2011 Missouri Traumatic Brain Injury Needs Assessment Report







A collaborative project of the Missouri Department of Health and Senior Services and the University of Missouri Kansas City-Institute for Human Development.

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This effort was guided by the Needs Assessment Workgroup, established by the Missouri Brain Injury Advisory Council. Workgroup members included:

Lori Brenneke, BHS, CPHQ TBI Project Director, Missouri Department of Health and Senior Services

Melody Boling, MSW, LCSW
TBI Project Coordinator, University of Missouri Kansas City-Institute for Human Development

Maureen Cunningham, CFRE Executive Director, Brain Injury Association of Missouri

Timothy Imhoff, MA
Vice-Chair, Missouri Brain Injury Advisory Council

Kate Koch, MSW Advocacy Specialist, Missouri Protection and Advocacy Services

Mike Sparks, BGS
TBI Project Volunteer Ombudsman
Member, Missouri Brain Injury Advisory Council

The report was authored by the University of Missouri Kansas City-Institute for Human Development: Tom McVeigh, MS
Waheeda Hossain, MD, MPH
Christy Miller, BA

IHD would also like to acknowledge the contributions of Jodi Arnold to the final report.

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Executive Summary

The 2011 needs assessment was conducted by the Missouri Traumatic Brain Injury (TBI) Implementation Partnership Project, which is supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The purpose of the needs assessment is to help determine the needs of TBI survivors and their families in Missouri and to guide the state's five-year planning process.

To support the assessment, two surveys were widely disseminated across Missouri. One survey targeted survivors and families, and one targeted professionals who serve people with TBI. (See full report for methodology and distribution.) Together, these surveys paint a picture of the current system of care, including gaps in service, quality of service, and the training needs of professionals.

Survey Participants

Survivors and Families: A total of 263 surveys were received - 134 from survivors, 110 from family, 6 from friends or other relatives, and 13 who did not identify themselves. Among the individuals with TBI, 31 (11.8%) identified themselves as former military, 20 (7.6%) lived in nursing facilities, 166 (63%) resided in urban counties, and 70 (26.6%) were from rural counties (not all respondents provided a zip code). Most of the participants (86%)

were white, 6% were black, and other ethnic and racial populations represented less than 2% each. The majority of survivors (219) were aged 21-64, 15 were over the age of 65, and 20 were youth and children.

Professionals: There were 629 professional surveys received, from a variety of fields and professions, as shown in Figure E-1.

Figure E-1. Affiliation of Professionals Surveyed

Impact of TBI on the Lives of Survivors and Families

To paint the most detailed picture of the needs of both TBI survivors and their families, the survey began by asking both groups to rate the impact of TBI on their lives in a number of key areas.

Figure E-2 compares the total number of health conditions before and after TBI. All the health conditions described in the graph show a two- to threefold increase post-TBI, with the exception of substance abuse (alcohol and drug), which decreased after TBI.

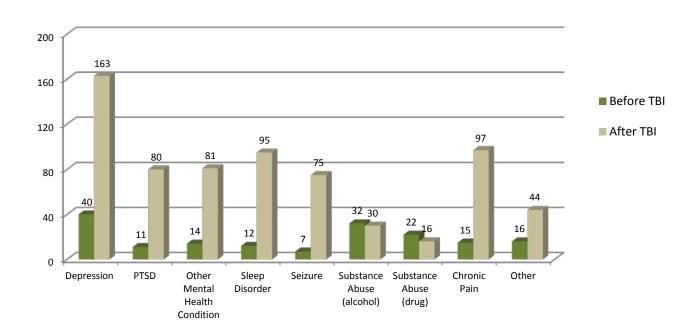


Figure E-2. Disabilities/Significant Health Conditions (n=246)

Respondents were also asked about the impact the TBI had on various aspects of their lives. Figure E-3 compares the survivors' perceptions of negative impact with the family members' perceptions. Survivors were more likely to say that education, employment and income were negatively affected, while more family members said that marriage and parenting were negatively affected.

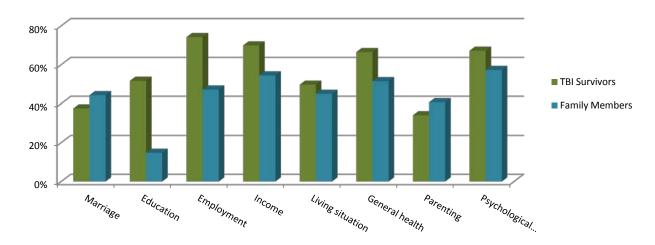


Figure E-3. Negative Impact as Perceived by Survivors and Family

In order to identify the areas of greatest need, the surveys focused on three main topics:

- The Continuum of Care: The needs and experiences of both survivors and their families, from the first medical care received after the TBI to ongoing community services and supports.
- People Living in Nursing Homes: The needs of people with TBI living in nursing facilities,
 including why they moved there, whether they would like to leave, and barriers to leaving.
- Professionals and the Public: The training, information and resource needs of professionals, community groups, and the public.

For each topic, a series of questions was designed to gather both quantitative and qualitative data about the experiences, needs, and perceptions of the respondents.

Continuum of Care

To serve the unique needs of each individual living with TBI, Missouri must offer a continuum of care (hospital to community) with many entry points and many possible paths. This continuum of care includes:

- Medical and Hospital Services (e.g., Emergency Room, Doctors Office, Hospital)
- Acute Rehabilitation Services (e.g., Inpatient/Outpatient Rehabilitation, Home Health Services)
- Community Services (e.g., Housing, Employment, Recreation, Counseling)

The surveys indicated that the continuum of care in Missouri is affected by lack of funding for services, lack of TBI training for professionals, lack of an easy way to learn about and connect to all available services, and scarcity of certain services, especially in rural areas. A brief summary of responses illustrates these challenges.

Living Situation

Gaps in the continuum of care often mean that survivors are not able to live where they would like to live. Among the survey respondents, 40% are not living where they want to. Asked where they want to live, the clear preference for most is to live on their own, with or without assistance (83%). Figure E-4 shows the interrelated factors of money and employment are the greatest barriers to moving. There is also a clear need for housing, service coordination, and specialized supports, which are issues that emerge consistently throughout the survey.

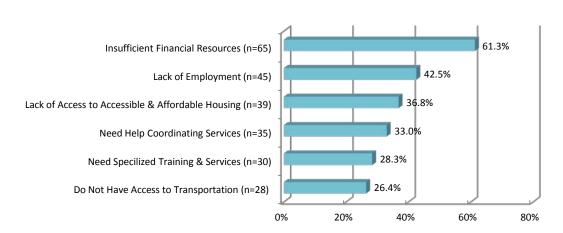


Figure E-4. Top Reasons People with TBI are not Living Where They Want

TBI Survivors in Nursing Homes

The 20 survey respondents who were living in nursing homes answered specific questions about their living situation and needs. Overwhelmingly they expressed a desire to move back to the community.

- 90% of TBI survivors in nursing homes wish to return to the community
- 75% entered the nursing home because they couldn't get the rehab services or medical care they needed at home
- 55% cited lack of financial resources and 35% cited lack of a job as reasons they can't leave the nursing home
- 12 nursing home residents were in rural areas, 7 in urban areas, and 1 unknown

Access to Care along the Continuum

It is clear that access to care changes as people move through the continuum from initial medical care to community supports and services. In both surveys and especially in the write-in comments, people repeatedly said that while acute care and rehabilitation were excellent, survivors and families returned home feeling extremely unprepared and not knowing where to turn for help. This was a matter of needing specific services as well as needing to find and connect with other survivors and families. Professionals were also asked to compare current services to those existing five years ago; across all categories there were small gains in the ratings (see full report). A look at responses in each service category helps to clarify the needs.

Medical and Hospital Care

These services were rated highest by both survivor/family and professional respondents. The average satisfaction for medical care on a 4-point scale was 3.16, compared to 3.03 for acute rehab and 2.68 for community services.

However, the write-in comments suggest that while survivors and families were largely satisfied with the quality of medical care received, they felt that communication with doctors and nurses was inadequate. Many people wrote of leaving the hospital with no understanding of how their lives would change and where to find services that might help. Similarly, when family members and survivors were asked which professionals needed to learn more about TBI, doctors and nurses were among the most frequently chosen (see full report for details on which professionals need to learn more).

Acute Rehabilitation (inpatient, home health, outpatient)

Within this category, home health (nursing or therapy) was rated lower than inpatient or outpatient rehabilitation. Survivors and families also said home health was the rehabilitation service they most often needed but did not receive (20.8%). Professionals as well as survivors/families raised the issue of limited insurance coverage for rehabilitation therapy. As one survivor wrote, "Therapy should be provided due to the person's health and not the insurance company's rules!"

Community Services

In both the survivor/family and professional surveys, community services were rated the lowest, reflecting the greater complexity of navigating this system. To get a full picture of needs related to community services, it is useful to consider these responses together with the data from the "problems accessing services" question and the write-in comments (See Figure E-5).

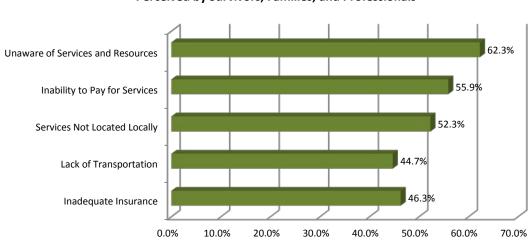


Figure E-5. Barriers to Service
Perceived by Survivors, Families, and Professionals

"Unaware of Services" was the greatest barrier to services from the viewpoint of both professionals and survivor/family respondents.

The military subset reported far fewer problems with insurance and paying for services than the total respondent group, while rural respondents were more likely to say services were not located locally and insurance didn't cover needed services.

Among services most often "needed but not received," recreation services were most often reported (36.2%), followed by information and referral (32.3%) and continuing education related to TBI (30%). Assistance with financial management was needed but not received by 26.4% of respondents, and TBI support groups by 25.9%.

Services needed but not received and barriers to services clearly overlap in a few key areas:

Information: The high need for both "information and referral" and "continuing education about TBI" is consistent with "unaware of services and resources" as a barrier to services. This is reinforced in the write-in comments, where a large number of people mentioned the difficulty of finding information

about services and supports. In addition, both professionals and survivors/families identified service coordination as an important but underfunded resource for families struggling to understand the service system.

Finances: Personal finances, insurance coverage and eligibility for benefits are clearly interrelated and show up consistently as top concerns across all sections of the survey. The write-in comments shed further light on the problem: 51 survivor/family comments identified paying for services as a concern. People went without necessary services because they were denied Medicare or Medicaid coverage, their private insurance did not cover services, or they lost income due to the TBI.

Services not located locally: This was the biggest problem for rural respondents (54.9% vs. 27.8% of urban respondents). Among the top six services needed but not received, rural respondents especially identified TBI support groups and continuing education. The other major differences between rural and urban areas were service coordination (18.5% rural, 11.5% urban) and community living skills training (32.3% rural, 22% urban). The only services for which urban areas reported greater unmet needs were housing and information & referral.

Needs of Professionals and the Public

Professionals: Survivors and families were asked which professionals needed more training and what kind of knowledge and training they needed. Professionals were asked to rate their own knowledge about TBI services and supports and to report any TBI training they had received. Both surveys indicate a need for more training and information for professionals at all levels.

In comparing the two surveys, some interesting correlations emerge:

- Seventy percent of survivors and family members have met professionals who need to learn more about TBI, and 60% of professionals rated themselves as having "no knowledge" to "minimal knowledge" about service and supports for people with TBI.
- Professionals cited by survivors/families as needing to learn more about TBI tended to be the same ones who

"The biggest challenge is trying to get
ALL the players at one table that offer
services for TBI, so we are all on the same
page for referral and we know all of the
services each of us has to offer"
TBI Professional

received the least TBI training as part of their professional education (medical, education, social work, and law enforcement personnel).

Adult Brain Injury Program providers (86.0%) and rehabilitation and therapy professionals (78.8%) had the highest percentages who received TBI training as part of their professional education.

Unsurprisingly, these groups were also more likely to rate their TBI knowledge as "moderate" to "a great deal." Groups with higher knowledge tended to receive training from their organization, while groups with less knowledge tended to access TBI training from external sources.

General Public: Education efforts for the public were seen as an area that has improved; comments from both surveys mentioned the sports concussion media campaign as well as a general increase in public awareness about prevention and treatment of TBI.

However, survivor/family respondents and professionals saw a great need to provide more information to families about TBI and available community resources that are available. Survivors and families also stressed the need to educate the public to promote acceptance and inclusion of people with TBI in workplaces, schools, social settings and housing.

Summary Statement

Overall, TBI survivors and family members, like professionals, felt strongly that access to information, education and services needs to be improved. This includes information about the range of services that may be necessary, but just as importantly, it includes emotional/peer support for both family members and survivors. One survivor recommended "survivor outreach for new TBIs to assist and answer questions...and represent hope." Another described TBI as a "very isolating injury." It is clear that gaps in the continuum of care contribute to the isolation and frustration experienced by many, as well as impacting outcomes for survivors. But the data also provides direction about what works to alleviate and prevent these problems.

Respondents identified inadequate funding as a barrier to receiving both information and services. The need for accurate diagnosis and timely information about follow-up services is also clear, as is the need for the employment, transportation, housing, recreation, and other services that can allow TBI survivors to live in the setting of their choice and enjoy greater quality of life. A continuum of care that addresses the unique and changing needs of each person living with TBI must be both flexible and comprehensive; as one survivor put it, "No two TBIs are the same. Be creative and work with us in whatever aspect we need."

2011 Missouri Traumatic Brain Injury Needs Assessment Report

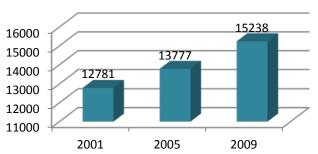
Background and Introduction

This needs assessment is supported through the Missouri Traumatic Brain Injury (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 some level of needs assessment every five years that is used to inform the development of a Missouri Five Year Plan designed to improve access to services and supports for individuals with TBI and their families. An intensive needs assessment was done five years ago that involved interviews and focus groups with survivors, their families, and the professionals that serve them. The assessment conducted over the past year was designed to build upon this effort through surveys focused on survivors, their families, and the professionals who serve them.

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 more than 13,000 people are treated for traumatic brain injury each year in Missouri. In 2009, the total was 15,238, of which 25% were admitted to the hospital and 75% were treated in the emergency room. 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, by some estimates the national figure is as high as 3 million annually. There is also a growing number of military personnel diagnosed with TBI due to blast injuries; nationally, the number has risen steadily from about 11,000 in 2001 to over 30,000 in 2011 (Missourispecific data on military TBI is not available.)

Figure 1 shows the trend in Missouri TBI numbers from 2001-2009: (The rate per 100,000, not shown in the figure, rose from 225 in 2001 to 255 in 2009.) For information on incidence numbers and rates by age, gender, race, and ethnicity, please see Appendix A.

Figure 1. Missouri TBI Incidence (Hospital and Emergency Room)



To support the development of the current needs assessment, a workgroup was developed that included representation from the Missouri Brain Injury Advisory Council, agency staff, and key stakeholders. At the initial meetings the workgroup identified three areas of focus to guide the needs assessment. These included:

- Focus on a Continuum of Care: Paint a picture of a services and support continuum of care
 (hospital to community) that examines the needs of both survivors and their families along this
 continuum.
- Focus on Hospital Discharge and Nursing Home Admissions: Examine the needs of people with TBI living in nursing facilities (e.g. why people enter, how many, who wants to leave, why people leave and stay).
- Focus on Providers, Other Professionals, and the Public: Explore the training, information and resource needs of professional and community groups.

Based upon these areas of identified focus, the workgroup developed a set of questions to be answered through the assessment. The following tables highlight these questions in relation to the three focus areas.

Focus on a Continuum of Care

Who are they?

- When injured?
- What services have they received?
- Co-occurring Disability: What other diagnoses, conditions or disabilities do they have? (e.g. depression, sleep disorder, diabetes)

How many TBI in 2000? How many TBI in 2005? How many TBI in 2008?

Where do they live? (e.g. in own home, with family, supported apartment, group living, nursing facility)

What has been the impact on their families (e.g. job loss, divorce, stress)?

What are the barriers and challenges for individuals from the different subgroups along the continuum?

- Hospital
 - 1. What services did they receive in the hospital?
 - 2. Did they get follow-up therapy when they left? What type?
 - 3. What services did they need but not get? Why?
 - 4. What worked and what did not?
- Acute Rehabilitation
 - 1. What services did they receive in the Rehabilitation Facility?
 - 2. Did they get follow-up therapy when they left? What type?
 - 3. What services did they need but not get? Why?
 - 4. What worked and what didn't?
- Community Support (e.g. residential, employment, therapies)
 - 1. What services are they receiving now?
 - 2. What services have they received in the past?
 - 3. What services do they currently need but aren't getting?
 - 4. What's working and what's not?

Focus on Hospital Discharges and Nursing Facility Admissions

How many in nursing facilities? For how long?

Are the numbers increasing?

How many transition from acute rehabilitation to nursing facility? Why?

How many transition from the hospital to nursing facilities? Why?

How many move from home/community to nursing facilities? Why?

How many move from nursing facilities to home/community? Why?

How many who live in nursing facilities want to return to the community? Why aren't they leaving the nursing facility?

Focus on Providers, Other Professionals, and the Public

Have survivors and families encountered professionals who need to learn more about brain injury? What do they need to know?

What type of training and information related to TBI do different professional groups receive? Where are the gaps?

Where do they get their information?

What are the best sources to educate different groups about TBI? Where are they?

What else do groups wish they knew?

Approach

The needs assessment workgroup also identified a priority to try and reach out to individuals who were less connected to the system (e.g. those not receiving state injury services and not members of a support group/association) and a wider range of professionals. In support of this they identified potential sources of existing data and information as well as identified a number of strategies through which to gather new information and data directly from survivors, families, and professionals. It was decided for this needs assessment that two surveys would be developed and disseminated. The primary reasons for this were 1) that it could be widely disseminated and have the potential to reach those less connected to the "system," 2) that this would be the most cost effective approach, and 3) it would complement the past needs assessment which relied primarily on interviews and focus groups to collect data.

The needs assessment surveys consisted of a Professional survey and a Survivor /Family survey as follows:

Professional Survey: This 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. This survey questionnaire included 42 questions regarding professional affiliation, services provided, knowledge, training needs and perception of barriers and gaps in service.

Traumatic Brain Injury Survivors and Family Survey: This survey was distributed to TBI survivors and their family members through a variety of channels (see below). It included 48 questions regarding their demographics, perceived needs, satisfaction regarding the services they received/are receiving as well as the barriers they are facing.

Both surveys were published in electronic form and disseminated through Survey Monkey. In addition to the electronic versions, the Survivor and Family survey was published in paper form to accommodate individuals who may not have access to internet services.

Dissemination of the surveys was accomplished through a number of means that included:

- The Missouri Department of Health and Senior Services placed the electronic needs assessment links on Missouri Traumatic Brain Injury website page.
- Links were sent out statewide to Adult Brain Injury Service Coordinators and Program Providers.
- Numerous state agencies disseminated electronic surveys through their list serves including the
 Department of Education Divisions of Early Childhood Education and Vocational Rehabilitation,
 Department of Mental Health, Missouri Veterans Commission, Department of Corrections, and
 Professional Registration.
- Programs within the Department of Health and Senior Services supported dissemination including Coordinated School Health, Special Health Care Services, Long Term Care Ombudsman, and Adolescent Health.

- Several organizations outside of the State systems of care agreed to assist with the
 dissemination of the Needs Assessment. These included Missouri Protection and Advocacy,
 Brain Injury Association of Missouri, Missouri Sheriff's Association, Missouri Police Chief's
 Association, Missouri National Guard, University of Missouri Systems, which include Health
 Psychology and School of Social Work, Independent Living Centers, and Missouri Head Start
 Collaboration Office to name a few.
- Several rehabilitation facilities agreed to assist with the dissemination such as Rehabilitation
 Institute of Kansas City, Centers for Head Injury Services St. Louis, Missouri Rehabilitation
 Center in Mt. Vernon, and Madonna Rehabilitation Hospital in Lincoln, Nebraska.

Survivor and Family Surveys were disseminated either by mail or electronically through the mentioned organizations that serve individuals with traumatic brain injury. In addition, exhibit opportunities such as the Missouri State Fair, Veterans Festival and other conferences were utilized to support the dissemination.

Survivor/Family and Professional Needs Assessment Survey Results

A total of 892 people responded to the needs assessment surveys. Among those, 263 responded to the survivor/family survey and 629 to the professional survey.

The following sections provide a review and analysis of the data collected from both surveys.

Survivor and Family Survey Results

Demographics

The following section compiles data on the demographics of the survivor/family survey including age, race, date and severity of injury, zip code and military affiliation.

Survivors and Families: A total of 263 surveys were received from TBI survivors and family members. Figure 2 shows the percentages of survivors (n=134), family (n=110), and others (n=6). There were 13 surveys returned by people who did not identify themselves.

Among the survivors, 31 (11.8%) identified themselves as former military service

TBI survivors

Family members

Other

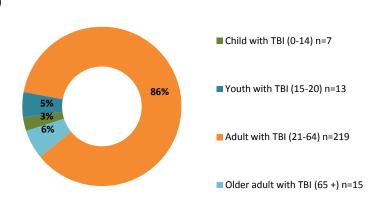
Figure 2. Description of Participants (n=220)

members and 20 (7.6%) resided in nursing facilities, 166 (63%) resided in urban counties and 70 (26.6%) were from rural counties.

Figure 3. Age Distribution

Attached to this report is a map (Appendix B) that shows the counties and regions from which surveys were received.

Age distribution of individuals with TBI: Age was reported for a total of 254 individuals with TBI. Of these, the large majority (86.2%) were adults with TBI, ranging from 21 to 64 years of age (Figure 3).



Gender: As seen in Figure 4, 33% of individuals with TBI were female and 67% were male.

Race/Ethnicity: The majority (86%) were white, 6% were black, with smaller representations from other racial/ethnic populations (see Figure 5).

Figure 4. Gender (n=252) Figure 5. Race/Ethnicity (n=250) ■ White Non-Hispanic (n=215)■ Black Non-Hispanic 86% (n=16)■ Hispanic (n=1) & Asian (n=1) ■ Male (n=168) ■ Native American ■ Female (n=84) (n=5)3% ■ Pacific Islander (n=2) 1% ■ White and Native American (n=2) Other (n=8)

Military: Among the 31 former military service members, 26 are adults with TBI (age 21-64) and 5 are older adults (65 and older), 28 male and 3 female. Regarding race/ethnicity, 27 are white –non Hispanic, 2 black –non Hispanic, 1 Native American and 1 Pacific Islander. Of the military personnel, 19 received their injury less than 10 years ago and 10 received it more than 10 years ago, 20 represent urban areas and 9 represent rural areas.

Urban/Rural: TBI survivors were represented from 242 zip codes in 48 Missouri counties, as well as two participants from Kansas, two from Illinois, and one from Colorado. Missouri counties were broken out into urban and rural using the Census Bureau criteria that are used by MICA (Missouri Information for Community Assessment).

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, 14 Missouri counties were classified as urban. The remaining 101 counties in Missouri were considered rural. Map 1 (see Appendix B) illustrates the rural and urban counties in Missouri using this classification system.

Under this classification, the survey included 164 individuals with TBI from urban counties and 70 from rural counties (not all respondents gave their zip code).

A total of 244 participants recorded the year of their TBI, including four participants who recorded dates for multiple injuries. The chart in Figure 6 shows the breakdown of injuries that occurred from 1954 to 2011: the years were divided into four groups, injury occurring 0 to 2 years ago, 3 to 5 years ago, 6 to 10 years ago and more than 10 years ago. More than 40% (100) of the participants who took part in this survey experienced TBI more than 10 years ago.

Classification of TBI at the Time of Injury: Severity of TBI was reported by 251 respondents, among whom 157 (63%) indicated that they or their family member had a severe TBI (Figure 7).

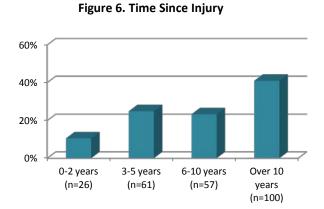
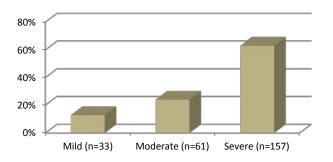


Figure 7. Severity of Injury



TBI and Other Health Conditions

Disabilities or Significant Health Conditions: Figure 8 illustrates disabilities or significant health conditions that survivors had *before* the TBI as compared to those that developed *after* the TBI.

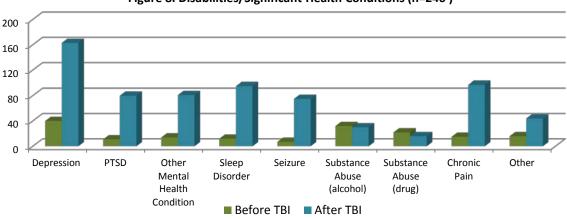


Figure 8. Disabilities/Significant Health Conditions (n=246)

All conditions show a two- to threefold increase post-TBI, with the exception of substance abuse (alcohol and drug), which decreased slightly post-TBI. (For detailed data on each condition, see Table C-1, Appendix C.)

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. Family members filling out the survey were asked to respond to this question based on the impact the TBI has had on their own lives, not the survivor's.

Across both survivor and family member responses, there were some "getting better" responses in all the areas (education with 13.6% and living situation with 12.8% are the highest). However, there was no area in which the "better" numbers were higher than either the "no change" or "worse" numbers.

Areas that Got Worse: Figure 9 shows the negative impact of select areas as perceived by TBI survivors and family members (for detailed data on all areas, see Table C2, Appendix C). Although there was an adverse effect on all the areas listed above for both TBI survivors and family members, some key differences emerge. Employment, education, and income were perceived as more affected by survivors, whereas family members said marriage and parenting were more affected.

80% 60% 40% 20% 0% Marriage Education **Employment** Income Living General Parenting Psychological Situation Status health ■ TBI Survivors ■ Family Members

Figure 9. Negative Impact of TBI on Survivors and Families

Living Situation

Data was 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. This includes data on where survivors currently live, where they would like to live, and any barriers they face regarding their living situation.

Current Living Situation: Table 1 shows where the TBI survivors are currently living; the highest number of survivors are currently living with family members (108), followed by living independently with no assistance (76).

Table 1. Current Living Situation of TBI Survivors

| Situation | Currently Living %/(n) |
|--|---------------------------|
| Living independently with no assistance | 30.2% (76) |
| Living with family member | 42.9% (108) |
| Living in own apartment/home with outside assistance | 14.3 (36) |
| Living in Assisted Living Facility | 1.6% (4) |
| Living in a Group Home (Residential Care Facility) | 0.4% (1) |
| Living in a Nursing Facility | 7.9% (20) |
| Other | 2.8% (7) |
| Total number of responses | 252 |

Those Not Living Where They Want To: Among these 252 responses, 106 want to live in a different place from where they are living, 120 are living where they want to live, and 26 did not indicate where they want to live.

As shown in Figure 10, of the TBI survivors who are not living where they want to live, the majority (63 or 59.4%) are currently living with family.

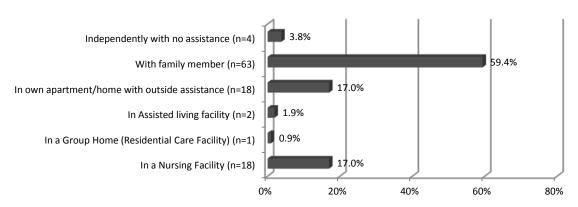


Figure 10. Living Situation of TBI Survivors Wanting to Change Where They Live (n=106)

Figure 11 indicates where these individuals would live if they had the choice. Combined, "independently with no assistance" and "in own apartment/home with outside assistance" make up 81.1% of these responses. Clearly, living on their own, with or without assistance, is the goal for most of the 106 survivors who reported not currently living where they want.

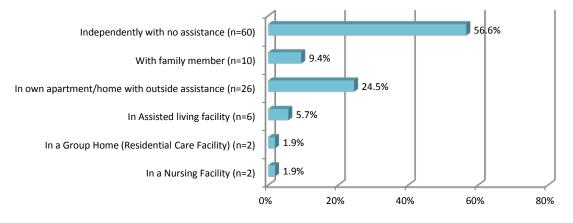


Figure 11. Living Preferences of Survivors not Currently Living Where They Want (n=106)

The reasons they are not living where they wish are detailed in Table 2: insufficient financial resources and lack of employment, which are clearly interrelated, present the greatest barriers.

Table 2. Reasons TBI Survivors are not Living Where They Want to Live

| Reason | Not living where they want to live %/(n) |
|--|--|
| Lack of access to accessible and affordable housing | 36.8% (39) |
| Insufficient financial resources | 61.3% (65) |
| Lack of employment | 42.5% (45) |
| Can't get the services I need (personal care, homemaking, etc.) | 17.9% (19) |
| Can't get the rehabilitation therapy I need (physical, speech, occupational, etc.) | 18.9% (20) |
| Can't get the medical care I need | 12.3% (13) |
| Do not have access to transportation | 26.4% (28) |
| Need help coordinating and planning for services | 33.0% (35) |
| Need specialized training and services (cognitive training, behavioral supports, community living skills training) | 28.3% (30) |
| Other | 7.5% (8) |
| Total number of respondents | 106 |

^{*}Respondents could choose more than one answer

Individuals Currently Living in Nursing Facilities

Data was compiled on the subgroup of individuals who are currently living in nursing facilities in order to learn about their reasons for admission, desire to move back to the community and barriers to doing so. Overwhelmingly, these survivors indicated a preference for living in the community; the data that follows illustrates the difficulties that they and their families face regarding this issue. A total of 20 TBI survivors, which is 7.6% of the total represented by the survey, currently live in nursing facilities. These include 14 males and 7 females, 1 youth (15-20 years) and 19 adults (21-64 years). Demographically, 17 are white non-Hispanic and 3 are black non-Hispanic. Two of them are former military service members. Twelve of the participants are from rural areas and seven from urban areas. Their injuries occurred from 1983 to 2010. As classified at the time of injury, 4(20%) had moderate TBI and 16 (80%) had severe TBI.

As seen in Figure 12, the highest numbers of participants have lived in a nursing facility for 1 to 3 years; however 25% (5) have lived there more than 5 years. Figure 13 shows that 50% (10) of the participants moved to a nursing facility from home and 20% moved from the hospital.

Figure 12. Time Living in the Nursing Facility (n=20)

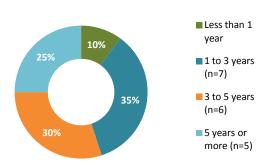
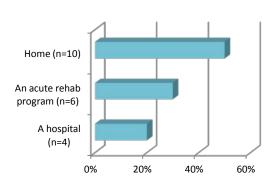


Figure 13. Where Survivors Entered the Nursing Facility From (n=20)



Among the participants living in nursing homes,

11(61.5%) were injured less than 10 years ago and 7 (38.9%) were injured more than 10 years ago. Comparisons between these two groups did not indicate significant differences.

The two most prevalent reasons for admission to the nursing home were "couldn't get the rehabilitation therapy I need" and "couldn't get the medical care I need". However, when "insufficient financial resources" and "lack of employment" are combined, they represent 55.0% of the responses to this question (see Table C3, Appendix C, for details.)

As shown in Figure 14, 90% (18) of the TBI survivors living in a nursing home want to return to the community. Among reasons for not returning to the community, financial resources and employment combined represent the largest percentage (90%). Other significant reasons for not leaving the nursing home include "can't get the rehabilitation therapy I need" (50%) and "don't

Figure 14. Wish to Return to the Community from the Nursing Home (n=20)

No (n=2)

Yes (n=18)

have access to transportation" (35%). For a complete table of responses, see Table C4, Appendix C.

Services and Supports

The survey participants were asked a number of questions related to a service continuum of care. The continuum of care included:

- Medical and Hospital Services (e.g. Emergency Room, Doctors Office, Hospital)
- Acute Rehabilitation Services (e.g. Inpatient/Outpatient Rehabilitation, Home Health Services)
- Community Services (e.g. Housing, Employment, Recreation, Counseling)

Within this continuum, 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. They also ranked their level of satisfaction with services received. In addition to a summary of overall responses, data is also provided for a subgroup of military personnel as well as those from rural and urban settings.

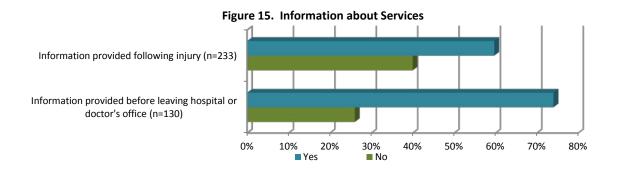
Information About Services: Participants were asked the following two questions regarding information received about services:

1. Following your injury, did anyone provide you or your family with information or advise you about services available for people with traumatic brain injury?

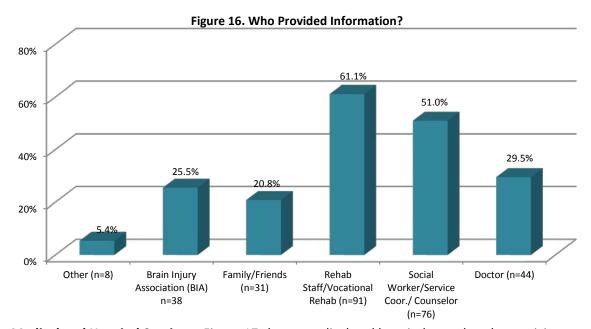
Those who responded "Yes" to the above question were asked to answer the next question:

2. Was this information provided before you left the hospital or doctor's office?

Figure 15 shows that 60% TBI survivors received information about TBI services following injury, and of that group, 74% received the information before leaving the hospital.



As Figure 16 illustrates, the highest number reported getting information about services from rehabilitation professionals (61%), followed by social workers or service coordinators (51%).



Medical and Hospital Services: Figure 17 shows medical and hospital care that the participants received at the time of their injuries. (Percentage is based on the total number of participants who responded for each area of service.) The highest number of survivors, a total of 229 (93.5%), received emergency room care at the time of injury. A very high number (213 or 88.8%) were also admitted to the hospital, and hospital discharge planning services were received by 152 (70.0%).

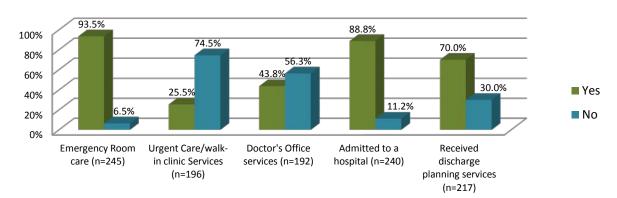


Figure 17. Medical and Hospital Services

Acute Rehabilitation Services: Participants were also asked about acute rehabilitation services received after the injury, as shown in Figure 18. The largest numbers of people received inpatient (64%) and/or outpatient (66%) rehabilitation, although home health was most frequently reported as needed but not received (20.8%).

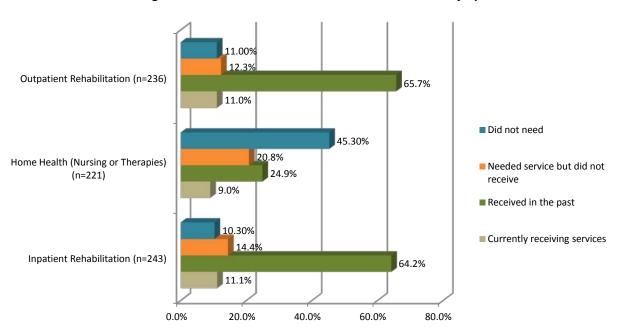


Figure 18. Acute Rehabilitation Services Received after Injury

Community-Based Services: Participants were also asked about community-based services received after the injury (for full data on each service, see Table C5 Appendix C). 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.

Among services currently received by respondents, service coordination was the most frequent (39.1%), followed by assistance applying for social security (28.1%). The services most often received in the past were TBI support groups (28%), mental health services (27.7%) and service coordination (26.4%).

For most services, "did not need" was the most frequent response, with exceptions for information and referral, support groups and service coordination services. Under "needed but did not receive," the most frequent responses were recreation services, information and referral services and continuing education related to TBI (see Figure 19).

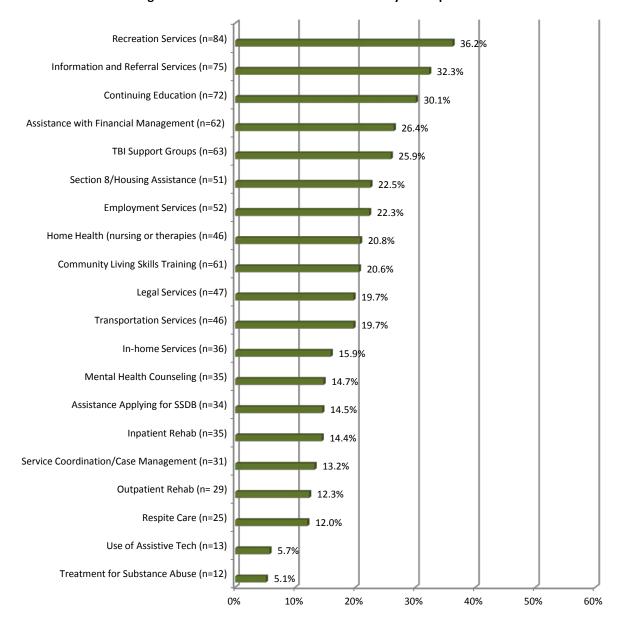


Figure 19. Services Needed but not Received by all Respondents

The "needed but not received" services indicated by the military subgroup are shown in Table 3. "Information and Referral" was the greatest need (34.8%), compared to recreation for the total group. Military respondents were more likely to report needing but not receiving legal services (24%) than was the total group (19.7%). In addition, 18.5% of the military group said they needed but did not get inpatient rehab, compared with 14.4% of the overall group. The area in which significantly more of the total group reported unmet needs was home health (20.8% vs. just 8.3% of military).

Table 3. Services Needed but Not Received, Military subset

| Services | Responses %/(n) |
|--|--------------------|
| Acute Rehabilitation Services | 707 (117 |
| Inpatient Rehabilitation (n=27) | 18.5% (5) |
| Outpatient Rehabilitation (n=26) | 11.5% (3) |
| Home Health (Nursing or Therapies) (n=24) | 8.3% (2) |
| Community Services and Supports | |
| Information and Referral Services (n=23) | 34.8% (8) |
| Continuing Education related to TBI (n=27) | 33.3% (9) |
| Assistance with Financial Management (n=25) | 28.0% (7) |
| Recreation Services (n=25) | 28.0% (7) |
| Legal Services (n=25) | 24.0% (6) |
| TBI Support Groups (n=27) | 22.2% (6) |
| Community Living Skills Training (n=25) | 20.0% (5) |
| Employment Services (n=27) | 14.8% (4) |
| Transportation Services (n=27) | 14.8% (4) |
| In-home Services (n=25) | 8.0%% (2) |
| Mental Health Counseling (n=26) | 7.7% (2) |
| Service Coordination or Case Management (n=25) | 4.0% (1) |
| Section 8 or other Housing Assistance (n=24) | 4.2% (1) |
| Treatment for Substance Abuse (n=26) | 3.8% (1) |
| Assistance applying for Social Security Disability Benefits (n=27) | 3.7% (1) |
| Use of Assistive Technologies (n=24) | 0.0% |
| Respite Care (n=23) | 0.0% |

Urban and rural areas were also compared in regards to unmet needs. As shown in Figure 20, rural areas report the same or greater unmet service needs in 16 of 20 categories (within 1% counted as same). Exceptions were information and referral, section 8/housing, in-home services, and home health. The biggest contrast between urban and rural was the need for support groups; 35.5% of rural respondents said they needed but did not have access to this service, compared to 20.3% of urban respondents. Other significant differences included service coordination (18.5% rural vs. 11.5% urban) and legal services (24.6% rural vs. 17% urban). The only area in which urban respondents had significantly higher unmet needs was in-home services (17.8%), compared to 13.6% of rural respondents.

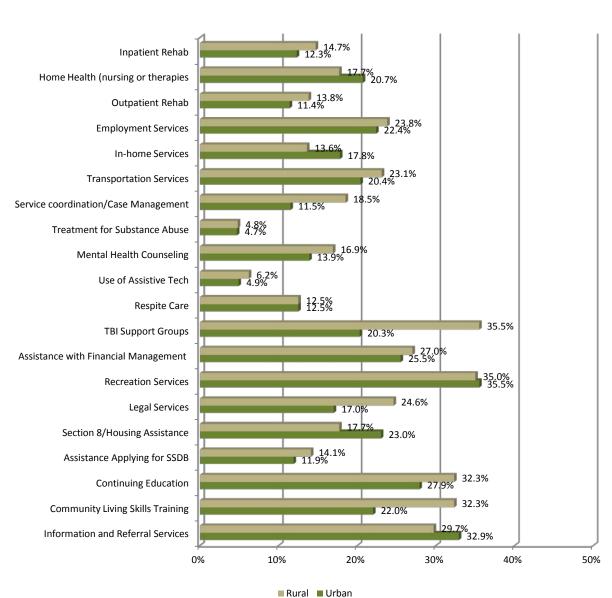


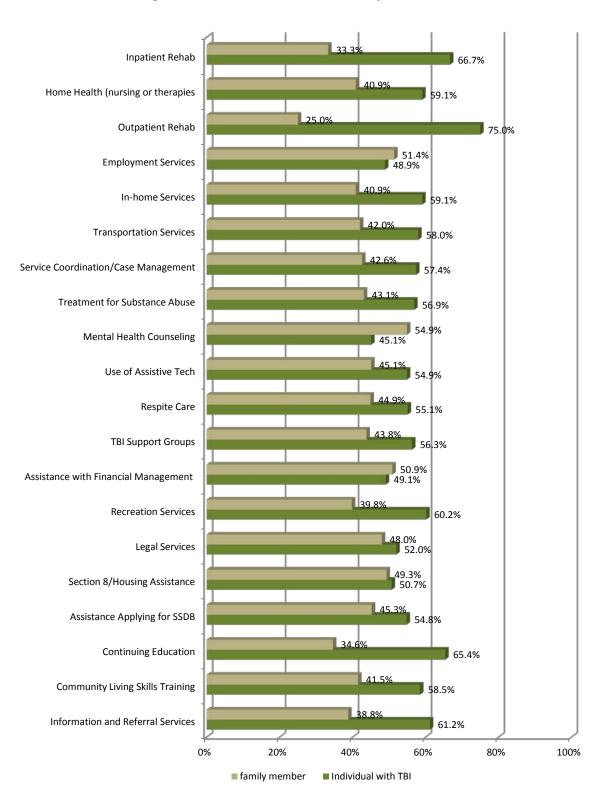
Figure 20. Services Needed but not Recieved, Rural vs. Urban

Regarding services needed but not received, individuals were compared according to when they received their injury. TBI survivors who have had their TBI for less than 10 years and those who have had their TBI for more than 10 years both recorded "home health (nursing or therapy) services" as the service most often needed but not received. Those who received their TBI over 10 years ago reported greater unmet needs related to inpatient and outpatient rehabilitation.

TBI survivors who have had injuries for more than 10 years recorded "recreation services" and "information and referral" as high unmet needs but at a lower rate than those with injuries under 10 years. For detailed data, see Table C6, Appendix C.

Further analysis was done to compare the "do not need" responses of family members and survivors (see Figure 21). In most of the categories, higher percentages of survivors responded that they did not need services. The exceptions were employment services, assistance with financial management, section 8/housing assistance and legal services. In these areas, survivors and family members had similar responses. The biggest contrast between survivors and family members were the outpatient rehabilitation service (75% survivor vs. 25% family), inpatient rehab (66.7% survivor vs. 33.3 % family), continuing education related to TBI (65.4% survivor vs. 34.6% family) and information and referral services (61.2% survivor vs. 38.8% family). The only area where family members responded higher compared to survivors was mental health counseling (54.9% family vs. 45.1% survivor).





Average Ratings of Services: In order to assess which services are working best in the perception of survivors and families, respondents were asked to rate satisfaction with each medical, rehab, and community service received on a scale of 1 to 4. As shown in Figure 22, medical and hospital services (green) were rated highest (all above 3.1). Acute rehab services (blue) were all highly rated with the exception of home health (2.8).

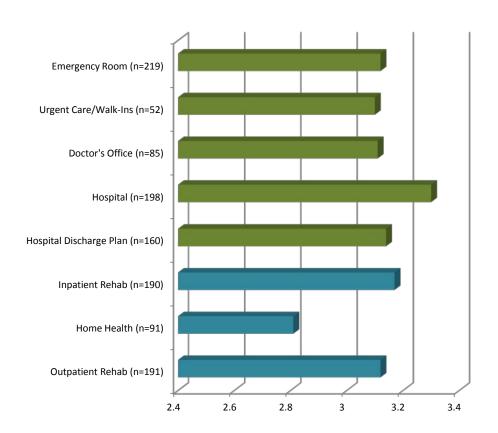


Figure 22. Medical/Hospital and Acute Rehabilitation

Community services and supports, as shown in Figure 23, were in general rated lower than medical and acute rehabilitation. Among community services and supports, "assistance applying for social security disability benefits" was rated highest (3.03). Employment (2.5), "treatment for substance abuse" (2.5) and recreation (2.6) were rated lowest.

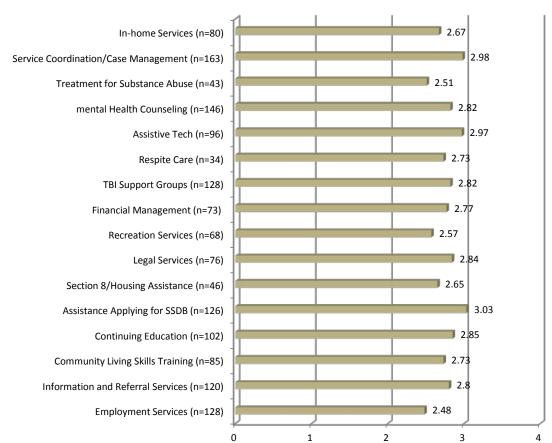


Figure 23. Community-Based Services and Supports

Problems Accessing Services: In analyzing the problems that survivors and family have accessing services, it is again informative to compare certain subgroups. Table 4 compares all respondents to the military subgroup. The greatest differences had to do with insurance and finances. As seen in the table, "inability to pay," "don't have insurance," and "insurance doesn't cover services" are much larger concerns for the larger group than for the military. In addition, 21.3% of the overall group reported "don't have support to live where I want to live," compared with just 1 military respondent (3% of all military respondents). A similar difference is observed in the "difficulty understanding process or paperwork" response (29.2% overall vs. 5% military).

Table 4. Problems Accessing Services, Total vs. Military

| Problem* | Total responses (%/n) | Military (%/n) |
|---|--------------------------|-------------------|
| Lack of transportation | 35.1% (61) | 35.0% (7) |
| Inability to pay for needed services | 43.1% (75) | 15.0% (3) |
| Don't have insurance | 14.9% (26) | 10.0% (2) |
| Insurance doesn't cover needed services | 36.2% (63) | 0.0% (0) |
| Services and resources not located locally | 37.9% (67) | 40.0% (8) |
| Don't have support to live where I want to live | 21.3% (37) | 5.0% (1) |
| Don't have support to find a job | 29.9% (52) | 20.0% (4) |
| Lack of support/patient advocacy | 33.3% (58) | 25.0% (5) |
| Unaware of services and resources | 48.3% (84) | 45.0% (9) |
| Difficulty with enrollment/admissions | 11.5% (20) | 5.0% (1) |
| Difficulty understanding process or paperwork | 29.9% (52) | 5.0% (1) |
| Difficulty with English language | 1.7% (3) | 5.0% (1) |
| Need help with financial management | 22.4% (39) | 25.0%" (5) |
| Other | 4.6% (8) | 0.0% (0) |
| Responses from total number of participants | 174 | 20 |

^{*}Participants chose multiple responses.

The differences between urban and rural respondents, as shown in Table 5, also present useful contrasts. Rural respondents reported "services not located locally" (54.9%) more often than urban respondents (27.8%). "Lack of support/patient advocacy" was also more of a problem in rural areas (45% rural vs. 28.7% urban). The urban group was more likely to report being "unaware of services and

resources" (55.6% urban vs. 41.2% rural). Urban areas also reported more difficulty getting support to "live where I want to live."

Table 5. Rural/Urban Comparison of Problems Accessing Services

| Responses | Urban | Rural | Total |
|---|-------|-------|-------|
| | (%/n) | (%/n) | (%/n) |
| Lack of Transportation | 37.0% | 35.3% | 35.1% |
| | (40) | (18) | (61) |
| Inability to Pay for Needed Services | 45.5% | 45.1% | 43.1% |
| | (47) | (23) | (75) |
| Don't Have Insurance | 17.6% | 13.7% | 14.9% |
| | (19) | (7) | (26) |
| Insurance Doesn't Cover Needed Services | 35.2% | 43.1% | 36.2% |
| | (37) | (22) | (63) |
| Services and Resources not Located Locally | 27.8% | 54.9% | 37.9% |
| | (30) | (28) | (67) |
| Don't Have Support to Live Where I Want to Live | 25.0% | 13.7% | 21.3% |
| | (27) | (7) | (37) |
| Don't Have Support to Find a Job | 29.6% | 29.4% | 29.9% |
| | (31) | (15) | (52) |
| Lack of Support/Patient Advocacy | 28.7% | 45.1% | 33.3% |
| | (29) | (23) | (58) |
| Unaware of Services And Resources | 55.6% | 41.2% | 48.3% |
| | (60) | (21) | (84) |
| Difficulty with Enrollment/Admissions | 13.0% | 9.8% | 11.5% |
| | (14) | (5) | (20) |
| Difficulty Understanding Process or Paperwork | 25.0% | 31.4% | 29.9% |
| | (27) | (16) | (52) |
| Difficulty with English Language | 1.9% | 2.0% | 1.7% |
| | (2) | (1) | (3) |
| Need Help with Financial Management | 20.4% | 25.5% | 22.4% |
| | (22) | (12) | (39) |
| Responses from total number of participants | 108 | 51 | 174 |

Professionals Who Need to Learn More about TBI

A majority of TBI survivors and family members (156 or 69%) indicated that they had met professionals who needed to learn more about TBI. Table 6 details which professionals needed to know more about TBI. Family doctors and emergency room doctors were selected most often, followed by nurses, law enforcement personnel, teachers, social workers, and discharge planners.

Table 6. Professionals Needing to Learn More about TBI

| Professionals | Responses (%/n) |
|---|-----------------|
| Medical/Hospital Personnel | |
| Emergency Room Doctor | 48.7% (76) |
| Family Doctor | 60.2% (94) |
| Nurse | 44.9% (70) |
| Discharge Planner | 40.1% (63) |
| Rehabilitation Personnel | |
| Physical Therapist | 32.0% (50) |
| Speech Therapist | 25.6% (40) |
| Occupational Therapist | 26.3% (41) |
| Rehabilitation Facility Administrator | 27.6% (43) |
| Educator/School Personnel | |
| School Nurse | 26.9% (42) |
| Teacher | 41.0% (64) |
| Principal | 27.6% (43) |
| Coach | 21.1% (33) |
| Community service Providers & Professionals | |
| Adult Brain Injury Program Provider | 20.5% (32) |
| Mental Health Professional | 32.7% (51) |
| Social Worker | 41.7% (65) |
| Vocational Rehabilitation Personnel | 30.1% (47) |
| Law Enforcement Personnel | 42.9% (67) |
| First Responders | 25.05 (39) |
| In-home Care Provider | 22.4% (35) |
| Military Service Personnel | 9.6% (15) |

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. As seen in Figure 24, among 157 participants who responded, "general knowledge about TBI," "specific knowledge about the needs of people with TBI," and "understanding cognitive changes" were perceived as the areas of greatest need.

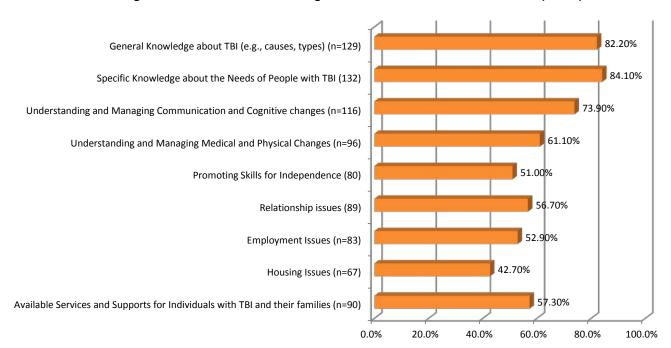


Figure 24. What Additional Training or Information do Professionals Need? (n=157)

Survivor/Family Survey Summary

Top Service Needs:

- Information & referral
- Recreational services
- Transportation services
- TBI support groups

Major Barriers to Accessing Services:

- Difficulty finding information
- Insurance and benefits limitations
- Inability to pay for services
- Services not located locally

Overall, TBI survivors and family members felt strongly that access to information, funding, and services needs to be improved. This includes information about the range of services that may be necessary, but just as importantly, it includes emotional/peer support for both family members and survivors.

Professional Needs Survey Results

Profile of Participating Professionals

As shown in Figure 25, the individuals who responded to the professional needs assessment survey questionnaire represent a diverse set of professions that directly and indirectly provide services to TBI survivors and their family members.

Figure 25. Professional Affiliation

Professionals who responded to the survey (629) were sub-divided into five categories, as shown in Table 7. School nurses are classified as a separate group because of their high number of responses.

Table 7. Professional Affiliation

| Medical/ Hospital Personnel (n=105) | |
|---|--------------------|
| Emergency Room Doctor | 0 |
| Family Doctor | 2 |
| Nurse | 95 |
| Discharge Planner | 0 |
| Hospital Administrator | 1 |
| Other Medical Personnel/Hospital Personnel | 7 |
| Therapy & Rehabilitation Personnel (n=41) | |
| Physical Therapist | 6 |
| Speech Pathologist | 9 |
| Occupational Therapist | 12 |
| Rehab Facility Administrator | 5 |
| Other Rehab/Therapy Personnel | 9 |
| Educator/School Personnel (n=2) | |
| Teacher | 11 |
| Principal | 2 |
| School Administrator | 33 |
| Coach | 1 |
| Other School Personnel | 8 |
| School Nurse (n=244)** | |
| | |
| Community Based Service Provider and Others (n=125) | |
| Community Based Service Provider and Others (n=125) Mental Health Personnel | 29 |
| | 29 |
| Mental Health Personnel | |
| Mental Health Personnel Military Service Personnel | 1 |
| Mental Health Personnel Military Service Personnel Vocational Rehab Personnel | 1 29 |
| Mental Health Personnel Military Service Personnel Vocational Rehab Personnel Law Enforcement Personnel | 1 29 13 |
| Mental Health Personnel Military Service Personnel Vocational Rehab Personnel Law Enforcement Personnel First Responder | 1 29 13 1 |

Some participants did not acknowledge their affiliation

In order to understand respondents' level of experience and knowledge regarding TBI, a series of questions was asked about how long they've been in their job, who they serve, what services they provide, and how they rate their own knowledge of TBI supports and services. The majority have been in their jobs for 5-10 years, with very few over 30 years or under 2 years. Within separate groups, this varies somewhat: more community providers have been in their jobs 1-3 years (28.4%), and more

rehabilitation personnel have been in their jobs over 10 years (43.6%) See Table C7, Appendix C for full data on each group.

Professionals were asked whether they serve only individuals with TBI or other populations as well.

Overall, 90% or more of respondents serve others in addition to individuals with TBI. Only among rehab personnel and community providers were there significant numbers serving only individuals with TBI. No education/school personnel reported serving only individuals with TBI.

Across all groups, the highest numbers of professionals indicated they served or had contact with 1-10 individuals with TBI in the last five years (2005-2010), with the exception of therapy & rehabilitation personnel. This group of professionals indicated that they served or had contact with over 100 individuals with TBI in the last five years. Within each group, with the exception of therapy & rehabilitation personnel, at least some professionals indicated they had not served or had contact with any individuals with TBI in the last five years. School nurses had the highest percentage (23.3%) reporting they have not served any individuals with TBI in the last five years. For detailed data on each professional group, see Table C8, Appendix C.

Type of Services Provided to Individuals with TBI: Figure 26 shows the type of service that respondents and their organizations provide to people with TBI. Supportive services and education/special education received the most responses, followed by clinical service. Neurobehavioral training received the fewest responses.

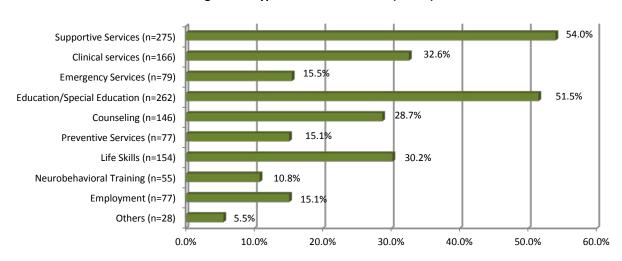


Figure 26. Type of Service Provided (n=509)

Knowledge Levels: Finally, professionals were asked to rate their own knowledge of available services and supports for individuals with TBI and their families (for complete table see Table C9, Appendix C). Medical professionals, education professionals, and school nurses most frequently ranked themselves as having minimal knowledge. Among rehabilitation personnel and community providers/others, the most frequent ranking was moderate knowledge. These two groups also had the highest percentages of "great deal of knowledge" responses (35% and 21.6%).

Among all participants, a total of 228 (41%) regarded themselves as having moderate to a great deal of knowledge about available services and supports for individuals with TBI and their families. A total of 334 (59%) reported having no knowledge or minimal knowledge.

Figure 27 compares the combined moderate/great deal and minimal/no knowledge categories of the five professional groups. Just 29.8% among medical/ hospital personnel, 22.5% among educator/ school personnel, and 25.5% among school nurses considered themselves to have moderate to a great deal of knowledge. In contrast, 77.5% of therapy & rehabilitation personnel and 63.3% among community based service providers & professionals considered themselves to have moderate to a great deal of knowledge about available services and supports for individuals with TBI and their families.

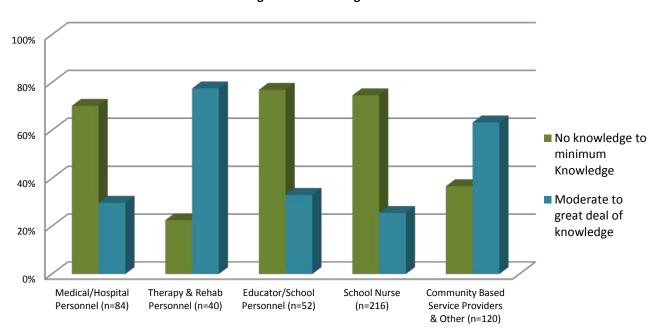


Figure 27. Knowledge Levels

Services and Supports

Adequacy of Service Ratings: Professionals who reported moderate or a great deal of knowledge were then asked to rate the adequacy of medical, rehabilitation, and community services as they currently exist and as they existed 5 years ago. In rating adequacy, they considered accessibility, quality, and appropriateness of service. Rating was done on a scale of 1 to 4: Very inadequate =1, somewhat inadequate =2, somewhat adequate =3, very adequate =4. Table 8 compares the rating average for each category of service 5 years ago and currently. (For the ratings of each individual service, see Table C10, Appendix C.)

Table 8. Adequacy of Services as Rated by Professionals

| | Rating Average 5 years ago Mean/(n) | Rating Average Currently Mean/(n) |
|---------------------------------|---|---|
| Medical/Hospital Services | 2.8 (1,022) | 3.2 (1,047) |
| Acute Rehabilitation | 2.7 (611) | 3.1 (622) |
| Community Services and Supports | 2.3 (3,181) | 2.5 (3,230) |

Medical/Hospital services were rated highest: The average satisfaction for medical care on a 4-point scale was 3.2, compared to 3.1 for acute rehab and 2.5 for community services. All services had a higher rating average for current services than services offered 5 years ago. The highest rating average was for "Hospital inpatient services" (3.4) and the lowest rating average was for "Section 8/Subsidized housing assistance" (2.3). Within the Acute Rehab category, home health (nursing or therapy) was rated lower than inpatient or outpatient rehabilitation. Community services were rated the lowest by professionals and by survivors/families.

Barriers to Service

"Unaware of services and resources" was considered the number one barrier by all groups except therapy & rehab personnel, who indicated "inability to pay for services" as the greatest barrier. Therapy & rehabilitation personnel and community service providers also ranked transportation substantially higher (66.7% and 74.1% respectively) than did other professionals. (For detailed tables of each professional group's responses, see Table C11 in Appendix C.)

Figure 28 shows the top six barriers identified by survivors and family members as compared to the top six barriers identified by professionals in Figure 29.

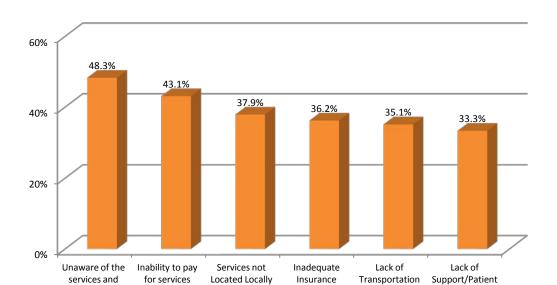
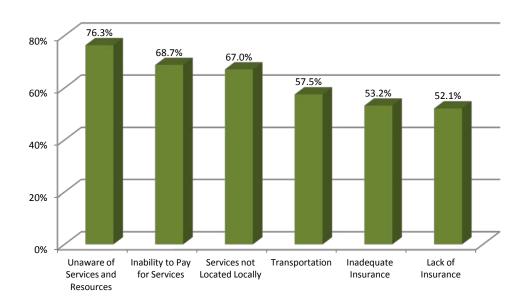


Figure 28. Barriers Indicated by Survivors and Families (n=174)



Advocacy

resources



Education and Training

To evaluate the ongoing education and training available to professionals and the community, four questions were asked of all the professionals. This section of the survey produced a large amount of data that invites a number of comparisons across professional groups regarding knowledge levels and access to training. Several key findings are listed in Table 9.

Table 9. Organizational Training Questions

| | Response Yes | Response No |
|--|-----------------|----------------|
| 1. Does your organization provide education or training to the community on TBI? (n=429) | 26.8% (115) | 73.2% (314) |
| 2. Did you receive TBI training as part of your professional/job training? (n= 488) | 45.1% (220) | 54.9% (268) |
| 3. Does your organization currently offer TBI training and information to staff (not from outside source)? (n=415) | 26.0% (108) | 74.0% (307) |
| 4. Do you or other staff within your organization access training or information regarding TBI from external sources? (n= 476) | 65.8% (313) | 34.2% (163) |

^{*} In Question 1, 60 participants responded as unsure and in Question 3, 74 responded as unsure.

Question 1: Does your organization provide education or training to the community on TBI? Of the five professional groups, only therapy & rehabilitation (57.6%) had a significant percentage providing community training. The next highest were the community-based providers/others, with 38.5%.

Question 2: Did you receive TBI training as part of your professional/job training? As seen in Table 10, therapy & rehabilitation professionals were most likely to receive TBI information as part of their professional training (78.8%). School nurses had the lowest percentage who received TBI training during job training (30.9%).

Table 10. Did You Receive TBI Training as Part of Your Professional Training?

| | Medical personnel %/(n) | Therapy & Rehabilitation %/(n) | Education %/(n) | School Nurses %/(n) | Community- Based/Other %/(n) | All groups %/(n) |
|-------|-------------------------------|--------------------------------------|--------------------|------------------------|------------------------------------|---------------------|
| Yes | 39.25% | 78.8% | 38.3% | 30.9% | 59.5% | 45.1% |
| | (29) | (26) | (18) | (55) | (66) | (220) |
| No | 60.8% | 21.2% | 61.7% | 69.1% | 40.5% | 54.9% |
| | (45) | (7) | (29) | (123) | (45) | (268) |
| Total | 74 | 33 | 47 | 178 | 111 | 488 |

Questions 3 and 4: Does your organization provide TBI training to staff, and Do you access external training regarding TBI? These questions are most interesting considered together. Groups that reported higher levels of knowledge tended to receive TBI training from their organization, while groups with less knowledge tended to access TBI training from external sources. Tables 11 and 12 further illustrate the relationships between knowledge level and type of training.

Table 11. Minimal to No Knowledge

| Community / Due feesie well Training | Professionals with no knowledge to minimal knowledge | | |
|---|--|--------------|--|
| Community/Professional Training | Yes %/(n) | No %/(n) | |
| 1. Does your organization provide education or training to the community on TBI? | 29% (91) | 71% (223) | |
| 2. Did you receive TBI training as part of your professional/job training? | 21% (56) | 79% (212) | |
| 3. Does your organization currently offer TBI training and information to staff (not from outside source)? | 32% (95) | 69% (212) | |
| 4. Do you or other staff within your organization access training or information regarding TBI from external sources? | 79% (129) | 21% (34) | |

Table 12. Moderate to a Great Deal of Knowledge

| Community/Professional Training | Professionals with moderate knowledge to a great deal of knowledge | | |
|---|--|----------------|--|
| | Yes %/(n) | No %/(n) | |
| 1. Does your organization provide education or training to the community on TBI? | 74% (85) | 26% (30) | |
| 2. Did you receive TBI training as part of your professional/job training? | 61% (134) | 39% (86) | |
| 3. Does your organization currently offer TBI training and information to staff (not from outside source)? | 73.1% (79) | 26.9% (29) | |
| 4. Do you or other staff within your organization access training or information regarding TBI from external sources? | 49.5% (155) | 50.5% (158) | |

Within each of the five professional groups, certain professionals were much more likely to receive TBI training as part of their professional education. Adult Brain Injury Program providers (86.7%), speech pathologists (77.7%), occupational therapists (75.0%), and vocational rehab personnel (72.4%) had the highest percentages. School nurses (22.5%) and nurses (29.5%) were the professions with the lowest percentage receiving TBI training during job training. (For details of training received by each profession, see Table C12, Appendix C.)

Overall, the data on training received corresponds with the survivor/family data regarding the additional training needs of professionals. The groups identified by survivors/families as needing more information (doctors, nurses, teachers, social workers, law enforcement) tend to be the same groups that rate themselves as having little knowledge about TBI. Type and source of training are also seen to be associated with professionals' self-reported knowledge levels.

Preferred method through which to obtain additional training and information to improve the capacity to serve people with TBI and their families.

Participants were asked to rate each training method individually on a scale from "very low preference" to "very high preference." While no one method stands out above the rest, in-service training was ranked slightly higher than the others and state conferences received the lowest ranking.

Professional Survey Summary

Top Needs of Survivors/Families:

• Improved access to information

- Increased funding for TBI services
- Increased insurance coverage
- Improved transportation services

Top Needs of Professionals

- One place to find out about all TBI resources
- General knowledge about TBI
- Resources for education professionals
- Training on community-based services

Professionals emphasized their own need for information about TBI supports and services to which they can refer individuals and families. They also cited the lack of services, especially transportation, in rural areas, and the difficulties that many survivors encounter with insurance, benefits, and inability to pay for services. Professionals expressed a preference for in-service and on-line training opportunities.

Qualitative Data

Overview

Both the survivor/family and the professional surveys included three open-ended questions where respondents had the chance to talk about their needs and experiences in their own words. This section summarizes the responses and offers some comparisons between the two surveys. The questions were worded the same or very similarly for each group:

- 1. In regards to needed services and supports, what do YOU think is working well for individuals with TBI and their families in Missouri?
- 2. *Survivor version:* What problems do you or your family member with TBI have in getting the services you need related to TBI?
 - *Professional version:* In your opinion, what barriers do individuals with TBI and their families face in accessing services and supports?
- 3. What additional comments do you have regarding how to improve statewide services and supports for individuals with TBI and their families?

Isolation

Taken together, responses to the three open-ended questions from both surveys present a theme of isolation experienced by survivors and family members. This trend is illustrated by comments about the social needs of survivors, lack of transportation, financial troubles, caregiver needs, and struggling alone to find information and resources. Both survivors/families and professionals also wrote that TBI is misunderstood by the public, which contributes to the sense of isolation.

Connection

In addition to needing specific services, people wrote about needing to find and connect with other survivors and families. Similarly, family members and survivors who wrote about nursing homes emphasized the social isolation as much as the lack of independence.

The comments about what is working well reinforce the importance of connectivity. Respondents expressed strong appreciation for support groups and other opportunities to "share experiences and ways of managing our new obstacles."

Solutions

Service coordination, funding, and education were identified in both surveys as avenues to address isolation and frustration. Both groups also talked about the need to educate the public to promote acceptance and inclusion of people with TBI in workplaces, schools, social settings, and housing.

Below is a summary of responses related to the continuum of care for TBI survivors and their families, as well as the training needs of professionals who serve them. The summary is organized according to the areas in the continuum of care:

- Medical and Hospital Services (e.g., Emergency Room, Doctors Office, Hospital)
- Acute Rehabilitation Services (e.g., Inpatient/Outpatient Rehabilitation, Home Health Services)
- Community Services (e.g., Housing, Employment, Recreation, Counseling)

Medical/Hospital

There were 30 responses from families and 21 from professionals related to medical care. In both surveys, respondents said that while medical care is very good, survivors and families returned home feeling extremely unprepared and not knowing where or to whom to turn for help. Survivors/families repeatedly said that medical personnel needed to communicate better with them about the ongoing effects of TBI and how to find the services that could help. They also wrote about emergency room doctors that did not recognize the TBI or the severity of the injury.

"Hospital had no idea how severe his injury was, sent us home and said to send him to school the next day. He had to drop out of school after the injury and still struggles." Family member

Professionals referenced advances in medical knowledge that have improved treatment and outcomes for TBI survivors. Both groups cited the need for more training for medical personnel.

"The acute care component is working well but the "forever care" is not." Professional

Acute Rehabilitation

Many comments praised the quality of inpatient and outpatient rehabilitation services and programs (12 from survivors/families and 26 from professionals). However, a large number of comments from both survivors/families (14) and professionals (17) highlighted the problem of insurance limits on rehabilitation. Both groups stressed that each TBI is unique and that access to therapy should be determined according to individual needs and not preset limits (maximum hours).

"The rehab facilities do a great job of assisting and getting you in contact with services." Family Member

"It's great. When I started I could not remember anything. Now I remember when I was a baby, can cook, clean and take care of myself. They couldn't believe how clean my house was and how I prepared my meal." Survivor "Therapy should be provided due to the person's health and not by insurance companies." Survivor

"Insurance will only cover 20 rehab visits per year...this is unfortunate as no two patients or their injuries are exactly the same" Professional

"She needs more PT for speech and to help with swallowing. Medicaid needs to continue with therapies." Family Member

Community Services

The bulk of qualitative responses focused on community supports and services. Many of these talked about the need for timely, easily accessible information about services.

Working Well: Survivors/families felt TBI support groups and the Brain Injury Association Conference were key sources of information as well as emotional and social support. Professionals felt service coordination worked well but said it is not available to all those who need it. Professionals consistently noted that survivors and families benefit from having one person to help access and manage the range of services and supports required.

The following list details some of the services mentioned as working well.

Survivor/Family

Service coordination (7) Public awareness (3) TBI support groups (13) BIA activities (13) Services in general (4) Vocational rehabilitation (7) Respite (2) Recreational/social services (2) In-home services (1) Mental health services (5)

Professional

Service coordination (33) Public awareness (22) TBI support groups (15) Services in general (10) Community living skills training (9) Vocational rehabilitation (7)) Information for professionals (7) In-home services (1) Mental health services (5) Services for and by schools (19)

Needs to be Improved: TBI survivors and family members, like professionals, felt strongly that access to information, education and funding needs to be improved. This included information about the range of services that may be necessary. Just as importantly, it included emotional/peer support for both family members and survivors. One survivor recommended "survivor outreach for new TBIs to assist and answer questions...and represent Hope."

Improvements to recreation, transportation, employment, mental health, and in-home services were also recommended. A number of comments pointed out the need for adequate in-home services to keep people out of nursing facilities. There were 12 responses commenting that these services are especially scarce in rural areas. Responses for this question are broken out by specific areas of concern.

Funding/Insurance/Benefits

In the survivor/family survey, 51 responses identified paying for services as a concern, whether because of limited insurance coverage, denial of benefits, or lost income due to the injury. Among professionals,

"Shorten the waiting list. Eliminate financial eligibility for paid services." Professional

there were 21 comments about funding problems; many referenced long waiting lists. In both surveys, people also mentioned the need for a TBI Medicaid waiver and for increased state funding, particularly for case management/service coordination.

"Funds for survivor and for family member who must care for them, therefore cannot be employed" Family Member

Education for Professionals

In the survivor/family survey, 15 narrative comments mentioned the need for professionals to know more about TBI. The majority of the comments had to do with the need for accurate and prompt diagnosis. But several also said that professionals need better understanding of the complex and ongoing needs of TBI survivors, and of the services and supports to which survivors should be referred.

They need to understand that people with TBI are slower to respond and need more time." Survivor

[&]quot;In-service training for all professionals who deal with people with TBI." Survivor

Professionals answered a separate question about their own training needs. The most frequent request was for all information about TBI services and supports to be easily accessible in one place.

General information about TBI (25)
Training on available resources (37)
Training on behavioral and social needs (14)
Training on needs of students with TBI (14)
Information about funding (6)
Information on navigating the service system (6)

"A single organization, office, or representative where someone can be directed."

"If we had a handbook, education tools, and community resource list, that would be terrific!"

"We need knowledge of how TBI affects students, how to support students, and how to help those students be successful."

"Benefits that are available to survivors and families and how to access them, with information that is easily understood and explained to individuals with TBI and their families."

Case Management/Service Coordination

Ten survivor/family comments and 11 professional comments called for improved access to service coordination. Survivors and families saw service coordination as a way to relieve the confusion and frustration of navigating a complex service system that often could not meet their needs. Many echoed the survivor who said, "All services and information post-hospital release I have painstakingly hunted down myself."

"Professionals need referral resources with exact names of people who can assist a family to navigate the service system for the first time." Professional "It would have been helpful to have someone walk us through TBI recovery." Family Member

Education/Support for Public, Survivors, Families

A total of 33 responses raised the issue of education and awareness. Both professionals and survivors/families praised recent awareness and prevention efforts. They also stressed the ongoing

need for community education that could target people living with TBI as well as the general public regarding TBI.

"The public needs to understand how TBI affects everyone." Survivor

"... We look ok on the outside but on the inside we are different." Survivor

"As soon as realistic for the survivor's family, let them know this fight is not theirs alone and there is a support system and people who care." Family Member

"More in-depth information for parents to help them realize that head hits during sports are serious." Professional

Psychological Needs of Survivor and Family

Mental health services were a concern in both surveys; people said the services were hard to find and often did not address the specific needs of TBI survivors. Family members also talked about their own stress and need for support. There were 12 survivor/family comments about psychological needs and 9 professional comments.

"He is dealing with depression, anger, and behavioral problems and we don't know where to turn." Family Member "Psychiatrist that specializes in TBI with emotional and anger issues affecting marriage." Family Member

"At our hospital, we have a real void in regards to behavioral/emotional counseling with both patients and families."
Professional

Transportation

Thirteen survivors/family members and 10 professionals mentioned the inadequacy of transportation services. Especially in rural areas, transportation is a major unmet need, according to these comments. However, even among urban/suburban respondents, this rated as a strong concern.

"Transportation was a problem. It became overwhelming driving to rehab, doctor, group etc. Clients had to be put on a waiting list OR it was very expensive. This aspect was draining." Family Member

"Transportation is such a significant barrier that its support needs should be reconsidered." Professional

"In our rural area, lack of transportation makes working impossible." Survivor

Need for Social Life/Recreation

Survivors and family members were more likely than professionals to call for additional recreation services (10 comments). Professionals did frequently say that social skills and the social needs of students with TBI were not adequately addressed (8 comments). Recreation was the greatest unmet need recorded in the quantitative data. These open-ended responses underscore the need for social and recreational outlets that connect TBI survivors with one another and with the larger community.

"Need someone his own age to visit him [in nursing home]. Most people are old there. Very sad to see someone who could do better not given tools to progress." Family Member

"Need recreational activities for young adults with TBI. This is a very isolating injury." Family Member

"Greater support and respect for agencies which provide social support, they are viewed as insignificant but they are vital to the TBI patients." Survivor

Other Services

A number of comments were received on a range of additional service needs. These are identified below along with some representative quotes.

Survivor/Family:

Housing (8)

Dental care (3)

Employment (4)

Need for post-acute follow-up care (4)

Professional
Need for post-acute follow-up care (13)
Needs of rural areas (6)
Housing (4)

"Many available services drop off after outpatient rehab. It would be beneficial to offer more services to assist with independent living and return to work." Professional

"Somebody to step in and help with huge housing problem." Survivor

"Improve job chances, prolong training, employers need to be more understanding." Survivor

"In rural areas, transportation and housing are not available, and therapeutic centers are more than an hour away" Professional

Appendix A

State and National TBI Incidence Data

TBI Data by Race and Age All Missouri data from Missouri Information for Community Assessment (MICA) Website

| Population | Missouri (Rate per 100,000 & | | 00,000 & | National |
|-----------------|------------------------------|---------|----------|---------------------------------|
| | | Number) | 1 | |
| | 2001 | 2005 | 2009 | |
| Total TBI | Rate | Rate | Rate | 1.7 million estimated annually* |
| | 227 | 237 | 255 | |
| | Number | Number | Number | |
| | 12,781 | 13,333 | 15,238 | |
| Age | | | | |
| Age 0-14 | Rate | Rate | Rate | 511,257 estimated annually |
| | 308 | 285 | 278 | |
| | Number | Number | Number | |
| | 3,633 | 3,340 | 3,284 | |
| Age 15-24 | Rate | Rate | Rate | |
| | 390 | 416 | 435 | |
| | Number | Number | Number | |
| | 3,130 | 3,500 | 3,658 | |
| Age 25-44 | Rate | Rate | Rate | |
| | 181 | 185 | 205 | 050 000 antimated annually |
| | Number | Number | Number | 950,899 estimated annually |
| | 2,927 | 2,890 | 3,192 | |
| Age 45-64 | Rate | Rate | Rate | |
| | 109 | 137 | 154 | |
| | Number | Number | Number | |
| | 1,414 | 1,992 | 2,446 | |
| Over 65 | Rate | Rate | Rate | 237,844 estimated annually |
| | 221 | 266 | 323 | , |
| | Number | Number | Number | |
| | 1,676 | 2,055 | 2,656 | |
| | | | | |
| | | | | |
| Race/Ethnicity* | 2001 | 2005 | 2009 | |
| | 2001 | 2005 | 2009 | |
| Black | Rate | Rate | Rate | 20% of total TBI** |
| | 249 | 239 | 244 | |
| | Number | Number | Number | |
| | 1,737 | 1,714 | 1,781 | |
| White | Rate | Rate | Rate | 67% of total TBI** |
| | 216 | 228 | 249 | |

| Population | Missouri (Rate per 100,000 & Number) | | 00,000 & | National |
|----------------|--------------------------------------|--------|----------|-------------------|
| | Number | Number | Number | |
| | 10,443 | 11,337 | 12,690 | |
| Hispanic (rate | Rate | Rate | Rate | 9% of total TBI** |
| not available) | 153.2 | 126.3 | 110.6 | |
| | Number | Number | Number | |
| | 223 | 241 | 239 | |

^{*2000-2006} compiled data from Centers for Disease Control
Data and Statistics Center database, 2011

TBI by Type, 2009

| Injury Type | Missouri | | National |
|--------------------|----------|-------|---------------------------|
| | Number | Rate | |
| Most serious | 4,628 | 74 | 75% mild/moderate (annual |
| Moderately serious | 10,131 | 173 | estimate, CDC) |
| Least serious | 479 | 8 | |
| Patient Type | Missouri | | National |
| Emergency Room | 4,222 | 67.5 | 1,365,000 |
| Inpatient | 11,016 | 187.6 | 275,000 |

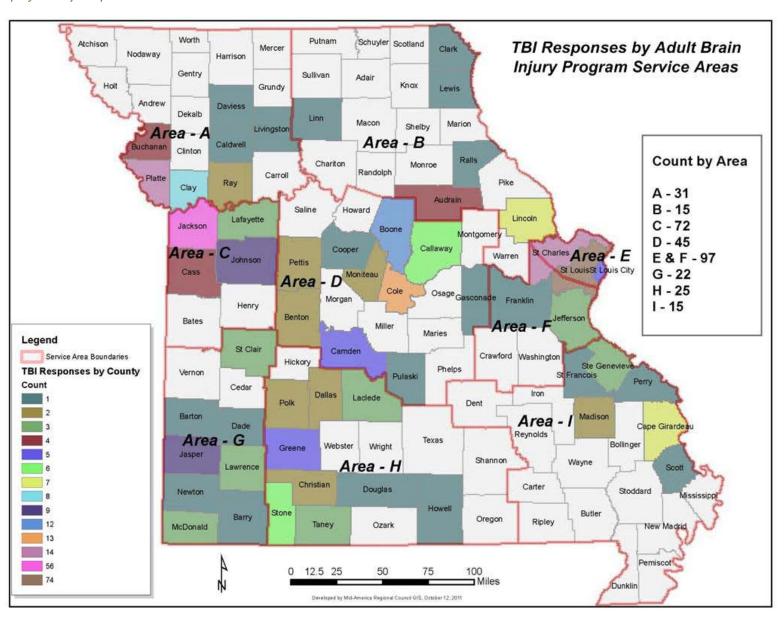
TBI by Disposition, 2009

| Disposition | | Miss | ouri | | National |
|---------------------------|--------|--------|--------|----------|-----------|
| | Total | White | Black | Hispanic | Not |
| Sent home | Number | Number | Number | Number | available |
| | 12,193 | 10,078 | 1,480 | 217 | |
| | Rate | Rate | Rate | Rate | |
| | 206.8 | 201.6 | 198.3 | 98.3 | |
| Transferred to acute care | Number | Number | Number | Number | |
| | 1,189 | 1,026 | 115 | 14 | |
| | Rate | Rate | Rate | Rate | |
| | 19.5 | 19.5 | 16 | 5.9 | |
| Transferred to SNF/ICF | Number | Number | Number | Number | |
| | 593 | 539 | 38 | 1 | |
| | Rate | Rate | Rate | Rate | |
| | 8.7 | 8.6 | 7.7 | 1.6 | |
| Transferred other | Number | Number | Number | Number | |
| | 601 | 527 | 51 | 4 | |
| | Rate | Rate | Rate | Rate | |
| | 9.5 | 9.5 | 8.1 | 2.1 | |
| Left hospital AMA | Number | Number | Number | Number | |
| | 135 | 107 | 19 | 2 | |
| | Rate | Rate | Rate | Rate | |
| | 2.3 | 2.1 | 2.8 | 1.0 | |

^{**}Percentages from the TBI National

APPENDIX B

Map of Survey Responses



Appendix C

Data Tables

Table C1. Disability/Health Conditions Present Before and After TBI (n=263)*

| rable et. Disability/ freatth conditions i resent before and Arter 151 (11-203) | | | | | |
|---|------------------------------|--------------------------------|--|--|--|
| Disability or Condition | Response Before TBI %/(n) | Response After TBI %/(n) | | | |
| Depression | 15.2% (40) | 62.0% (163) | | | |
| Post-traumatic stress disorder | 4.2% (11) | 30.4% (80) | | | |
| Other mental health conditions | 5.3% (14) | 30.8% (81) | | | |
| Sleep disorder | 4.6% (12) | 36.1% (95) | | | |
| Diabetes | 2.3% (6) | 7.2% (19) | | | |
| Seizure disorder | 2.7% (7) | 28.5% (75) | | | |
| Substance abuse (alcohol) | 12.2% (32) | 11.4% (30) | | | |
| Substance abuse (drugs) | 8.4% (22) | 6.1% (16) | | | |
| Chronic Pain | 5.7% (15) | 36.9% (97) | | | |
| Total number of participants | 263 | | | | |

Table C2. Impact of TBI on the Life of TBI Survivors and Family Members

| Area of Life | No Cha | ange | ls Bet | ter | ls W | orse |
|--|-----------------------|---------------------------|-----------------------|---------------------------|-----------------------|---------------------------|
| | TBI Survivor %/(n) | Family member %/(n) | TBI Survivor %/(n) | Family member %/(n) | TBI Survivor %/(n) | Family member %/(n) |
| Marriage TBI survivors (n=133) Family member (n=115) | 54.9% (73) | 47.8% (55) | 7.5% (10) | 7.8% (9) | 37.6% (50) | 44.3% (51) |
| Education TBI survivors (n=176) Family member (n=115) | 34.7% | 77.4% | 13.6% | 7.8% | 51.7% | 14.85 |
| | (61) | (89) | (24) | (9) | (91) | (17) |
| Employment TBI survivors (n=186) Family member (n=123) | 21.0% | 47.2% | 4.8% | 5.7% | 74.2% | 47.2% |
| | (39) | (58) | (9) | (7) | (138) | (58) |
| Income TBI survivors (n=186) Family member (n=123) | 23.1% | 41.5% | 7.0% | 4.1% | 69.9% | 54.5% |
| | (43) | (51) | (13) | (5) | (130) | (67) |
| Living situation TBI survivors (n=179) Family member (n=129) | 37.4% | 46.55 | 12.8% | 8.5% | 49.7% | 45.0% |
| | (67) | (60) | (23) | (11) | (89) | (58) |
| General health TBI survivors (n=188) Family member (n=130) | 24.5% | 42.3% | 9.0% | 6.2% | 66.5% | 51.5% |
| | (46) | (55) | (17) | (8) | (125) | (67) |
| Parenting TBI survivors (n=134) Family member (n=108) | 54.5% | 50.9% | 11.2% | 8.35 | 34.3% | 40.7% |
| | (73) | (55) | (15) | (9) | (46) | (44) |
| Psychological status TBI survivors (n=183) Family member (n=131) | 28.4% (52) | 37.4% (49) | 4.4% (8) | 5.3% (7) | 67.2% (123) | 57.3% (75) |

Table C3. Reason for Admission to the Nursing Facility (n=20)

| Reason*(n=20) | Response %/(n) |
|--|-------------------|
| Couldn't get the rehabilitation therapy I need (physical, speech, occupational, etc.) | 40.0% (8) |
| Couldn't get the medical care I need | 35.0% (7) |
| Insufficient financial resources | 30.0% (6) |
| Lack of needed specialized training and services (cognitive training, behavioral supports, community living skills training) | 30.0% (6) |
| Couldn't get the services (personal care, homemaking, etc.) | 25.0% (5) |
| Lack of employment | 25.0% (5) |
| Lack of access to transportation | 20.0% (4) |
| Lack of access to accessible and affordable housing | 15.0 % (3) |
| Lack of help coordinating and planning for services | 5.0% (1) |

Table C4. Reasons Preventing Return to the Community

| Reason (n=20) | Response |
|--|---------------|
| Insufficient financial resources | 55.0% (11) |
| Can't get the rehabilitation therapy I need (physical, speech, occupational, etc.) | 50.0% (10) |
| Can't get the in-home services I need (personal care, homemaking, etc.) | 45.0% (9) |
| Lack of employment | 35.0 % (7) |
| Don't have access to transportation | 35.0% (7) |
| Can't get the medical care I need | 30.0% (6) |
| Lack of access to accessible and affordable housing | 30.0% (6) |
| Need help coordinating and planning for services | 30.0% (6) |
| Need specialized training and services (cognitive training, behavioral supports, community living skills training) | 25.0% (5) |

Table C5. Community Services Received after Injury

| Table C3. Collinatility Services Received after | , , | | | |
|---|---|----------------------------------|---|--------------------------|
| Community Services and Supports | Currently receiving services (%/n) | Received in the past (%/n) | Needed service but did not receive (%/n) | Did not need (%/n) |
| Employment Services (n=233) | 21.0% | 24.5% | 22.3% | 32.2% |
| | (49) | (57) | (52) | (75) |
| In-home Services (n=226) | 17.7% | 11.5% | 15.9% | 54.9% |
| | (40) | (26) | (36) | (124) |
| Transportation Services (n=234) | 18.8% | 17.5% | 19.7% | 44.0% |
| | (44) | (41) | (46) | (103) |
| Service Coordination or Case Management (n=235) | 39.1% | 26.4% | 13.2% | 21.0% |
| | (92) | (62) | (31) | (50) |
| Treatment for Substance Abuse (n=234) | 3.8% | 9.8% | 5.1% | 81.2% |
| | (9) | (23) | (12) | (190) |
| Mental Health Counseling (n=238) | 26.9% (64) | 27.7% (66) | 14.7% (35) | 31.7% (73) |
| Use of Assistive Technologies (such as a communication board or wheelchair) (n=230) | 15.7% (36) | 21.7% (50) | 5.7% (13) | 57.0% (131) |
| Respite Care (n=208) | 5.8% | 7.7% | 12.0% | 74.5% |
| | (12) | (16) | (25) | (155) |
| TBI Support Groups (n=243) | 19.3% | 28.0% | 25.9% | 26.7% |
| | (47) | (68) | (63) | (65) |
| Assistance with Financial Management (n=235) | 14.5% | 8.9% | 26.4% | 50.2% |
| | (34) | (21) | (62) | (118) |
| Recreation Services (n=232) | 10.3% | 9.5% | 36.2% | 44.0% |
| | (24) | (22) | (84) | (102) |
| Legal Services (n=238) | 6.7% | 18.9% | 19.7% | 54.6% |
| | (16) | (45) | (47) | (130) |
| Section 8 or other Housing Assistance (n=227) | 8.4% | 2.2% | 22.5% | 67.0% |
| | (19) | (5) | (51) | (152) |
| Assistance applying for Social Security Disability Benefits (n=234) | 28.1% | 20.0% | 14.5% | 37.0% |
| | (66) | (47) | (34) | (87) |
| Continuing Education related to TBI (n=239) | 14.6% | 20.5% | 30.1% | 34.7% |
| | (35) | (49) | (72) | (83) |
| Community Living Skills Training (n=235) | 9.8% | 16.2% | 26.0% | 48.1% |
| | (23) | (38) | (61) | (113) |
| Information and Referral Services (n=232) | 19.4% | 25.4% | 32.3% | 22.8% |
| | (45) | (59) | (75) | (53) |
| | | | | |

Table C6. Time Since Injury Compared to Services Needed but Not Received

| Service Time since injury %/(n) | | | | | |
|---|---------------|---------------|--|--|--|
| | 0-10 years | Over 10 years | | | |
| Acute Rehabilitation Services | 0-10 years | Over 10 years | | | |
| | 21.0% | 22.4% | | | |
| Home Health (Nursing or Therapies) | (26) | (19) | | | |
| Increase Dala dell'Innellan | 11.6% | 16.5% | | | |
| Inpatient Rehabilitation | (16) | (15) | | | |
| Outpatient Rehabilitation | 9.0% | 16.5% | | | |
| | (12) | (15) | | | |
| Community Services and Support | | | | | |
| Recreation Services | 42.9% (54) | 28.0% (26) | | | |
| | 41.4% | 20.9% | | | |
| Information and Referral Services | (53) | (19) | | | |
| Continuing Education related to TPI | 35.9% | 20.2% | | | |
| Continuing Education related to TBI | (47) | (19) | | | |
| TBI Support Groups | 33.3% | 14.4% | | | |
| | (44) | (14) | | | |
| Assistance with Financial Management | 33.3% (43) | 15.2% (14) | | | |
| | 24.2% | 20.0% | | | |
| Employment Services | (31) | (18) | | | |
| Continue Courable of Haustine Assistance | 22.4% | 20.9% | | | |
| Section 8 or other Housing Assistance | (28) | (19) | | | |
| Legal Services | 20.9% | 18.7% | | | |
| | (27) | (16) | | | |
| Service Coordination or Case Management | 18.0% | 6.4% | | | |
| | (23) | (6) | | | |
| Transportation Services | 17.7% (23) | 24.2% (22) | | | |
| | 16.9% | 15.9% | | | |
| In-home Services | (21) | (14) | | | |
| Mental Health Counseling | 14.6% | 12.8% | | | |
| Wentai fleatti Counsellig | (19) | (12) | | | |
| Respite Care | 14.8% | 9.6% | | | |
| | (17) | (8) | | | |
| Assistance applying for Social Security Disability Benefits | 14.3% (19) | 12.4% (11) | | | |
| Use of Assistive Technologies (such as a communication board or | 5.4% | 6.9% | | | |
| wheelchair) | (7) | (6) | | | |
| Treatment for Substance Abuse | 4.6% | 4.4% | | | |
| Treatment for Substance Abuse | (6) | (4) | | | |

Table C7. Time in Current Position

| Years | Medical/ Hospital Personnel %/(n) | Rehabilitation Personnel %/(n) | Educator/ School Personnel %/(n) | School Nurse %/(n) | Community Service Providers & Professionals %/(n) | All Groups %/(n) |
|---------|--|--------------------------------------|---|-----------------------|---|---------------------|
| 0-1 | 2.9% | 0.0% | 0.0% | 0.4% | 6.0% | 2.0% |
| | (3) | (0) | (0) | (1) | (7) | (12) |
| 1-3 | 12.6% | 10.3% | 29.4% | 6.6% | 28.4% | 13.4% |
| | (13) | (4) | (15) | (15) | (33) | (80) |
| 3-5 | 24.3% | 12.8% | 17.6% | 23.3% | 17.2% | 23.4% |
| | (25) | (5) | (9) | (53) | (20) | (140) |
| 5-10 | 29.1% | 33.3% | 37.3% | 29.1% | 17.2% | 25.8% |
| | (30) | (13) | (19) | (66) | (20) | (154) |
| 10-15 | 11.7% | 23.1% | 3.9% | 22.0 % | 14.7% | 17.1% |
| | (12) | (9) | (2) | (50) | (17) | (102) |
| 15-20 | 12.6% | 5.1% | 7.8% | 12.3% | 6.9% | 11.2% |
| | (13) | (2) | (4) | (28) | (8) | (67) |
| 20-30 | 6.8% | 7.7% | 0.0% | 6.2% | 6.9% | 5.9% |
| | (7) | (3) | (0) | (14) | (8) | (35) |
| over 30 | 0.0% | 7.7% | 3.9% | 0.0% | 2.6% | 1.3% |
| | (0) | (3) | (2) | (0) | (3) | (8) |
| Total | 103 | 39 | 51 | 227 | 116 | 598 |

Table C8. The number of individuals with TBI that professionals have served or had contact with in the last five years (2005-2010)

| TBI survivors | Medical/ Hospital Personnel (%/n) | Therapy & Rehabilitation Personnel (%/n) | Educator/ School Personnel (%/n) | School Nurse (%/n) | Community Based Service Providers & Others (%/n) | All Groups (%/n) |
|------------------|--|---|---|-----------------------|--|---------------------|
| 0 | 20% | 0.0% | 3.8% | 23.3% | 3.3% | 13.8% |
| | (19) | (0) | (2) | (54) | (4) | (81) |
| 1-10 | 52.6% | 15.0% | 88.5% | 66.8% | 29.75 | 54.2% |
| | (50) | (6) | (46) | (155) | (36) | (319) |
| 11-20 | 7.4% | 5.0% | 5.8% | 7.3% | 17.4% | 9.7% |
| | (7) | (2) | (3) | (17) | (21) | (57) |
| 21-30 | 4.2% | 7.5% | 0.0% | 1.3% | 10.0% | 4.2% |
| | (4) | (3) | (0) | (3) | (12) | (25) |
| 31-40 | 2.1% | 5.0% | 0.0% | 0.4% | 3.3% | 2.4% |
| | (2) | (2) | (0) | (1) | (4) | (14) |
| 41-50 | 3.2% | 7.5% | 1.9% | 0.0% | 4.1% | 2.2% |
| | (3) | (3) | (1) | (0) | (5) | (13) |
| 51-60 | 1.1% | 2.5% | 0.0% | 0.4% | 4.1% | 1.5% |
| | (1) | (1) | (0) | (1) | (5) | (9) |
| 61-70 | 1.1% | 5.0% | 0.0% | 0.0% | 2.4% | 1.0% |
| | (1) | (2) | (0) | (0) | (3) | (6) |

| TBI survivors | Medical/ Hospital Personnel (%/n) | Therapy & Rehabilitation Personnel (%/n) | Educator/ School Personnel (%/n) | School Nurse (%/n) | Community Based Service Providers & Others (%/n) | All Groups (%/n) |
|------------------|--|---|---|-----------------------|--|---------------------|
| 71-80 | 1.1% | 0.0% | 0.0% | 0.0% | 2.4% | 0.7% |
| | (1) | (0) | (0) | (0) | (3) | (4) |
| 81-90 | 0.0% | 0.0% | 0.0% | 0.0% | 0.8% | 0.2% |
| | (0) | (0) | (0) | (0) | (1) | (1) |
| 91-100 | 2.1% | 0.0% | 0.0% | 0.4% | 4.1% | 1.4% |
| | (2) | (0) | (0) | (1) | (5) | (8) |
| Over 100 | 5.35 | 52.5% | 0.0% | 0.0% | 18.1% | 8.8% |
| | (5) | (21) | (0) | (0) | (22) | (52) |
| Total | 95 | 40 | 52 | 232 | 121 | 589 |

Table C9. Knowledge of Available Services and Supports for Individuals with TBI and their Families.

| Knowledge Level | Medical/ Hospital Personnel %/(n) | Therapy & Rehabilitation Personnel %/(n) | Educator/ School Personnel %/(n) | School Nurse %/(n) | Community Based Service Providers & Other %/(n) | All Groups %/(n) |
|---------------------------|--|---|---|-----------------------|---|---------------------|
| No knowledge | 11.9% | 0.0% | 7.7% | 14.4% | 4.2% | 9.3% |
| | (10) | (0) | (4) | (31) | (5) | (52) |
| Minimal | 58.3% | 22.5% | 69.2% | 60.2% | 32.5 | 50.2% |
| knowledge | (49) | (9) | (36) | (130) | (39) | (282) |
| Moderate | 26.2% | 42.5% | 19.2% | 23.6% | 41.7% | 31.0% |
| knowledge | (22) | (17) | (10) | (51) | (50) | (174) |
| A great deal of knowledge | 3.6% | 35.0% | 3.8% | 1.9% | 21.6% | 9.6% |
| | (3) | (14) | (2) | (4) | (26) | (54) |
| Total | 84 | 40 | 52 | 216 | 120 | 562 |

Table C10. Adequacy of Services as Rated by Professionals

| Medical/Hospital Services | Rating Average 5 years ago Mean (n) | Rating Average Currently Mean (n) |
|-------------------------------------|---|---|
| Emergency room services | 2.8 (206) | 3.3 (211) |
| Urgent care/Walk-in clinic services | 2.5 (202) | 3.0 (210) |
| | | |
| Doctor's office services | 2.7 (206) | 3.1 (209) |
| Hospital inpatient services | 3.0 (204) | 3.4 (206) |
| Hospital discharge planning | 2.6 (204) | 3.1 (211) |
| Group mean | 2.8 (1,022) | 3.2 (1,047) |
| Acute Rehabilitation | | |

| Inpatient rehabilitation | 3.0 (203) | 3.3 (207) |
|---|--------------------|--------------------|
| Home health (nursing or therapy) | 2.5 (202) | 2.9 (207) |
| Outpatient rehabilitation | 2.7 (204) | 3.0 (208) |
| Group mean | 2.7 (611) | 3.1 (622) |
| Community Services and Supports | | |
| Employment services | 2.2 (188) | 2.6 (192) |
| In-home services | 2.4 (191) | 2.7 (192) |
| Transportation services | 2.3 (187 | 2.4 (190) |
| Service coordination/Case management | 2.6 (189) | 3.0 (190) |
| Treatment for substance abuse | 2.2 (187) | 2.6 (189) |
| Mental health counseling | 2.3 (189) | 2.6 (192) |
| Assistive technology services | 2.5 (190) | 3.0 (189) |
| Respite care services | 2.2 (188) | 2.4 (191) |
| TBI support groups | 2.4 (187) | 2.8 (189) |
| Assistance with financial management | 2.1 (186) | 2.4 (192) |
| Recreation services | 2.1 (188) | 2.4 (190) |
| Legal Services | 2.1 (188) | 2.3 (190) |
| Section 8/Subsidized housing assistance | 2.1 (183) | 2.3 (188) |
| Access to social security disability benefits | 2.5 (188) | 2.8 (189) |
| Continuing education related to TBI | 2.3 (183) | 2.7 (188) |
| Community living skills training | 2.3 (183) | 2.5 (190) |
| Information and referrals | 2.5 (186) | 3.0 (189) |
| Group mean | 2.3 (3,181) | 2.5 (3,230) |
| | | |

Table C11. Barriers Faced by People with TBI and their Families in Accessing Services and Supports

| Barrier | Medical/ Hospital Personnel | Therapy & Rehabilitation Personnel | Educator/ School Personnel | School Nurse | Community Based Service Providers & Other | All Groups |
|---------------------------------------|-----------------------------------|--|----------------------------------|-----------------|---|---------------|
| Transportation | 55.2% | 66.7% | 50.0% | 48.1% | 74.1% | 57.5% |
| | (37) | (22) | (23) | (76) | (80) | (263) |
| Inability to pay for services | 67.2% | 90.9 % | 60.9% | 65.8% | 70.4 | 68.7% |
| | (45) | (30) | (28) | (104) | (76) | (314) |
| Lack of insurance | 49.3% | 78.8% | 41.3% | 51.9% | 52.8% | 52.1% |
| | (33) | (26) | (19) | (82) | (57) | (238) |
| Inadequate insurance | 52.2% | 84.8% | 56.5% | 51.9% | 47.2% | 53.2% |
| | (35) | (28) | (26) | (82) | (51) | (243) |
| Services not located near their homes | 61.2% | 72.7% | 65.2% | 67.1% | 71.3% | 67.0% |
| | (41) | (24) | (30) | (106) | (77) | (306) |

| Barrier | Medical/ Hospital Personnel | Therapy & Rehabilitation Personnel | Educator/ School Personnel | School Nurse | Community Based Service Providers & Other | All Groups |
|---|-----------------------------------|--|----------------------------------|-----------------|---|---------------|
| Inadequate support to live in setting of choice | 32.8% | 75.6% | 13.0% | 29.1% | 45.4% | 35.9% |
| | (22) | (19) | (6) | (46) | (49) | (164) |
| Inadequate support to find employment | 34.3% | 54.5% | 34.8% | 30.4% | 45.4% | 37.9% |
| | (23) | (18) | (16) | (48) | (49) | (173) |
| Lack of support/patient advocacy | 35.8% | 15.2% | 23.9% | 25.9% | 38.9% | 30.2% |
| | (24) | (5) | (11) | (41) | (42) | (138) |
| Unaware of services and resources | 76.1% | 78.8% | 71.7% | 70.9% | 84.2% | 76.3% |
| | (51) | (26) | (33) | (112) | (91) | (349) |
| Difficulty with enrollment/ Admissions | 16.4% | 18.2% | 13.0% | 19.0% | 31.5% | 22.3% |
| | (11) | (6) | (6) | (30) | (34) | (102) |
| Difficulty understanding paperwork | 28.4% | 51.5% | 34.8% | 34.2% | 61.1% | 44.8% |
| | (19) | (17) | (16) | (54) | (66) | (201) |
| Difficulty with English language | 7.5% | 9.1% | 2.2% | 7.6% | 5.6% | 7.4% |
| | (5) | (3) | (1) | (12) | (6) | (34) |
| Need help with financial management | 41.8% | 54.5% | 37.0% | 39.2% | 56.5% | 45.5% |
| | (28) | (18) | (17) | (62) | (61) | (208) |
| Others | 6 | 0 | 2 | 6 | 16 | 30 |
| Responses from total number of participants | 67 | 33 | 46 | 158 | 108 | 457 |

Table C12. Professionals Receiving Training

| Table C12. Professionals Receiving Training | | | | | |
|---|------------------------------|--|--|--|--|
| Medical/ Hospital Personnel (n=105) | Total number of participants | Received training as part of professional/job training %/(n) | | | |
| Family Doctor | 2 | 0% (0)* | | | |
| Nurse | 95 | 29.5% (28) | | | |
| Hospital Administrator | 1 | 100% (1)* | | | |
| Other Medical Personnel/Hospital Personnel | 7 | 0% (0)* | | | |
| Therapy & Rehabilitation Personnel (n=41) | | | | | |
| Physical Therapist | 6 | 50% (3) | | | |
| Speech Pathologist | 9 | 77.8% (7) | | | |
| Occupational Therapist | 12 | 75% (9) | | | |
| Rehab Facility Administrator | 5 | 60% | | | |
| Other Rehab/Therapy Personnel | 9 | 44.4% (4) | | | |
| Educator/School Personnel (n=55) | | | | | |
| Teacher | 11 | 18% (2) | | | |
| Principal | 2 | 0% (0)* | | | |
| School Administrator | 33 | 39.4% (13) | | | |
| Coach | 1 | 100% (1) | | | |
| Other School Personnel | 8 | 25% (2) | | | |
| School Nurse (n=244) ** | | | | | |
| School Nurse | 244 | 22% (55) | | | |
| Community Based Service Provider and Others (n=125) | | | | | |
| Mental Health Personnel | 29 | 41.3% (12) | | | |
| Military Service Personnel | 1 | 0% (0)* | | | |
| Vocational Rehab Personnel | 29 | 72.4% (21) | | | |
| Law Enforcement Personnel | 13 | 23.1% | | | |
| First Responder | 1 | 0% (0)* | | | |
| Social Worker | 37 | 45.9% (17) | | | |
| Adult Brain Injury Program Provider | 15 | 86.7% (13) | | | |