

***2020 Missouri Traumatic Brain Injury  
Targeted Needs Assessment:  
Key Findings Report***

*Report on the TBI Survivor and Family Needs Assessment Survey*


June 24, 2020

Submitted to:



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Submitted by:

  
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## Executive Summary

In 2018, the Missouri Department of Health and Senior Services (DHSS) was awarded the three-year Missouri Traumatic Brain Injury (TBI) Partnership Grant, funded by the Administration for Community Living (ACL). In partnership with the Missouri Brain Injury Advisory Council (MBIAC), the Brain Injury Association of Missouri (BIA-MO), the University of Missouri Kansas City Institute for Human Development (UMKC-IHD), the overall goal of the project is *to maximize the independence, well-being, and health of individuals with TBIs and their families within Missouri*. Each year, the evaluation team at UMKC-IHD will gather targeted assessment data; we will use the results to draft an *Annual State Plan*. The current report presents findings from the Year 2 *Targeted Annual Needs Assessment*, conducted with 173 TBI survivors and families between mid-February and late April of 2020.

Development of the current needs assessment was guided by findings the 2017 *Five Year Needs Assessment*. According to the results, over a quarter of TBI survivors and their families reported having unmet service needs in the following areas: information and referral, recreation services, continuing education related to TBI, financial management, TBI support groups, and service coordination. The aim of the Year 2 *Targeted Annual Needs Assessment* is to better understand how to address unmet needs of TBI survivors and their families in the identified service areas.

### Key Findings

#### *Information and Referral*

- Over 70% of respondents identified at least one unmet information and referral need
- Most common unmet needs: counseling services (30.0%), advocating for accessing services (29.4%), support groups (26.3%), and transportation (25.0%)
- Among those who reported no unmet needs, over 75% stated that either their information and referral needs were already met or they never had needs

#### *Recreation Services*

- Almost 65% of respondents identified at least one unmet recreation services / access need
- Most common unmet needs: social (40.5%), physical (32.2%), transportation to activities (29.7%), life skills / community integration (28.5%), sports (24.7%), nature (20.3%)

#### *Continuing Education Related to TBI*

- Almost 85% of respondents identified at least one unmet continuing education need
- Over 50% identified unmet continuing education needs related to aging with brain injury
- Over a third identified unmet continuing education needs related to coping or adjustments to living with TBI (44.6%), changes in relationships (38.0%), ongoing care / support (36.1%), managing behaviors (34.3%), and mental health challenges (34.3%)

### *Assistance with Financial Management*

- Almost 55% of respondents identified at least one unmet financial management need
- Most common unmet needs: budgeting (26.1%), securing financial assistance to access services (22.9%), and securing financial assistance to pay bills (17.6%)

### *TBI Support Groups*

- Nearly 25% of respondents attend weekly or monthly support group meetings
- Over half either had never attend a support group meeting (35.3%) or had not attended in over a year (21.6%)
- Most common reasons for not attending: no support groups held in respondents' area (25.5%), inconvenient meeting times (22.3%), and transportation challenges (21.3%)
- Several respondents reported a lack of awareness about support groups

### *Service Coordination*

- Over 43% reported not having a service coordinator through DHSS or another program
  - Over 45% reported that they did not know how to get one
  - About a quarter reported that they did not want or need one
- Many did not know whether they had a service coordinator through either
- Nearly a quarter reported having a DHSS ABI service coordinator and almost 30% reported having a service coordinator through another program
  - 75% said he/she links them to information and resources that meet their needs

### *Preferences for Sharing Information*

- Respondents typically learn about TBI-related services through the BIA-MO (46.1% vs. 57.7% who prefer this way), support groups (27.9% vs. 39.9% who prefer this way), professionals (27.9% vs. 50.3% who prefer this way), websites (27.9% vs. 38.0% who prefer this way), and service coordinators (25.5% vs. 45.5% who prefer this way)

### *Barriers to Services and Supports*

- 80% of reported experiencing at least one barrier related to accessing TBI services and supports
- Over 25% currently experiencing at least one of the following barriers: unaware of services and resources, difficulty understanding process or paperwork, inability to pay for needed services, and lack of transportation

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*“We need [support] groups that navigate and push one another over the battles.”*

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## Background

In 2018, the Missouri Department of Health and Senior Services (DHSS) was awarded the three-year Missouri Traumatic Brain Injury (TBI) Partnership Grant, funded by the U.S. Department of Health and Human Resources, Administration for Community Living (ACL). The overall goal of the project is *to maximize the independence, well-being, and health of individuals with TBIs and their families within Missouri*. Project objectives and outcomes include:

1. Increasing collaborations;
2. Enhancing Missouri's person-centered system of services;
3. Improving individual and family supports, access to local, state and federal resources, and the capacity of professionals to serve individuals with TBI and their families;
4. Linking of individuals with TBI to needed services through an enhanced State Registry; and
5. Promoting ongoing quality improvement and sustainability

Over the course of this project, the Missouri DHSS, in partnership with the Missouri Brain Injury Advisory Council (MBIAC), the Brain Injury Association of Missouri (BIA-MO), the University of Missouri Kansas City Institute for Human Development (UMKC-IHD), and other key stakeholders, will expand access to a comprehensive and coordinated system of services and supports for individuals with traumatic brain injury (TBI). Individuals with TBI and their families will be involved in all aspects of this initiative as advisors, staff, and as participants in topical workgroups.

## Targeted Annual Needs Assessment

For each year of the proposed project, the evaluation team at UMKC-IHD will gather targeted assessment data for priority areas where we have gaps in information; we will use the results to draft an action-oriented *Annual State Plan*. Project partners identified community service providers and professionals as the target population for Year 1 of the *Targeted Annual Needs Assessment*, based on results from the statewide *Five Year Needs Assessment* conducted in 2017 with Missouri's TBI survivors, their families, and service professionals (Gotto, Barton, Chiang, & Clark, 2018). These professionals were selected as the target population because in 2017 (1) response rates were relatively low from this population and (2) survey respondents

specifically identified community service providers and professionals as needing additional training on TBI, especially related to managing cognitive changes and available services. The aim was to gather additional information from these professionals on their role in supporting TBI survivors and families, as well as on training and resource needs. Results from the Year 1 *Targeted Annual Needs Assessment* were presented in a report and used to draft our first action-oriented *Annual State Plan*. The current report presents findings from the Year 2 *Targeted Annual Needs Assessment*, conducted with TBI survivors and families between mid-February and late April of 2020.

## Methods

Development of the Year 2 *Targeted Annual Needs Assessment* was also guided by findings the 2017 *Five Year Needs Assessment* ( $n=276$ ). According to the results, between about a quarter to a third of TBI survivors and their families reported having unmet service needs (“needed but did not receive”) in the following areas: information and referral (37.3%), recreation services (30.8%), continuing education related to TBI (29.3%), assistance with financial management (29.0%), TBI support groups (28.6%), and service coordination (24.6%). Based on these results, the aim of the Year 2 *Targeted Annual Needs Assessment* is to better understand how to address unmet needs of TBI survivors and their families in the identified service areas. Survey items were developed to identify specific information, resource, or assistance needs, explore barriers associated with unmet service needs, and investigate effective methodologies for communication and information sharing.

The survey includes 29 questions regarding TBI survivors’ demographics, health status, preferences for receiving information, and unmet needs and associate barriers in the follow services areas: information and referral recreation services, continuing education related to TBI, assistance with financial management, TBI support groups, and service coordination. The Year 2 *Targeted Annual Needs Assessment* survey was distributed to TBI survivors and their family members through a variety of channels, where links to the online version and paper copies were disseminated throughout the state by support coordinators, service provider organizations, and at support group meetings, via DHSS Brain Injury Program, BIA-MO, and MBIAC listservs. The survey was voluntary and anonymous and took approximately 20 minutes to complete.

## Results

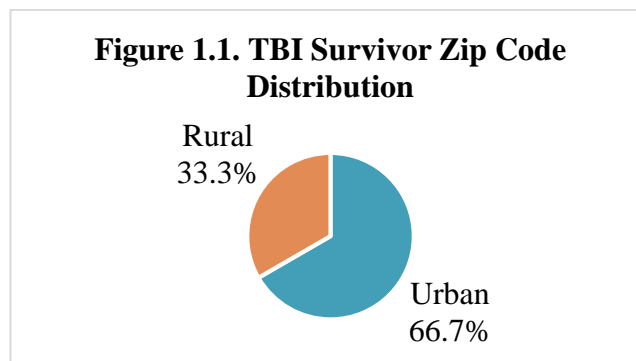
### Section 1. Demographics

A total of 173 TBI survivors and family members completed Year 2 *Targeted Annual Needs Assessment* survey online ( $n=150$ ) or via hard copy ( $n=23$ ). Almost 53% ( $n=91$ ) of respondents identified as a person with a TBI, whereas 34.1% identified as a family member of a person with a TBI, 12.1% identified as “other,” and 1.2% did not respond. Table 1.1 displays the demographic profile of TBI survivors represented in the survey.

<i>TBI Survivor Characteristics</i>	<i>n</i>	<i>%</i>
<i>Age</i>		
Child with TBI (0-14 yrs. old)	6	3.5
Youth with TBI (15-20 yrs. old)	2	1.2
Adult with TBI (21-64 yrs. old)	141	81.5
Older adult with TBI (65 yrs. or older)	11	6.4
Missing	13	7.5
<i>Gender</i>		
Female	71	41.0
Male	96	55.5
Missing	6	3.5
<i>Ethnicity</i>		
Not Hispanic or Latino	159	91.9
Hispanic or Latino	7	4.0
Missing	7	4.0
<i>Race</i>		
White	148	85.5
Black or African American	11	6.4
Asian or Asian American	3	1.7
American Indian or Alaska Native	2	1.2
Native Hawaiian or Pacific Islander	1	0.6
Other	6	3.5
<i>Military service</i>		
Never a military service member	149	86.1
Former military service member	11	6.4
Current military service member	2	1.2
Missing	11	6.4

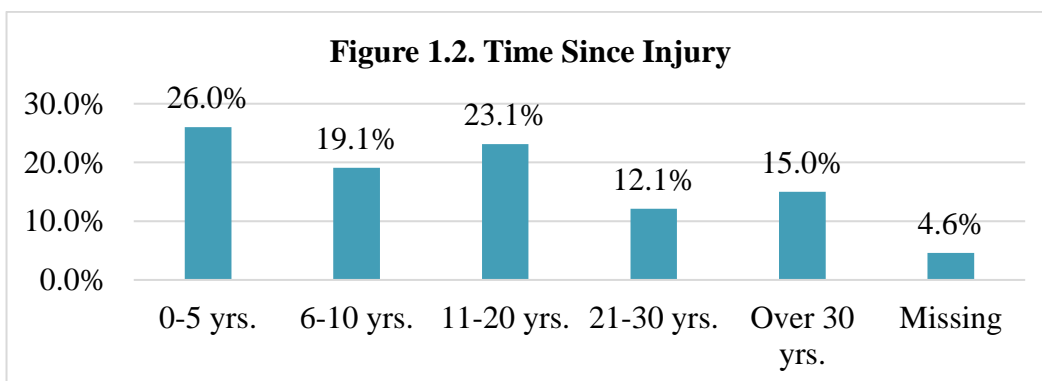
The majority of TBI survivors represented in the survey were between the ages of 21 and 64 years old (81.5%) and just over half were male (55.5%). The majority of TBI survivors identified as white (85.5%) and Not Hispanic or Latino (91.9%) and fewer than 10% identified as a current or former military service member.

Respondents ( $n=153$ ) identified 93 zip codes in 37 Missouri counties. Missouri counties were categorized into urban and rural, guided by the Census Bureau criteria used by Missouri Information for Community Assessment (MICA). Urban counties are defined as those with a population density over 150 persons per square mile, plus any county that contained at least part of the central city of a Census-defined Metropolitan Statistical Area (MSA). Using this definition, eleven Missouri counties were classified as urban. The remaining 26 counties in Missouri were considered rural. As shown in Figure 1.1, about 66% of TBI survivors reportedly reside in urban areas.



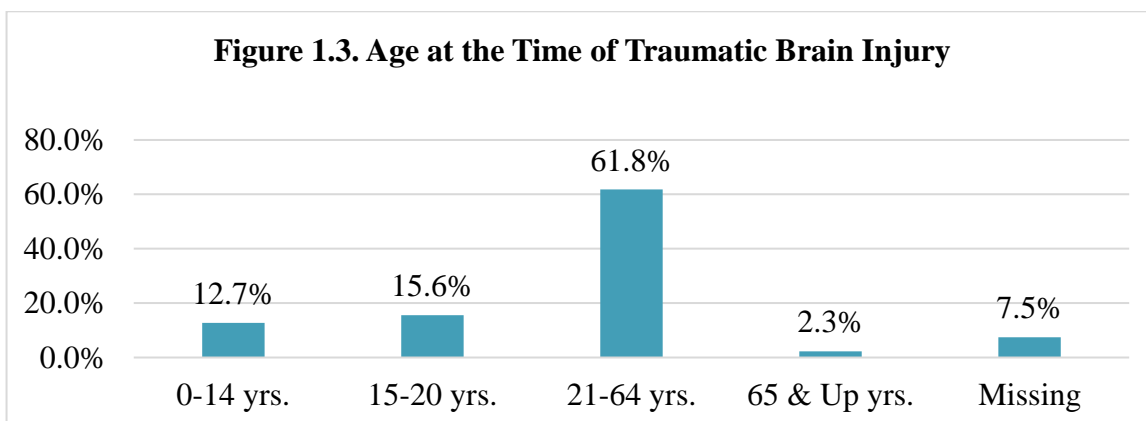
### ***TBI and Other Health Conditions***

Figure 1.2 displays approximate amount time since the traumatic brain injury occurred, reported years ranged from 1962 to 2017.



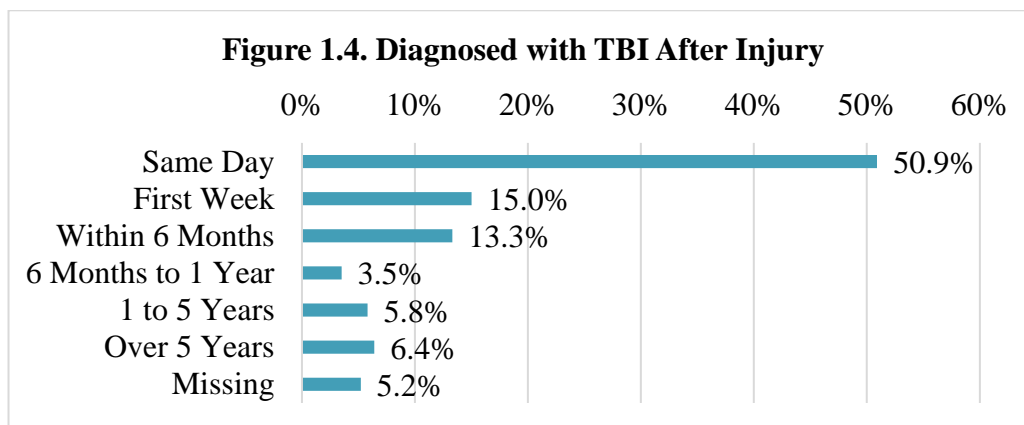
Over 25% of survivors experienced their TBI within the last five years. Additionally, about 19% of reported injuries occurred 6-10 years ago and 23% occurred 11-20 years ago. More than 27% of survivors experienced their TBI over 20 years ago.

Figure 1.3 shows the age range of the TBI survivors at the time of the injury.



Over half of the survivors reported experiencing the injury in adulthood (61.8%), followed by youth (15.6%), childhood (12.7%), and older adulthood (2.3%).

Figure 1.4 shows how long after the injury survivors were diagnosed with a TBI.



About half of the TBI survivors (50.9%) reported that they were diagnosed with a TBI the same day as the injury, whereas 15% reported diagnosis in the first week. Interestingly, almost 30% of respondents reported that diagnosis occurred more than a week after injury, with over half of those (54.0%;  $n=27$ ) occurring after 6 months.

Table 1.2 displays a comparison of significant health conditions that survivors reported experiencing before and after the TBI occurred.



**Table 1.2. Health Conditions Before and After Injury**

	Before		After		Change
	n	%	n	%	% Δ
<b>Language</b>	6	3.5	94	54.3	1467%
<b>Sensory</b>	5	2.9	78	45.1	1460%
<b>Cognitive</b>	15	8.7	144	83.2	860%
<b>Physical</b>	14	8.1	115	66.5	721%
<b>Chronic pain</b>	12	6.9	77	44.5	542%
<b>Behavior change</b>	17	9.4	106	61.3	524%
<b>Seizure disorder</b>	7	4	42	24.3	500%
<b>Sleep disorder</b>	18	10.4	76	43.9	322%
<b>PTSD</b>	15	8.7	50	28.9	233%
<b>Diabetes</b>	3	1.7	10	5.8	233%
<b>Depression</b>	44	25.4	108	61.3	145%
<b>Other mental health</b>	32	18.5	75	43.4	134%
<b>Substance use disorder (drugs)</b>	14	8.1	8	4.6	-43%
<b>Substance use disorder (alcohol)</b>	24	13.9	18	10.4	-25%

The average number of identified health condition increased from 1.4 ( $SD=2.1$ ) before injury to 5.9 ( $SD=3.1$ ) after injury. In general, more TBI survivors reported experiencing the identified health conditions after their injury occurred, compared to before injury. For example, the number of survivors experiencing language (e.g. communication, expression, and understanding) or sensory conditions increased by over 1400% post-injury. There was also an increase in the number of survivors experiencing the following conditions after injury, compared to before: cognitive (memory, processing, problem solving, +860%), physical (balance, other mobility, +721%), chronic pain (+542%), behavior / personality change (e.g. acting out, aggression, social inappropriateness, +524%), seizure disorder (+500%), sleep disorder (+322%), PTSD (+233%), diabetes (+233%), depression (+145%), and other mental health conditions (+134%).

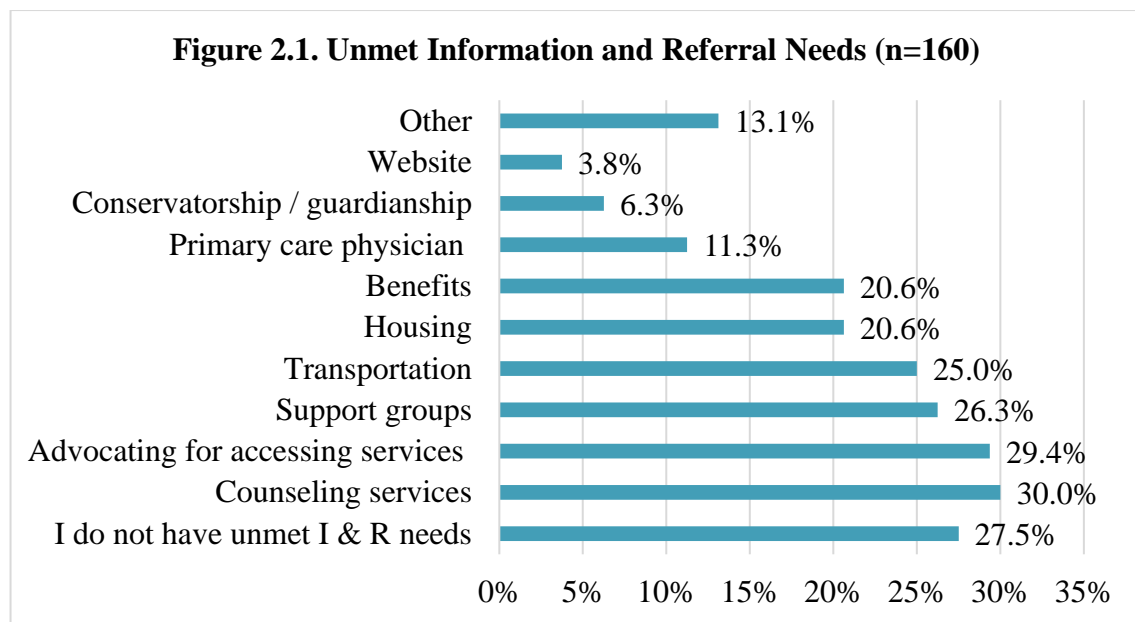
Interestingly, the number of TBI survivors reporting substance use disorder after their injury, compared to before, decreased by 43% for drugs and 25% for alcohol. This finding warrants further study.

## Section 2: Targeted Annual Needs Assessment Results

As noted earlier, development of the current *Targeted Annual Needs Assessment* was guided by findings the 2017 *Five Year Needs Assessment* ( $n=276$ ) which showed that between about a third to a quarter of TBI survivors and their families reported having unmet service needs (“needed but did not receive”) in six service areas. The six service areas include *information and referral, recreation services, continuing education related to TBI, assistance with financial management, TBI support groups, and service coordination*. Based on these results, the aim of the current *Targeted Annual Needs Assessment* is to better understand how to address unmet needs of TBI survivors and their families in the identified service areas. Results of this assessment are outlined below.

### *Information and Referral*

Figure 2.1 displays the responses selected when respondents were asked to identify information and referral needs (respondents were asked to select all that apply).

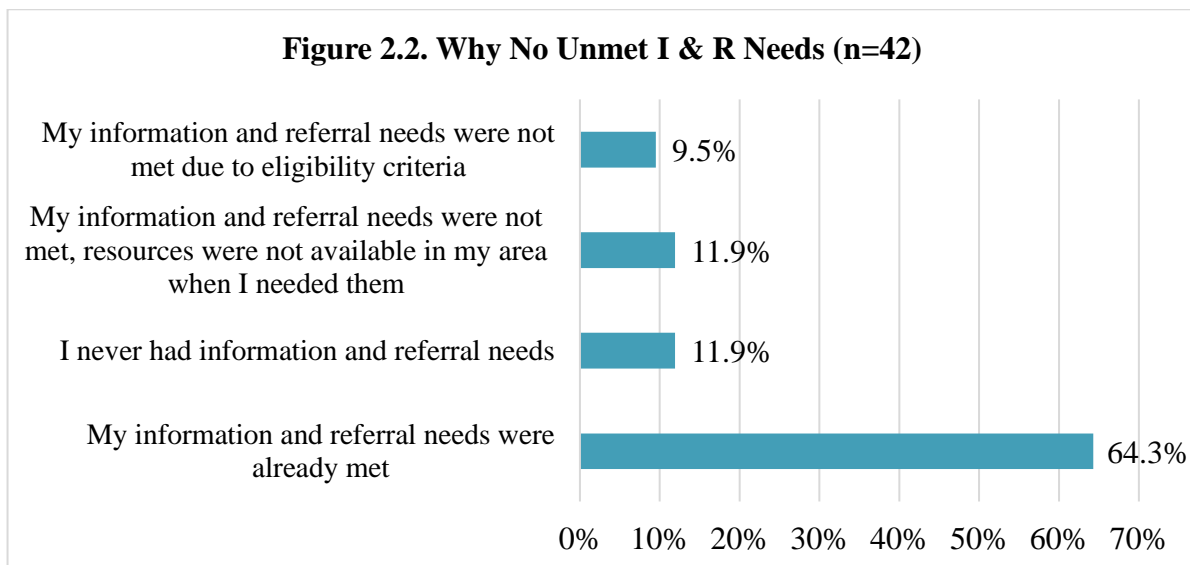


About a quarter (27.5%) of the 160 participants who responded to this item reported having no unmet needs. Thus, over 70% of respondents identified at least one unmet information and referral need, with a range of between one and seven response items selected (of 11 possible options,  $M=2.2$ ,  $SD=1.4$ ). The most frequently identified unmet information and referral needs include: counseling services (30.0%), advocating for accessing services (29.4%), support groups

(26.3%), transportation (25.0%), housing (20.6%), and benefits (Medicare / Medicaid / Social Security; 20.6%).

Among those who selected that they had “other” information and referral needs ( $n=21$ ), multiple respondents identified needing benefit specific information on SSDI, Medicare, and coverage of / access to medication and therapy. Respondents also reported needs related to identifying local medical providers who specialize in TBI, such as a physiatrist, integrative practitioner / nutritionist, and functional neurologist. Additional areas of unmet information and referral needs identified by respondents include finding local support groups, meeting basic financial and dietary needs, employment, legal / rights, personal assistance / in-home supports, and future planning. Related to future planning, one participant expressed concern about what might happen if the survivor’s primary caregiver passes away, “We have no one to jump in and take care of financial needs, paperwork, doctor [appointments], groceries.”

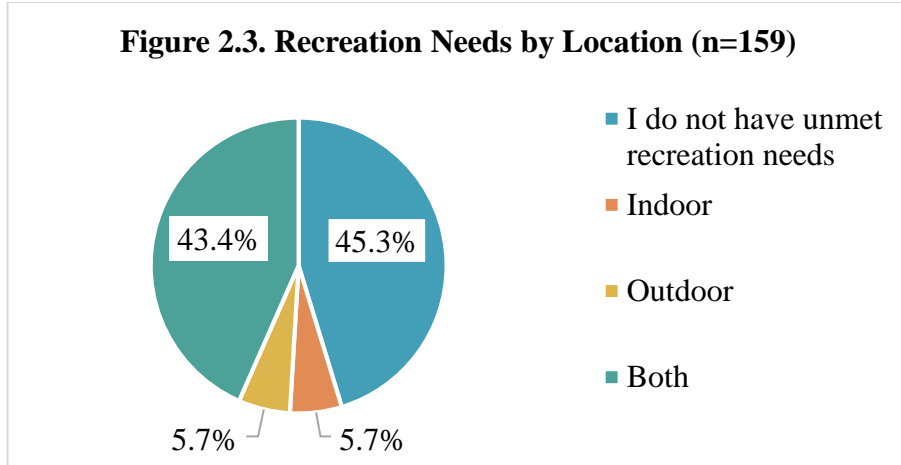
Figure 2.2 outlines reasons why respondents reported that they had no unmet needs (respondents were asked to select all that apply).



Among the 42 respondents who reported having no unmet needs and who responded to the follow up question, most (64.3%) stated that their information and referral needs were already met and another almost 12% reported that they never had information and referral needs. Others reported having unmet information and referral needs because resources were not available in their area when they needed them (11.9%) or due to eligibility criteria (9.5%).

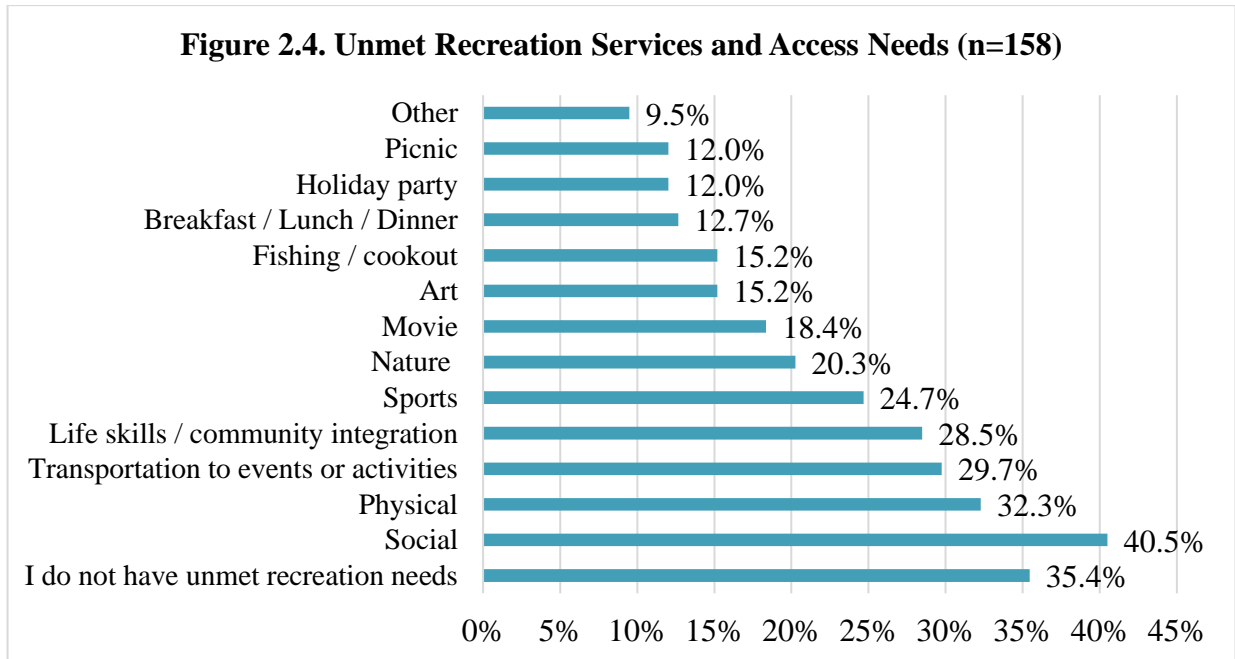
**Recreation Services**

Recreation services needs were explored in two ways; results are outline in Figures 2.3 and 2.4. Figure 2.3 displays recreation services needs by location preference.



Among the 159 item respondents, about 45% reported having no unmet, whereas almost 44% reported having both indoor and outdoor recreation services / access needs.

Figure 2.4 displays recreation services or access needs by recreational activity.

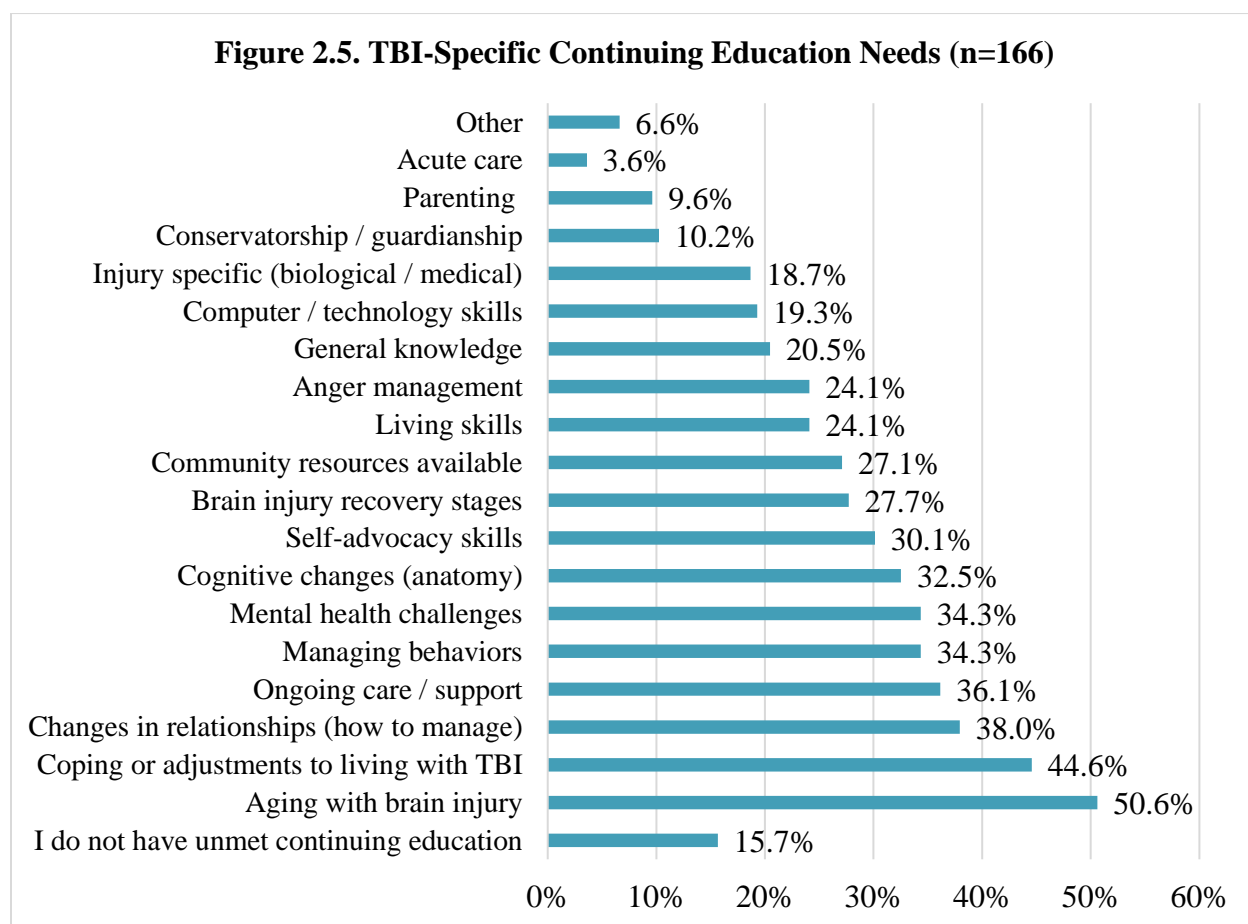


Over a third (35.4%) of the 158 participants who responded to this item reported having no unmet needs. Thus, almost 65% of respondents identified at least one unmet recreation services

or access need, with a range of between one and twelve response items selected (of 13 possible options,  $M=4.2$ ,  $SD=3.1$ ). The most frequently identified areas where participant reported having unmet recreations service or access needs include social (40.5%, e.g. meet or spend time with others), physical (32.2%, e.g. exercise), transportation to recreational events or activities (29.7%), life skills / community integration (28.5%, e.g. cooking, behaviors, etc.), sports (24.7%, e.g. swimming, basketball), and nature (20.3%). “Other” write-in suggestions include horse therapy, cave tours, hunting (firearms and archery), and rural options or transportation to out of town events and activities. Interestingly, when given a detailed listed of activities, almost 65% of respondents identified at least one area where they have an unmet recreation service or access need, compared to about 55% when asked about recreation services needs more broadly (indoor versus outdoor, see Figure 2.3).

### ***Continuing Education Related to TBI***

Figure 2.5 shows the TBI-specific continuing education needs identified by respondents.



Only about 16% of respondents reported having no unmet needs. Thus, almost 85% of respondents identified at least one unmet continuing education need, with a range of between one and eighteen response items selected (of 19 possible options,  $M=5.8$ ,  $SD=3.8$ ). Over a third of respondents identified unmet TBI-specific continuing education needs related to aging with brain injury (50.6%), coping or adjustments to living with TBI (44.6%), changes in relationships (how to manage, 38.0%), ongoing care / support (36.1%), managing behaviors (34.3%), and mental health challenges (34.3%). Over a quarter of respondents identified unmet TBI-specific continuing education needs related to cognitive changes (anatomy, 32.5%), self-advocacy skills (30.1%), brain injury recovery stages (functioning level / progression, 27.7%), and community resources available (27.1%).

“Other” TBI-related continuing education topic requests include: victimization, information and resources on pursuing higher education, individualized post-injury employment training, transportation options / planning, availability of resources for survivors who experienced a TBI after the age of 21, and how to ask for help / depend on others. Further elaborating on technology related continuing education needs, one respondent requested, “specific skills related to technology and brain injury with regards to supporting memory and problem solving.” Another respondent expressed a broader systemic need for continuing education, stating, “Agency, guardian, regional case manager and state administration staff need to have better knowledge of TBI and how it impacts life skills, especially language, and best practice for interventions. Support is needed as is advocacy of...individual rights.”

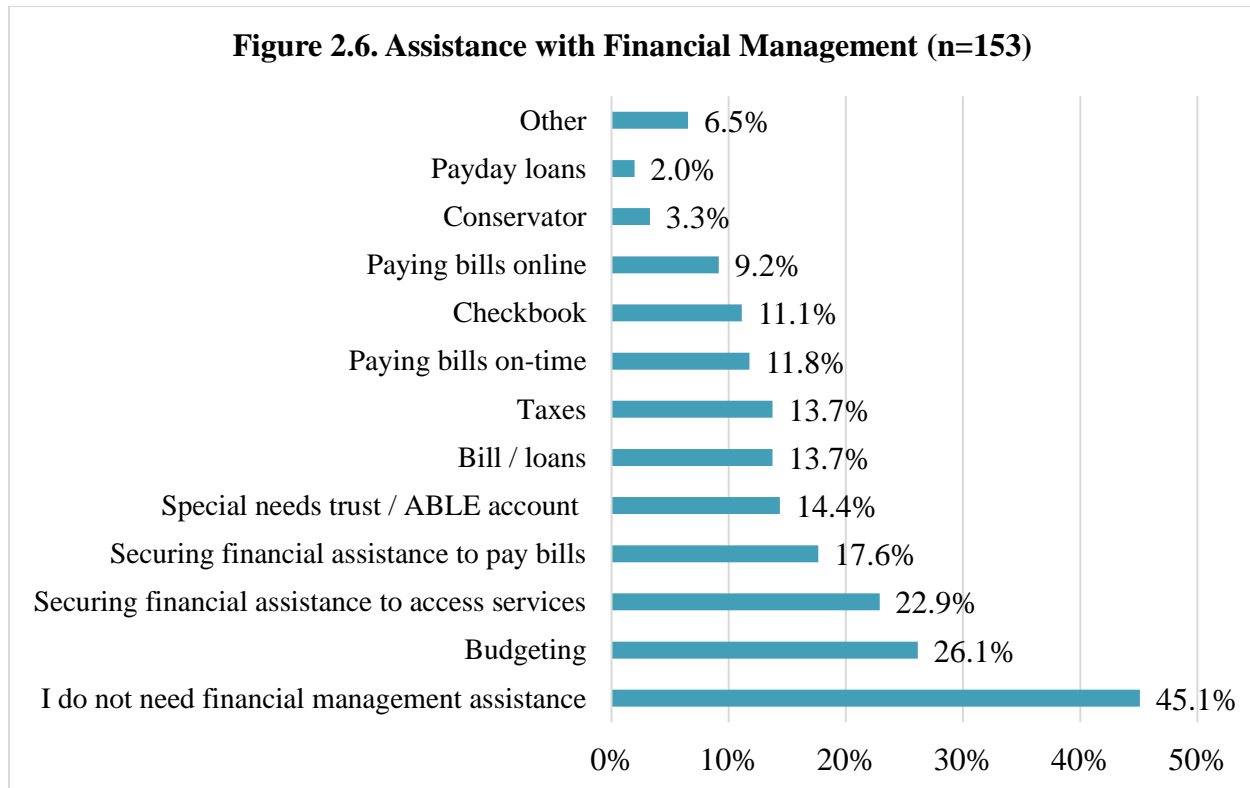
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Over 50% of respondents identified unmet continuing education needs related to aging with brain injury

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## Assistance with Financial Management

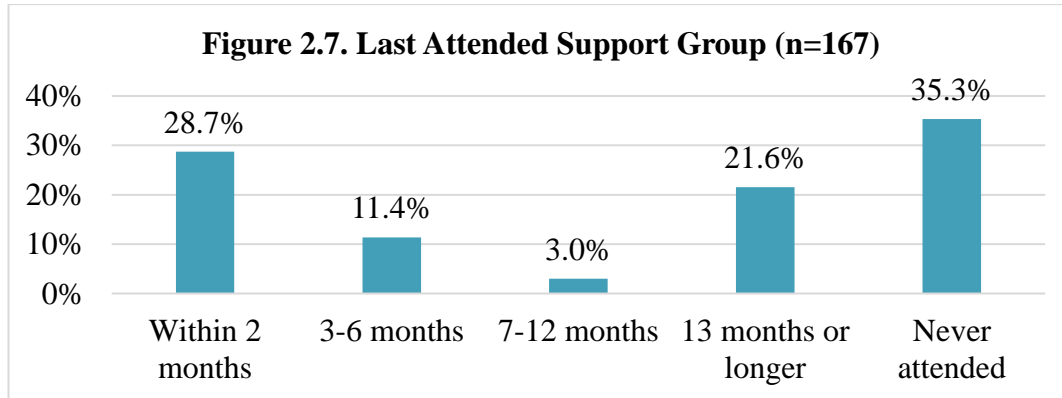
Figure 2.6 displays the responses selected when respondents were asked to identify financial management-related needs (respondents were asked to select all that apply).



Over 45% of the 153 participants who responded to this item reported having no unmet needs. Thus, almost 55% of respondents identified at least one unmet financial management need, with a range of between one and eleven response items selected (of 12 possible options,  $M=2.8$ ,  $SD=2.4$ ). The most frequently identified areas where participants reported having unmet financial management-related needs include: budgeting (26.1%), securing financial assistance to access services (e.g. counseling, transportation, medical, etc., 22.9%), and securing financial assistance to pay bills (17.6%). “Other” financial management-related information or resource needs included: assistance with paperwork and assessing eligibility, power of attorney, inventory of financial needs to live in own home, and understanding special needs trusts.

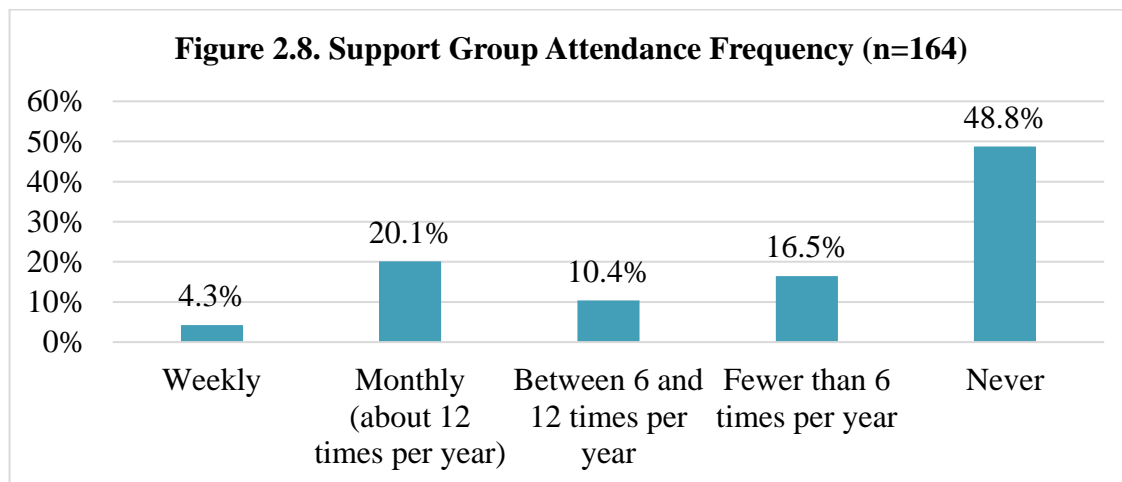
## TBI Support Groups

Survivor and family support group needs and preferences were assessed through a series of items. Figure 2.7 displays results related to most recent support group attendance.



Over half (56.9%) of respondents reported that they had never attend a support group meeting or event (35.3%) or had not attended in over a year (21.6%). Over a quarter (28.7%) of respondents reported having attended a support group meeting within the previous two months.

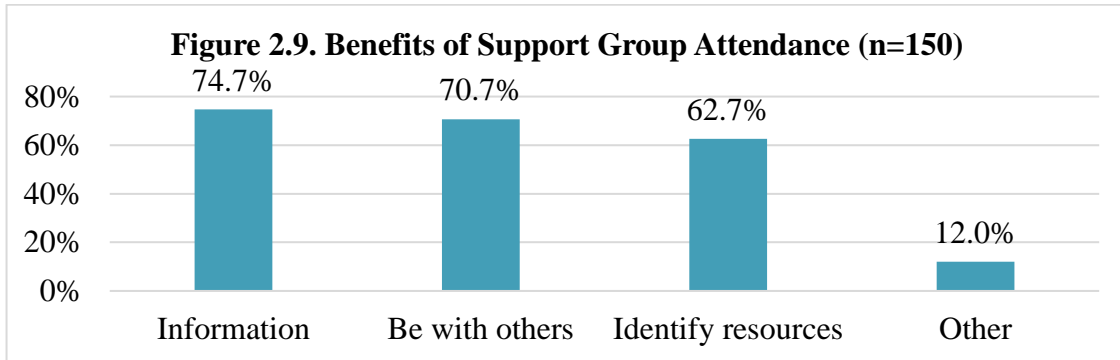
Figure 2.8 displays results related to how frequently respondents currently attend support group meetings or events.



Almost half of item respondents (48.8%) reported that they / their family never attend support group meetings or events and another 16.5% reported currently attending fewer than six times per year. Nearly a quarter of respondents (24.4%) reported weekly or monthly attendance.



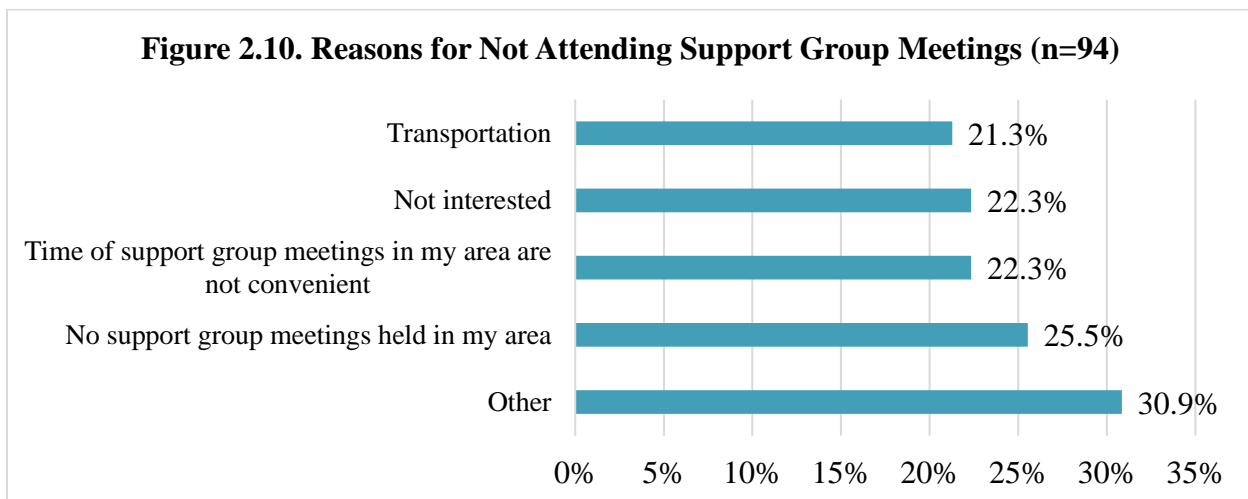
Figure 2.9 shows respondent identified benefits of support group attendance.



The number of benefits selected by respondents ranged from one to four, with a mean of 2.2 ( $SD=0.9$ ). Among the 150 respondents who selected at least one of the provided response choices, almost 75% selected “information,” 70.7% selected “be with others,” and 62.7% chose “identify resources” as a benefit of attending support group meetings or events.

Among the respondents who selected “other,” several expressed the importance of being around people who have a shared experience and who “get it.” Elaborating on the benefits of support groups, one respondent added, “education of TBI, best practices when working with individuals with TBI, education of assistive technology and how one can be supported and respected.” Another respondent expressed a need for support groups to move beyond repeated sharing of individual stories, stating, “Most support groups repeat their stories over and over again. This is not helpful. We need groups that navigate and push one another over the battles.”

Figure 2.10 shows reasons survivors and families do not attend support group meetings.

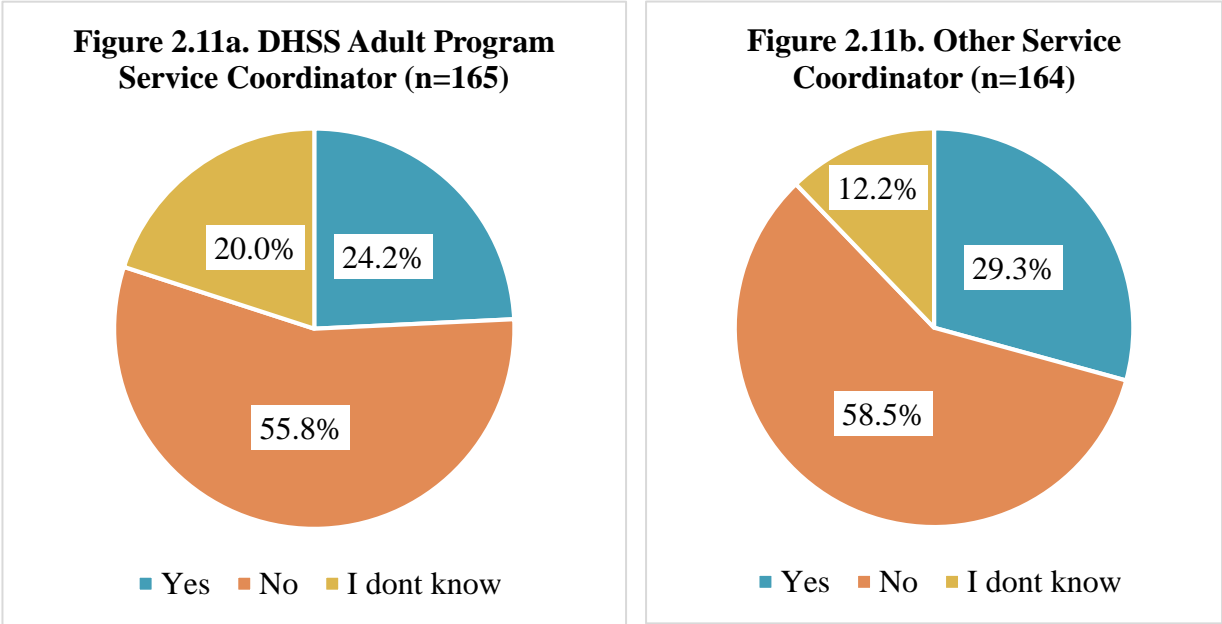


A total of 94 respondents selected between one and three of the five possible response choices, with a mean of 1.2 ( $SD=0.5$ ). The most frequently identified reason for not attending support group meetings or events is that no support groups are held in respondents' area (25.5%), followed by inconvenient meeting times (22.3%), and transportation challenges (21.3%). Over 30% of respondents also identified additional reasons.

Among other identified reasons, a lack of awareness about support groups was the most frequently mentioned reason ( $n=8$ ), followed by not needed or not helpful ( $n=4$ ). Three respondents identified the time commitment / conflicting commitments as a barrier. Three respondents also commented on the tone of support groups, with one caregiver expressing a fear of being judged and another stating, "support groups are not attended regularly as we cannot spend time dwelling on the incident. We are pushing forward and want others with this same frame of mind. Yes, there is time for grief also, but this cannot be the sole focus." Another comment on the tone of support group meetings suggested that the meetings attended "focus[ed] on the need of one attendee when others needed support too."

**Service Coordination**

Figures 2.11a and 2.11b show the percentage of respondents who have a service coordinator, through either Missouri Department of Health and Senior Services (DHSS) Adult Brain Injury (ABI) Program or another program.



To aid respondents in answering questions about service coordination, the follow language was provided on the survey:

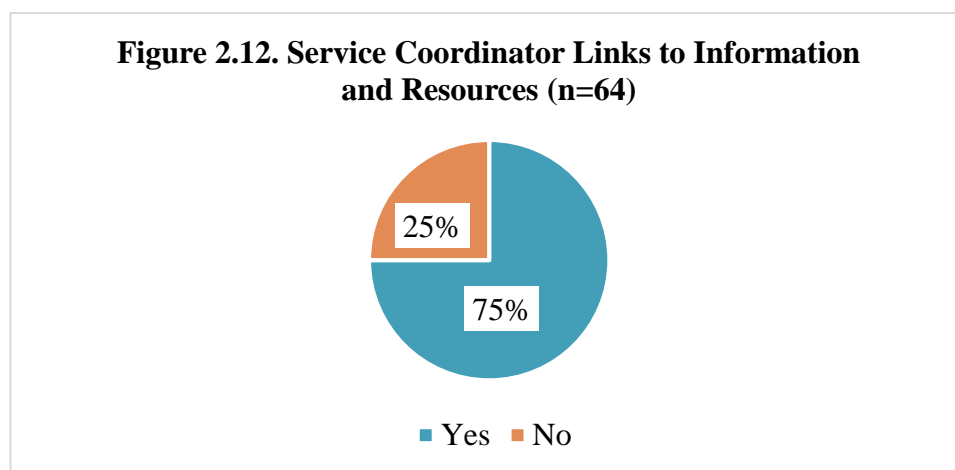
*Note: The Missouri Department of Health and Senior Services (DHSS) Adult Brain Injury (ABI) Program assists Missouri residents, ages 21 to 65, who are living with a traumatic brain injury (TBI). Through service coordination, the program links participants to resources to enable each person to obtain goals of independent living, community participation and employment.*

*The following questions refer to DHSS Adult Brain Injury (ABI) Program Service Coordination, which includes:*

- *Evaluation and assessment of needs*
- *Development, regular evaluation and updates of a service plan*
- *Assistance in locating and accessing resources such as medical care, housing, counseling, transportation, rehabilitation, vocational training, and cognitive/behavior training*
- *Information, education and advocacy*

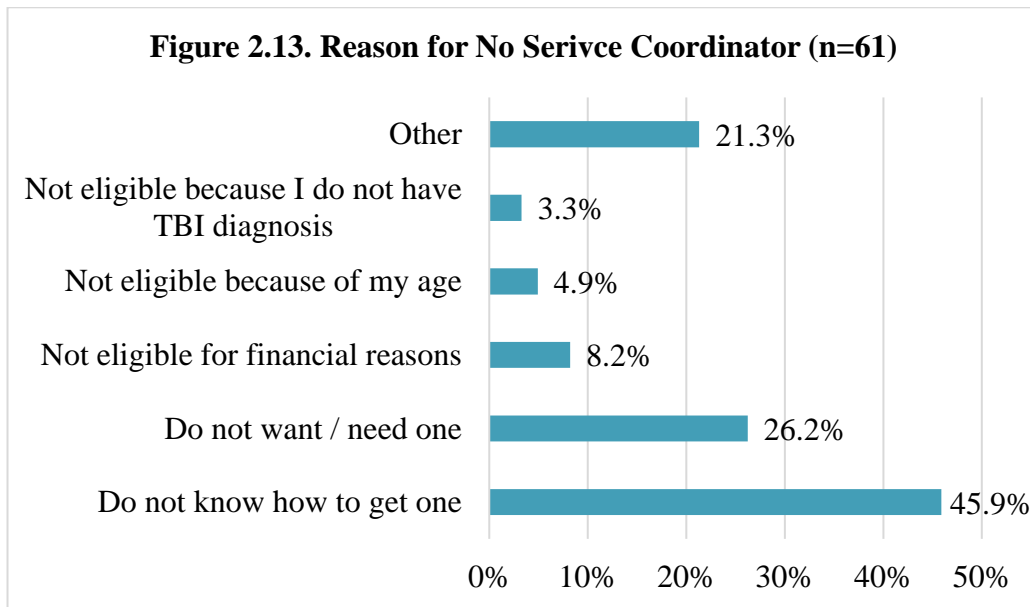
Nearly a quarter (24.2%) of respondents reported having a DHSS ABI service coordinator (Figure 2.11a) and almost 30% reported having a service coordinator through another program (Figure 2.11b). Among participants who provided a response to both survey items ( $n=164$ ), almost 11% ( $n=18$ ) reported having both a service coordinator through DHSS ABI and one through another program. In addition, over 43% of respondents ( $n=71$ ) stated that they did not have a service coordinator through either program. Interestingly, many respondents indicated that they did not know whether they had a service coordinator through the DHSS ABI program (20.0%, Figure 2.11a) or another program (12.2%, Figure 2.11b).

Figure 2.12 displays the responses to the question, “if you have a service coordinator / cage manager, do they link you to the information and resources that meet your needs?”



Three quarters of participants who have a services coordinator and who responded to the item reported that their service coordinator links them to information and resources that meet their needs.

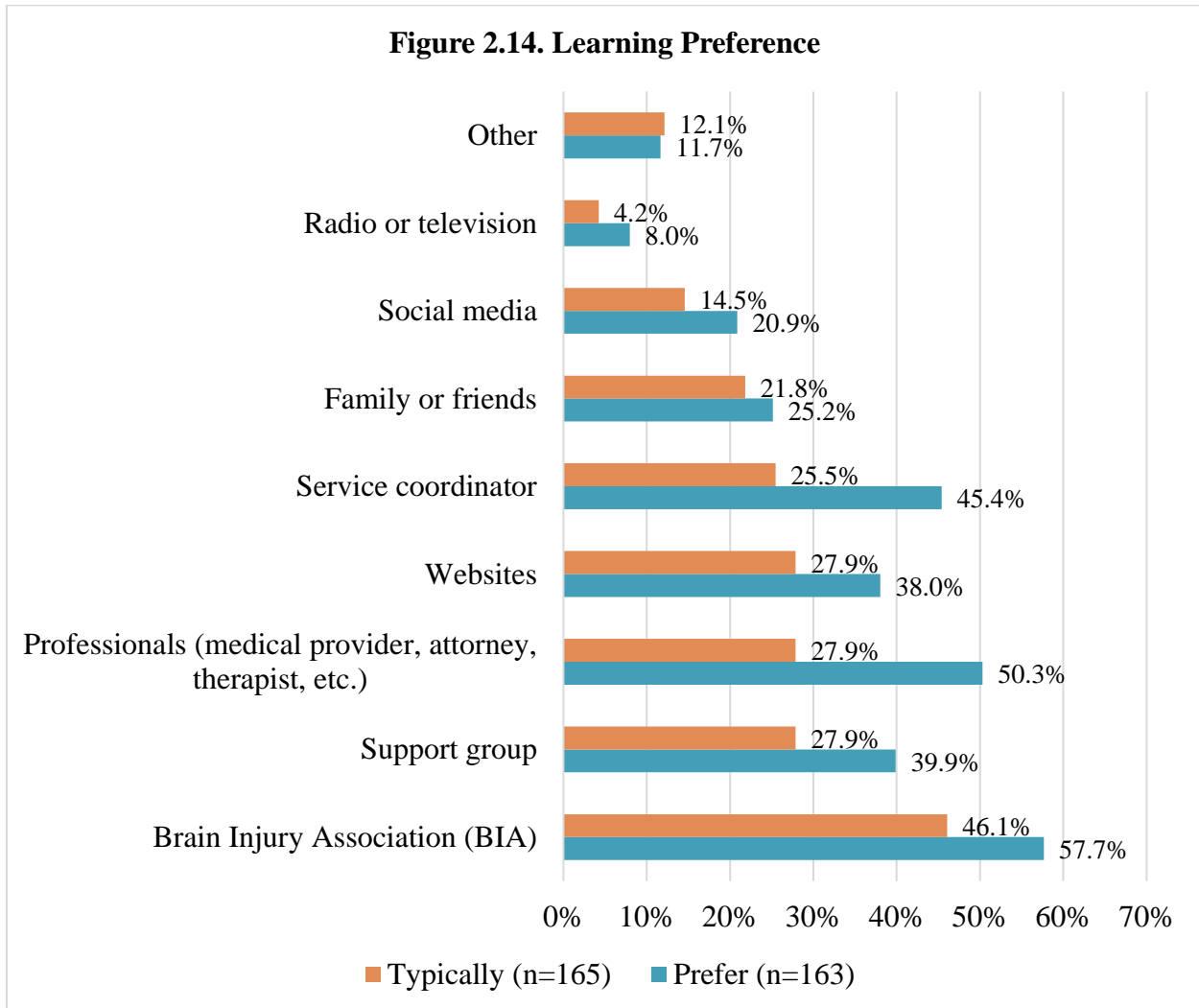
Figure 2.13 displays results related to why respondents do not have a service coordinator.



Respondents selected up to two reasons out of a possible of six response choices, with a mean of 1.1 ( $SD=0.3$ ). Among the 61 participants who responded to the survey item, over 45% reported that they did not have a service coordinator because they did not know how to get one, others reported that they were no eligible because of age (4.9%) or they do not have a TBI diagnosis (3.3%). About a quarter (26.2%) of respondents reported that they did not want or need a service coordinator.

## Preferences for Sharing Information

Figure 2.14 displays results related to how respondents typically learn, as well as how they prefer to learn, about TBI-related supports and services (respondents were asked to select all that apply).

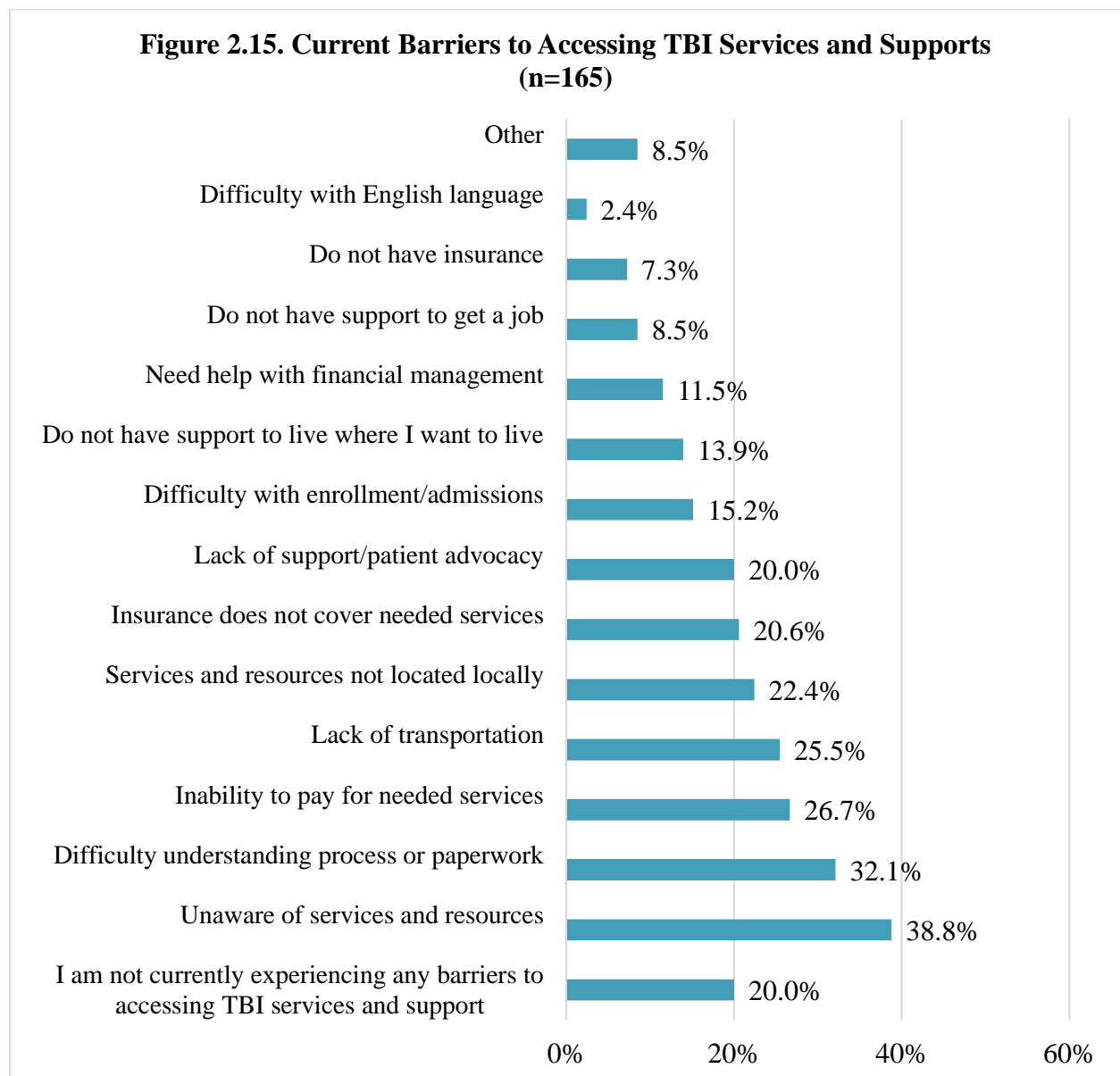


Respondents selected between one and eight ways in which they typically learn about TBI-related supports and services that they have accessed (out of a possible of nine response choices), with a mean of 2.1 ( $SD=1.5$ ). Respondents selected between one and nine ways in which they prefer to learn about TBI-related supports and services (out of a possible of nine response choices), with a mean of 3.0 ( $SD=1.8$ ). Respondents typically learn about TBI-related supports and services that they have accessed through the MO-BIA (46.1% vs. 57.7% who prefer this

way), support groups (27.9% vs. 39.9% who prefer this way), professionals (27.9%, vs. 50.3% who prefer this way), websites (27.9% vs. 38.0% who prefer this way), and service coordinators (25.5% vs. 45.5% who prefer this way). Other ways respondents prefer to learn about TBI-related supports and services include: email / e-newsletters, website with local resources, mail, Brain Injury Advisory Council, and talking to someone one-on-one.

**Barriers to Services and Supports**

Figure 2.15 displays current barriers to accessing TBI services and supports (respondents were asked to select all that apply).



Twenty percent of respondents reported that they are not currently experiencing barriers to accessing TBI services and support. Thus, 80% of respondents reported that they are experiencing at least one barrier related to accessing TBI services and supports, with a range of between one and eleven response items selected (of 14 possible options,  $M=3.2$ ,  $SD=2.3$ ). Over a quarter of respondents reported that they are currently experiencing the following barriers to accessing TBI services and supports: unaware of services and resources (38.8%), difficulty understanding process or paperwork (32.1%), inability to pay for needed services (26.7%), and lack of transportation (25.5%).

With regard to “other” barriers, one respondent stated, “Family support and understanding of TBI is limited and desire to learn is not there.” Many of the remaining barriers mentioned expand upon the provided response options. For example, related to transportation barriers, one respondent wrote, “The fact I am unable to drive myself where I need / want to go. I do have people I can ask, however it's more of a pride thing. I already have unsettling feelings about being a bother to my family and others in my life...” Respondents also lack of employment options, difficulty finding affordable housing that meets wants and needs, inadequate insurance coverage for routine dental care, and limited resources in rural areas as barriers.

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*“The fact I am unable to drive myself where I need / want to go. I do have people I can ask, however it's more of a pride thing. I already have unsettling feelings about being a bother to my family and others in my life...”*

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