding and insurance coverage is a concern (*n* = 19)
- Making access to services easier (*n* = 8)
- TBI care facilities and programs (*n* = 8)
- Case management/service coordination (*n* = 7)