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TRAUMATIC BRAIN INJURY (TBI)

*California
Community Health Needs Assessment*

ON BEHALF OF:

DOR DEPARTMENT of
REHABILITATION
Employment, Independence & Equality

REPORT PREPARED BY:

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Frequently Asked Questions

What is this report?

This report explains what individuals with traumatic brain injury (TBI) need most in California. For example, they need help finding doctors, therapists, and other resources. People with TBI, caregivers, and professionals (like counselors and doctors) were interviewed and given a survey. This report gives information from the interviews and survey.

Who wrote this report?

This report was written by a nonprofit organization called HARC, which has written many other reports on health. HARC wrote the report for the California Department of Rehabilitation, which is the state agency in charge of helping people with TBI.

This report is long! Where do I start?

If you want to see all the facts from the report, see the Executive Summary (page 8).

If you want to know the most important things from the report, read the Conclusion (page 136). The Conclusion also says what the state government can do to make things better for people with TBI.

We will also soon have an infographic (in English and Spanish) that will explain the most important things about the report: <https://harcddata.org/infographics/>

What are the most important things to know?

People with TBI have great needs: They need help finding doctors, therapists, and services. They need help finding jobs. They need help applying for disability income or they need more disability income. They need help getting health insurance to pay for TBI medicines and treatments. They need help finding psychologists or counselors. And they need help finding friends and other people to help them recover.

In summary, people with TBI greatly need these things:

Help finding TBI resources

Help finding jobs

Disability income

Health insurance coverage

Mental health care

Social support

Empiece Aquí

Preguntas Frecuentes

¿Qué es este informe?

Este informe explica lo que más necesitan las personas con lesión cerebral traumática (LCT) en California. Por ejemplo, necesitan ayuda para encontrar médicos, terapeutas, y otros recursos. Personas con LCT, cuidadores, y profesionales (como consejeros y médicos) fueron entrevistados y se les realizó una encuesta. Este informe presenta información sobre estas entrevistas y la encuesta.

¿Quién escribió este informe?

Este informe fue escrito por una organización sin fines de lucro llamada HARC, que ha escrito muchos otros informes sobre la salud. HARC escribió este informe para el Departamento de Rehabilitación de California, que es la agencia estatal a cargo de ayudar a las personas con LCT.

¡Este informe es muy largo! ¿Por dónde puedo empezar?

El resto de este informe está en inglés. Si desea ver todos los hechos del informe en inglés, consulte el Executive Summary (página 8). También se puede leer la conclusión en inglés (página 136) que explica lo más importante del informe y que dice lo que el gobierno estatal pueda hacer para mejorar la situación de las personas con LCT.

Pronto, tendremos una infografía disponible en español que explicará las cosas más importantes del informe: <https://harcdata.org/infographics/>

¿Cuáles son las cosas más importantes que se deben saber?

Las personas con LCT tienen grandes necesidades: Necesitan ayuda para encontrar médicos, terapeutas, y servicios. Necesitan ayuda para encontrar trabajo. Necesitan ayuda para solicitar ingresos por discapacidad o necesitan más ingresos por discapacidad. Necesitan ayuda para obtener un seguro de salud para pagar todos los medicamentos y tratamientos de LCT. Necesitan ayuda para encontrar psicólogos o consejeros. Y necesitan ayuda para encontrar amigos y otras personas que les ayuden a recuperarse.

En resumen, las personas con LCT necesitan estas cosas:

Ayuda para encontrar recursos de LCT

Ingresos por discapacidad

Cuidado de la salud mental

Ayuda a encontrar trabajo

Cobertura de seguro de salud

Apoyo interpersonal/social

Acronyms

DOR:	California Department of Rehabilitation
ED:	Emergency department
FPL:	Federal poverty level
HARC:	Health Assessment and Research for Communities
HCBS:	Home and Community Based Services
TBI:	Traumatic brain injury

Executive Summary

Introduction

Disabling illness and injury are always more than isolated experiences, as they impact an individual's relationships and place in society. Traumatic brain injury (TBI) is of special concern due to its totalizing and long-term effects, high prevalence, and lack of sufficient resources for recovery.

Outside of the critical care setting, TBI treatment and rehabilitation often fall on the labor of family caregivers and the ability to assemble an ad-hoc team of outpatient therapists and community-based service providers. Individuals with TBI must learn to navigate a new landscape of therapies and treatments, health insurance protocols and limits, and state and non-profit community programs. The State of California, through the Department of Rehabilitation (DOR), provides support through the California TBI Program, which helps fund six TBI sites throughout the state. Despite these available resources, existing state services and funding remain inadequate for addressing the widespread and multiple needs of individuals with TBI.

To improve state services for those with TBI, DOR has convened a TBI Advisory Board to assess needs and make recommendations. DOR contracted with a research nonprofit, Health Assessment and Research for Communities (HARC), to conduct a statewide TBI needs assessment. HARC is a nonprofit organization based in Riverside County, California, that provides research and evaluation services related to health, wellness, and quality of life. HARC has been providing needs assessments to various clients for over a decade. The California TBI needs assessment aims to document and detail the most pressing unmet needs related to TBI.

The needs assessment focuses on the needs of three groups: individuals with TBI, caregivers who provide care for individuals with TBI, and professionals who serve individuals with TBI. The needs assessment thus has sought to gain a multi-faceted view of TBI needs.

HARC undertook data collection through key informant interviews with TBI survivors, caregivers, and professionals and through three online surveys, one for each of the groups. This report offers the findings and conclusions from this data collection.

Methods

A mixed-methods approach was utilized to identify the needs of individuals with TBI, caregivers of individuals with TBI, and professionals providing services to individuals with TBI. Interviews and open-ended questions were the starting point of this needs assessment, so as to inform questions and areas of exploration in the survey. HARC created three interview guides with approximately ten questions each, as well as follow-up prompts. Each interview guide (as well as the survey described below) was

customized to better understand the needs/experiences of individuals with TBI, caregivers of individuals with TBI, and professionals/service providers of individuals with TBI.

Interviews were conducted from February 23 to April 21, 2022. Interviews were conducted virtually and typically comprised 40-to-60-minute sessions. DOR staff sent announcements regarding the interviews to take place through their networks, including California's TBI Program. These contacts included the six state-funded TBI sites, DOR Vocational Rehabilitation offices and staff, and 28 Independent Living Centers throughout California. HARC also contacted over 20 local and state organizations to publicize the interviews. Members of the TBI Advisory Board, Assistive Technology Advisory Committee, Blind Advisory Committee, California Committee on Employment of People with Disabilities, and Disability Advisory Committee were also asked to disseminate information about the interviews to their respective networks.

After a substantial portion of interviews were completed, HARC began developing three surveys, with content customized to understand the identified groups. Development of the surveys were completed in partnership with the Needs Assessment Committee, DOR staff, and public members who attended Needs Assessment Committee meetings.

The content of these surveys was developed from the themes that emerged during the interview process. The surveys were programmed into an online survey-taking platform and were available in English and Spanish. The survey was active for approximately one month, from March 30th to May 2nd of 2022. HARC worked with DOR staff to send the survey links to its networks, including advisory bodies, throughout California. HARC also sent notifications to the 20 organizations that were contacted for interview recruitment, as well as 16 additional organizations and over 100 California community colleges. HARC also invited all interviewees to complete the survey. In addition, HARC posted survey announcements to several social media platforms.

Individuals with TBI

Demographics

A total of 135 individuals with TBI participated in the individuals with TBI survey, and 25 individuals with TBI were interviewed. Nearly all (98.5%) completed an English survey. Individuals with TBI who were surveyed tended to be middle aged, with the largest proportion (36.3%) being aged 40-59 years, followed by 29.6% aged 60 and over and 28.9% aged 20-39. The average (mean) age of individuals with TBI was 49 years, and the median age was also 49. The standard deviation for the age was 14.7 years. Over two thirds (67.8%) identified as White, and only 16.3% identified as Hispanic. About half (50.4%) identified as female, two quarters (41.1%) as male, 2.3% as transgender, and 6.2% as nonbinary (neither female, male, nor transgender). These demographics, compared with statewide TBI hospitalization and emergency department

records,¹ show that individuals with TBI who were White or non-Hispanic were overrepresented and those who were male were underrepresented in the survey dataset. This was statistically significant.

Most individuals with TBI lived in households alone by themselves (total of one person; 41.7%) or with someone else (total of two people; 25.8%). Most reported either living alone (33.1%), living with a spouse/partner (25.2%), or living with other family member(s) (31.5%). Among those surveyed, most (54.9%) do not have a caregiver; 37.0% do have a caregiver. For those with a caregiver, caregivers were usually either their spouse/partner (44.7%) or parent (29.8%). Most surveyed individuals with TBI are not currently working. Nearly two-fifths (38.3%) were unable to work, 28.1% were unemployed, and 26.6% were employed for wages. Further, 24.2% were students, and 21.1% were retired.

Most surveyed individuals with TBI were well educated, with 31.3% having a postgraduate or professional degree, 28.1% being a college graduate, and 26.6% having some college. Despite this high level of education, over one quarter (27.5%) of individuals with TBI were living in poverty, twice as high as the poverty rate for the general state population (11.5%).²

TBI Characteristics and Impacts

One third (32.6%) of individuals with TBI had a severe TBI, 23.0% had a moderate TBI, 22.2% had a mild TBI, and 22.2% were “not sure.” The majority (57.6%) had their TBI caused by a motor vehicle accident, followed by injury purposely inflicted by other persons (19.6%) and accidental fall (17.4%). Nearly all (96.9%) did not get their TBI while serving in the military. Most (60.1%) got their TBI in the past 12 years. One third (34.3%) were diagnosed in the past five years, and one tenth (9.9%) were never diagnosed. Further, two fifths (21.1%) reported never having been provided with information or resources about TBI.

TBI can cause numerous challenging symptoms for any individual. The most common symptoms reported were difficulty with memory (80.7%), cognitive fatigue (77.0%), physical fatigued (73.3%), difficulty maintaining concentration (71.9%), and mental health (depression, anxiety, etc.) (68.1%).

TBI can also have negative impacts on aspects of one’s life. The most reported life domains negatively affected by TBI were employment (76.7%), friendships (74.4%), activities of daily living (67.4%), access to community events/services/activities (60.5%), and family (59.7%). Interviews also revealed the devastating nature of these

¹ EpiCenter: California Injury Data Online. (2022). California Department of Public Health. <https://epicenter.cdph.ca.gov/Default.aspx>

² Quick Facts: California. (2022). U.S. Census Bureau. <https://www.census.gov/quickfacts/CA>

social impacts, with some individuals losing friends and family connections. In interviews, social isolation was a common theme.

While TBI results in hardship, some interviewees explained that their lives had also change positively. Some took up new hobbies, some grew closer to their spouse, and others forged new friendships. In interviews, these positive impacts were never devoid of struggle—they were rather the result of accepting one’s injury and having the support necessary to turn hardship into new meaning and connection.

Satisfaction with TBI Care

Individuals with TBI tended to be more satisfied with their TBI recovery currently than during the first six months of their recovery. For recovery during the first six months, the most common ratings were “acceptable” (33.3%), “very poor” (26.5%), and “good” (18.2%). For current recovery, the most common ratings were “acceptable” (31.3%), “good” (26.9%), and “poor” (20.9%).

Satisfaction with TBI medical care/services received in the last six months was even across satisfaction levels. About one fifth (20.6%) were very satisfied, 22.9% somewhat satisfied, 22.9% neither satisfied nor dissatisfied, 12.2% somewhat dissatisfied, and 21.4% very dissatisfied. In total, 43.5% were either somewhat or very satisfied, and 33.6% were either somewhat or very dissatisfied with their TBI care in the last six months.

Satisfaction with health care providers’ knowledge of TBI also showed an even distribution across satisfaction levels: 21.2% were very satisfied, 22.0% were somewhat satisfied, 23.5% were neither satisfied nor dissatisfied, 14.4% were somewhat dissatisfied, and 18.9% were very dissatisfied. In total, 43.2% were either somewhat or very satisfied, and 33.3% were either somewhat or very dissatisfied with their providers’ knowledge of TBI.

Most individuals with TBI have health insurance that covers some or most of their TBI care: 42.3% reported that their health insurance covers most of their TBI care, 43.1% reported that their insurance covers some of their TBI care, 11.5% reported their insurances covers none of their TBI care, and 3.1% do not have health insurance. In total, 14.5% do not have any insurance coverage for TBI care. Interviews reveal that even among those whose insurance covers “most” of their care, there might still be major gaps in their coverage, making it difficult or impossible to get needed TBI care even when one has “robust” health insurance.

The most reported type of health insurance was Medicaid/Medi-Cal, with nearly two fifths of the sample (38.1%). This was followed by Medicare (35.7%), employment-based insurance (27.8%), privately purchased insurance (11.1%), and insurance through the U.S. Department of Veterans Affairs (6.3%). In addition, 10.3% selected “Other.”

Individuals with TBI Unmet Needs

Needs as Reported by Group

All three survey groups (individuals with TBI, caregivers, and professionals) were asked which services and resources do individuals with TBI currently needed. Responses were largely consistent across groups, with a few important variations.

Individuals with TBI reported that the most needed services and resources include “help finding TBI resources, such as therapists, support groups, etc.” (61.9%); “mental health counseling” (51.2%); “support groups” (49.6%); “financial support” (41.6%); “help with developing and maintaining friendships” (41.6%); and “help accessing community events/services/activities” (40.8%).

Caregivers reported that the top unmet needs of individuals with TBI include “help finding TBI resources, such as therapists, support groups, etc.” (62.5%); “help with developing and maintaining friendships” (56.3%); “mental health counseling” (52.1%); “support groups” (50.0%); “help with activities of daily living” (47.9%), and “medical treatments and services” (45.8%).

Professionals reported that the top unmet needs of individuals with TBI include “help finding TBI resources, such as therapists, support groups, etc.” (84.9%); “mental health counseling” (84.9%); “assistive technologies” (83.6%); “help with transportation” (83.6%); “financial assistance” (75.3%); and “support groups” (75.3%).

“Help finding TBI resources” was the highest ranked need among all three groups. In interviews, this manifested as a need to find experienced TBI care providers, to find financial support, or to find employment. All three groups also highly ranked “mental health counseling” and “support groups.”

The need for “educational materials in Spanish” and “educational materials in languages other than English and Spanish” was rated considerably higher by professionals (43.8% and 34.2%) than by individuals with TBI (4.0% and 2.4%) or caregivers (2.1% and 2.1%). This likely reflects the nature of the survey samples. The surveyed individuals with TBI and caregivers overrepresented English-speaking people for each group when compared with demographics from the general population. However, professionals, because they might serve a patient/client population that is more linguistically and culturally diverse than the survey sample, likely provide a more accurate reflection of the need for educational materials in languages other than English.

Needs: Correlations and Causes

The needs above can vary as a function of demographics such as number of years with TBI and age. The average number of years that someone has had their TBI is higher for needs such as home modifications (average = 16.6 years with a TBI), housing assistance

(average = 15.6 years), assistive technology (average = 15.0 years), and help finding TBI resources (average = 15.0 years). On the other hand, the average number of years that someone has had their TBI is lower for needs such as adult day programs (average = 9.1 years), help with medication management (average = 10.5 years), and help returning to pre-injury employment (average = 11.2 years).

In addition, there is slight variation in the average age of an individual with TBI by need. For instance, older TBI survivors reported needing support groups (average = 51.4 years old), help with activities of daily living (average = 51.3 years old), and assistive technologies (average = 50.5 years old). On the other hand, younger TBI survivors reported needing housing assistance (average age = 45.2 years old), help with finding employment (45.3 years old), and help returning to pre-injury employment (average age = 45.4 years old).

Individuals with TBI were asked what the reasons for their needs were not being met. The most reported reason for needs not being met was “limited personal finances” (61.0%), followed by “I didn’t know about the resource” (48.3%). Other commonly reported reasons were “limited health insurance” (43.2%) and “the resource was not available” (42.4%).

In interviews, key informants reported how difficult it can be to not only find the right care provider or therapist but to even learn that such care and therapies exist. Key informants also reported how essential are support groups, providing practical guidance and connection to a community.

Mental Health and Social Support

For individuals with TBI, mental health care is essential. Nearly three quarters (71.3%) said mental health care is *very important*. About one quarter (23.3%) said it is *somewhat important*. Only 3.1% said *neither [important nor unimportant]* and 2.3% said *not important at all*. Thus, 94.6% said that mental health care is either *somewhat* or *very important* for their recovery.

A common type of social support mentioned by interviewees was support groups, which can be a vital tool both to connect with others and to learn about resources. Individuals with TBI were asked their preferred format: 16.4% preferred virtual support groups, 24.6% preferred in-person support groups, and 59.0% preferred both virtual and in-person support groups.

Employment and Economic Security

Employment is a critical need for individuals with TBI. As stated above, 76.7% of individuals with TBI reported that their TBI negatively affected their employment (more than any other life domain). Further, 41.5% reported “I want to work, but I am unable to work because of my TBI.” Nearly one quarter (26.0%) reported “I am currently working in a new job.” Further, 15.4% reported “I want to work, and I’m trying to find a job,”

11.4% reported “I don’t want to return to work,” and 5.7% reported “I am currently working in the same job I had before my injury.”

For those who were working or looking for work, the resources reported to be most helpful were “having co-workers who understand TBI” (45.6%), followed closely by “part-time work schedule” (43.9%). Further, 35.1% selected “helping find a new career/field,” 33.3% selected “helping find a new job,” and 31.6% selected “training in new skills.”

Individuals with TBI were also asked what areas they need financial support most. The areas in which financial support is needed most were “I have disability income (SSI or SSDI), but it isn’t enough” (55.2%), “I need a well-paying job” (51.7%), “I need better health insurance coverage” (43.1%), and “I do NOT have disability income (SSI or SSDI), and I need it” (29.3%). Thus, 84.5% either have disability income (but this income is not enough) or they are in need of disability income.

Caregivers Demographics

A total of 53 caregivers participated in the caregiver survey, and 12 caregivers were interviewed. Most (98.1%) completed an English survey. Caregivers were generally on the older side of the age distribution, with 58.0% being age 60 or older. The average age of caregivers was 62, whereas the median age was 65. The standard deviation for the age of caregivers was 11.5 years.

Over three-quarters (77.8%) of caregivers identified as White, and about three-quarters (74.5%) identified as non-Hispanic. About three-quarters (73.5%) of caregivers identified as female, and slightly over a quarter identified as male (26.5%). These demographics, compared with statewide data on all types of caregivers,³ show that caregivers who were either White, non-Hispanic, or female were statistically significantly overrepresented in the survey dataset.

Most caregivers live in households with two (37.3%) or three (37.3%) people, and most caregivers live with a spouse or partner (62.7%).

Caregivers were well educated. Over a third (37.3%) reported being college graduates, whereas another third (37.3%) had at least some college education. Half (49.0%) of caregivers reported being retired. Another common response was being employed for wages (31.4%) or being a homemaker (19.6%). Two-thirds (62.1%) of caregivers were living in households that are greater than 300% of the federal poverty level (FPL). Conversely, there were some caregivers that were still living in lower-income homes, with some being at 0 to 100% FPL (10.3%) and other being at 101%-200% FPL (13.8%).

³ California Health Interview Survey (2020). UCLA Center for Health Policy Research. <https://healthpolicy.ucla.edu/chis/Pages/default.aspx>

Most caregivers were providing care for their child (65.4%) or their spouse or partner (23.1%).

TBI Recovery

Caregivers tended to rate the recovery of the individual with TBI in the first six months on the poorer side. For instance, 27.5% stated that recovery was *poor*, and 21.6% stated that the recovery was *very poor*. When rating current recovery, fewer caregivers stated that the recovery was *very poor* (5.8%), thus indicating some individuals with TBI were making improvements. However, there were still many caregivers stating that the recovery is currently *poor* (28.8%) or *acceptable* (26.9%).

While TBI survivors rated their recovery progress favorably, caregivers were less optimistic about recovery, and indicated that their current recovery was *acceptable* (26.9%), *poor* (28.8%), or *very poor* (5.8%). The discrepancy between these two reports may be due to several factors: for example, the level of reliance on the caregiver may not have declined, which leads the caregiver to feel a lack of improvement or progress in recovery. However, the TBI survivor may experience cognitive and behavioral improvements, such as regaining balance, memory, emotional control, or speech, and therefore feel they have made tremendous progress in their recovery. The invisibility of many of the effects of TBI is one of the many reasons why support groups play a significant role for TBI survivors in their recovery; it is impossible to measure what cannot be seen in others unless you can “see it” as well.

Satisfaction with TBI Care

Satisfaction with medical services in the last six months appears to be mixed. That is, 32.0% reported being *somewhat* or *very dissatisfied*, whereas 42.0% stated they were *somewhat* or *very satisfied*.

Ratings slightly leaned towards the positive side but were still mixed when rating health care providers’ knowledge of TBI. A larger number of caregivers reporting being *somewhat* or *very satisfied* (44.9%), whereas others reported being *somewhat* or *very dissatisfied* (26.5%).

Health Insurance Coverage

Most caregivers reported that the individuals they care for have “most” of their care covered by their health insurance (59.1%). Another 38.1% reported that some of their care is covered. A common interview theme was the inadequacy of Medi-Cal and private health insurance to cover needed medication/treatments or to cover experienced care providers.

Impact of Being a Caregiver

Common areas of life negatively affected by being a caregiver include the caregivers' relationship with spouse/partner (64.6%), friendships (58.3%), access to community events/services/activities (56.3%), activities of daily living (56.3%), and being able to leave the house (50.0%). These needs, as reported by caregivers, were similar to the needs reported by professionals and individuals with TBI. Indeed, there is a need among caregivers, professionals, and individuals with TBI to be properly connected to TBI resources.

Caregiver Unmet Needs

Most caregivers need help finding TBI resources (71.1%). More than half also reported needing mental health counseling (51.1%), whereas others need support groups (46.7%) or respite care (44.4%).

The needs above can vary as a function of other demographics. For this reason, the unmet needs of caregivers were analyzed by the average number of years the individual with TBI has had the TBI as well as the age of the caregiver. The average number of years that the individual has had their TBI is higher for needs such as respite care (average = 13.7 years), help finding TBI resources (average = 12.1 years), and help with how to communicate with health professionals (average = 10.4 years). There was some slight variation in the average age of a caregiver by need. For instance, older caregivers reported needing respite care (average = 64.0 years), help finding TBI resources (average = 61.3 years), legal assistance (average = 60.7 years), and help communicating with health professionals (average = 60.4 years). An analysis of caregiver needs by TBI severity was also performed. However, nearly all caregivers reported caring for a person with a severe TBI; one reported "mild", three reported "moderate," and the remaining reported "severe" ($n = 37$) or "not sure" ($n = 3$). Thus, an analysis of need by TBI severity was unwarranted.

Professionals Demographics

A total of 97 professionals completed the professional survey, and 13 professionals were interviewed. All professionals completed the survey in English.

Professionals were generally middle-aged; the mean age of professionals was 50 years old. (The standard deviation was 12.3 years.) The majority of professionals (70.7%) identified as White, and a similar percentage (70.3%) identified as non-Hispanic. About three-quarters (75.4%) identified as female, and slightly less than a quarter identified as male (24.6%). These demographics, compared with statewide data on the general adult population,⁴ show that professionals who were either White, non-Hispanic, or female were overrepresented in the survey dataset.

⁴ U.S. Census (2020) U.S. Census Bureau <https://data.census.gov/cedsci/>

The most common profession among survey participants was vocational rehabilitation counselor (37.2%), followed by “other” profession (26.9%), which included educators, non-profit leaders, and service coordinators.

Nearly a quarter (22.8%) of surveyed professionals have worked with people with a TBI for less than five years. The average number of years of having worked with individuals with TBI is 15.1 years. Most professionals (54.7%) have worked with one to five people with a TBI in the past six months, and most professionals (53.3%) work with people with a TBI between one to five hours weekly.

Care/Services for Individuals with TBI

Most professionals (54.7%) have provided care for one to five individuals with TBI in the past six months, and most (53.3%) provide care for one to five hours per week, on average. Professionals most commonly see their TBI patients/clients once a week (37.7%), with fewer seeing TBI patients/clients twice a month (14.8%) or once a month (14.8%) or less often.

Most professionals (67.6%) were either *satisfied* or *very satisfied* with the average number of visits with each TBI patient/client; 13.8% of professionals are either *somewhat* or *very dissatisfied* with the average number of visits. Most professionals (67.1%) were *somewhat* or *very satisfied* with the amount of time with each TBI patient/client, while 17.1% were *somewhat* or *very dissatisfied*. Further, 38.2% of professionals have received formal TBI education/training for several months or years, while 15.8% have received no formal training.

Needs of Surveyed Professionals

Professionals were asked what resources would be helpful for them to better meet the needs of people with a TBI. A high proportion of professionals have a need for a centralized list of TBI resources (78.3%), mental health counseling available for persons with a TBI (77.1%), and community-based service options (75.4%).

Needs of Other Professionals

Professionals were asked what resources *other* professionals would need to better meet the needs of individuals with TBI. The resources most highly rated as needed for other professionals include education on TBI in general (83.1%), mental health counseling available for persons with TBI (78.9%), funding programs available for persons with TBI (77.5%), and housing options available for persons with TBI (77.5%).

Conclusion

The needs expressed by individuals with TBI, caregivers, and professionals are wide in scope and complex in nature, but these needs can be simply summarized. In addition to necessities like health care and income, individuals with TBI need ways to reintegrate

themselves into their communities. Caregivers need social support and respite care. Professionals emphasize the need for mental health and community-based services they can offer to patients/clients. And all three groups need help finding TBI resources.

Foremost, individuals with TBI need help finding TBI resources, funding for treatments (including mental health), greater economic support (both for employment and disability benefits), and services that reintegrate them into their communities. To meet these many needs, individuals with TBI need tools or guidance to help them access resources. Specifically, there is a need for lists of programs, therapies, and other resources. In addition, there is a need to examine the requirements for health insurance to cover needed TBI medications/therapies. There is also a need for improved vocational training/job placement and expansion of disability income (SSI or SSDI). Lastly, there is a need for services that prioritize community reintegration (such as support groups, adult day care, and assistance with employment).

Caregiver and professional needs mirror the above. Caregivers need help finding TBI resources, along with mental health counseling and respite care. To meet these needs, caregivers would need access to caregiver support groups, mental health counseling, and respite care, as well as tools to help find TBI resources.

Professionals also need help finding TBI resources, as well as the ability to refer patients/clients to mental health counseling and community-based service options. In interviews, professionals often expressed a strong need to have a list or record of all available TBI resources (i.e., employment programs, disability income assistance, in-home care support, non-profit community organizations, therapies, advocates, etc.). To meet these needs, in addition to the above, professionals would need a list of statewide resources as well as educational seminars or workshops on TBI care and resources. These educational forums could fulfill requirements for continuing education or continuing medical education.

This evaluation has illustrated that with support, individuals with TBI can achieve stability as well as a renewed sense of meaning and life purpose. These positive outcomes—that meet both the basic and most essential human needs—are possible only when adequate social support, medical care, and financial resources are made available and accessible. Meeting these needs can help people not only survive but to flourish.

Introduction

Disabling illness and injury are always more than isolated experiences, as they impact an individual's relationships and place in society. Traumatic brain injury (TBI) is one such cause of disability that is of special concern due to its totalizing and long-term effects, high prevalence, and lack of sufficient resources for recovery.

TBI is multifaceted, an experience that is physical/physiological, personal/subjective, and interpersonal/social. Basically, TBI can be defined as
an alteration in brain function or other evidence of brain pathology caused by an external force such as a jolt, blow, or penetration to the head. Most non-fatal TBIs are caused by falls, motor vehicle accidents, or being struck by a person or an object, such as in sports.⁵

While the cause of a TBI might be a single event—traced to a single moment—its symptoms and sequelae can be multiple and lifelong. It often results in challenges (difficulty with memory, cognitive fatigue, difficulty controlling emotions, etc.) that result in an inability to work, the loss of relationships, and major barriers to community reintegration. TBI is also correlated with long-term disorders (such as dementia⁶) and negative outcomes (such as suicide,⁷ homelessness,⁸ drug addiction,⁹ and incarceration¹⁰). A TBI can impact a person's very identity as well as their ties with family and friends and their role in society.

In addition to being an injury with broad and varied impacts, TBI is extremely common. The World Health Organization has projected that TBI has now become the main cause of death and disability in the world.¹¹ In the State of California, there are, on average, over 227,000 hospitalizations or emergency department visits every year due to non-

⁵ California Department of Rehabilitation. (25 April 2022) California Traumatic Brain Injury Program State Plan.

⁶ Mendez M. F. (2017). What is the Relationship of Traumatic Brain Injury to Dementia? *Journal of Alzheimer's. JAD*, 57(3), 667–681. <https://doi.org/10.3233/JAD-161002>

⁷ Lu, Y. C., Wu, M. K., Zhang, L., Zhang, C. L., Lu, Y. Y., & Wu, C. H. (2020). Association between suicide risk and traumatic brain injury in adults: a population based cohort study. *Postgraduate medical journal*, 96(1142), 747–752. <https://doi.org/10.1136/postgradmedj-2019-136860>

⁸ Stubbs, J. L., Thornton, A. E., Sevick, J. M., Silverberg, N. D., Barr, A. M., Honer, W. G., & Panenka, W. J. (2020). Traumatic brain injury in homeless and marginally housed individuals: a systematic review and meta-analysis. *The Lancet. Public health*, 5(1), e19–e32. [https://doi.org/10.1016/S2468-2667\(19\)30188-4](https://doi.org/10.1016/S2468-2667(19)30188-4)

⁹ Olsen, C. M., & Corrigan, J. D. (2022). Does Traumatic Brain Injury Cause Risky Substance Use or Substance Use Disorder?. *Biological psychiatry*, 91(5), 421–437. <https://doi.org/10.1016/j.biopsych.2021.07.013>

¹⁰ McIsaac, K. E., Moser, A., Moineddin, R., Keown, L. A., Wilton, G., Stewart, L. A., Colantonio, A., Nathens, A. B., & Matheson, F. I. (2016). Association between traumatic brain injury and incarceration: a population-based cohort study. *CMAJ open*, 4(4), E746–E753. <https://doi.org/10.9778/cmajo.20160072>

¹¹ Hyder AA, et al. The impact of traumatic brain injuries: a global perspective. *NeuroRehabilitation* 2007;22:341-53. Quoted in California Department of Rehabilitation. (25 April 2022) California Traumatic Brain Injury Program State Plan.

fatal TBIs.¹² Yet TBIs can go undetected in standard medical imaging diagnostics (e.g., MRIs or CT scans) and often appear days later in less visible signs like cognitive, psychological, and social impairments. As the injury can readily go undiagnosed, hospital and emergency department figures are likely great underestimates of the occurrence of TBI.

Given the injury's wide impacts—both on the individual and across society—the importance of supporting individuals in the experience of TBI is critical. However, the resources and infrastructures necessary to treat and rehabilitate individuals with a TBI are still nascent. Emergency medicine and critical care have profoundly improved over the past half century, allowing far more patients with severe head injuries to survive. However, outside of the critical care setting, TBI treatment and rehabilitation often fall on the labor of family caregivers and the ability to assemble an ad-hoc team of outpatient therapists and community-based service providers. Individuals with TBI must learn to navigate a new landscape of therapies and treatments, health insurance protocols and limits, and state and non-profit community programs. There is a major need for post-critical care TBI resources to be increased and coordinated.

The State of California, through the Department of Rehabilitation (DOR), provides support to the California TBI Program. The TBI Program is authorized to provide funding to six nonprofit organizations to serve adult Californians living with TBI through California Welfare and Institutions Code sections 4353-4357, and the California Code of Regulations, Title 9, Rehabilitative and Developmental Services, Division 3, Department of Rehabilitation. This funding is provided by the State General Fund and distributed through a competitive bidding process that requires the TBI Program Sites to provide core services designed to increase independent living skills to maximize the ability of individuals with TBI to live independently in a community of their choice. The TBI core services include community reintegration, supported living, vocational supportive services, professional and public education, and information and referral.

These core services are also preventative, as many TBI survivors who do not have access to a network of services and supports are at a higher risk of chronic homelessness, institutionalization, incarceration, and placement in skilled nursing facilities due to an inability to perform activities of daily living and impaired emotional regulation. From April 1, 2022, through March 31, 2024, the TBI Program has been authorized to provide additional funding to the TBI Program Sites and fund up to six new TBI sites utilizing Home and Community Based Services (HCBS) Spending Plan funding. The HCBS funding will expand the capacity of the six TBI Program Sites and fund up to six TBI HCBS Program Sites to provide services in unserved/underserved areas.

¹² There were an average annual number of 227,124 non-fatal TBI hospitalizations and emergency department visits during 2006-2015, the most recent period for which data are available. EpiCenter: California Injury Data Online. (2022). California Department of Public Health. <https://epicenter.cdph.ca.gov/ReportMenus/TraumaticBrainInjury.aspx>

To guide the expansion and improvement of state services for those with TBI, DOR has convened a TBI Advisory Board to assess needs and make recommendations. DOR contracted with a research nonprofit, Health Assessment and Research for Communities (HARC), to conduct a statewide TBI needs assessment. HARC is a nonprofit organization based in Riverside County, California, that provides research and evaluation services related to health, wellness, and quality of life. For more than a decade, HARC has provided needs assessments to many clients, including county agencies, clinics, and hospitals. The California TBI needs assessment aims to document and detail the most pressing unmet needs related to TBI.

This needs assessment focuses on three groups: individuals with TBI, caregivers who provide care for individuals with TBI, and professionals who serve individuals with TBI. Individuals with TBI are, naturally, the chief focus of the needs assessment. Caregivers are also a vital component of treatment and rehabilitation. The labor offered by caregivers is often undervalued and uncompensated. Professionals are likewise necessary to meet the needs of TBI survivors. These professionals, which range from medical providers to case managers, offer useful insight into the needs of survivors and caregivers, as well as having their own needs, such as for professional training and funding. The needs assessment thus has sought to gain a multi-faceted view of TBI needs.

HARC collected data from the three groups through key informant interviews and an online survey; interview and survey tools were designed to be unique to each group. This report offers the findings and conclusions from this data collection. Interviews were conducted with 25 individuals with TBI, 12 caregivers, and 13 professionals. In total, the three online surveys yielded results from 135 individuals with TBI, 53 caregivers, and 79 professionals. The survey sample overrepresented individuals with TBI who were White and non-Hispanic and underrepresented those who were male, as compared to statewide data on TBI patients (statistically significant at the $p < .05$ level). The survey sample also overrepresented caregivers who were White, non-Hispanic, and female, as compared to statewide data on the general caregiver population (statistically significant at the $p < .05$ level).

The greatest unmet needs for individuals with TBI (as reported by surveyed individuals with TBI, caregivers, and professionals) were help finding TBI resources (such as therapists, community resources, etc.), mental health counseling, and TBI support groups. In interviews, key informants reported how difficult it can be to not only find the right care provider or therapist but to even learn that such care and therapies exist. Key informants also reported how essential are support groups, providing practical guidance and connection to a community. Interviews and survey data also demonstrated a strong need for professional TBI education/training.

There was also a large need for financial support, through either disability income or employment. Surveyed individuals with TBI tended to be well educated. Over half had a college degree or had a postgraduate or professional degree. However, over one quarter indicated they were living in poverty, a rate twice as high as the general state population.

Methods

A mixed-methods approach was utilized to better understand the unique experiences and needs of individuals with TBI, caregivers of individuals with TBI, and professionals providing services to individuals with TBI. HARC conducted background research on best practices for interviewing/surveying individuals with TBI, while also working with DOR staff to ensure all desired topical areas would be addressed during the interview and survey phases. Interviews and open-ended questions were the starting point of this needs assessment to inform specific questions and further areas of exploration in the surveys.

Key Informant Interviews

HARC created three interview guides with approximately ten questions each. Each interview guide was customized to better understand the needs/experiences of the following groups: 1) individuals with TBI, 2) caregivers of individuals with TBI, and 3) professionals/service providers of individuals with TBI. See Appendix 48. Individual with TBI Interview Script (English Version) for the individuals with TBI interview guide, Appendix 49. Caregiver Interview Script (English Version) for the caregiver's interview guide, and Appendix 50. Professional Interview Script (English Version) for the professionals/service providers interview guide.

Recruitment

DOR staff sent announcements for the interviews through their network, including California's TBI Program. These contacts included the six state-funded TBI sites, DOR Vocational Rehabilitation offices and staff, and 28 Independent Living Centers throughout California. HARC also contacted over 20 local and state organizations to recruit key informants for interviews.¹³ Additional outreach occurred through the networks among members of the TBI Advisory Board, Assistive Technology Advisory Committee, Blind Advisory Committee, California Committee on Employment of People with Disabilities, and Disability Advisory Committee.

Interviews were conducted from February 23 to April 21, 2022. HARC staff worked with DOR staff to schedule interviews via a scheduling software, Koalender. Potential interviewees could select from a variety of timeslots and were then subsequently contacted by HARC staff for an interview. Interviews were conducted virtually (by Zoom) and typically comprised 40-to-60-minute sessions. Interviews were available in

¹³ HARC sent a single notification for interview recruitment. Contacted organizations included the Making Headway Center, Santa Clara Valley Medical Center, California Chapters of Synapse, Brain Injury Association of California, Palo Alto Polytrauma Rehabilitation Center, Loma Linda Medical Center - Possibilities TBI support program, the Schurig Center for Brain Injury Recovery, Sharp Rehab, the Southern Caregiver Resource Center, the Brain Injury Coalition (Chico), Stanford University, the Center for Neuro Skills, and state contacts from Kaiser Permanente.

English or Spanish. Because no interviewees requested interviews in Spanish, all interviews were conducted in English.

Analysis

Interview audio recordings were transcribed by a transcription service. The transcripts were then analyzed by HARC staff using the qualitative analysis software MAXQDA to identify recurring themes. Select quotes were also drawn from the transcripts. All quotes that appear in this or subsequent reports have been anonymized to ensure the confidentiality of all key informants.

Survey

After a substantial portion of interviews were completed, HARC began developing three surveys, again with content customized to understand the following groups: 1) individuals with TBI, 2) caregivers of individuals with TBI, and 3) professionals/service providers of individuals with TBI. See Appendix 45. Individual with TBI Survey (English Version) for the individuals with TBI survey, Appendix 46. Caregiver Survey (English Version) for the caregivers of individuals with TBI survey, and Appendix 47. Professional Survey (English Version) for the professionals/service providers of individuals with TBI survey.

The content of these surveys was developed from the themes that emerged during the interview process. Areas highlighted by any of the groups were included on the surveys. The development of the surveys was carried out in partnership with the Needs Assessment Committee, DOR staff, and public members attending Needs Assessment Committee meetings. The surveys were programmed into an online survey-taking platform and were available in English or Spanish. The survey was active for approximately one month, from March 30th to May 2nd, 2022.

Recruitment

Like the interviews, HARC worked with DOR staff to send the survey links through their extensive networks, including advisory bodies, throughout California. HARC also sent notifications to the 20 organizations that were contacted for interview recruitment, as well as 16 additional organizations and over 100 California community colleges.¹⁴ HARC

¹⁴ HARC sent two notifications for survey recruitment: an invitation for survey participation and a reminder. Contacted organizations include the California Psychological Association, California Rehabilitation Institute, Neuro Vitality Center, Collage Rehabilitation Partners, NeuroRestorative, Mission Veteran, California Veterans, the Family Caregiver Alliance, the Well Spouse Association, Caregiver Action Network, National Alliance for Caregiving, the American Caregiver Association, the Jodi House Brain Injury Support Center, the Head Trauma Support Project of Sacramento, and the Brain Trauma Foundation. In addition, announcements were sent to Disabled Student Programs and Services offices at all 109 California community college campuses. HARC also sent a single notification through its own listserv and to the Inland Empire Disabilities Collaborative.

also invited all interviewees to complete the survey. In addition, HARC posted survey announcements to social media.¹⁵ TBI Advisory Board members were asked to distribute the survey links via their networks.

Analysis

Following the close of the survey data collection, HARC staff uploaded and cleaned the data and analyzed survey responses using the software SPSS (Statistical Package for the Social Sciences). HARC collaborated with the Needs Assessment Committee and DOR staff to identify approaches to analyzing the data.

Study Limitations

There are a few limitations of this project that merit consideration. First, this needs assessment had a small survey sample which then limits our ability to explore the needs of subgroups. The survey sample size was modest for all subgroups (135 individuals with TBI, 53 caregivers, and 79 professionals) and underrepresented non-White and Hispanic participants. The sample is therefore insufficient to identify needs specific to demographics such as non-White racial groups. Second, the sample overrepresented a few specific urbanized counties. For example, among individuals with TBI, 43.9% were from San Diego County, 11.2% Sacramento County, and 10.3% Orange County. This makes the sample insufficient to identify needs specific to regions of the state. Third, the sample of individuals with TBI tended to be more educated than the general population and also those who are already connected to TBI resources (since survey recruitment relied on existing resource networks). Thus, the survey sample skews toward including individuals who are relatively advantaged and privileged—those who identify as White, non-Hispanic, English-speaking, well-educated, or already in touch with (if not using) TBI resources. Although the needs identified in the study are acute and profound, such needs are likely much greater among non-White, Hispanic, non-English-speaking, and less educated TBI populations.

Although the study limitations limit conclusions about the needs of subgroups, the study's data is sufficient to identify common unmet needs. The comprehensiveness of the surveys (with between 25 to 45 questions) and open-ended interviews (with 50 key informants) provides sufficient data on the structural challenges that define the TBI experience. The unmet needs presented here—such as finding resources, economic stability, mental health, and social support—are systemic, rooted patterns that are generalizable to the state's TBI population.

That said, the survey was designed to provide a diversity of perspectives which help compensate for, although not overcome, its limitations. First, key informant interviews augmented survey data. For example, survey data was insufficient to identify needs

¹⁵ This included HARC's followers on Facebook, Instagram, and Twitter, as well as posts to a TBI subreddit and nine TBI Facebook groups.

specific to rural areas. However, several key informants spoke often and in detail about the challenges they face in their rural communities. Second, surveyed professionals provided input sometimes different than that of individuals with TBI and caregivers. For example, only 4.0% of individuals with TBI identified Spanish-language educational materials as an unmet need. However, 43.8% of professionals identified this as an unmet need (perhaps because professionals are exposed to clients/patients who are more diverse than the survey sample).

Recommendations for Future Needs Assessments

To overcome the study's limitations, future TBI needs assessments may try different strategies to increase survey samples. It is often a challenge for needs assessments to reach populations that are under-resourced and socially marginalized. Individuals with TBI are a population that is especially difficult to reach. Some individuals might not know or suspect that they have a TBI. Many are also socially isolated due to their injury. Additionally, symptoms such as memory challenges and cognitive fatigue can preclude or limit a person's survey participation.

Despite these and other challenges, future needs assessments can consider different strategies to increase survey participation. First, contacts can be made ahead of time with leaders at the various medical, academic, and non-profit organizations who serve individuals with TBI. This would increase the likelihood of cooperation with survey recruitment. Second, a study could use both online and paper surveys, although this would require more time to print, mail, and enter data for paper surveys. These paper surveys could be mailed to clinics and program offices to then be distributed to survey participants. (This was not practical for this study, because of the limited in-person services provided during the COVID-19 pandemic.) Telephone surveys and interviews could also be a viable research method for individuals who have impairments that limit use of computers or video calls. Third, future studies could offer survey participation incentives. Although the grant that funded this study did not pay for incentives, future studies could find alternative funding to cover incentives. This could include, for example, a drawing for a \$50 Visa gift card. Such incentives have reliably increased survey participation rates for past studies. It is also ethically just to compensate people in exchange for their time, particularly for a group that has difficulty obtaining paid work and the esteem that comes with paid work. These approaches could help future needs assessments attain not only depth but also breadth.

INDIVIDUALS WITH A TBI

Individuals living with a TBI.

Individuals with a TBI

A total of 135 individuals with TBI participated in the individuals with TBI survey. Of these 135 individuals, 98.5% completed an English survey, and 1.5% (two people) completed a survey in Spanish. In addition, key informant interviews were conducted with 25 individuals with TBI.

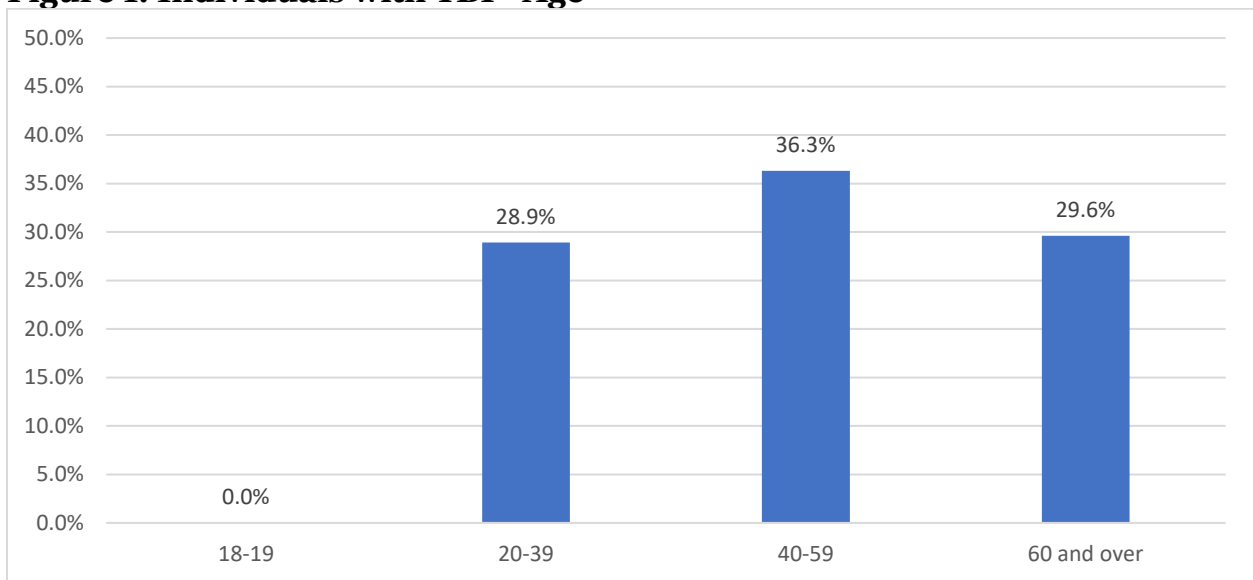
Demographics

Age

The average (mean) age of individuals with TBI was 49 years, and the median age was also 49. The standard deviation was 14.7 years. The youngest individual with TBI who was surveyed was 20, and the oldest was 82. The age groups were as follows:

- 28.9% were 20 to 39 years old (adult).
- 36.3% were 40 to 59 years old (middle-aged adult).
- 29.6% were 60 years old and over (senior adult).

Figure 1. Individuals with TBI - Age



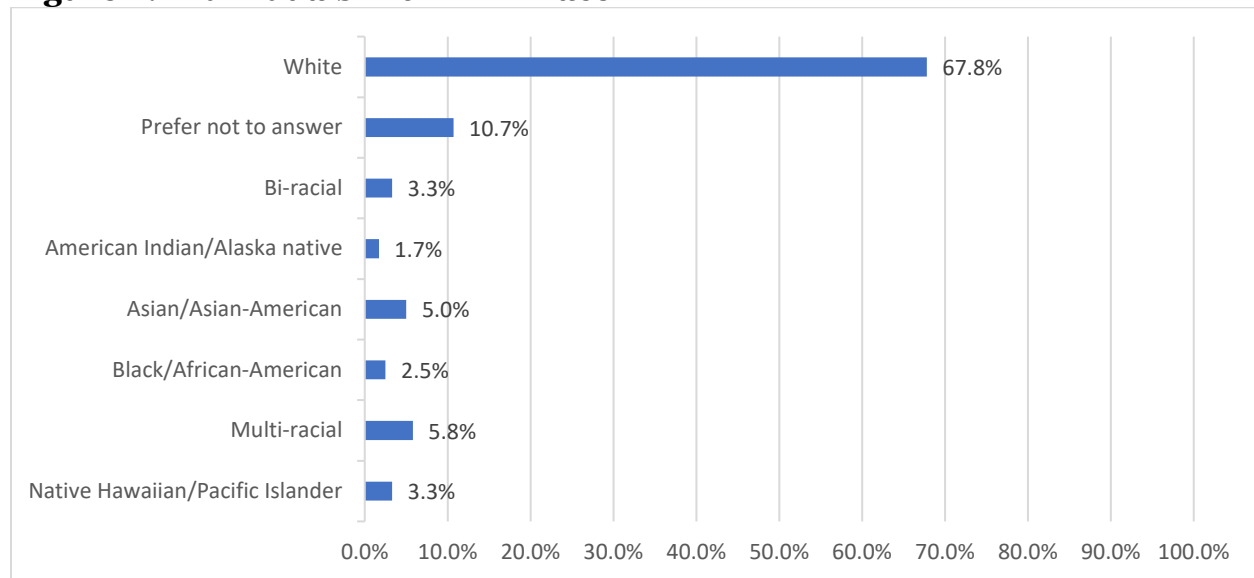
Note: $n = 135$.

Race and Ethnicity

Individuals with TBI were asked, “Which one of these groups would you say best represents your race? For the purposes of this survey, Hispanic is not a race.” As illustrated in the figure below, over two thirds (67.8%) of individuals with TBI identified as White. The next largest racial group was multi-racial (5.8%), followed by Asian/Asian-American (5.0%). One tenth (10.7%) of participants selected “prefer not to answer.”

EpiCenter, a state database on injuries maintained by the California Department of Public Health, tracks non-fatal hospitalizations and emergency department (ED) visits for individuals diagnosed with TBI.¹⁶ For the most recent year available (2015), White individuals with TBI comprised 46.1% of all non-fatal TBI hospitalizations and ED visits in California. In contrast, 67.8% of individuals with TBI in the present survey identified as White. This difference in percentages is statistically significant at the $p < .05$ level. Thus, the White racial group in the survey sample is overrepresented.

Figure 2. Individuals with TBI - Race



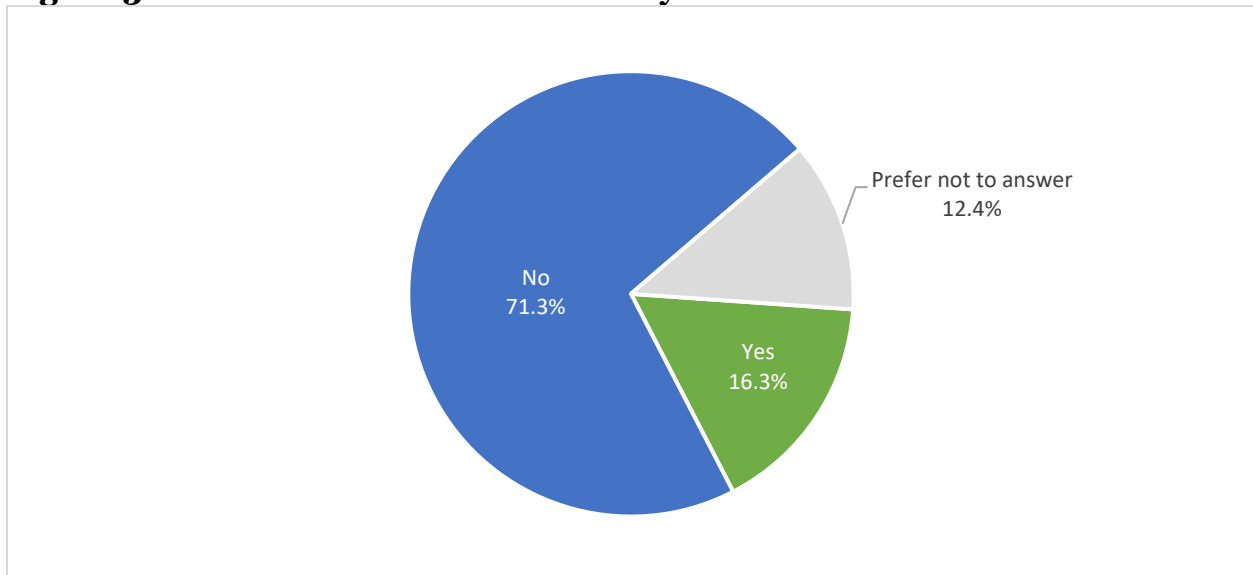
Note: $n = 121$.

¹⁶ EpiCenter: California Injury Data Online. (2022). California Department of Public Health. <https://epicenter.cdph.ca.gov/Default.aspx>

Individuals with TBI were also asked if they were of Hispanic, Latino, or Spanish origin. Less than three quarters (71.3%) reported, “no” they were not of Hispanic, Latino, or Spanish origin. See the figure below for details.

According to the EpiCenter database (2015), Hispanic individuals with TBI comprised 33.2% of all non-fatal TBI hospitalizations and ED visits in California.¹⁷ In contrast, 16.3% of individuals with TBI in the present survey identified as Hispanic. This difference in percentages is statistically significant at the $p < .05$ level. Thus, Hispanic individuals with TBI are underrepresented.

Figure 3. Individuals with TBI - Ethnicity



Note: $n = 129$.

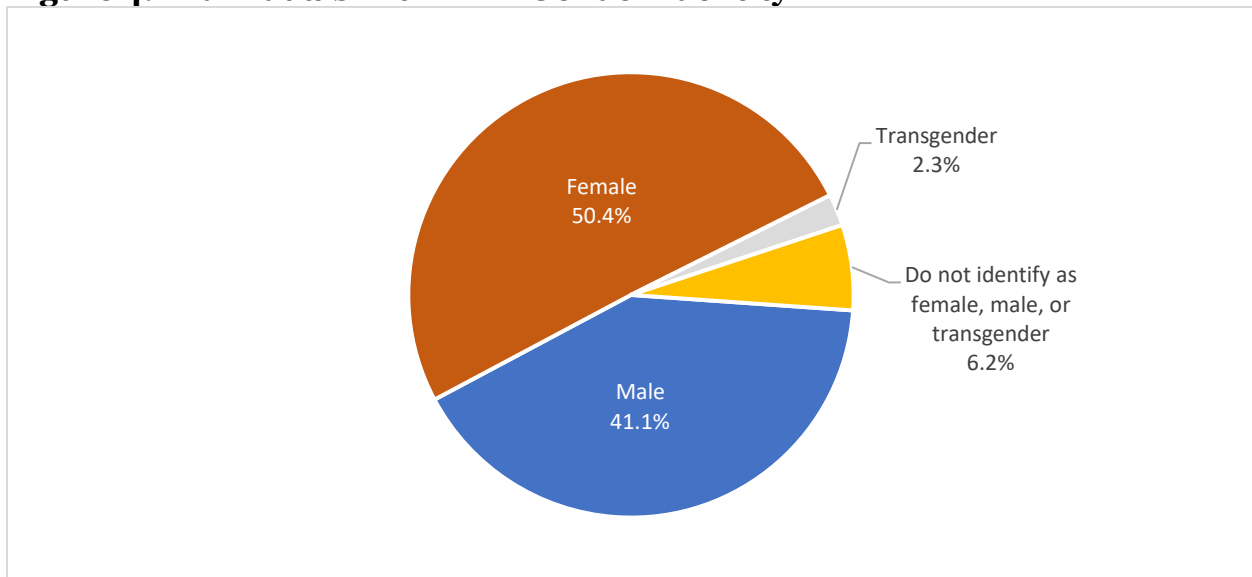
¹⁷ EpiCenter: California Injury Data Online. (2022). California Department of Public Health. <https://epicenter.cdph.ca.gov/Default.aspx>

Gender Identity

Individuals with TBI were asked, “How do you describe yourself?” and were given several options to choose from. As illustrated in the figure below, about half (50.4%) identified as female, and over two-fifths (41.1%) identified as male. Further, 2.3% identified as transgender, and 6.2% identified as non-binary (“Do not identify as female, male, or transgender”).

According to the EpiCenter database (2015), male individuals with TBI comprised 54.1% and female individuals with TBI comprised 45.9% of all non-fatal TBI hospitalizations and ED visits in California.¹⁸ In contrast, 41.1% of individuals with TBI in the present survey identified as male, and 50.4% identified as female. The difference in percentages between males is statistically significant and the difference in percentages between females is not statistically significant at the $p < .05$ level. Thus, male individuals with TBI are underrepresented.

Figure 4. Individuals with TBI - Gender Identity

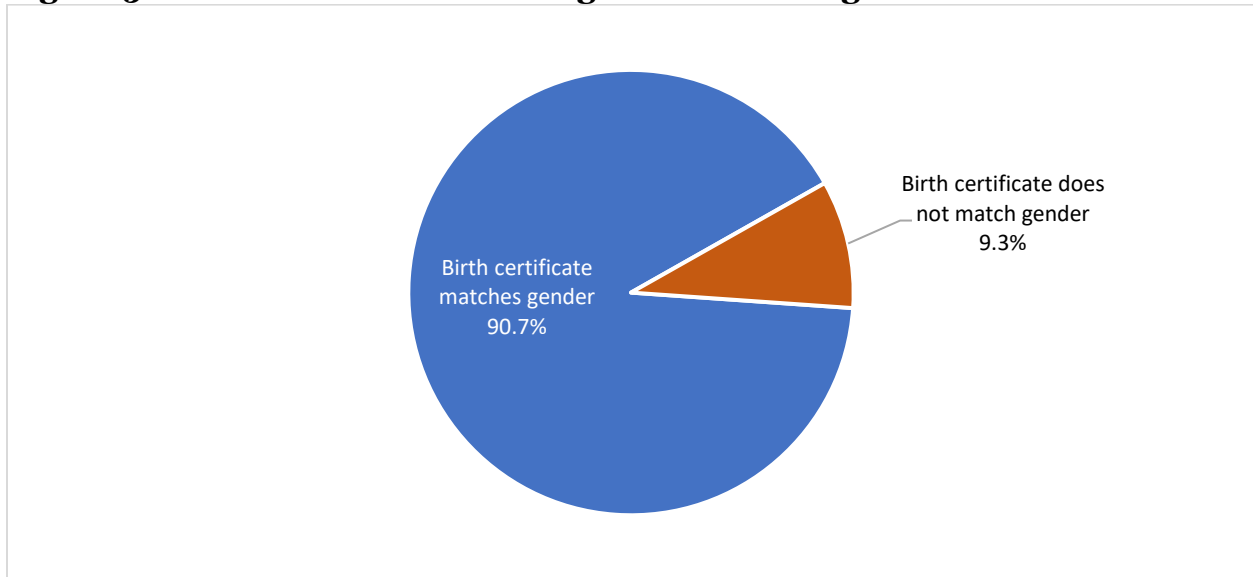


Note: $n = 129$.

¹⁸ EpiCenter: California Injury Data Online. (2022). California Department of Public Health. <https://epicenter.cdph.ca.gov/Default.aspx>

Individuals with TBI were also asked “What sex were you assigned at birth, on your original birth certificate?” These answers were compared to stated gender identity to determine how many participants have a gender that matches the sex they were assigned at birth. This method of measurement helps to identify people with a different gender identity from birth, as recommended by the UCLA William’s Institute¹⁹. As illustrated in the figure below, 90.7% reported genders that matched their birth certificate (cisgender), and 9.3% reported genders that did not match their birth certificate (transgender).

Figure 5. Individuals with TBI - Cisgender or Transgender Status



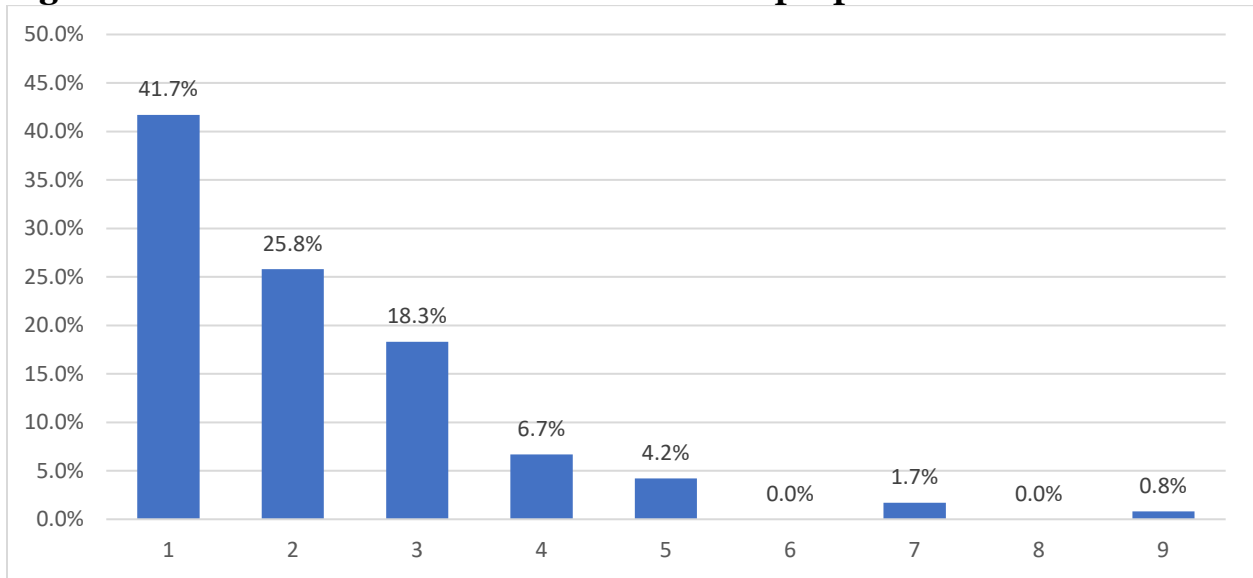
Note: $n = 129$.

¹⁹ UCLA School of Law Williams Institute (2020). Sexual Orientation and Gender Identity (SOGI) Adult Measures Recommendations FAQs. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Measures-FAQ-Mar-2020.pdf>

Living Situation

Individuals with TBI were asked, “How many people, including yourself, reside in your household?” Individuals with TBI could state how many adults and how many children were living with them. As illustrated below, most participants lived in households with one (41.7%) or two (25.8%) people. The median number of people per household was two.

Figure 6. Individuals with TBI - Number of People per Household

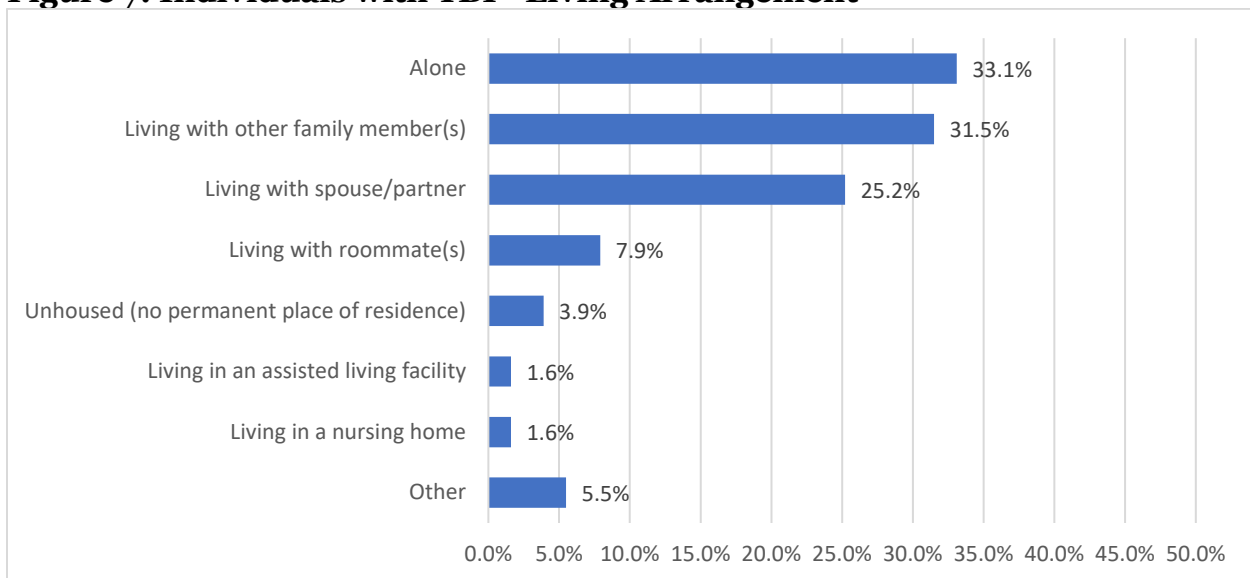


Note: $n = 120$.

Individuals with TBI were also asked about their current living arrangements. As illustrated below, one-third (33.1%) were living alone, one quarter (25.2%) were living with a spouse/partner, and about one-third (31.5%) were living with other family members (e.g., parents, children, etc.). Further, 7.9% were living with a roommate(s), and 3.9% were unhoused.

Those who selected “Other” indicated they used to be homeless (1), were now homeless (1), were about to be homeless (1), lived in their house (1), were in unsafe/unstable housing (1), and preferred not to say (1).

Figure 7. Individuals with TBI - Living Arrangement



Note: $n = 127$.

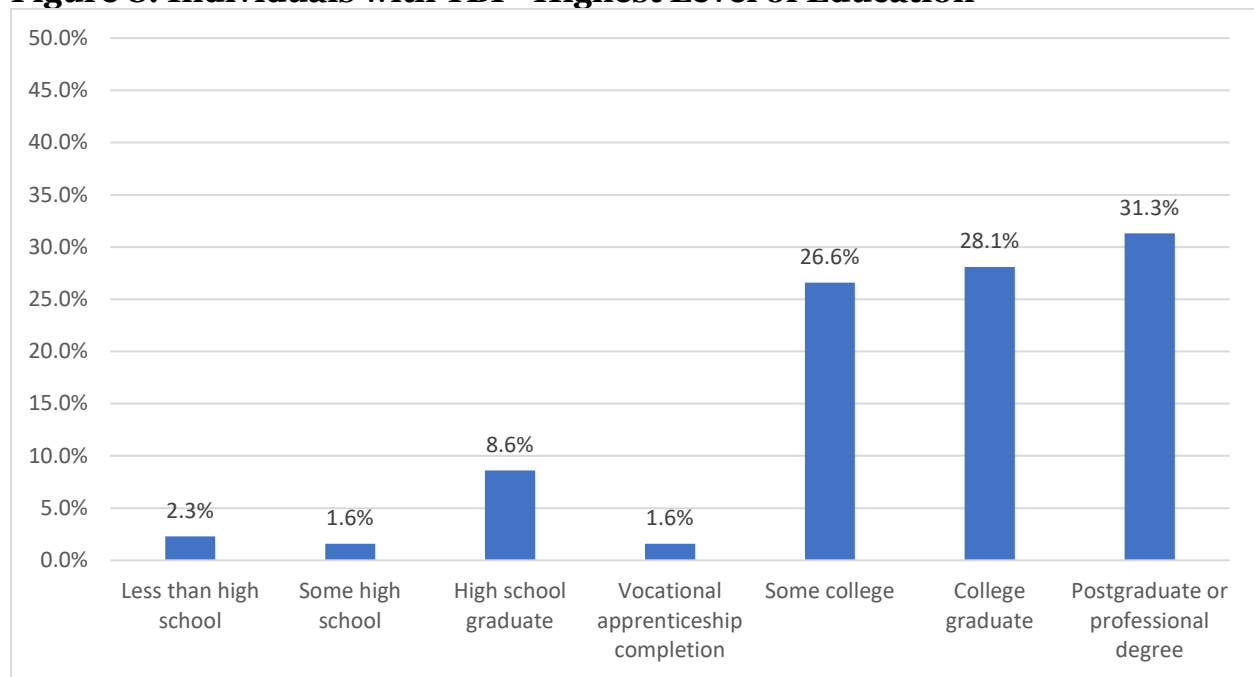
Individuals with TBI were also asked, “In which city do you live in California?” The most commonly reported city was San Diego (21.5%), followed by Sacramento (5.6%), Oceanside (3.7%), and El Cajon (2.8%). The most commonly reported counties of residence were San Diego County (43.9%), Sacramento County (11.2%), and Orange County (10.3%). Because these percentages are disproportionate to the counties’ general populations, it is likely that individuals who live in these counties are overrepresented in the survey sample. For a list of all reported cities and counties of residence, see Appendix 1. Individuals’ with TBI Cities of Residence and Appendix 2. Individuals’ with TBI Counties of Residence.

Social and Economic Class

Individuals with TBI were asked, “What is your highest level of education?” As illustrated below, the largest proportion were those with a postgraduate or professional degree, who comprised nearly one-third of participants (31.3%). This was followed by 28.1% who were college graduates and 26.6% who had “some college.” Further, 8.6% were high school graduates. Thus, over half (59.4%) have either a college degree or a postgraduate or professional degree. The surveyed participants were mostly well educated.

The education levels of the survey sample are higher than the average for California residents. This suggests the surveys were accessed to those already connected to education rather than being a reliable indicator of the average levels of education among Californians with TBI.

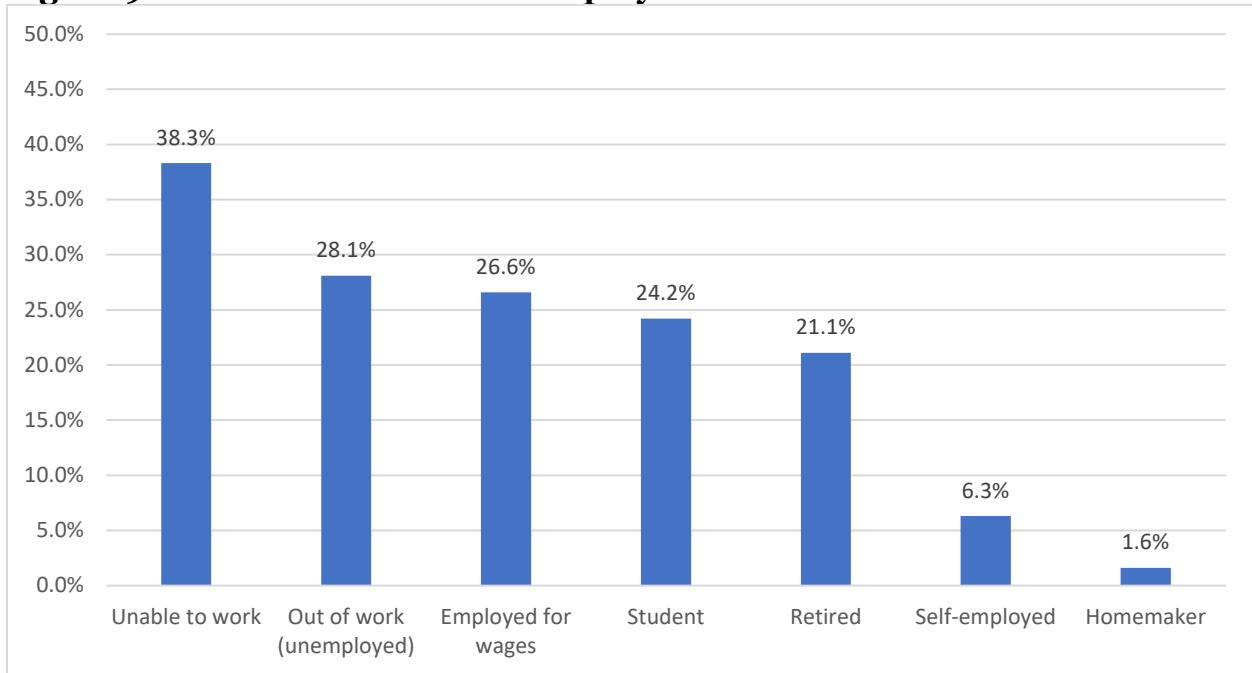
Figure 8. Individuals with TBI - Highest Level of Education



Note: $n = 128$.

Individuals with TBI were asked about their employment status and were instructed to “Select all that apply” from several options. As illustrated below, over one-third (38.3%) are unable to work, followed by over one-quarter (28.1%) who are unemployed and one-quarter (26.6%) who are employed for wages. Further, about one-quarter (24.2%) are students, and one-fifth (21.1%) are retired.

Figure 9. Individuals with TBI - Employment Status



Note: $n = 128$.

Individuals with TBI were asked, “Last year, what was your household income from all sources before taxes?” The median annual household income (before taxes) was \$29,141, whereas the mean (average) annual household income was \$67,246. The lowest reported household annual income was \$0 and the highest was \$1,000,000.

More than two-thirds (67.8%) were living in households with combined incomes of less than \$50,000. See the figure below for additional income details.

Figure 10. Individuals with TBI - Household Income



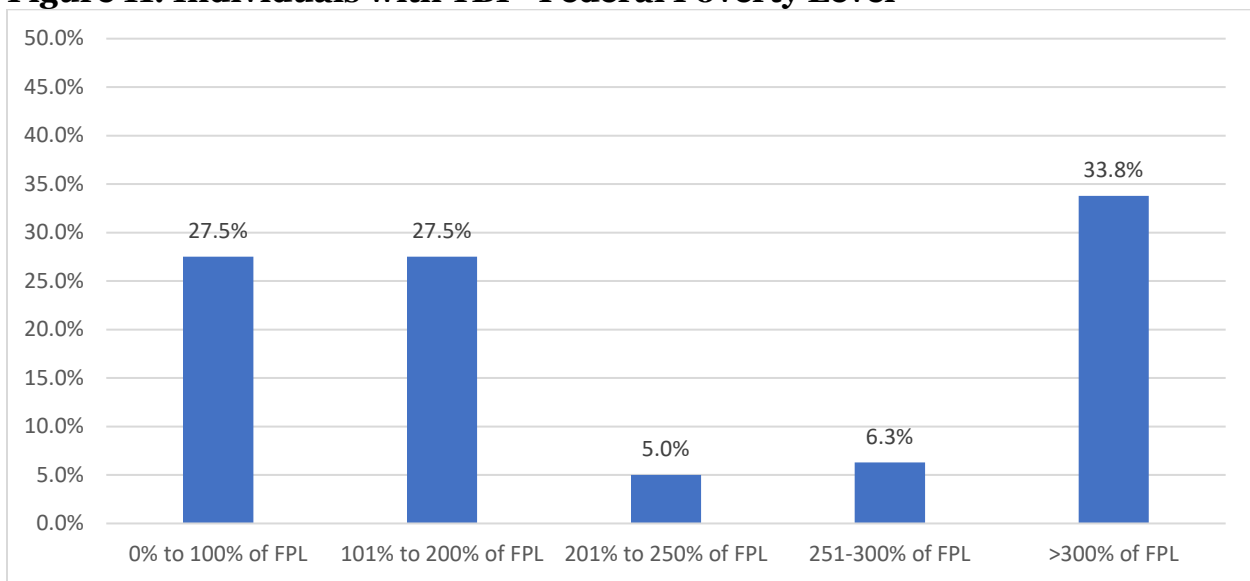
Note: $n = 84$.

The number of people living in the individual's household was compared against household income level to calculate federal poverty level (FPL). Federal poverty lines for 2022²⁰ were used for in the calculation below. As an example, under the 2022 guidelines, a household of two people making less than \$18,310 would be living below the poverty line.

As illustrated in the figure below, approximately one-third (33.8%) of individuals with TBI are living in a home that is above 300% of the federal poverty line.

The proportion of individuals with TBI living in poverty (27.5%) is over twice as high as the poverty rate for the general population in California (11.5%).²¹

Figure 11. Individuals with TBI - Federal Poverty Level



Note: $n = 80$.

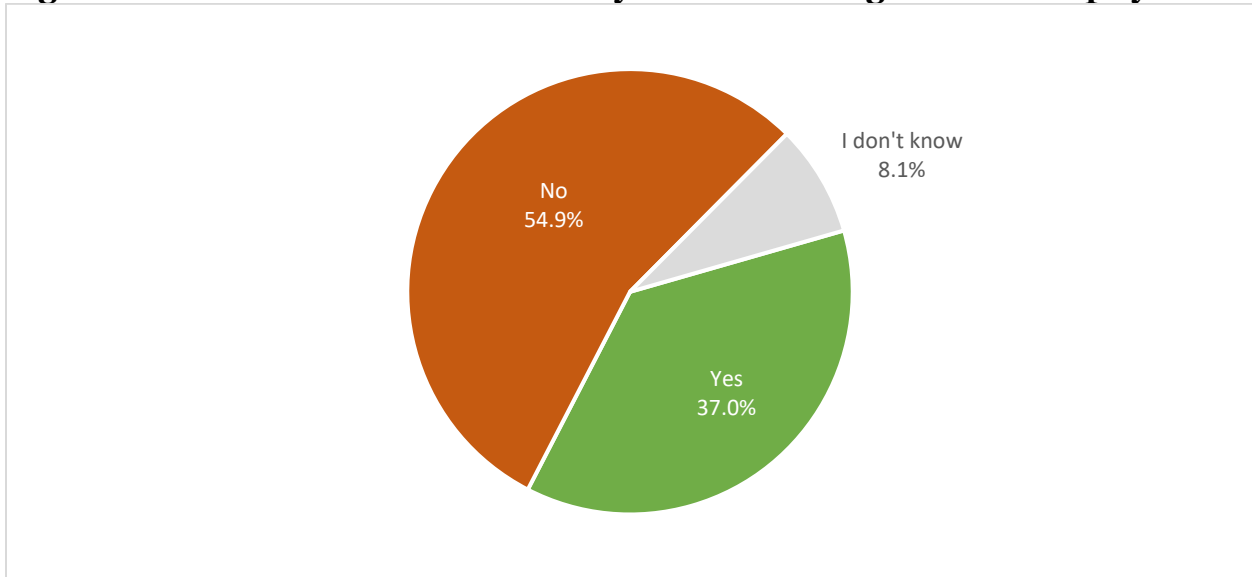
²⁰ HHS Office of the Assistance Secretary for Planning and Evaluation (2022). Poverty Guidelines. <https://aspe.hhs.gov/topics/poverty-economic-mobility/poverty-guidelines>

²¹ Quick Facts: California. (2022). U.S. Census. <https://www.census.gov/quickfacts/CA>

Relationship with Caregiver

Individuals with TBI were asked, “Do you have a caregiver who helps you?” As illustrated below, more than half (54.9%) do not have a caregiver who helps them, while 37.0% do have a caregiver who helps them.

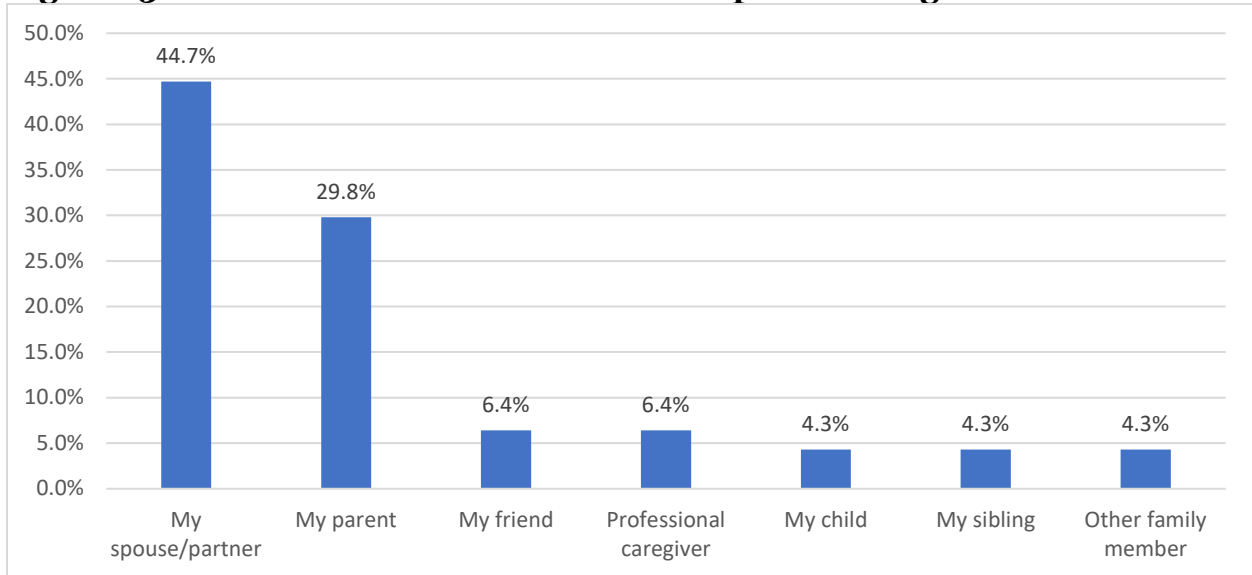
Figure 12. Individuals with TBI - “Do you have a caregiver who helps you?”



Note: $n = 135$.

Among those individuals who reported having a caregiver, they were asked, “What relationship do you have with your caregiver? If you have more than one caregiver, think about the caregiver who provides you the MOST amount of care.” As illustrated below, about three-quarters (74.5%) of individuals with TBI had a caregiver who was either a spouse/partner or a parent.

Figure 13. Individuals with TBI - Relationship with Caregiver

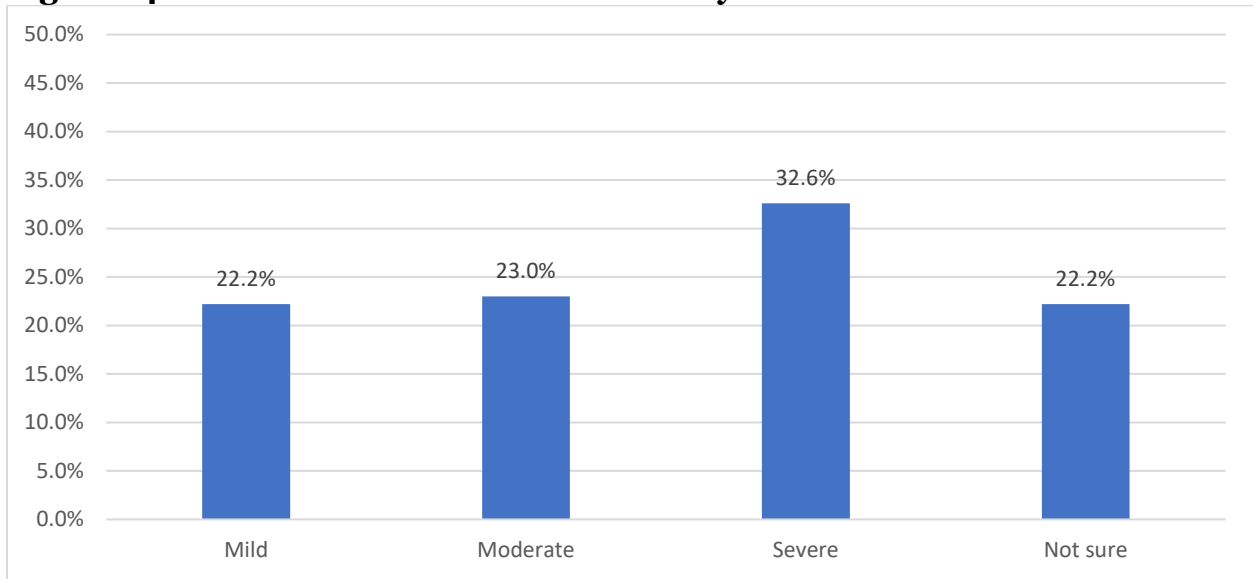


Note: $n = 47$.

TBI Characteristics and Impacts

Individuals with TBI were asked, “How was your TBI characterized as?” As illustrated below, one-third (32.6%) of individuals with a TBI reported it is *severe*. One-fifth (22.2%) of individuals reported that their TBI is *mild*, and one-fifth (23.0%) reported their TBI is *moderate*. Another one-fifth (22.2%) of individuals reported they are not sure about the severity of their TBI.

Figure 14. Individuals with TBI - “How was your TBI characterized as?”

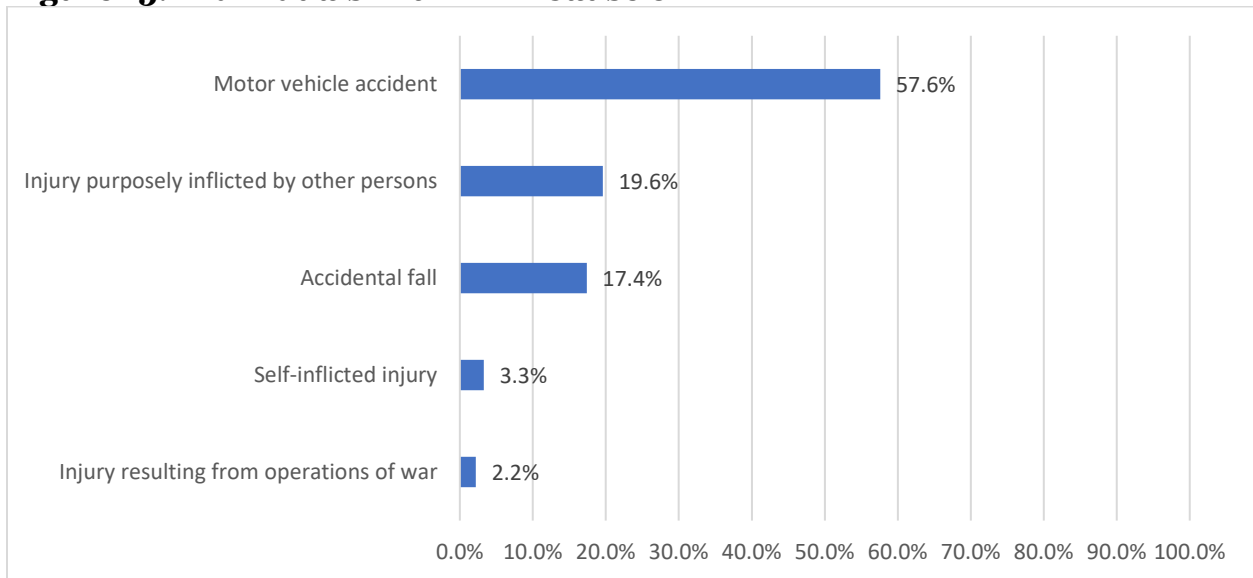


Note: $n = 135$.

People with TBI most commonly get TBIs from falls, firearm-related injuries, motor vehicle crashes, or assaults.²² While the exact proportions for cause of TBI are not available among living persons at the national level, it has been reported that accidental falls lead to almost half of TBI-related hospitalizations, and motor vehicle accidents and assaults are other common ways of people getting a TBI.²³ Thus, the cause of TBI (as reported by individuals with TBI, below) is slightly skewed compared to national trends.

Individuals with TBI were asked, “What was the cause of your TBI?” and were given several options to choose from. The majority (57.6%) reported that the cause of their TBI was a motor vehicle accident. There was also a high percentage of individuals who reported the cause of their TBI was an injury purposely inflicted by other persons (19.6%) and from an accidental fall (17.4%).

Figure 15. Individuals with TBI - Cause of TBI



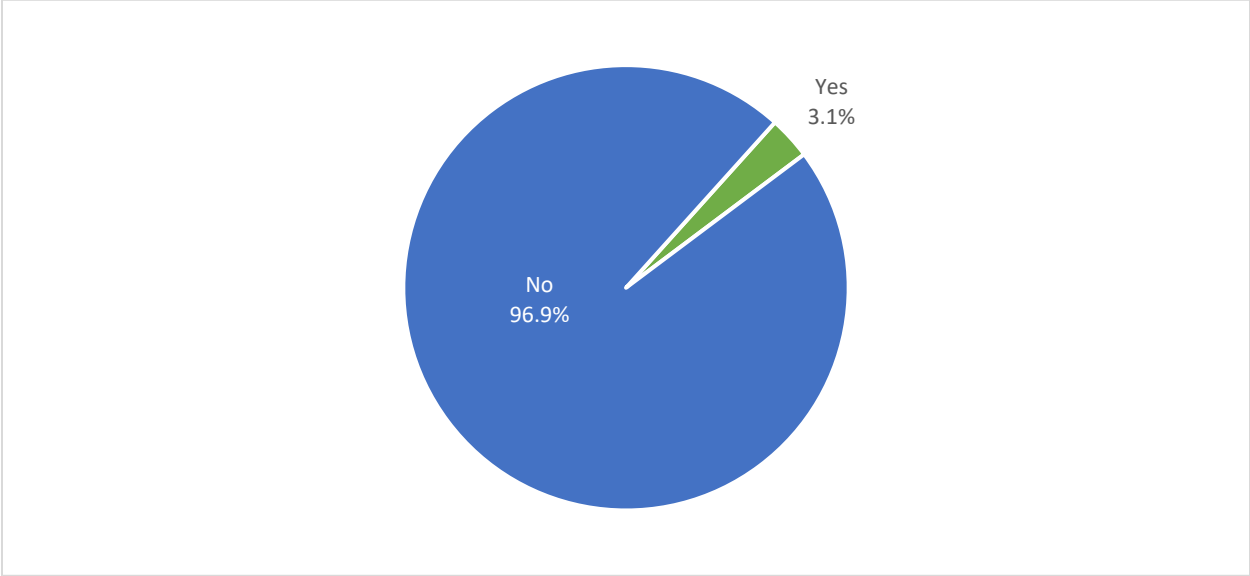
Note: $n = 92$.

²² Traumatic Brain Injury & Concussion (2022). Centers for Disease Control and Prevention. https://www.cdc.gov/traumaticbraininjury/get_the_facts.html

²³ Ibid.

Individuals with TBI were asked, “When you got your TBI, were you serving in the military?” Most individuals with a TBI were not in the military at the time of their TBI (96.9%); however, 3.1% were in the military at the time of their TBI.

Figure 16. Individuals with TBI - “When you got your TBI, were you serving in the military?”

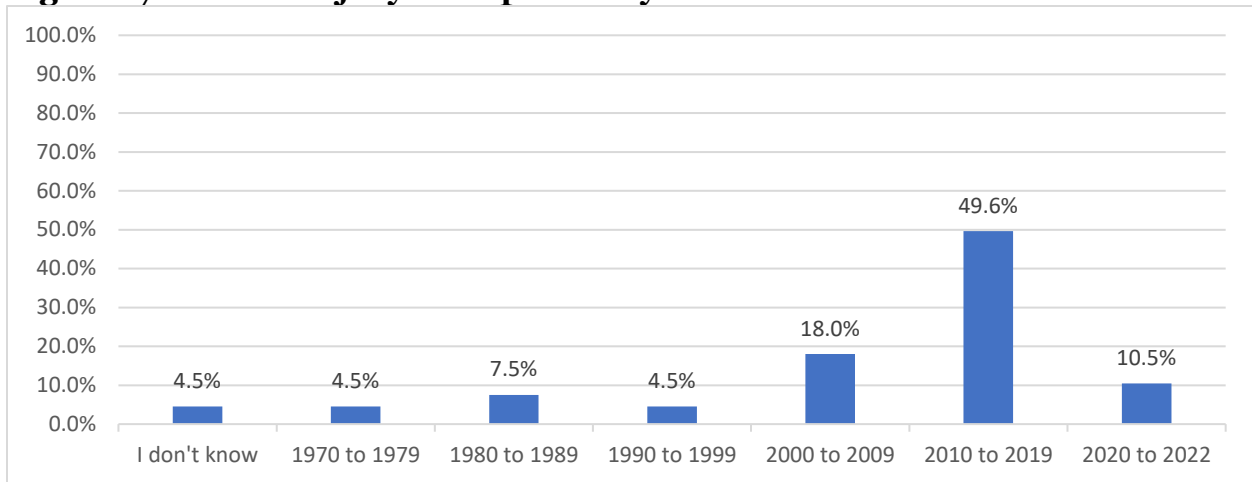


Note: *n* = 129.

Individuals with TBI were asked, “In what year did you get your TBI?” As illustrated below, one tenth (10.5%) got their TBI in the past two years and half (49.6%) got their TBI between 2010 and 2019. Another 18.0% got their TBI between 2000 and 2009. Thus, 78.1% got their TBI in the past 22 years.

The year of injury was compared to reported age to determine the age at which individuals incurred their TBI. The youngest age that individuals got their TBI was 2 years; the oldest age was 72. The average (mean) age when individuals incurred their TBI was 33.5 years; the standard deviation was 16.4 years. Further, 11.0% incurred their TBI before the age of 18.

Figure 17. Year of Injury as Reported by Individuals with TBI

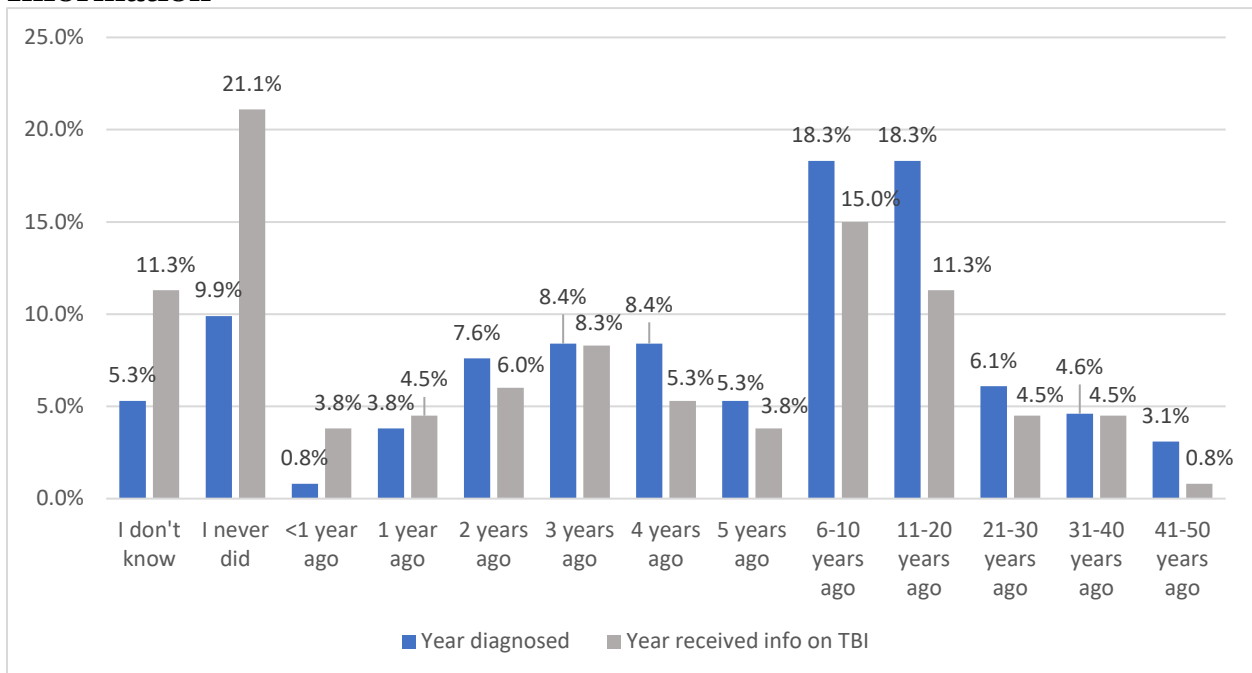


Note: $n = 133$.

Individuals with TBI were then asked, “When were you told by a health care provider that you had a TBI?” As illustrated below, nearly one-tenth (9.9%) reported never having received a diagnosis. One-third (34.3%) were diagnosed in the past five years. Further, 18.3% were diagnosed between six to 10 years ago and 18.3% were diagnosed 11 to 20 years ago.

Individuals with TBI were also asked, “When were you provided with information or resources about your TBI?” As illustrated below, 11.3% reported “I don’t know,” and one-fifth (21.1%) reported never having been given information or resources about TBI.

Figure 18. Individuals with TBI - Year Diagnosed and Year Receive TBI Information



Note: $n = 131$ and $n = 133$, respectively.

Individuals with TBI can experience a variety of different symptoms. Furthermore, individuals with TBI can experience different symptoms depending on the type of injury, the severity, and the area of the brain.²⁴

Individuals with TBI were asked, “What are the most challenging symptoms you’ve experienced because of your TBI?” Participants could select from 21 options and were instructed to “Select all that apply.” The most common reported TBI symptoms were difficulty with memory (80.7%), cognitive fatigue (77.0%), feeling physically tired or fatigued (73.3%), difficulty maintaining concentration (71.9%), and mental health challenges (68.1%).

See the table below for further details.

Table 1. Individuals with TBI - TBI Symptoms

Symptom	Percentage	<i>n</i>
Difficulty with memory	80.7%	109
Difficulty thinking or being mentally overwhelmed (Cognitive fatigue)	77.0%	104
Feeling physically tired or fatigued	73.3%	99
Difficulty maintaining concentration	71.9%	97
Mental health (depression, anxiety, etc.)	68.1%	92
Difficulty solving problems	62.2%	84
Difficulty with balance or feeling dizzy	61.5%	83
Difficulty controlling emotions	60.0%	81
Less social	58.5%	79
Discomfort in public/crowds	57.8%	78
Difficulty sleeping	57.0%	77
Sensitivity to noise	54.8%	74
Difficulty with daily living tasks	54.1%	73
Headaches	50.4%	68
Sensitivity to light	47.4%	64
Difficulty walking	41.5%	56

²⁴ What are common symptoms of traumatic brain injury (TBI)? (2020). US Department of Health and Human Services. <https://www.nichd.nih.gov/health/topics/tbi/conditioninfo/symptoms>

Difficulty speaking	40.7%	55
Poor eyesight	34.8%	47
Difficulty with sexual function	28.1%	38
Difficulty visualizing images in your mind	28.1%	38
Other	25.2%	34
Hearing loss	17.0%	23
Experiencing seizures	17.0%	23
Total	-	135

One quarter (25.2%) marked “Other,” with some specifying their symptoms. These “Other” responses included symptoms already listed, as well as other symptoms such as chronic or physical pain ($n = 2$), having no taste or smell ($n = 1$), ringing ears ($n = 1$), autonomic dysfunction ($n = 1$), proprioception impairment ($n = 1$), aphasia ($n = 2$), and apraxia ($n = 1$). For a full list of reported “Other” symptoms, see Appendix 3. Individuals with TBI – “Other” TBI Symptoms.

One theme that appeared in the interviews was the injury’s invisibility. Some TBIs might be outwardly evident with, for example, speech impairments or signs of physical trauma. However, many TBIs go unseen. The individual with TBI may be able to speak “normally” and present as unimpaired. Yet most symptoms listed above— from cognitive fatigue to sensitivity to light—can go unnoticed by others, even when symptoms are severely disabling. These unnoticed symptoms can result in profound social isolation.

“Most people don’t know you have [a TBI]. Most people treat you like you don’t have one, and you are truly suffering in silence.”

Individual with TBI

Individuals with TBI were also asked, “Which of these has your TBI negatively affected? Select all that apply.” Participants could select from 11 options. As shown in the table below, the most reported life domains negatively affected by TBI were employment (76.7%), friendships (74.4%), activities of daily living (67.4%), access to community events/services/activities (60.5%), and family (59.7%). Other than effects on employment, relationship impacts are the most widely reported negative impact.

Table 2. Individuals with TBI - Domains That TBI Has Negatively Affected

Category	Percentage	n
Employment	76.7%	99
Friendships	74.4%	96
Activities of daily living (for example, going shopping, doing chores around home, etc.)	67.4%	87
Access to community events/services/activities	60.5%	78
Family	59.7%	77
Relationship with spouse/partner	55.0%	71
Being able to leave the house	51.2%	66
School	42.6%	55
Living arrangements	41.9%	54
Managing my health care	41.9%	54
Getting access to health care	32.6%	42
Total	-	129

In interviews, a common theme was the sudden, often devastating loss of close relationships. Among the 25 interviews, there were 15 mentions of losing close relationships, such as spouses, siblings, or best friends. Other relationships, like with caregivers, may also be strained. These effects were sometimes attributed to friends and family not being able to understand the injury and the survivor’s experience (mentioned by 8 of the 25 caregivers). Such changes in relationships could be disorienting and distressing, adding to the challenge of accepting and adapting to the injury.

“I have lost every relationship in my life. There is not anyone that’s still there.”

-Individual with TBI

“A lot of people... can’t see [the injury]... At first, it’s important to them, and then as time goes on, they get tired of it. It’s not that they don’t care it’s just that they get desensitized to it. They feel helpless because they don’t know what to do. They just start distancing themselves, and I don’t blame them.”

-Individual with TBI

Although negative impacts were universally found across interviews, some key informants also spoke of positive impacts. These included new friendships, a sense of solidarity with the TBI community, and a new life perspective. These positive impacts were not due to a lack of struggle or hardship. Rather, these positive impacts were due to the presence of social support, medical care, and economic resources. Some survivors take up new hobbies, some grow closer to their spouse, and others find community with fellow TBI survivors. Such outcomes are a result of accepting one’s injury, embracing a new reality, and having the support necessary to turn devastating hardship into new meaning and connections.

“My goal was to completely let go of who I was, and completely accept who I am now, and be totally open to whatever life I’m meant to have.... It forced me to add more dimensions to my life. I had to exercise. I had to get emotional therapy, physical therapy... I had to eat better. I had to be vulnerable. I had to cry. I had years’ worth of crying that apparently needed to come out. I got really into caring for plants and having pets. I learned to play the piano. I made a lot of new connections with people I never would have made.”

-Individual with TBI

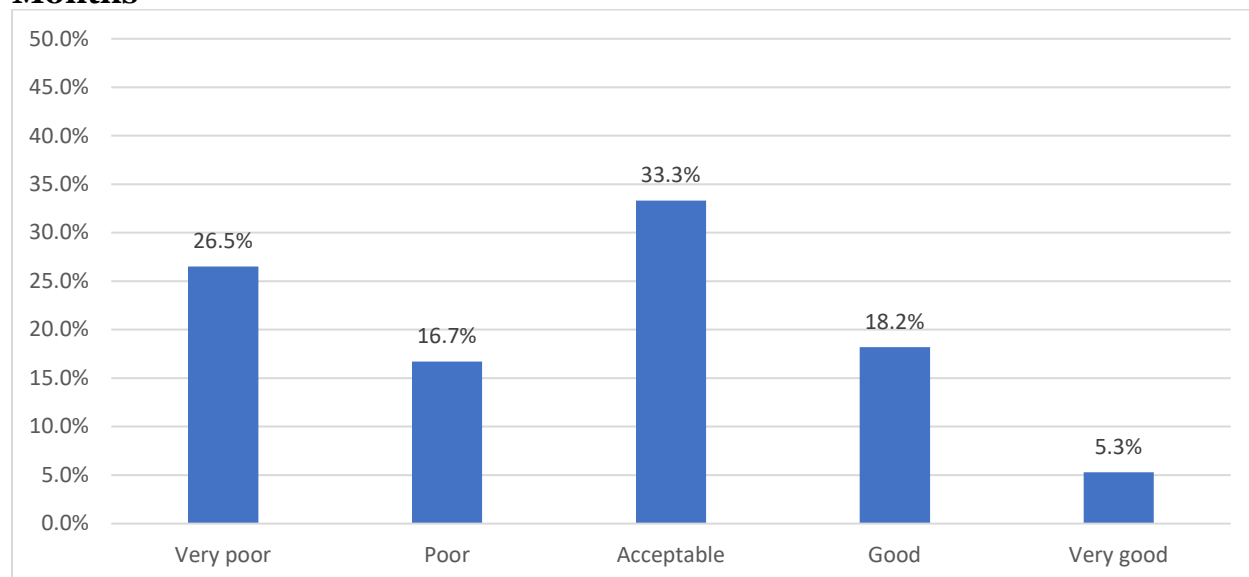
“Obviously, I got a divorce. That impacted my life. The brain recovery was just too much for [my ex-husband] to deal with.... I now have more of a circle [of] the friends that I do have. They're there for me no matter what.... Even though I've lost a lot, I have gained a lot as well. My relationships are closer.”

-Individual with TBI

Satisfaction with TBI Care

Individuals with TBI were asked, “How would you rate your TBI recovery during the first **six months** of recovery?” As illustrated below, one third (33.3%) rated this early period of their recovery as *acceptable*, and one quarter (26.5%) rated it as *very poor*. Further, 16.7% rated it as *poor*, 18.2% rated it as *good*, and only 5.3% rated it as *very good*.

Figure 19. Individuals with TBI - Rating of TBI Recovery During the First Six Months



Note: $n = 132$.

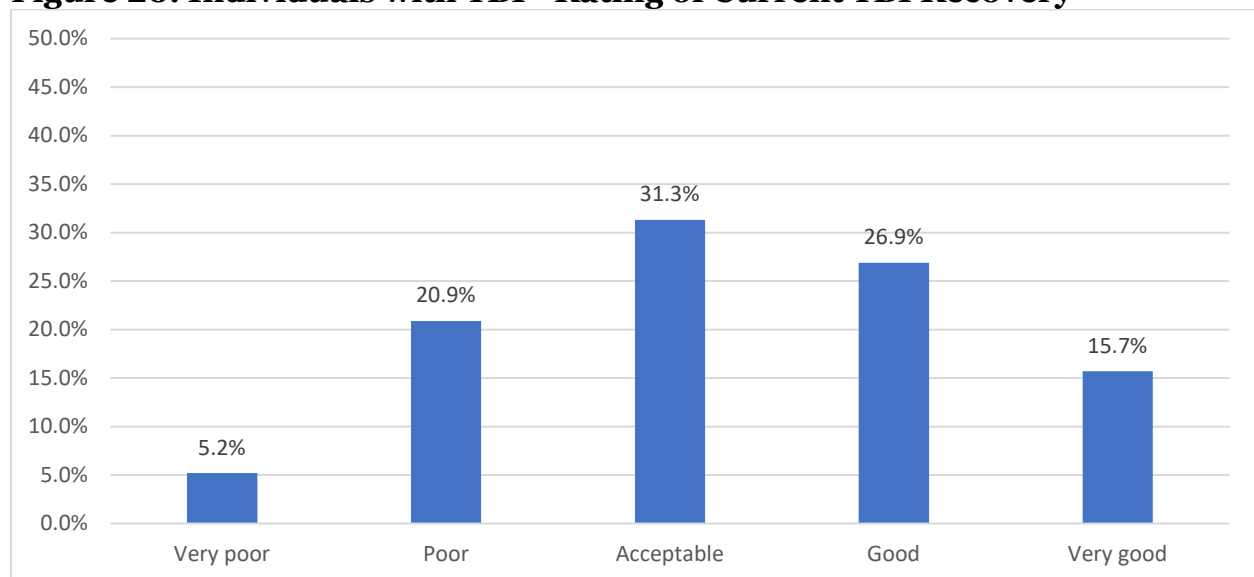
Individuals with TBI were then asked, “Please explain, why your six-month recovery was [option they selected earlier]?” Responses were varied. Those who rated their six-month recovery as *poor* or *very poor* explained that they had no help or not enough help/support/services (13). Others explained that they had not received referrals to TBI treatment/therapy (9), that they had severe/acute symptoms (9), or that they were undiagnosed/misdiagnosed (8). For a full list of responses, see Appendix 4. Individuals with TBI – Why Six-Month Recovery Was *Poor* or *Very Poor*.

Those who rated their six-month recovery as *acceptable* had mixed explanations, either discussing the positive or negative outcomes of their recovery. The most common explanations were that they made good recovery progress (7) or that they could now walk/walk better (6). For a list of all responses, see Appendix 5. Individuals with TBI – Why Six-Month Recovery Was *Acceptable*.

Those who rated their six-month recovery as *good* or *very good* explained that they had lots of improvement/progress (8) or that they had great treatment/therapies/providers (7). For a full list of responses, see Appendix 6. Individuals with TBI – Why Six-Month Recovery Was *Good* or *Very Good*.

Individuals were then asked, “How would you rate your TBI recovery **currently**?” Ratings for current recovery were higher than ratings for the first six months of recovery. Close to one-third (31.3%) rated their current recovery as *acceptable*, and one-quarter (26.9%) rated it as *good*. Further, 20.9% rated it as *poor*, and only 5.2% rated it as *very poor*. In addition, 15.7% rated it as *very good*.

Figure 20. Individuals with TBI - Rating of Current TBI Recovery



Note: *n* = 134.

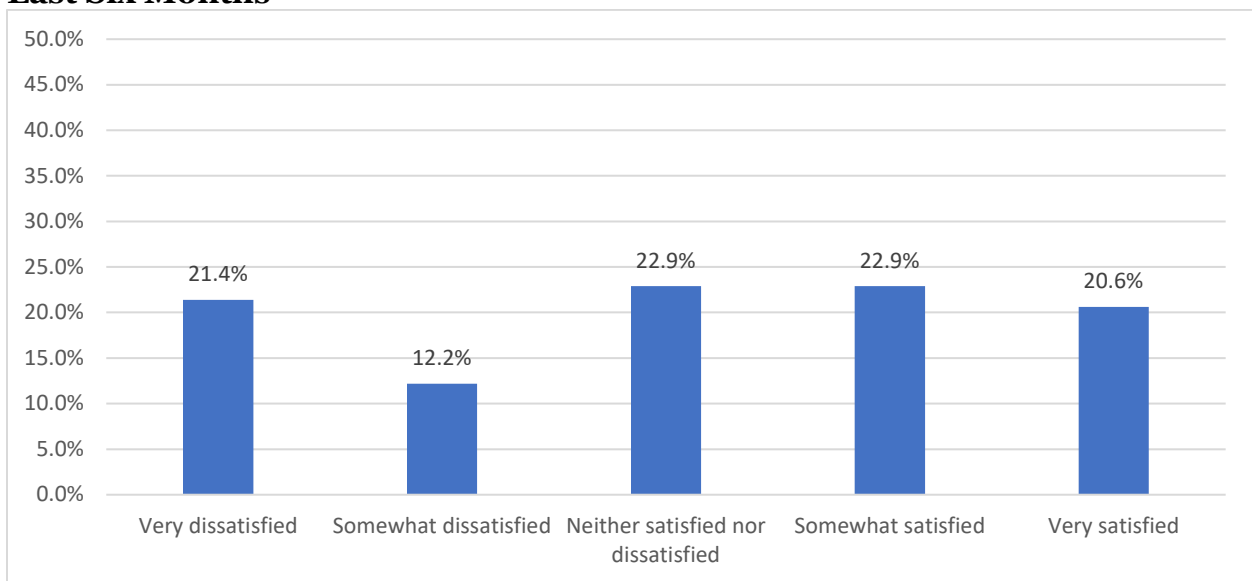
Individuals with TBI were then asked, “Please explain why your recovery currently is [option they selected earlier]?” Responses were varied. Those who rated their current recovery as *poor* or *very poor* explained that have symptoms/symptoms persist (15) or that their symptoms/condition worsened (7). For a full list of responses, see Appendix 7. Individuals with TBI - Why Current Recovery Is *Poor* or *Very Poor*.

Those who rated their current recovery as *acceptable* had responses that varied widely. Some, for example, explained that they are making slow progress (3), they still have symptoms (3), and their insurance will not cover needed treatment (3). For a full list of responses, see Appendix 8. Individuals with TBI – Why Current Recovery Is *Acceptable*.

Those who rated their current recovery as *good* or *very good* explained that they are making progress in their recovery (13), can live independently (11), and can drive (6). For a full list of responses, see Appendix 9. Individuals with TBI - Why Current Recovery Is *Good* or *Very Good*.

Individuals with a TBI were asked, “Overall, how satisfied are you with the medical services/care you have received for your TBI in the last **six months**?” As illustrated below, there was an even distribution of reported satisfaction levels: 20.6% were *very satisfied*, 22.9% were *somewhat satisfied*, 22.9% were *neither satisfied nor dissatisfied*, 12.2% were *somewhat dissatisfied*, and 21.4% were *very dissatisfied*. In total, 43.5% were either *somewhat satisfied* or *very satisfied*, and 33.6% were either *somewhat satisfied* or *very dissatisfied* with their TBI care in the last six months.

Figure 21. Individuals with TBI - Satisfaction with Medical Care/Services in Last Six Months



Note: *n* = 131.

Individuals with TBI were asked to explain their satisfaction, neutrality, or dissatisfaction with their services/care. Individuals who were *very satisfied* or *somewhat satisfied* explained they feel this way because they are receiving good quality care ($n = 12$), they have a caring provider/physician ($n = 4$), rehabilitation services are available to them ($n = 3$), and that they feel healthy ($n = 2$).

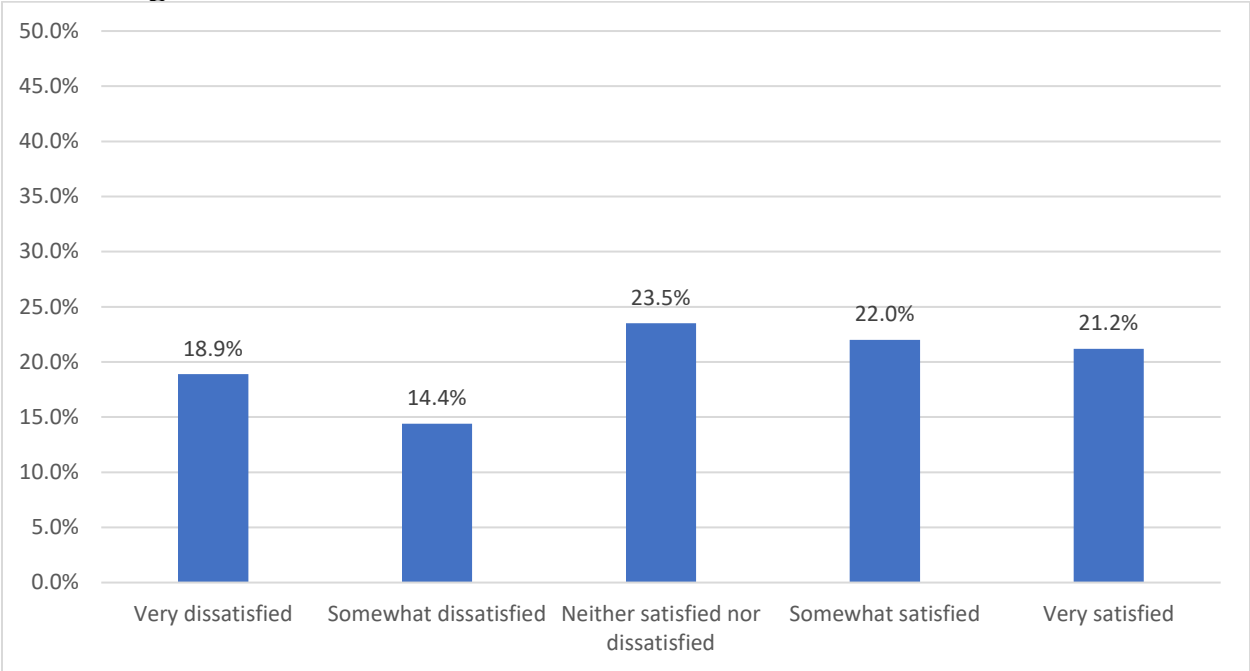
Individuals with TBI who feel *neither satisfied nor dissatisfied* explained they feel this way because they aren't receiving care or are not in need of care at the moment ($n = 11$), services are not available at the moment ($n = 6$), their health is staying the same ($n = 3$), or they are currently getting care ($n = 2$).

Individuals with TBI who feel *somewhat dissatisfied* or *very dissatisfied* explained they feel this way because it's hard to navigate/access care ($n = 11$), have not received any care ($n = 8$), providers don't know how to help ($n = 7$), poor health care ($n = 6$), denied services/not covered by insurance ($n = 5$), healthcare won't treat TBI insurance ($n = 5$), mistreatment/providers don't believe me ($n = 5$), care is too expensive ($n = 2$), and hard to get an appointment ($n = 2$).

Individuals with TBI were asked, "How satisfied are you with your health care providers' (doctors, nurses, therapists, etc.) knowledge of TBI?" As illustrated below, there was again a roughly equal distribution of satisfaction levels. Approximately 43.2% are either *very satisfied* or *somewhat satisfied* with their healthcare providers' knowledge of TBI; 33.3% are either *somewhat dissatisfied* or *dissatisfied* with their providers' knowledge of TBI.

Individuals with TBI were asked, "How satisfied are you with your health care providers' (doctors, nurses, therapists, etc.) knowledge of TBI?" As illustrated below, there was again an even distribution of satisfaction levels. Approximately 43.2% are either *very satisfied* or *somewhat satisfied* with their healthcare providers' knowledge of TBI; 33.3% are either *somewhat dissatisfied* or *dissatisfied* with their providers' knowledge of TBI.

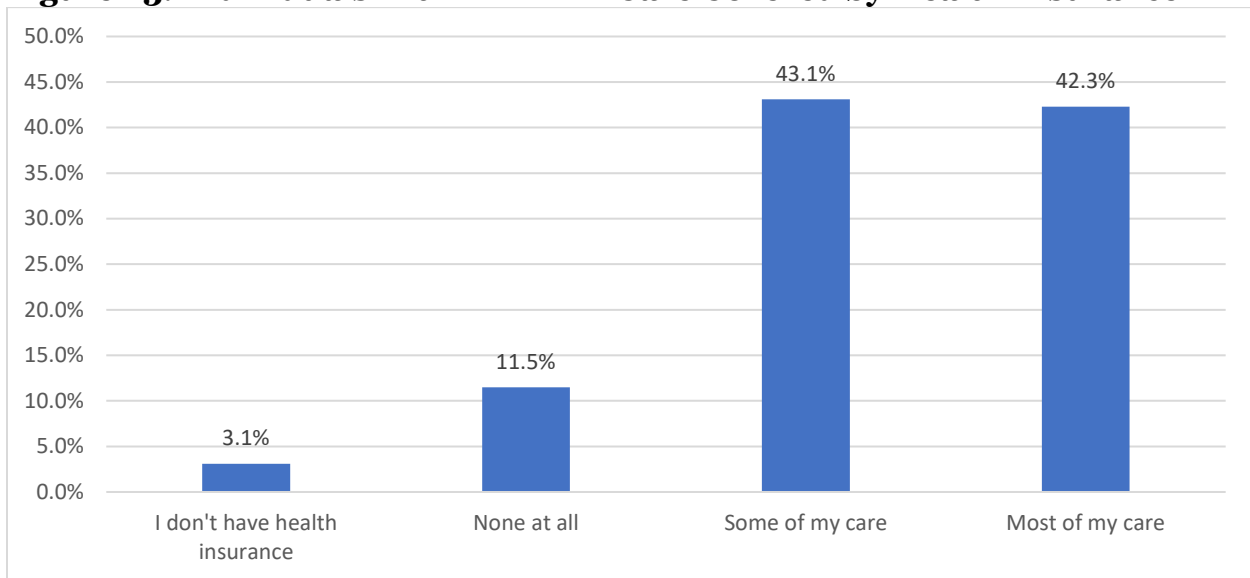
Figure 22. Individuals with TBI - Satisfaction with Health Care Providers' Knowledge of TBI



Note: *n* = 132.

Individuals with TBI were asked, “How much of your care for your TBI has your health insurance covered?” As illustrated below, 42.3% reported that their health insurance covers most of their TBI care, and 43.1% reported that their insurance covers some of their TBI care. Further, 11.5% reported their insurance covers none of their TBI care, and 3.1% do not have health insurance. In total, 14.5% do not have any insurance coverage for TBI care.

Figure 23. Individuals with TBI - TBI Care Covered by Health Insurance



Note: $n = 130$.

One theme that arose in interviews was the difficulty of having health insurance cover TBI care, including Medi-Cal and private health insurance. Some individuals with TBI shared that they went without some treatments because they cannot afford them out of pocket or because they cannot find local experienced providers. This difficulty in navigating the health care system was reported to be compounded by emotional stress and financial vulnerability.

Individual with TBI: “Well, it’d be nice if my [private health insurance] would help pay for some of the outsourcing [of care] that I have to do because they don’t have the capacity to help. Because I have really good health insurance, but they don’t do anything for me.”

Interviewer: “They don’t cover the specialists that you need, many of them?”

Individual with TBI: “They do not.”

“I actually had to fight Medi-Cal to get them to cover [a medication].... Basically, this medication was only covered for people that had a stroke or some type of other neurological issue, but not covered for brain injuries. I put on my ‘lawyer cap’ and wrote this really intense letter with a lot of attachments and information to support why they should cover it, and ultimately, they did cover it.... My neurologist told me that all of his patients had been denied coverage [by] Medi-Cal for this particular medication, but I was the only one who got it.... By the way, this medication is \$1,500 a month.... That's a huge issue for people with brain injuries who need such an expensive medication every single month.”

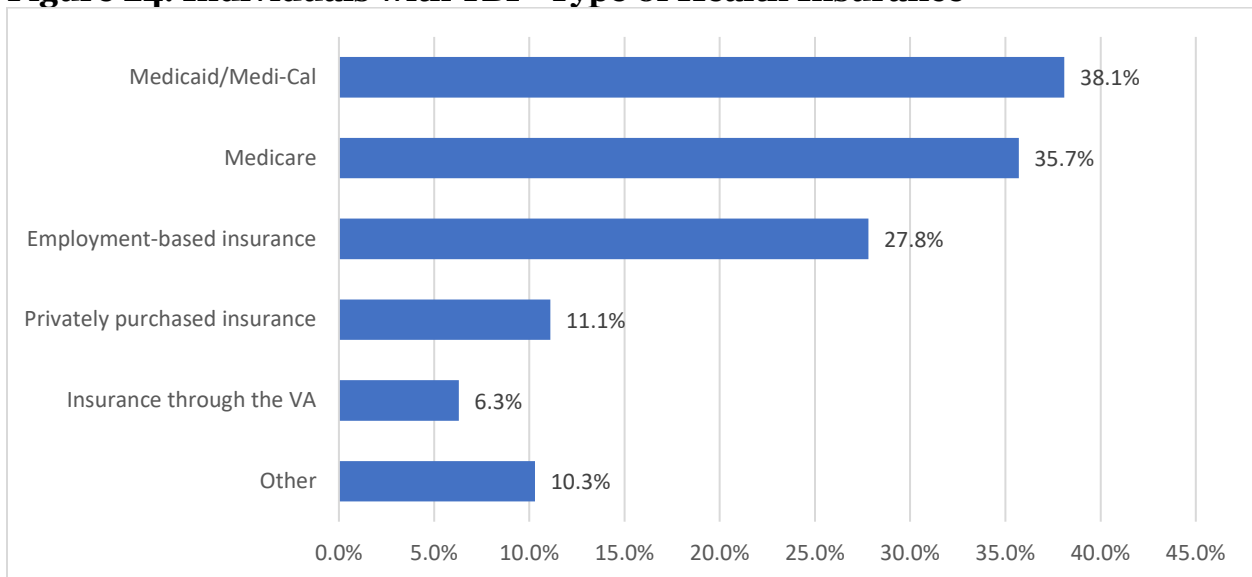
Individual with TBI

Individuals with TBI who reported not having insurance were asked, “How do you pay for health care for your TBI?” There were four responses: “I don’t,” “I got in DEBT... I am still paying a decade later,” “out of pocket,” and “Medi-Cal.”

Individuals with TBI were asked, “What kind of health insurance do you currently have? Select all that apply.” As illustrated below, the most reported type of health insurance was Medicaid/Medi-Cal, with 38.1%, followed by Medicare with 35.7% and employment-based insurance with 27.8%. Further, 11.1% had privately purchased insurance, and 6.3% had insurance through the U.S. Department of Veterans Affairs (the VA). In addition, 10.3% selected “Other.”

Those who selected “Other” health insurance reported having Medicare/Medi-Cal ($n = 2$), a Medicare supplement ($n = 2$), CalOptima ($n = 1$), Cigna ($n = 1$), federal workers’ compensation (DOL OWCP FECA; $n = 1$), insurance through spouse’s employer ($n = 1$), supplemental insurance through former employer ($n = 1$), insurance through own employer ($n = 1$), none ($n = 1$), and Covered California ($n = 1$).

Figure 24. Individuals with TBI - Type of Health Insurance



Note: $n = 126$.

Those that health insurance covered *some of my care, none at all, or I don't have insurance*, were asked, "What services or treatment for your TBI do you need insurance to help with more?"

Respondents explained that the services or treatment they need insurance to help with more were counseling or mental health services ($n = 17$), physical therapy ($n = 16$), and cognitive therapy ($n = 14$). See the table below for a list of all responses.

Table 3. Individuals with TBI – What services or treatment for your TBI do you need insurance to help with more?

Category	Percentage	<i>n</i>
Counseling or mental health services	14.3%	17
Physical therapy	13.4%	16
Cognitive therapy	11.8%	14
"I don't know/I'm not sure"	10.1%	12
Vision treatment or vision rehab	10.1%	12
No help	10.1%	12
Occupational therapy	7.6%	9
Medication	6.7%	8
Speech therapy	6.7%	8
TBI rehabilitation services in general (not specified)	6.7%	8
Chiropractor	4.2%	5
Transportation	4.2%	5
Hyperbaric Oxygen Therapy	4.2%	5
Additional care or assistance in daily life	4.2%	5
Hearing treatment or rehabilitation	4.2%	5
Other comments	4.2%	5
Experienced doctors on TBI	2.5%	3
Help with all services	2.5%	3
Food and nutrition	2.5%	3
Dental	1.7%	2
Biofeedback	1.7%	2
Acupuncture therapy	1.7%	2
Follow-up or post-release treatment after accident	1.7%	2
Case Management	1.7%	2
Help with cost of services	1.7%	2
Housing	1.7%	2
Naturopathic doctors	1.7%	2
Work	0.8%	1
Exercise	0.8%	1
Early TBI intervention	0.8%	1
Total		119

Professionals were asked “Some people have poor health insurance or difficulty paying for treatment or services. Among patients/clients like this, what treatment or services could health insurance pay more for?” The most common treatment or services health insurance could pay for includes counseling/psychological support ($n = 16$), therapies/rehabilitation services ($n = 14$), in-home support care ($n = 4$), cognitive evaluation/rehabilitation ($n = 3$), medications/prescriptions ($n = 3$), neurological services ($n = 3$), vocational rehabilitation ($n = 3$), community resources ($n = 2$), day programs specifically for individuals with TBI ($n = 2$), housing ($n = 2$), life skills training ($n = 2$), transportation to programs ($n = 2$), caregiver respite ($n = 1$), caregiving ($n = 1$), case management ($n = 1$), case management ($n = 1$), community reintegration ($n = 1$), easier referrals to needed services ($n = 1$), education ($n = 1$), long-term follow-up ($n = 1$), medical supplies ($n = 1$), medical treatments ($n = 1$), ongoing assistive technology ($n = 1$), sliding scale and donation-based treatments ($n = 1$), substance use counseling ($n = 1$), and support groups/leisure groups ($n = 1$).

Needs of Individuals with TBI

All three groups (individuals with TBI, caregivers, and professionals) were asked which services and resources do individuals with TBI currently need. They were instructed to select all that apply. The needs of individuals with TBI, as reported by each group, were consistent, with minor variations across group.

Individuals with TBI were asked, “Which of the following services and resources do you currently need? Select all that apply.” As illustrated below, the services and resources reported as being most currently needed included “help finding TBI resources, such as therapists, support groups, etc.” (61.9%); “mental health counseling” (51.2%); “support groups” (49.6%); “financial support” (41.6%); “help with developing and maintaining friendships” (41.6%); and “help accessing community events/services/activities” (40.8%).

Individuals with TBI were then asked, “What other needs do you have that are not being met? These could be services, information, education, or any kind of resource to help you.” Responses widely ranged. These included transportation ($n = 4$), work/school/ADA²⁵ accommodations ($n = 4$), finding providers with experience treating TBI ($n = 3$), therapy/medications ($n = 3$), a patient advocate ($n = 3$), and legal assistance ($n = 3$). In addition, some replied not sure/nothing ($n = 12$). For a full list of responses, see Appendix 37. Needs of Individuals with TBI – “What other needs do you have that are not being met?”

²⁵ Americans with Disabilities Act

Table 4. Needs of Individuals with TBI - As Reported by Individuals with TBI, Caregivers, and Professionals

Category	Individuals with TBI	Caregivers	Professionals
Help finding TBI resources, such as therapists, support programs, etc.	61.6%	62.5%	84.9%
Mental health counseling	51.2%	52.1%	84.9%
Support groups	49.6%	50.0%	75.3%
Financial support	47.2%	35.4%	75.3%
Medical treatments and services	41.6%	45.8%	61.6%
Help with developing and maintaining friendships	41.6%	56.3%	50.7%
Help accessing community events/services/activities	40.8%	43.8%	72.6%
Assistive technologies	38.4%	43.8%	83.6%
Help with activities of daily living (for example, going shopping, doing chores around home, etc.)	38.4%	47.9%	65.8%
Education on what TBI is and what to expect	36.0%	33.3%	72.6%
Help with transportation	36.0%	37.5%	83.6%
Help with finding employment	30.4%	33.3%	74.0%
Help returning to pre-injury employment	28.8%	37.5%	64.4%
Housing assistance	27.2%	31.3%	58.9%
Legal assistance	27.2%	31.3%	43.8%
Help with dating	27.2%	27.1%	
Food assistance	25.6%	25.0%	47.9%
Adult day programs (for example, a place you go to and spend the day doing supervised activities)	19.2%	41.7%	63.0%
Home modifications	19.2%	20.8%	43.8%

Help with medication management	18.4%	31.3%	50.7%
Sexuality counseling	17.6%	14.6%	28.8%
Educational materials in Spanish	4.0%	2.1%	43.8%
Educational materials in languages other than Spanish or English	2.4%	2.1%	34.2%
Substance use counseling	2.4%	12.5%	27.4%

Note: $n = 125$ for individuals with a TBI; $n = 48$ for caregivers; $n = 73$ for professionals.

Caregivers were asked, “Thinking of the person with TBI you provide care for the most, which of the following resources and services do they currently need? Select all that apply.” As illustrated above, the services and resources caregivers reported as being most currently needed included “help finding TBI resources, such as therapists, support groups, etc.” (62.5%); “help with developing and maintaining friendships” (56.3%); “mental health counseling” (52.1%); “support groups” (50.0%); “help with activities of daily living” (47.9%), and “medical treatments and services” (45.8%).

Caregivers were asked, “What other needs does the person with TBI have that are not being met? These could be services, information, education, or any kind of resource to help them.” Responses included education ($n = 2$), transportation ($n = 2$), and social groups/activities ($n = 2$). For a full list of response, see Appendix 11. Other Unmet Needs of Individuals with TBI as Reported by Caregivers.

Professionals were asked, “Which of the following resources and services do your patients/clients with TBI need? Select all that apply.” As illustrated above, the services and resources professionals reported as being most currently needed included “help finding TBI resources, such as therapists, support groups, etc.” (84.9%); “mental health counseling” (84.9%); “assistive technologies” (83.6%); “help with transportation” (83.6%); “financial assistance” (75.3%); and “support groups” (75.3%).

Professionals were then asked, “What other needs do your clients/patients with TBI have that are not being met?” The responses to this question were quite varied and many of these responses were consistent with topics mentioned in the table on the previous page. Other needs that clients/patients with TBI have that are not being met include family therapy ($n = 3$), more education/awareness ($n = 3$), help with socializing/dating ($n = 2$), housing/affordable housing ($n = 2$), acknowledging that the individual needs support services ($n = 1$), affordable care ($n = 1$), authorization for headache medication ($n = 1$), better quality care in nursing facilities ($n = 1$), case management ($n = 1$), create TBI specific rehabilitation facilities ($n = 1$), dating help ($n = 1$), help for incarcerated who are TBI survivors ($n = 1$), help with isolation ($n = 1$), homeless support ($n = 1$), long-term follow-up ($n = 1$), neuro optometrists ($n = 1$), peer

support ($n = 1$), services specialized for veterans ($n = 1$), substance abuse support for individuals with TBI ($n = 1$), tax breaks for caregivers ($n = 1$), vocational training for a longer amount of time ($n = 1$), and yoga ($n = 1$).

Across all three groups (individuals with TBI, caregivers, and professionals), several needs were consistently ranked highly. “Help finding TBI resources” was the highest ranked need among all three groups. All three groups also ranked highly “mental health counseling” and “support groups.”

The need for “educational materials in Spanish” and “educational materials in languages other than English and Spanish” was rated much higher by professionals (43.8% and 34.2%) than by individuals with TBI (4.0% and 2.4%) or caregivers (2.1% and 2.1%). This reflects the nature of the survey samples. The individuals with TBI and caregivers who were surveyed likely overrepresent the number of native English-speaking people for each group. However, professionals, because they likely serve a patient/client population that is more linguistically and culturally diverse than the survey sample, provide a more accurate reflection of the need for educational materials in languages other than English.

The need for “housing assistance” was also rated higher by professionals (58.9%) than by individuals with TBI (27.2%) or caregivers (31.3%). Housing was also a theme that arose in interviews with professionals, who attested to the difficulty for some TBI clients to find and maintain housing.

“I think that there are plenty of patients out there who it's really hard for. Maybe they don't have caregivers who are quite up to the challenge of dealing with some of the behavioral issues, and they don't really need to be hospitalized anymore. There are just so few places where these types of patients can be, and then there's no funding.... There are some places in the community where they and live, but they cost a lot and there's not funding for that, and it's not standard practice for insurers to pay for those types of places. I think that that's a huge need area.”

-Neuropsychologist

Individuals with TBI Needs by Number of Years with TBI

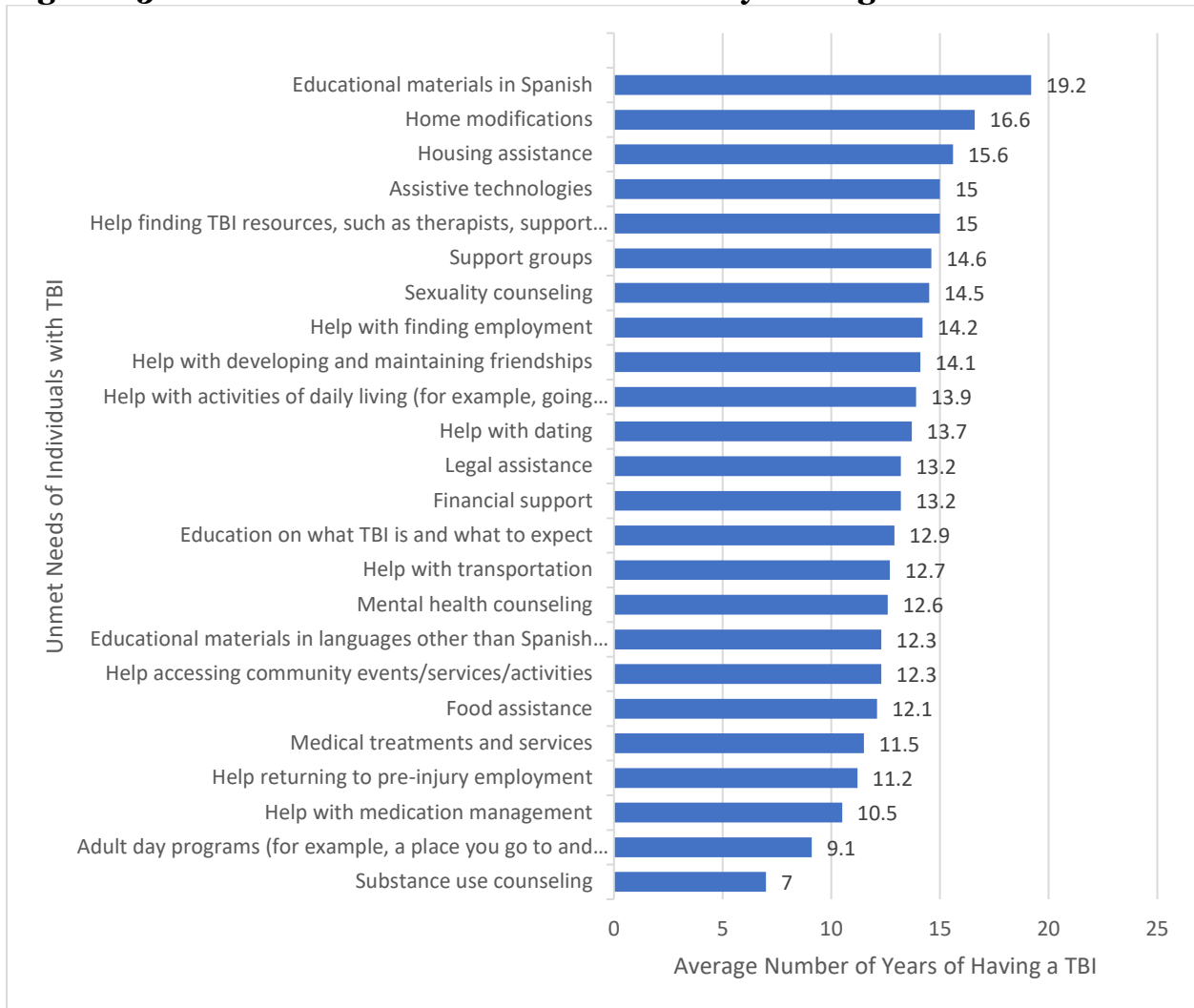
The needs illustrated previously can vary as a function of other demographics. For this reason, the unmet needs of individuals with TBI were analyzed by the average number of years the individual had had their TBI. That is, the figure below illustrates this analysis with each unmet need, and the corresponding average number of years for having a TBI.

The average number of years for that the individual has had a TBI is higher for needs such as home modifications (average = 16.6 years), housing assistance (average = 15.6 years), assistive technology (average = 15 years), and help finding TBI resources (average = 15 years). Conversely, the average number of years for the individual with TBI is lower for needs such as adult day programs (average = 9.1 years), help with medication management (average = 10.5 years), and help returning to pre-injury employment (average = 11.2 years).²⁶

See the figure on the following page for additional details.

²⁶ The sample sizes for those selecting substance abuse counseling (total 3), educational materials in languages other than English or Spanish (total 3), and educational materials in Spanish (total 5) are far smaller than the other sample sizes for the other variables (totals ranging from 22 to 77).

Figure 25. Individuals with TBI Unmet Needs by Average Years with TBI

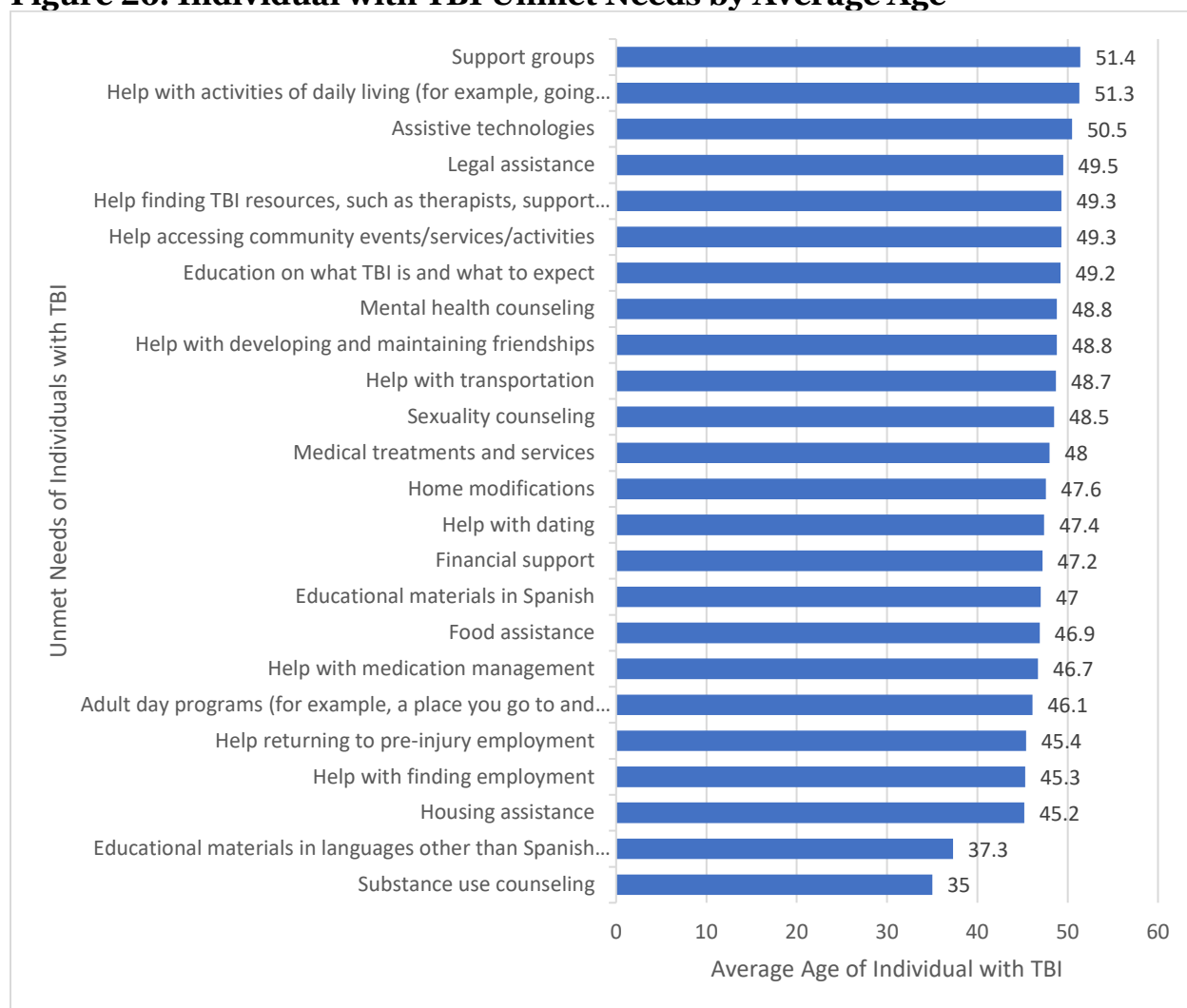


Note: $n = 125$.

Individuals with TBI Needs by Age

Unmet needs were also analyzed as a function of the age of the individuals with TBI. As illustrated in the figure below, there is slight variation in the average age of an individual with TBI by need. For instance, older TBI survivors reported needing support groups (average = 51.4 years), help with activities of daily living (average = 51.3 years), and assistive technologies (average = 50.5 years). Conversely, younger TBI survivors reported needing housing assistance (average age = 45.2 years), help with finding employment (45.3 years), and help returning to pre-injury employment (average age = 45.4 years).²⁷

Figure 26. Individual with TBI Unmet Needs by Average Age



Note: $n = 125$.

²⁷ As above, the sample sizes for those selecting substance abuse counseling (total 3), educational materials in languages other than English or Spanish (total 3), and educational materials in Spanish (total 5) are far smaller than the other sample sizes for the other variables (totals ranging from 22 to 77).

Reasons for Needs Not Being Met

Individuals with TBI were asked, “Of your top unmet needs, what were the reasons for these needs not being met? Select all that apply.” As illustrated below, the most reported reason for needs not being met was “limited personal finances” (61.0%), followed by “I didn’t know about the resource” (48.3%). Other commonly reported reasons were “limited health insurance” (43.2%) and “the resource was not available” (42.4%).

Those who selected “Other” responded that their needs were not being met because they were undiagnosed/misdiagnosed ($n = 3$) or they need guidance access resources ($n = 3$). For a list of “other” responses, see Appendix 38. “Other” Reasons for Needs Not Being Met as Reported by Individuals with TBI.

Table 5. Individuals with TBI - Reasons for Needs Not Being Met

Category	Percentage	n
Limited personal finances	61.0%	72
I didn't know about the resource	48.3%	57
Limited health insurance	43.2%	51
The resource was not available	42.4%	50
Lack of family/social support	33.1%	39
Lack of transportation	31.4%	37
Other	16.9%	20
Total	-	118

Help Finding TBI Resources

As illustrated above, the most selected unmet need for individuals with TBI, as chosen by individuals with TBI, caregivers, and professionals, was help finding TBI resources. In addition, this was a common theme in interviews. In interviews, help finding TBI resources was mentioned in the context of other needs (for example, getting support for employment, finding therapists, or accessing recovery programs). For many individuals with TBI, it is daunting to navigate an unknown landscape of treatment options and support programs. Some individuals mentioned connecting to resources through support groups or health care providers. Yet these modes of finding resources were fortuitous and happenstance—individuals with TBI expressed a need for assistance that would be standardized and comprehensive.

“What I would say is that the Department of Rehab, if they’re capable of helping, even more, it would be nice to have those resources out in the community or having the neurologist bring that up. I heard it from my vestibular therapist. She was a specialist and she's the one who turned me on to the Department of Rehab. She's like, ‘They have these programs.’ I was like, ‘Well, this is great.’ More of that I think would be great.”

-Individual with TBI

“The one thing I want to mention, I think that when a person has a TBI in the hospital, before they're discharged, as soon as they're conscious, they should be given a packet along with a family member or whoever's there for them. Here is a TBI information packet, what you could expect, things you could look for, here's some resources. That would have been helpful.”

-Individual with TBI

Both caregivers and professionals, in interviews, spoke of the major need of connecting individuals with TBI to resources. The burden of finding care is often placed on patients/clients, who encounter barriers to access due to both socio-economic challenges and the cognitive challenges presented by their injury.

“The biggest challenges... that I've had would be probably navigating the system, trying to find the resources that were needed. There were things that we didn't even know existed as possibilities, like the neurofeedback program.”

-Caregiver of Person with TBI

“If you have a disability of your brain, doing things is hard. Knowing that you need services, knowing how to get the services, knowing how to access them, how to overcome all the annoying things, you need to do 800 forms and call and be on hold for hours and hours. That, like you said, it's so hard for anybody, let alone someone with a cognitive disability. I think that becomes such a huge barrier.”

- Program Director at brain injury support center

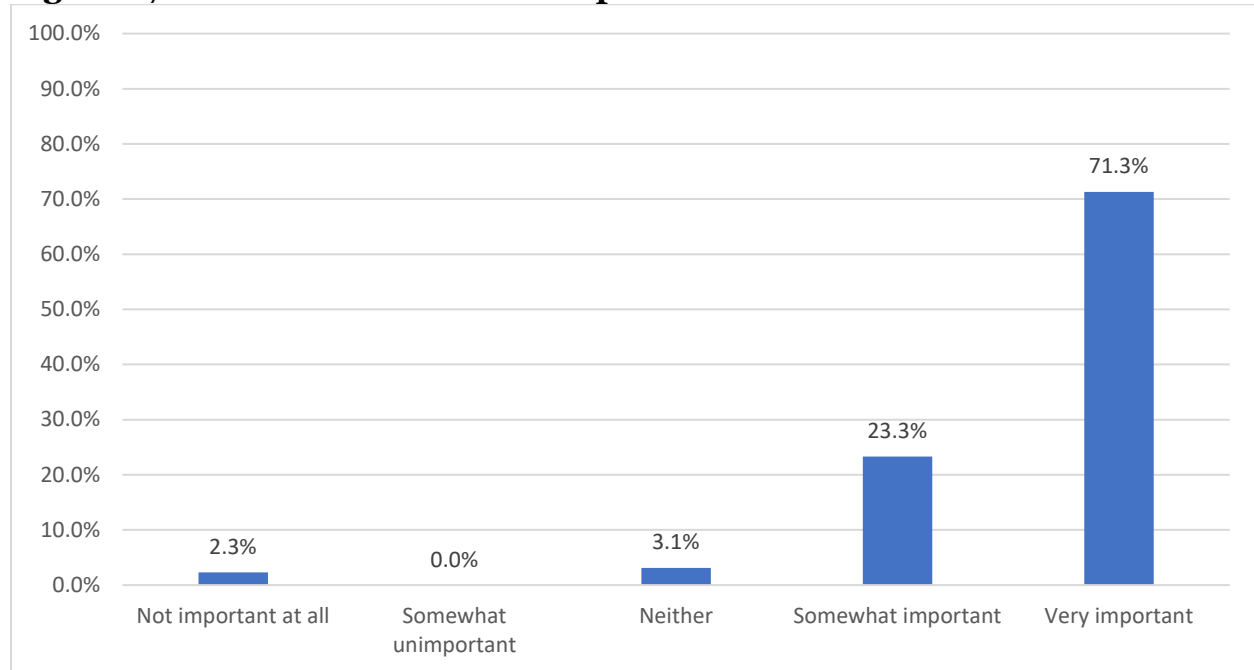
Survey participants who selected “help finding resources” as an unmet need were asked, “What would help you to better find/get TBI resources you need?” The most common response was health care providers or other professionals who are trained/educated in TBI ($n = 11$). The next most common response was a regularly updated “central access point” or “one-stop shop” that lists resources ($n = 9$); some suggested that this could be a website ($n = 3$) that lists local services ($n = 2$). The next most common responses were support groups ($n = 6$) and a case manager/caseworker/mentor/patient advocate ($n = 4$). For a list of all responses, see Appendix 10. Individuals with TBI – “What would help you to better find/get TBI resources you need?”

These survey responses mirror interview themes. Key informants either reported finding resources through a knowledgeable provider or expressed a need for a knowledgeable provider. Key informants also reported finding resources through support groups.

Mental Health

Individuals with TBI were asked, “How important would you say mental health care is for your recovery (for example, seeing a counselor or psychological therapist)?” Nearly three quarters (71.3%) said mental health care is “very important.” About one quarter (23.3%) said it is “somewhat important.” Only 3.1% said “neither [important nor unimportant],” and 2.3% said “not important at all.” Thus, 94.6% said that mental health care is either “somewhat” or “very” important for their recovery.

Figure 27. Individuals with TBI - Importance of Mental Health Care



Note: $n = 129$.

A major theme in interviews was mental health challenges. Individuals with TBI spoke at length about experiencing anxiety (17/25 mentions), depression (16/25), difficulty controlling emotions (9/25), and post-traumatic stress disorder (8/25). These challenges can be caused by social isolation, economic hardship, and uncertainty about one’s future.

“I am so angry. I’m so angry. I’m angry every day. I’m irritable and I’m cranky and everything irritates me.... I seem ungrateful, but I’m really grateful. It seems like I’m complaining, but I just feel trapped, like I can’t do anything for myself anymore.... The worst part about it is it’s so hard to get connected to mental health [resources].”

-Individual with TBI

“Anybody going through a traumatic injury, you have to have an in-depth understanding, they're going through a lot of emotional stuff just beyond the physical things that are going on with them. How do I get my income? What do I do? What if I didn't plan well for retirement? What if this and what if that? Will I get a job?”

-Individual with TBI

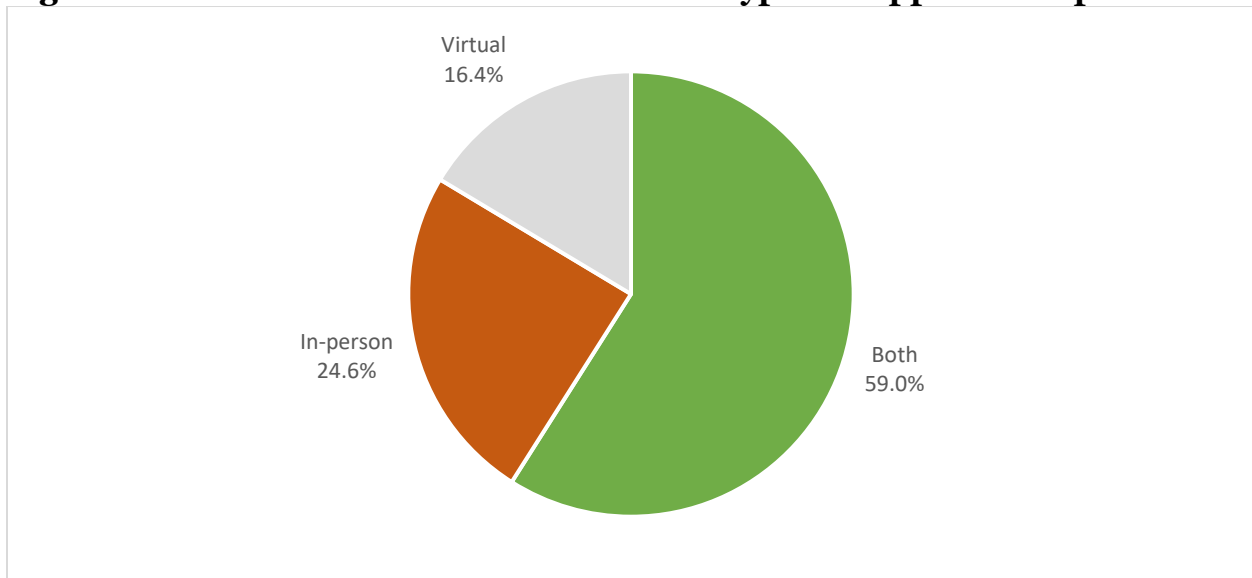
“The first few weeks after my brain injury... I guess you could say [I was] depressed. I was worried about, ‘What am I going to do now? It just doesn't feel like I'm going to get any better. What am I going to do for the rest of my life?’”

-Individual with TBI

Social Support

Individuals with TBI were asked, “Support groups for people with TBI provide the chance to learn from others and share your own experience. How would you like support groups set up?” They were given three options. In total, 16.4% preferred virtual support groups, 24.6% preferred in-person support groups, and 59.0% preferred both virtual and in-person support groups.

Figure 28. Individuals with TBI - Preferred Type of Support Group



Note: $n = 61$.

A common theme in interviews was the wide-ranging value of support groups. Among interviews with 25 individuals with TBI, there were 19 mentions of support groups. Support groups provide socialization, catharsis, education on TBI, and connection to TBI resources. Some key informants discovered new treatment options or novel methods of managing symptoms through support groups. Others made friends and found a “sense of community.” TBI support groups were the main way that these individuals with TBI met their unmet needs—educating themselves, connecting with others, and learning to live with their injury.

Employment and Economic Stability

Employment is a critical need for individuals with TBI. As stated above, 76.7% of individuals with TBI reported that their TBI negatively affected their employment (more than any other life domain), a surprising finding given their relatively high degree of education. This was reflected also in interviews, in which individuals with TBI commonly (18/25 mentions) discussed not being able to work. In addition to financial security, employment can provide a sense of purpose and integration into one's community. These benefits—economic, psychological, and social—are vital, especially for those who encounter poverty, mental health challenges, and social isolation.

"I'd love to go back to work. I think the stress of not working is great."

-Individual with TBI

"There was a period of time where I couldn't work. I didn't have income. I had to take early retirement. My retirement is less than \$1,000 a month. It was devastating. I had to dip into retirement money, and I'm really too young to be doing that."

-Individual with TBI

Individuals with TBI were asked, “What goals do you have for working?” As illustrated below, 41.5% reported “I want to work, but I am unable to work because of my TBI.” One quarter (26.0%) reported “I am currently working in a new job.” Further, 15.4% reported “I want to work, and I’m trying to find a job,” 11.4% reported “I don’t want to return to work,” and 5.7% reported “I am currently working in the same job I had before my injury.”

Table 6. Individuals with TBI - Goals for Working

Category	Percentage	n
I want to work, but I am unable to work because of my TBI	41.5%	51
I am currently working in a new job	26.0%	32
I want to work, and I’m trying to find a job	15.4%	19
I don’t want to return to work	11.4%	14
I am currently working in the same job I had before my injury	5.7%	7
Total	100%	123

A common interview theme was the need for vocational training and job placement that was tailored to the skills, background, and ambitions of the individual with TBI. In the survey sample, most individuals with TBI are well educated, demonstrating a potential for qualifying for well-paid jobs. Individuals with TBI expressed a need to find work that is fulling and makes use of their abilities. Caregivers also spoke to this, of needing guidance and assistance in placing their loved ones in good jobs that were well-suited to their talents rather than low-wage or “low-skilled” jobs.

“I need help with getting more training that will be useful in the working world... Since I'm on disability, obviously my funds are zero. Having access to that [training], and I know the Department of Rehab can help with that, but I don't know how to navigate that. That's what I'm working on ... how to navigate and get resources like that.... I think because I'm so focused on making an impact and trying to go back to a full-time [job] placement, I feel I need training or something to help me.”

- Individual with TBI

“I would say what she [person with TBI] needs right now is a place or some advice maybe from recruiters ... who place people with disabilities back into the workforce to know that there's a pathway back that doesn't include just service industries.”

- Caregiver

Those who selected “I am working in the same job I had before my injury,” “I am currently working in a new job,” or “I want to work, and I’m trying to” were then asked, “What resources would best help you with working? Select all that apply.” As illustrated below, the most common response was “having co-workers who understand TBI” (45.6%), followed closely by “part-time work schedule” (43.9%). Further, 35.1% selected “help finding a new career/field,” 33.3% selected “help finding a new job,” and 31.6% selected “training in new skills.”

Those who selected “Other” said being able to work from home ($n = 3$) would best help with working. Other responses included flexible work schedules ($n = 1$), helping future employers understand TBI ($n = 1$), a less stressful work environment ($n = 1$), and retraining to return to one’s job ($n = 1$).

Table 7. Individuals with TBI - Most Helpful Resources for Working

Category	Percentage	<i>n</i>
Having co-workers who understand TBI	45.6%	26
Part-time work schedule	43.9%	25
Help finding a new career/field	35.1%	20
Help finding a new job	33.3%	19
Training in new skills	31.6%	18
California Department of Rehabilitation	31.6%	18
Changes in the workplaces so it’s easier for me to work	29.8%	17
Support from family	26.3%	15
Support from friends	26.3%	15
Private rehabilitation agency/company	17.5%	10

Other	15.8%	9
Total	100%	57

Another theme that arose in interviews was the need for workplace accommodations, including a need for practical adjustments in the workplace, such as flexible hours or assistance with tasks. Interviews also revealed a need for co-workers to better understand the nature and limitations associated with TBI.

“The thing I was literally in tears [about]... is [that] I can do my job. I just need a little grace, just a little help. Just a little bit, and there was no one to help me. I tried getting hold of all these state agencies to see if they could help [with workplace accommodations] No one would help me.... There's been no grace, there's been no kindness, there's been no mercy. Even with my boss.”

-Individual with TBI

“Maybe help finding a job that would be more understanding with the things I have to deal with. Nobody wants to hire someone who's always late and who forgets everything. I'm capable as heck. I can do so many things.... I can weld, I paint murals, I do portraits. I'm so talented. I really am.”

-Individual with TBI

Individuals with TBI were asked, “What areas do you need financial support most? Select all that apply.” They were presented with eight options. The areas in which financial support is needed the most were “I have disability income (SSI or SSDI), but it isn’t enough” (55.2%), “I need a well-paying job” (51.7%), “I need better health insurance coverage” (43.1%), and “I do NOT have disability income (SSI or SSDI), and I need it” (29.3%). See the table below for the full list of responses. Thus, 84.5% either have disability income (but this income is not enough) or they are in need of disability income.

Those who selected “Other” reported that they need access to housing ($n = 3$), legal representation ($n = 3$), and food ($n = 2$). For a list of all “Other” responses, see Appendix 36. “Other” Areas Financial Support Is Needed Most – Individuals with TBI.

Table 8. Individuals with TBI - Financial Support Needs

Category	Percentage	<i>n</i>
I have disability income (SSI or SSDI), but it isn’t enough	55.2%	32
I need a well-paying job	51.7%	30
I need better health insurance coverage	43.1%	25
I do NOT have disability income (SSI or SSDI), and I need it	29.3%	17
Other	17.2%	10
I have personal disability insurance income, but it isn’t enough	6.9%	4
I have income through an injury settlement or court decision, but it isn’t enough	5.2%	3
I have Workers’ Compensation insurance income, but it isn’t enough	3.4%	2
Total	-	58

CAREGIVERS

Caregivers for individuals living with a TBI.

Caregivers

Approximately 22.8% of the California adult population (6.7 million adults) provide care to a family member/friend with an illness/disability.²⁸ It is important to understand the health, financial, and social needs of this population that encounter unique challenges in providing ongoing care.

Certainly, there are positive experiences with caregiving such as providing for family/friends and experiencing a sense of fulfillment.²⁹ However, there are also consequences that merit attention, such as increased stress, depression, financial strain, and maintaining a healthy lifestyle.³⁰

Demographics

A total of 53 caregivers of individuals with TBI participated in the caregiver survey. Of these, 98.1% completed the survey in English, and 1.5% (one person) completed the survey in Spanish. Key informant interviews were conducted with 12 caregivers.

Age

The average age of caregivers was 62, whereas the median age was 65. The standard deviation for age of caregivers was 11.5 years. The youngest caregiver was 37, and the oldest was 84. The age groups were as follows:

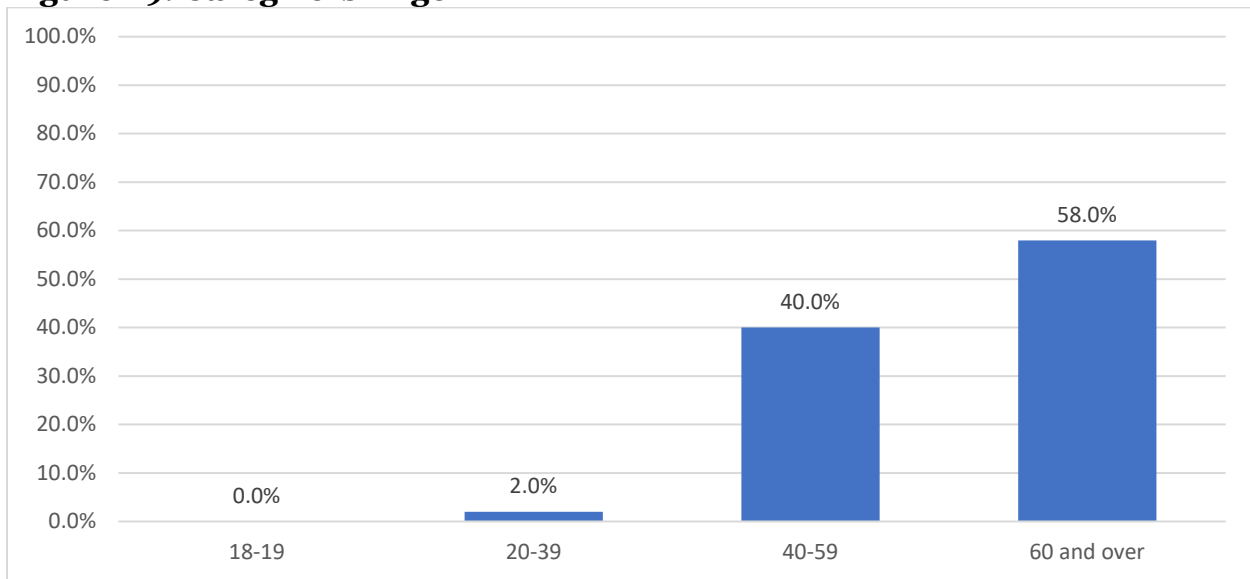
- 2.0% were 20-39 years old (adult).
- 40.0% were 40-59 years old (middle-aged adult).
- 58.0% were 60 years old and over (senior adult).

²⁸ California Health Interview Survey (2020). UCLA Center for Health Policy Research. <https://healthpolicy.ucla.edu/chis/Pages/default.aspx>

²⁹ Caregiving (2019). Centers for Disease Control and Prevention. <https://www.cdc.gov/aging/caregiving/index.htm>

³⁰ Ibid.

Figure 29. Caregivers - Age



Note: $n = 50$.

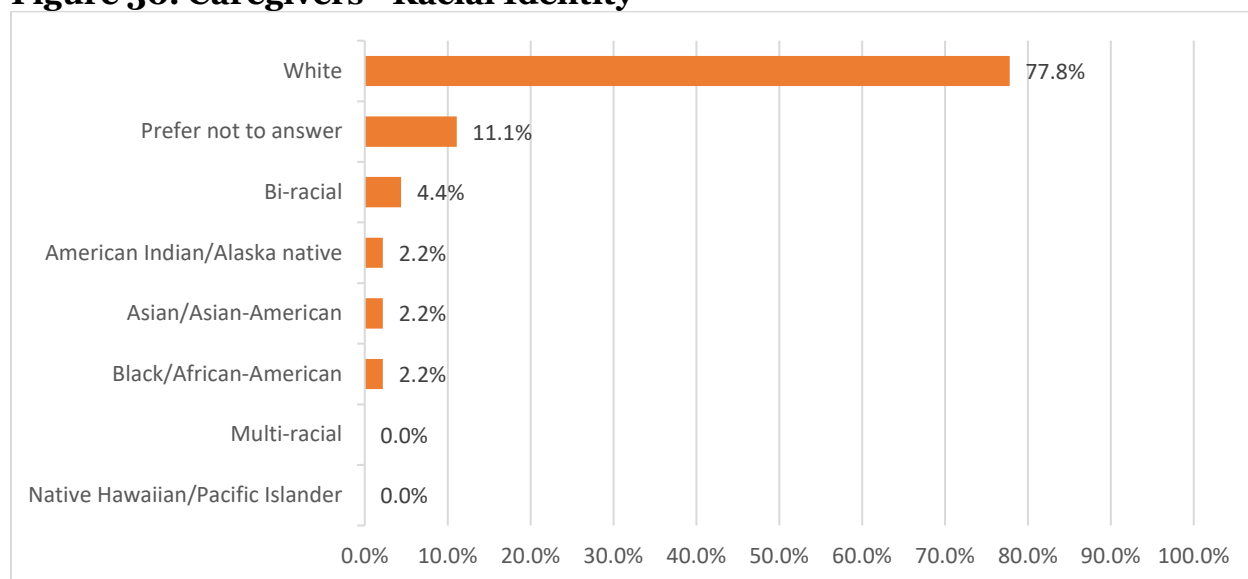
Race and Ethnicity

Caregivers were asked, “Which one of these groups would you say best represents your race? For the purposes of this survey, Hispanic is not a race.” As illustrated below, over three-quarters (77.8%) of caregivers identified as “White.” Other racial groups had lower representation.

White caregivers were overrepresented in the caregiver dataset. For context, 98.0% of caregivers in the present survey reported providing care to a friend/family member. The California Health Interview Survey, administered by the University of California, Los Angeles, collects data on adults providing care to a family member/friend with an illness/disability. The percentage of White adults providing care to family/friends with an illness/disability was 62.6% in 2020.³¹ Comparatively, 77.8% of caregivers in the present survey identified as White. This difference in percentages is statistically significant at the $p < .05$ level. Thus, the White racial group is slightly overrepresented, whereas other racial groups are underrepresented.

³¹ California Health Interview Survey (2020). UCLA Center for Health Policy Research. <https://healthpolicy.ucla.edu/chis/Pages/default.aspx>

Figure 30. Caregivers - Racial Identity



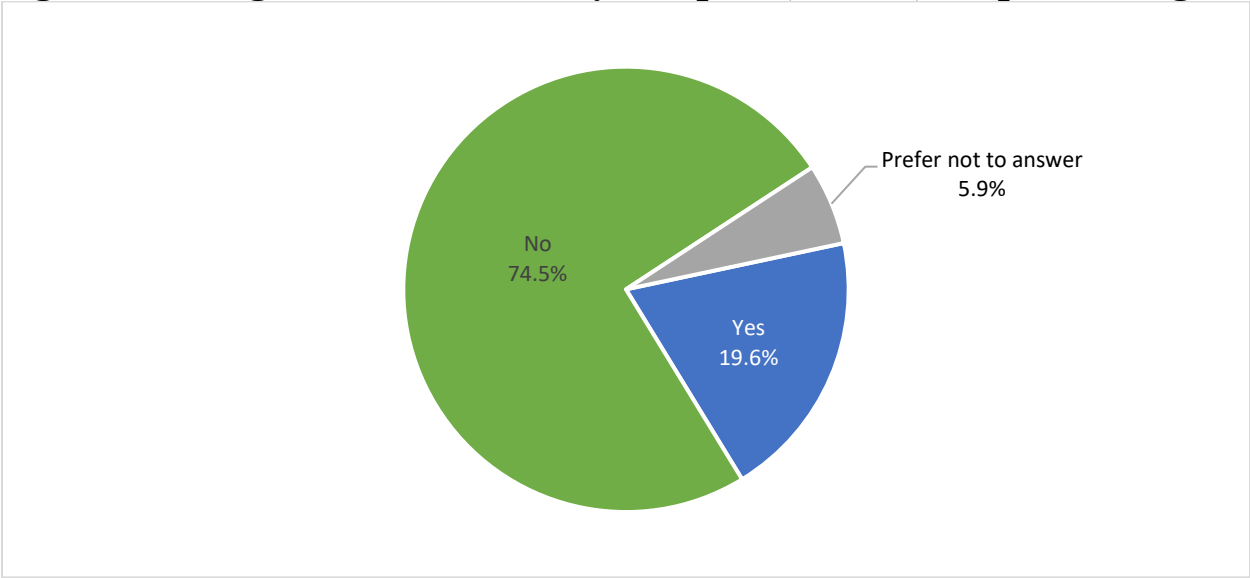
Note: $n = 45$.

Caregivers were also asked if they were of Hispanic, Latino, or Spanish origin. About three quarters (74.5%) reported “no” they were not of Hispanic, Latino, or Spanish origin. See the figure below for details.

Hispanic/Latino/Spanish-origin adults were slightly underrepresented in the caregiver survey. The percentage of Hispanic/Latino/Spanish origin adults providing care to family/friends with any illness/disability was 37.4% in 2020³². However, 19.6% of caregivers in the present survey identified as being of Hispanic/Latino/Spanish origin. This difference in percentages is statistically significant at the $p < .05$ level. Thus, the Hispanic/Latino/Spanish group is underrepresented.

³² California Health Interview Survey (2020). UCLA Center for Health Policy Research. <https://healthpolicy.ucla.edu/chis/Pages/default.aspx>

Figure 31. Caregivers' Ethnic Identity - Hispanic, Latino, or Spanish Origin?



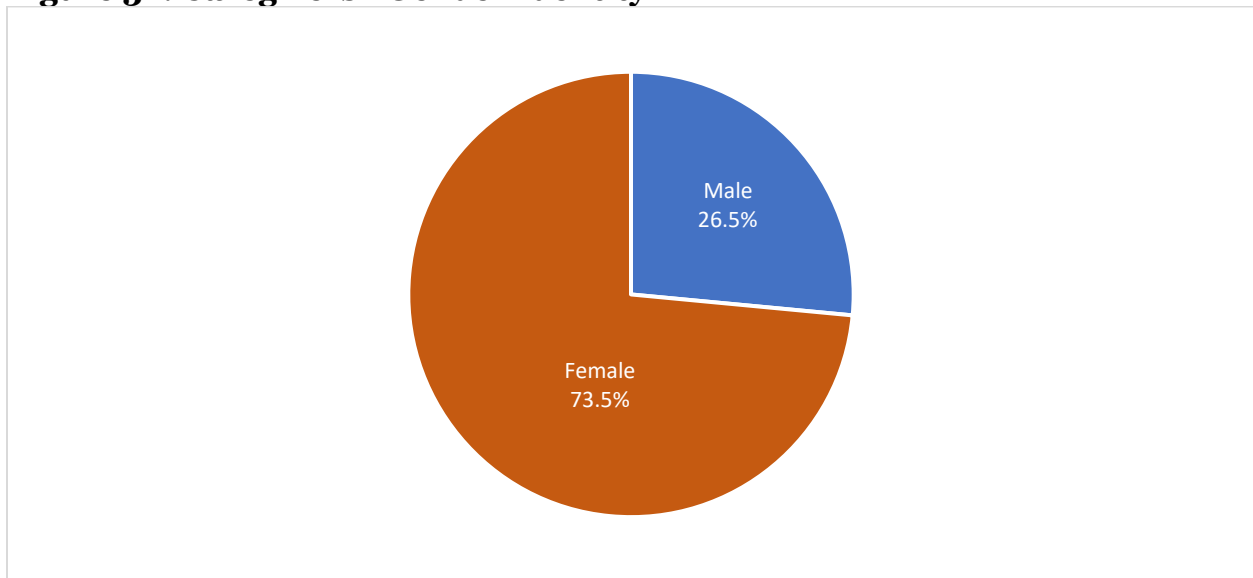
Note: $n = 51$.

Gender Identity

Caregivers were asked, “How do you describe yourself?” and were given several options to choose from. As illustrated in the figure below, about three quarters (73.5%) identified as female, and slightly over a quarter identified as male (26.5%). No caregivers reported “transgender,” and no caregivers reported, “Do not identify as female, male, or transgender.”

Similar to representation of race and ethnicity, female adults were overrepresented in the caregiver survey. The percentage of female adults providing care to family/friends with any illness/disability was 57.7% in 2020³³. However, 73.5% of caregivers in the present survey identified as female. This difference in percentages is statistically significant at the $p < .05$ level. Thus, the female caregiver group is overrepresented.

Figure 32. Caregivers - Gender Identity



Note: $n = 49$.

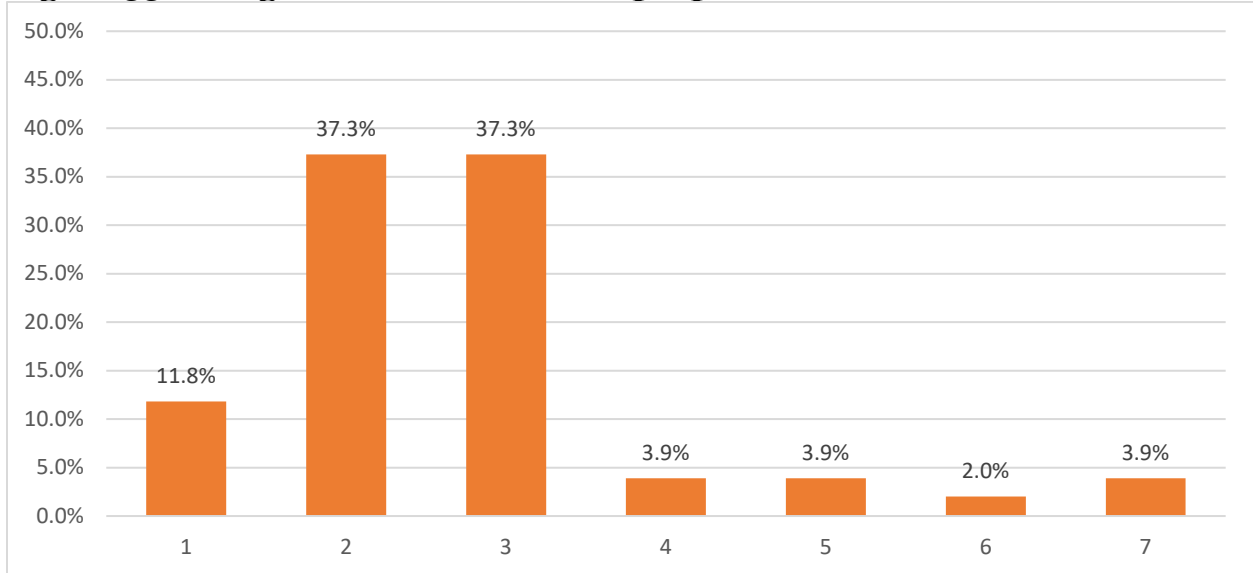
Caregivers were also asked what sex they were assigned at birth. All caregivers have a gender identity that matches their assigned sex at birth.

³³ California Health Interview Survey (2020). UCLA Center for Health Policy Research. <https://healthpolicy.ucla.edu/chis/Pages/default.aspx>

Living Situation

Caregivers were asked, “How many people, including yourself, reside in your household?” Caregivers could state how many adults and how many children were living with them. As illustrated below, most caregivers lived in households with two (37.3%) or three (37.3%) people. The median number of people per household was three.

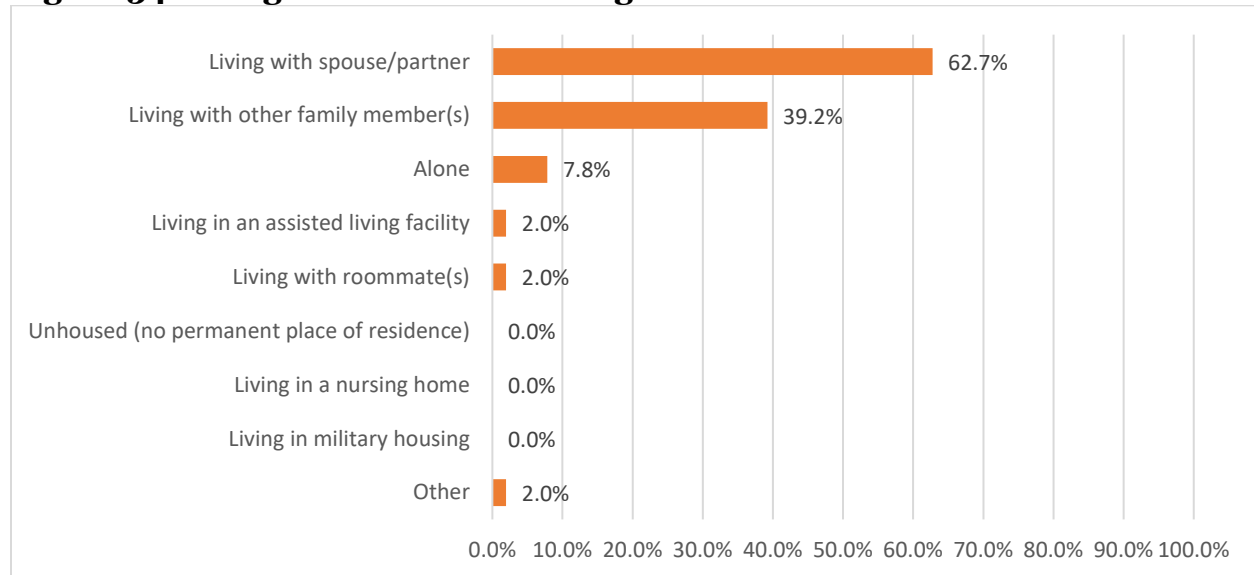
Figure 33. Caregivers - Number of People per Household



Note: $n = 51$.

Caregivers were also asked about their current living situation and could “select all that apply.” The figure below illustrates that most caregivers live with a spouse or partner (62.7%).

Figure 34. Caregivers - Current Living Situation



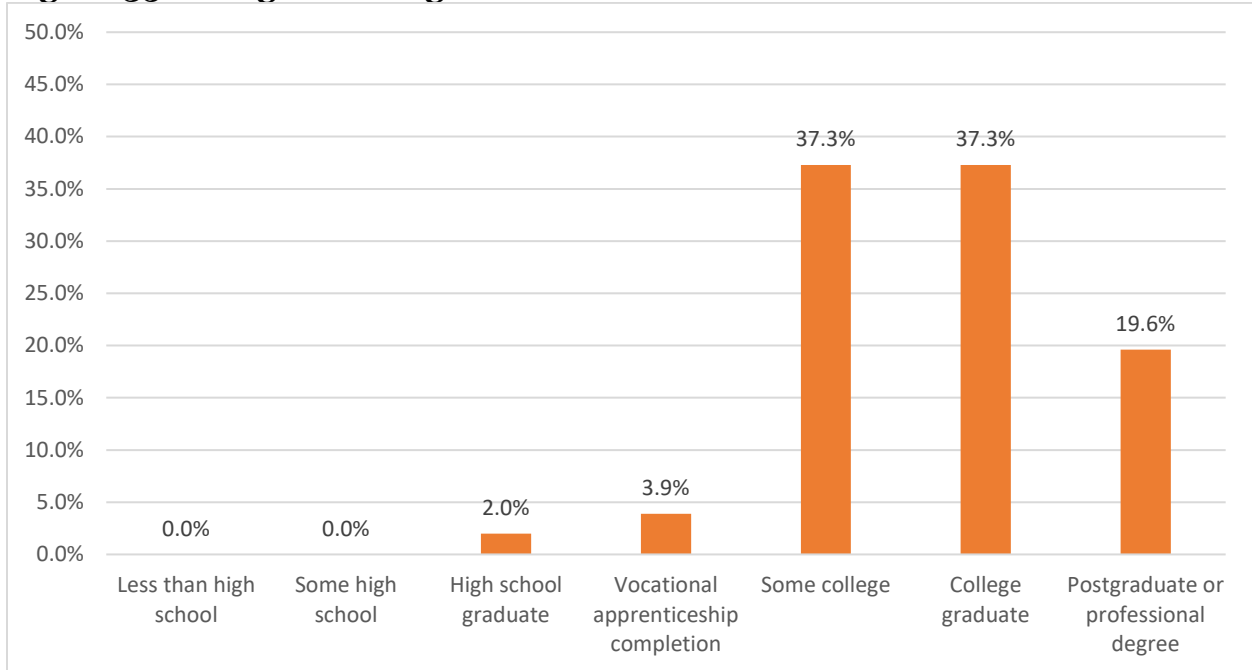
Note: $n = 51$.

Caregivers most often reported living in San Diego (25.6%). Fewer reported Chico (7.7%), San Marcos (5.1%), and other cities. The most commonly reported counties of residence were San Diego County (41.0%) and Butte County (12.8%). Because these percentages are disproportionate to the counties’ general populations, it is likely that individuals who live in these counties are overrepresented in the survey sample. For a list of all reported cities and counties of residence, see Appendix 12. Caregivers’ Cities of Residence and Appendix 13. Caregivers’ Counties of Residence.

Social and Economic Class

Caregivers were asked, “What is your highest level of education?” Caregivers were well educated, as illustrated in the figure below. Over a third (37.3%) reported being college graduates, whereas another third (37.3%) had at least some college education. Another 19.6% were postgraduate or professional degree holders.

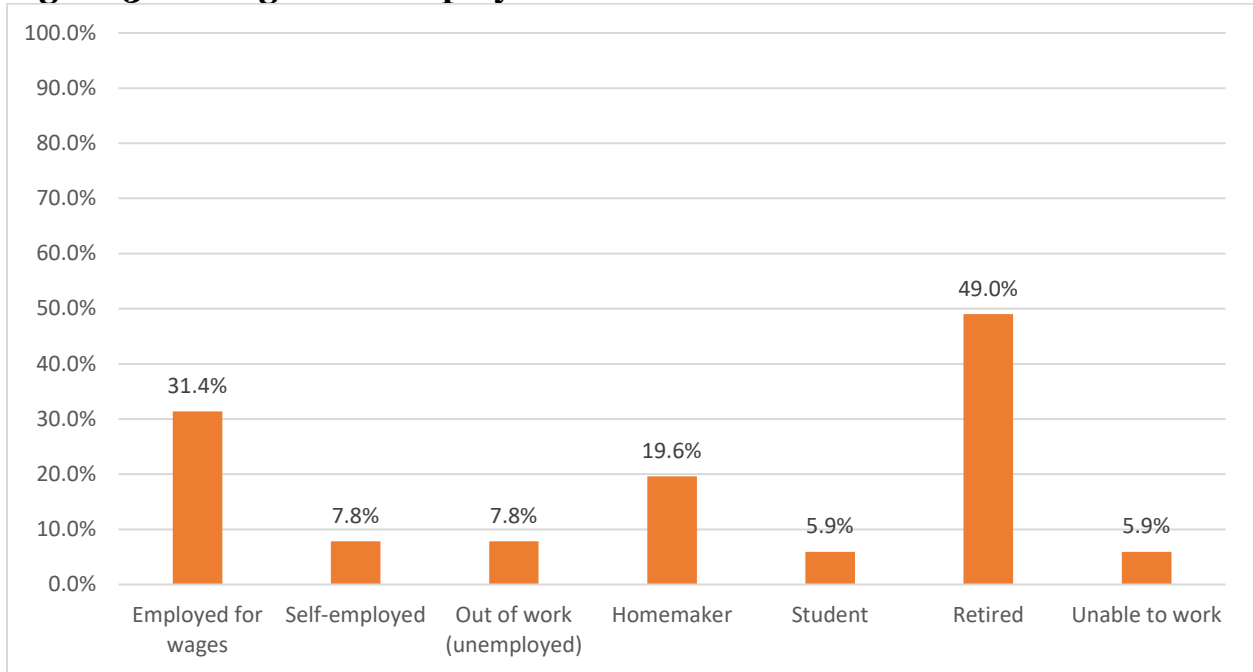
Figure 35. Caregivers - Highest Level of Education



Note: $n = 51$.

Caregivers were asked about their employment status and could “select all that apply.” Nearly half (49.0%) of caregivers reported being retired. Another common response was being employed for wages (31.4%) or being a homemaker (19.6%). See the figure below for additional details.

Figure 36. Caregivers - Employment Status

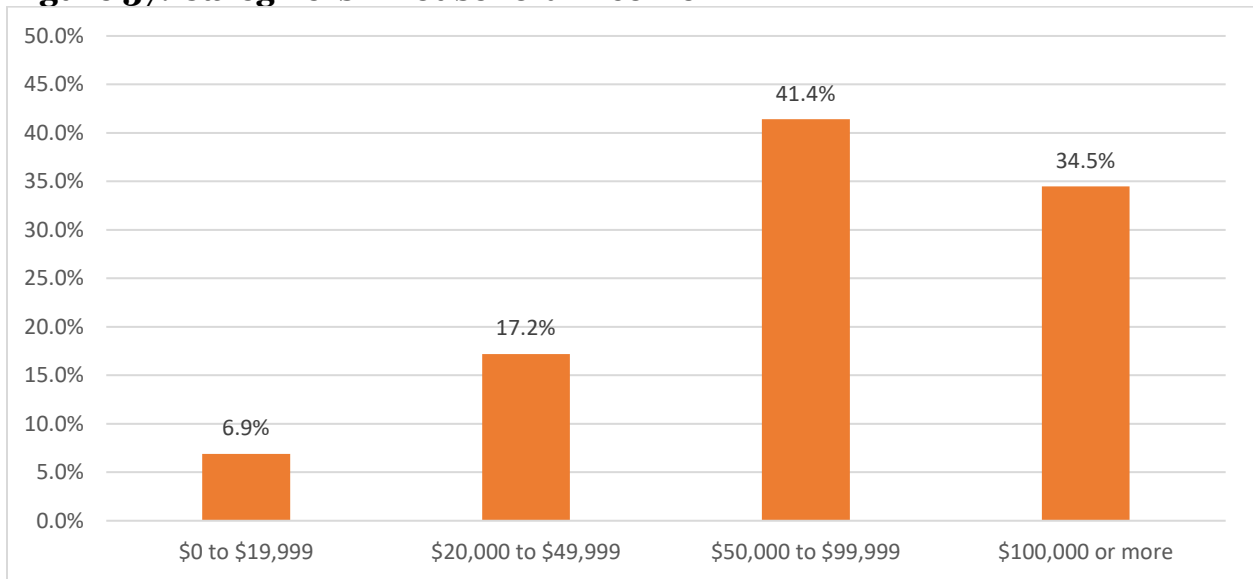


Note: $n = 51$.

Caregivers were also asked, “Last year, what was your household income from all sources before taxes?” The median annual household income (before taxes) was \$72,000, whereas the mean (average) annual household income was \$75,876. The lowest reported household income was \$10,000 per year, and the highest was \$150,000 per year.

More than three quarters (75.9%) were living in households with combined incomes of \$50,000 or more. See the figure below for additional income details.

Figure 37. Caregivers - Household Income

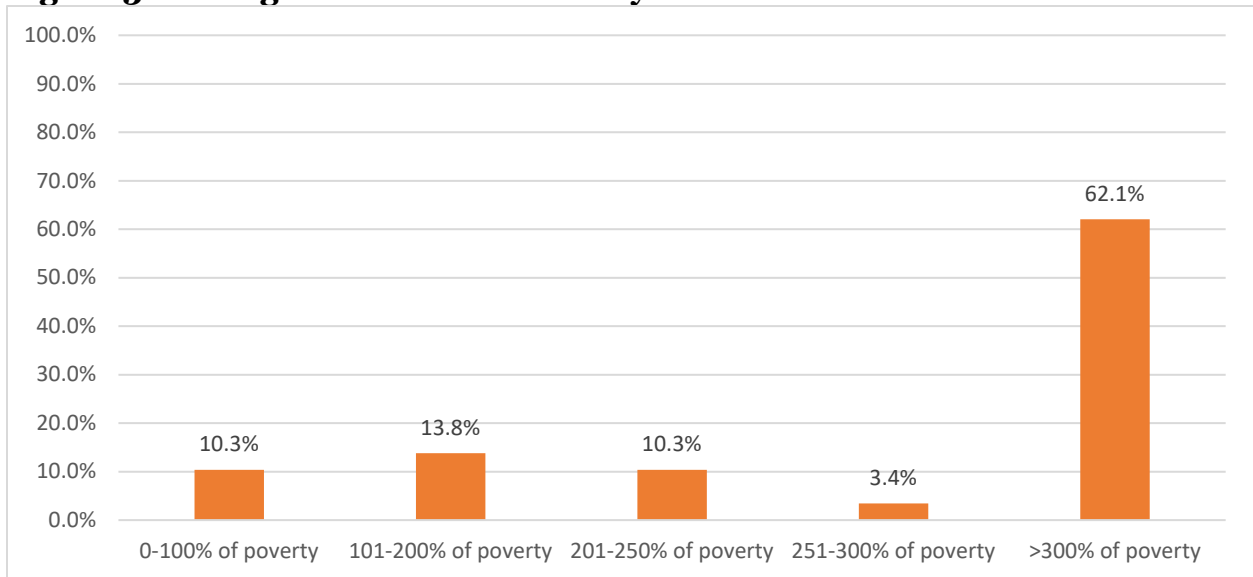


Note: $n = 29$.

The number of people living in the caregiver’s household was compared against household income level to calculate the federal poverty level (FPL). FPL for 2022³⁴ was utilized in the calculation. As an example, using the 2022 guidelines, a household of two people making less than \$18,310 would be living below the poverty line.

As illustrated in the figure below, the majority of caregivers were living in homes that were not in poverty. Nearly two thirds (62.1%) of caregivers were living in households that are greater than 300% of the FPL. Conversely, there were some caregivers that were still living in lower-income homes, with some being at 0-100% FPL (10.3%) and some more being at 101%-200% FPL (13.8%).

Figure 38. Caregivers - Federal Poverty Level



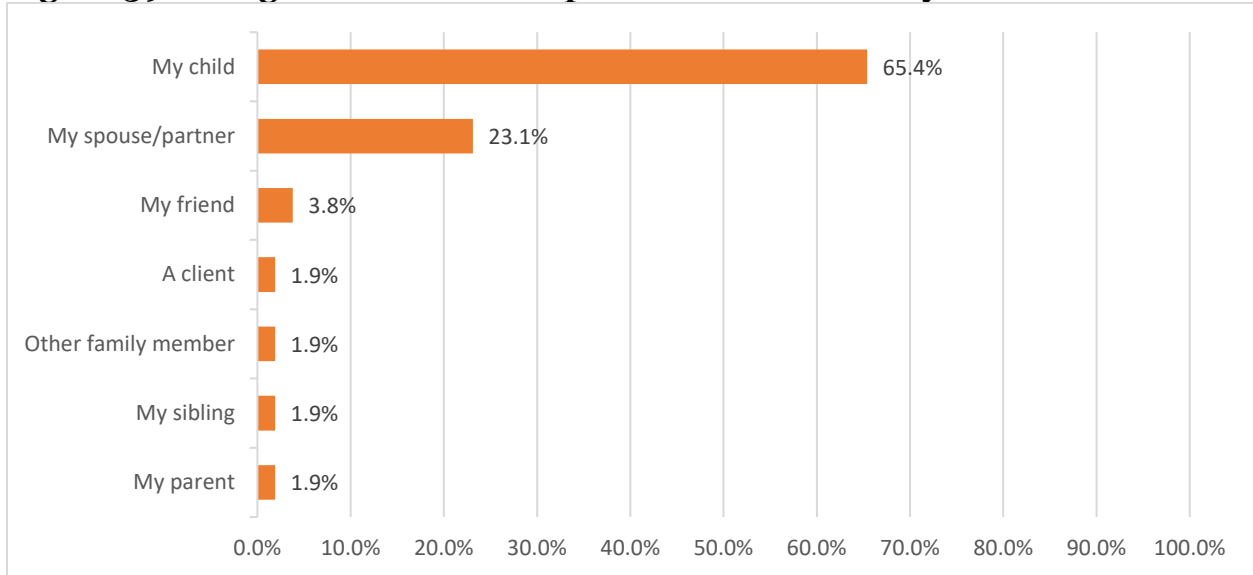
Note: *n* = 29.

³⁴ HHS Office of the Assistance Secretary for Planning and Evaluation (2022). Poverty Guidelines. <https://aspe.hhs.gov/topics/poverty-economic-mobility/poverty-guidelines>

Caregivers' Relationship

Caregivers were asked, "What relationship do you have with the person you care for? If you care for more than one person, think about the person for whom you provide the MOST amount of care." The majority of caregivers were providing care for their child (65.4%). The next most common relationship was a spouse or partner (23.1%).

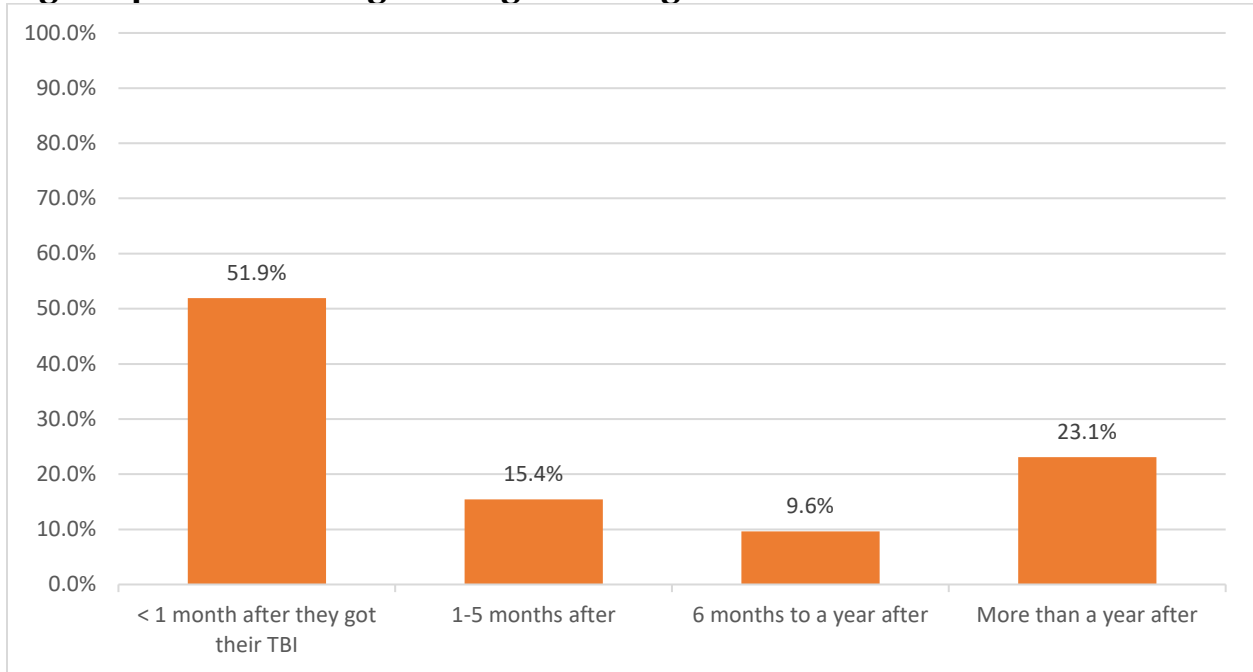
Figure 39. Caregivers' Relationship with the Person They Care for



Note: $n = 52$.

Most caregivers began providing care soon after the individual got their TBI. For instance, 51.9% began caring for the individual less than one month after they got a TBI. However, at the other end of the spectrum, there were some (23.1%) who began providing care more than a year after the individual got a TBI.

Figure 40. When Caregiver Began Caring for Person with TBI



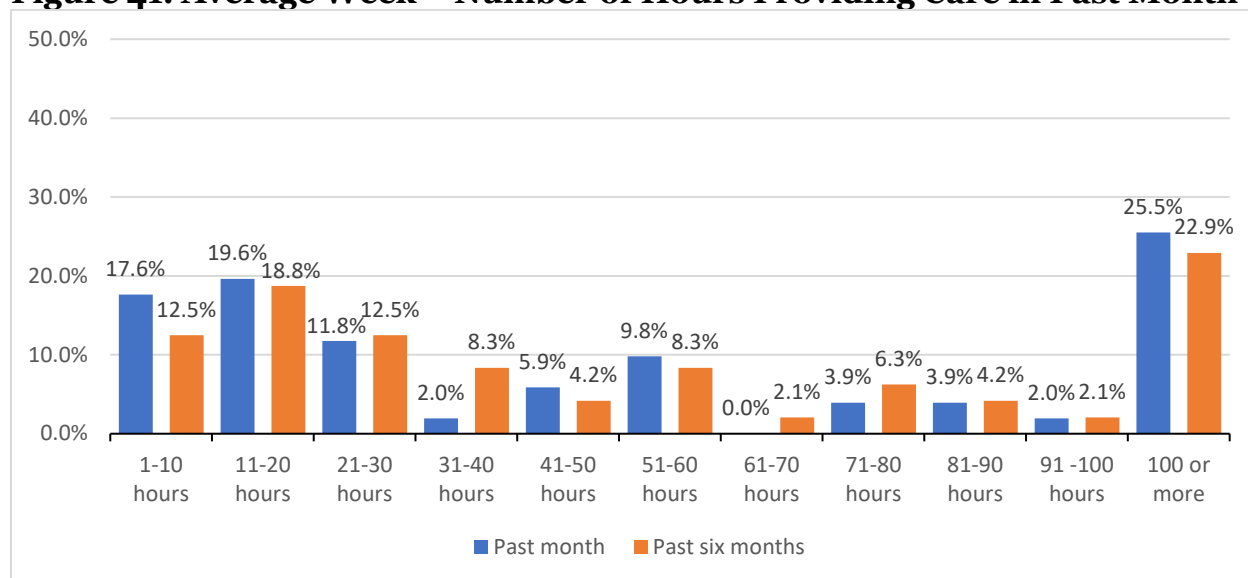
Note: $n = 52$.

Caregivers were asked, “How many people with a TBI have you provided care for in the past 30 days?” A total of 96.2% of caregivers provided care for one person in the past 30 days. The remaining 3.8% have provided care for two people.

To assess how often caregivers are providing care and how that may have changed over time, they were asked about providing care within the past month and then the past six months. Specifically, they were asked, “In the past 30 days/six months, in an average week, how many hours are you providing care to people with TBI?”

The average number of weekly hours of care was 57.5 hours, whereas the median was 38 hours when asked about the past month, and the standard deviation was 50.7 hours. When asked about the past six months, the average number of weekly hours of care work was 57.8 hours, whereas the median was 40 hours, and the standard deviation was 47.5 hours. As illustrated in the figure below, the number of hours providing care varies widely. However, the number of hours is similar, regardless of the timeline (i.e., past month compared to past six months). Some caregivers provide care at 20 hours or less (19.6% for the past month and 12.5% for the past six months), whereas others provide care for 100 hours or more (25.5% for past month and 22.9% for past six months).

Figure 41. Average Week – Number of Hours Providing Care in Past Month



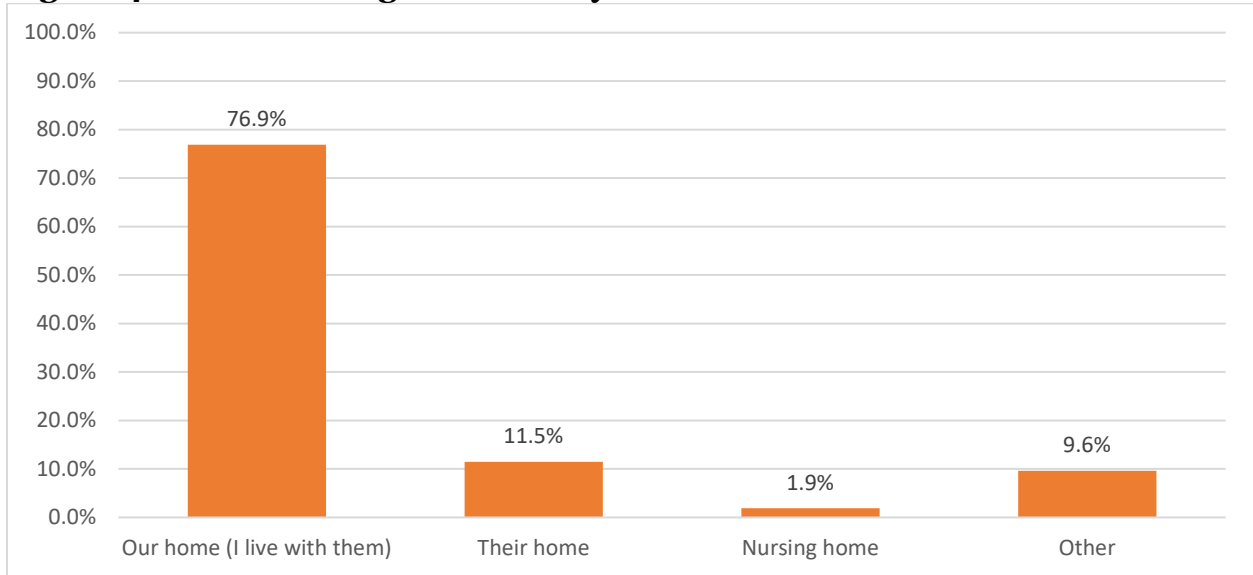
Note: Past month, $n = 51$. Past six months, $n = 48$.

“It’s like the 24-hour—It’s the responsibilities, it’s a huge responsibility, like raising kids.”

- Caregiver of Person with TBI

Caregivers were asked, “Where do you usually provide care for the person with TBI?” As illustrated in the figure below, more than three-quarters (76.9%) of caregivers provide care in the home of the person with the TBI (the caregiver lives with them).

Figure 42. Where Caregivers Usually Provide Care

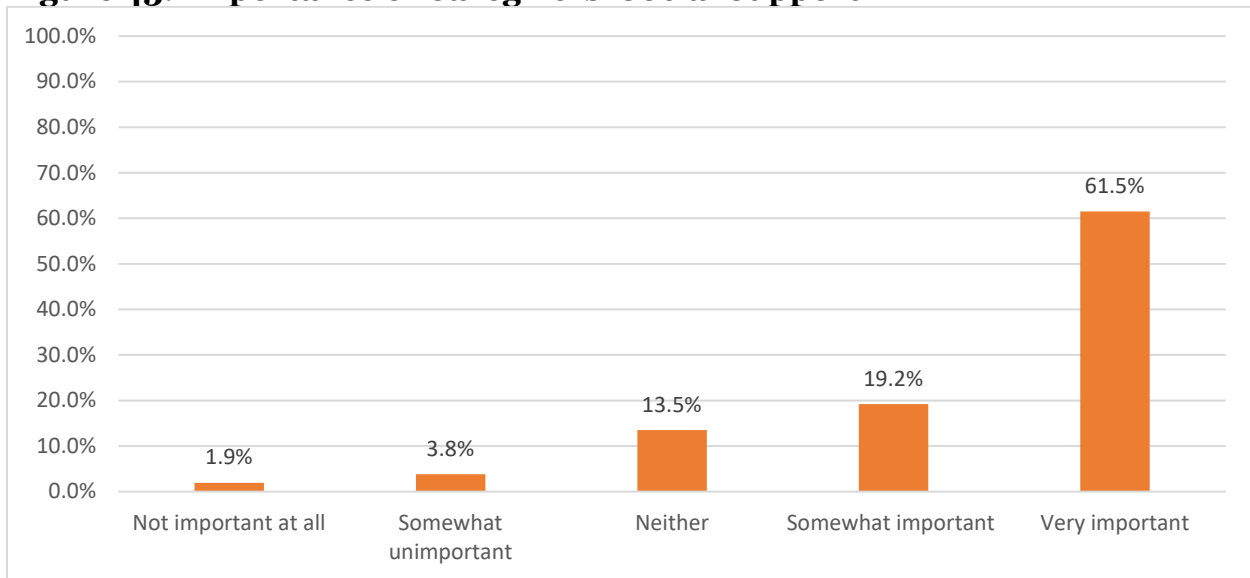


Note: $n = 52$.

Those who stated “Other” typically provided care both at the caregiver’s and individual’s houses ($n = 2$), both at home and in the community ($n = 1$), at school ($n = 1$), and at the caregiver’s home ($n = 1$).

Caregivers were asked, “How important would you say social support is for you as a caregiver (for example, seeing a counselor, going to support groups, having a circle of friends, etc.)?” As illustrated in the figure below, most caregivers stated that social support is *very important* (61.5%), and many also reported that it is *somewhat important* (19.2%).

Figure 43. Importance of Caregivers’ Social Support



Note: $n = 52$.

“I do not feel that anyone cares about the caregivers really. From that standpoint, I’m just going to plug myself here. I created a caregiver support group for TBIs because there’s no one to help us.”

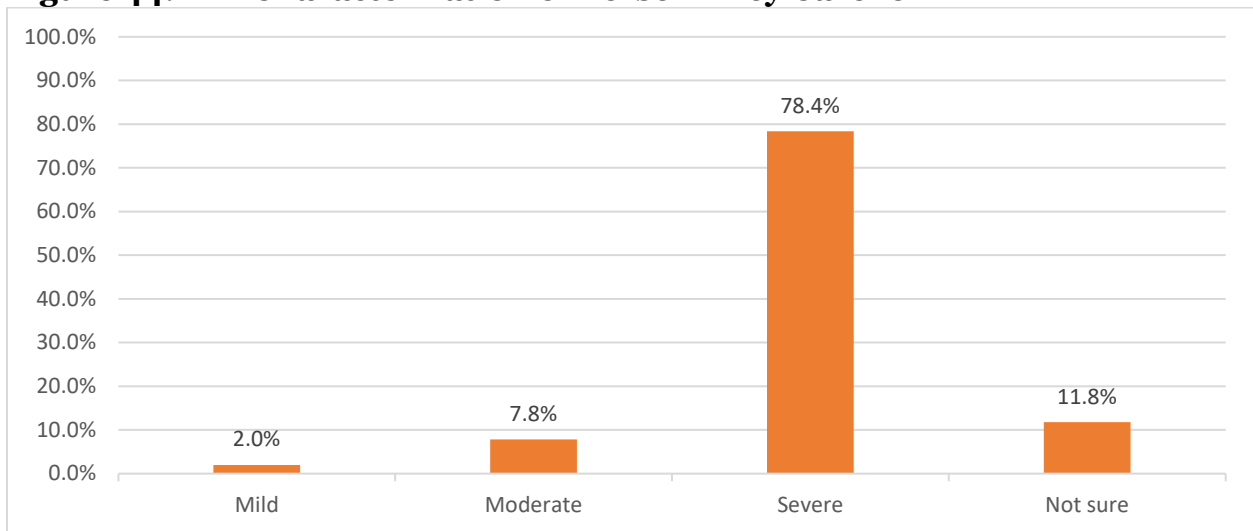
- Caregiver of Person with TBI

Caregivers who stated that social support was *somewhat* or *very important* were asked a follow-up question: “What kind of social support would be most help for you?” Only a handful of responses were provided. The most common response was mental health counseling ($n = 7$), followed by support groups ($n = 5$) and meeting other caregivers of individuals with TBI ($n = 4$). For a full list of responses, see Appendix 30. Caregivers – “What kind of social support would be most help for you?”

Some people have more severe forms of TBI requiring closer attention and around-the-clock care. To assess the severity of the TBI, caregivers were asked, “For the person you care for the most, how was their TBI characterized as?”

As illustrated in the figure below, over three-quarters (78.4%) of caregivers reported that the TBI was *severe*. Fewer reported *mild* (2.0%) or *moderate* (7.8%) cases of TBI. Notably, some caregivers reported they were *not sure* (11.8%) of the severity, which has the potential to be problematic for providing care.

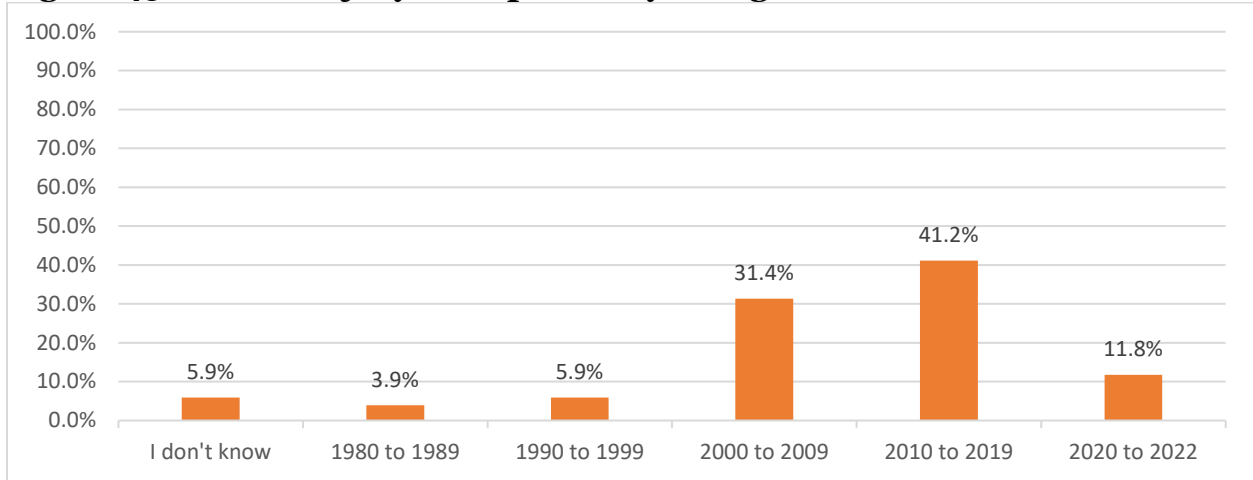
Figure 44. TBI Characterization of Person They Care for



Note: $n = 51$.

Caregivers could also state the year of injury for the person they care for the most. These years were categorized into decades. As illustrated below, a plurality of caregivers reported that the TBI occurred from 2010 to 2019 (41.2%).

Figure 45. Year of Injury as Reported by Caregivers



Note: $n = 51$.

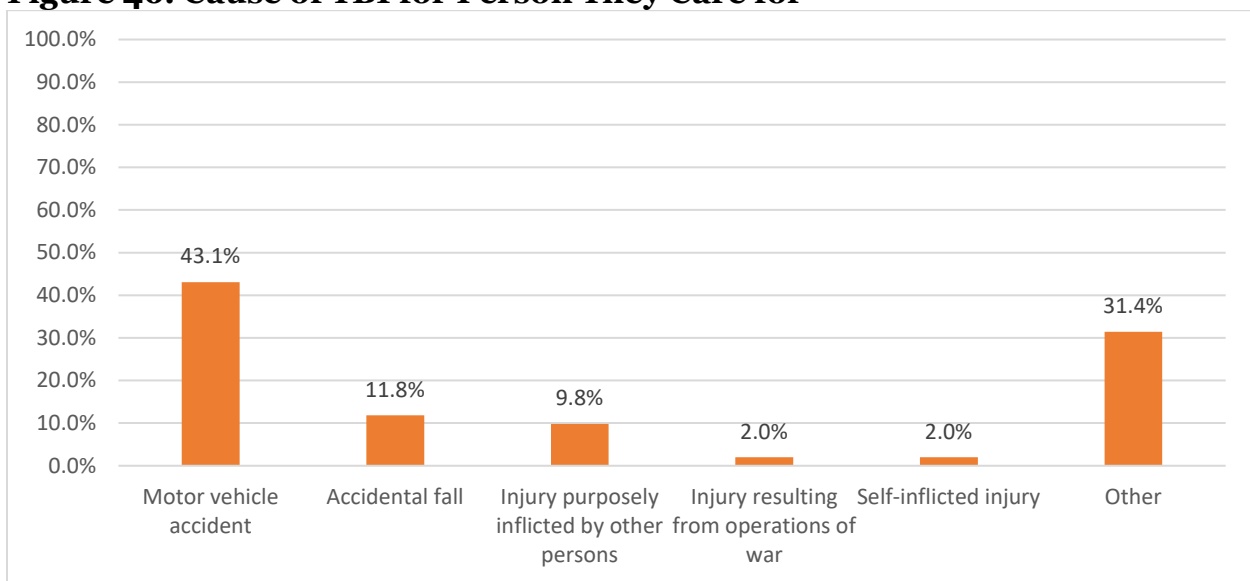
“We asked, ‘Is this a TBI?’ Then we started having dialogue about, ‘Well, yes, it’s a form of TBI,’ and I’m thinking, ‘God, should have thought about it before.’”

- Caregiver of Person with TBI

As noted above, people with TBI most commonly get TBIs from falls, firearm-related injuries, motor vehicle crashes, or assaults.³⁵ While the exact proportions for cause of TBI are not available among living persons at the national level, it has been reported that accidental falls lead to almost half of TBI-related hospitalizations, and motor vehicle accidents and assaults are other common ways of people getting a TBI.³⁶ Thus, the cause of TBI (as reported by caregivers below) is slightly skewed compared to national trends.

Caregivers were asked about the cause of the TBI for the person that they care for. As illustrated in the figure below, the most common response was that the TBI was caused by a motor vehicle accident (43.1%) or some “other” incident (31.4%).

Figure 46. Cause of TBI for Person They Care for



Note: $n = 51$.

Those who stated “other” typically reported stroke ($n = 3$), vehicle accident ($n = 2$), aneurysm ($n = 2$), hit and run ($n = 2$), brain abscess/inflammation ($n = 2$), and one reference for each of the following: horseback riding, infection, work injury, and explosion.

³⁵ Traumatic Brain Injury & Concussion (2022). Centers for Disease Control and Prevention. https://www.cdc.gov/traumaticbraininjury/get_the_facts.html

³⁶ Ibid.

Individuals with TBI can experience a variety of different symptoms. Furthermore, individuals with TBI can experience different symptoms depending on the type of injury, the severity, and the area of the brain.³⁷

To assess symptomology, caregivers were asked, “For the person you care for the most, what are the most challenging symptoms they’ve experienced because of their TBI? Select all that apply.”

As illustrated in the table below, a variety of symptoms were reported, and there were often multiple symptoms reported. Common symptoms included difficulty with memory (86.5%), mental health (75.0%), difficulty maintaining concentration (75.0%), and difficulty solving problems (73.1%). Many also reported difficulty with daily living tasks (65.4%), difficulty controlling emotions (61.5%), difficulty thinking or being mentally overwhelmed (61.5%), and feeling physically tired or fatigued (61.5%).

Only a handful of caregivers selected “Other” symptoms. To see what “Other” symptoms were specified, see Appendix 14. Caregivers – “Other” Reported Symptoms.

See the table below for all symptoms selected by caregivers.

Table 9. TBI Symptoms for the Person They Care for

Symptom	Percentage	N
Difficulty with memory	86.5%	45
Mental health (depression, anxiety, etc.)	75.0%	39
Difficulty maintaining concentration	75.0%	39
Difficulty solving problems	73.1%	38
Difficulty with daily living tasks	65.4%	34
Difficulty controlling emotions	61.5%	32
Difficulty thinking or being mentally overwhelmed (cognitive fatigue)	61.5%	32
Feeling physically tired or fatigued	61.5%	32
Difficulty walking	53.8%	28
Less social	51.9%	27
Difficulty sleeping	48.1%	25
Discomfort in public/crowds	46.2%	24
Difficulty with balance or feeling dizzy	42.3%	22
Poor eyesight	38.5%	20
Sensitivity to noise	36.5%	19
Difficulty speaking	34.6%	18
Sensitivity to light	28.8%	15
Experiencing seizures	28.8%	15

³⁷ What are common symptoms of traumatic brain injury (TBI)? (2020). US Department of Health and Human Services. <https://www.nichd.nih.gov/health/topics/tbi/conditioninfo/symptoms>

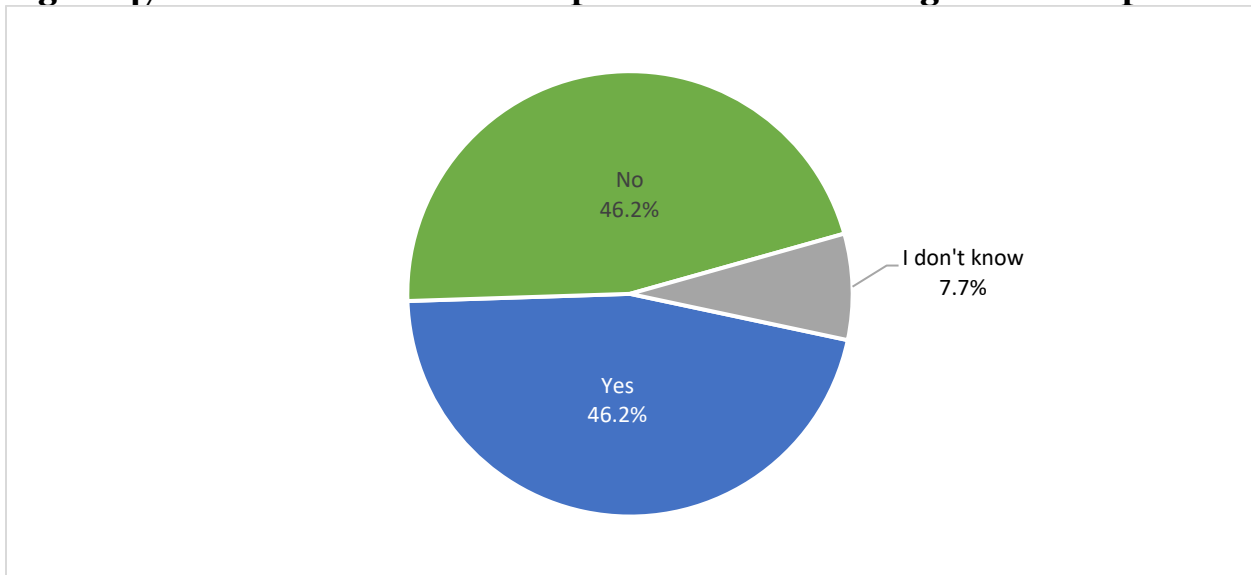
Headaches	25.0%	13
Hearing loss	15.4%	8
Difficulty with sexual function	13.5%	7
Difficulty visualizing images in their mind	11.5%	6
Other	11.5%	6
Total	-	52

Note: Total percentage does not add to 100% as caregivers could “select all that apply.”

Often, when family members learn about a loved one’s TBI, they must quickly adopt the roles and responsibilities of a caregiver. This sudden change in lifestyle can be difficult for anyone but is particularly challenging if one is not prepared for the challenges to come. As such, caregivers were asked, “For the person you provide care for the most, upon their discharge from the hospital, were you ever provided information/resources about caring for the person with TBI?”

When being discharged, 46.2% were not provided information/resources about providing care for a person with a TBI. See the figure below for additional details.

Figure 47. Provided Information upon Person’s Discharge from Hospital?



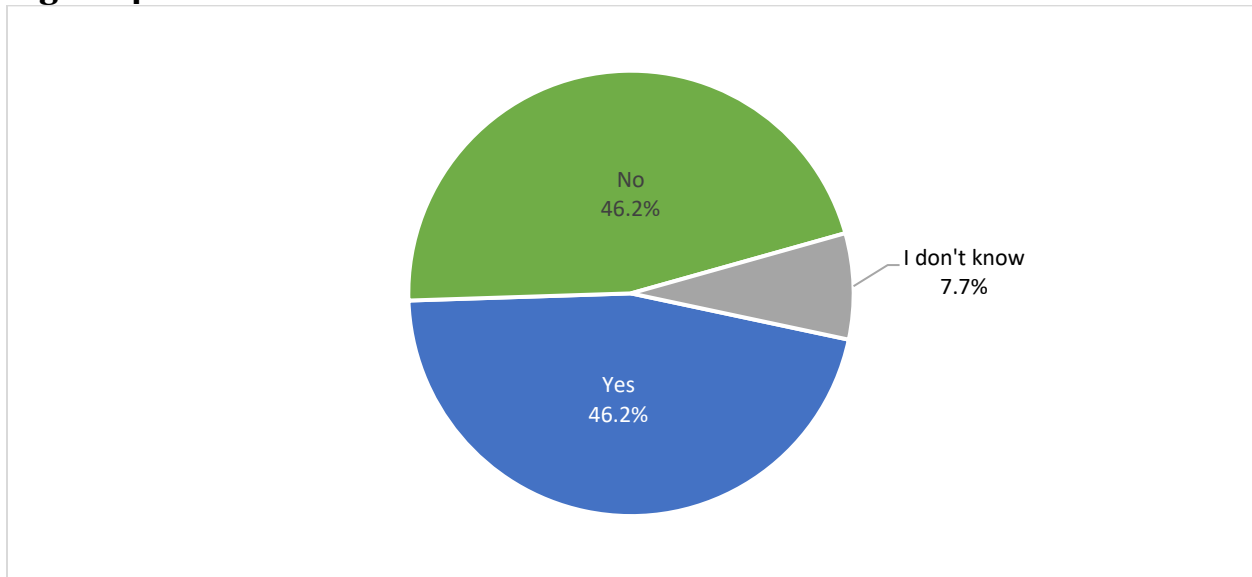
Note: $n = 52$.

Caregivers who stated, “yes” in that they received information about caring for a person with a TBI upon discharge were subsequently asked, “How helpful was this information?” There were only a handful of responses, which included very helpful ($n = 6$), adequate/OK ($n = 4$), and helpful ($n = 3$). For a full list of responses, see Appendix 16. Caregivers – How Helpful Was TBI Information Provided Upon Hospital Discharge?

Having the correct information and resources for providing care is critically important for a caregiver. Caregivers were asked, “For the person you provide care for the most, at any time later in their recovery, were you ever provided information/resources about caring for the person with TBI?”

Half of caregivers (46.2%) have never been provided with information/resources about caring for a person with TBI. See the figure below for additional details.

Figure 48. Ever Provided with Information?



Note: $n = 52$.

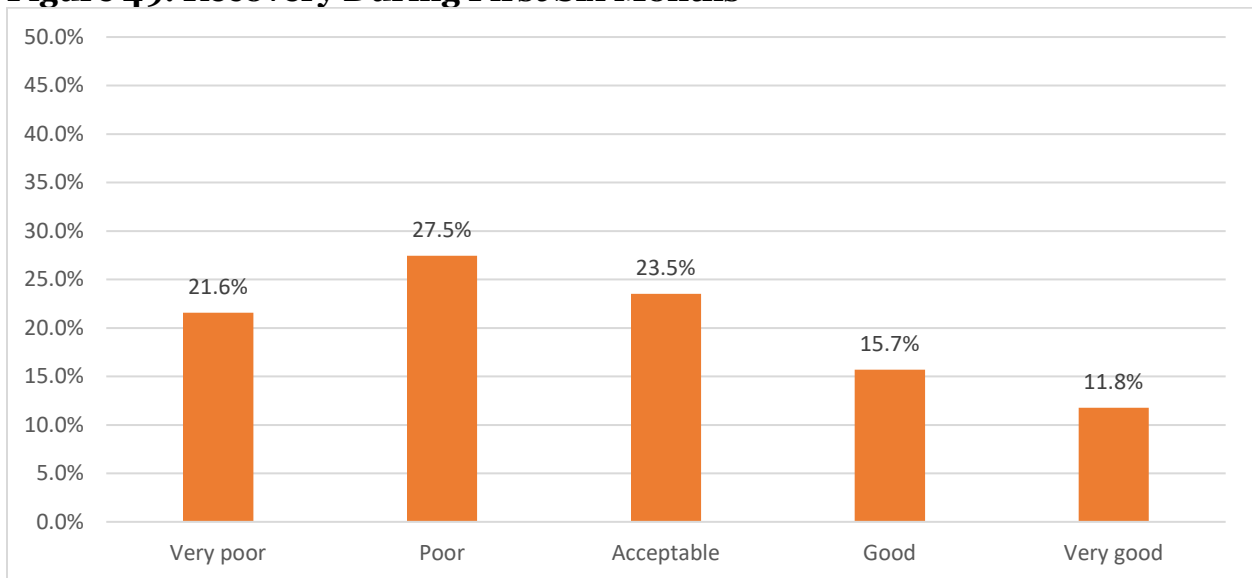
Caregivers who stated, “yes” in that they received information about caring for a person with a TBI any time later in their recovery were subsequently asked, “How helpful was this information?” Responses included the following: very helpful ($n = 7$), helpful ($n = 3$), and the caregiver did research on their own ($n = 2$). For a full list of responses, see Appendix 17. Caregivers – How Helpful Was TBI Information Provided at Any Other Time?

TBI Recovery

Indeed, recovering from a TBI depends on the severity of the TBI, health status prior to injury, family/social support, and access to healthcare and specialized care.³⁸ That said, some health problems from moderate/severe TBI can be prevented/lessened during the recovery process.³⁹

Caregivers were asked to rate the recovery of the person with TBI: “How would you rate their TBI recovery during the first **six months** of recovery?” As illustrated in the figure below, responses varied, but tended to be more on the poorer side of recovery. For instance, 27.5% stated that recovery was *poor*, and another 21.6% stated that the recovery was *very poor*. Fewer caregivers reported that the recovery was *good* (15.7%) or *very good* (11.8%) during the first six months.

Figure 49. Recovery During First Six Months



Note: $n = 51$.

³⁸ Recovery from a Moderate or Severe TBI. (2021). Centers for Disease Control and Prevention. <https://www.cdc.gov/traumaticbraininjury/moderate-severe/recovery.html>

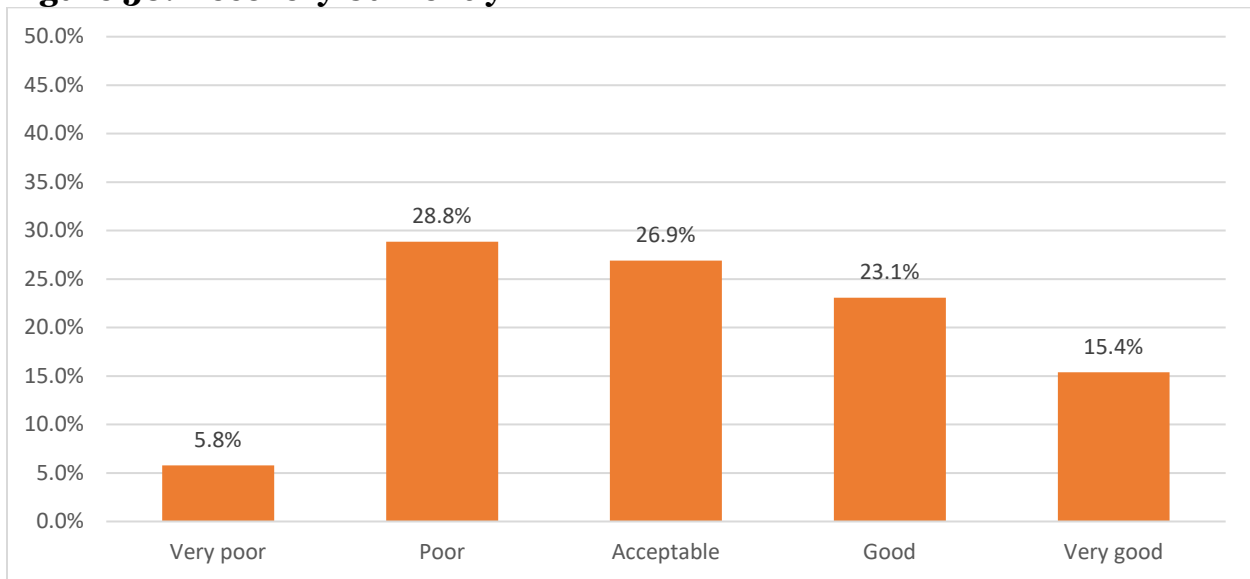
³⁹ Ibid.

Caregivers were asked to elaborate on the rating that they provided for recovery in the first six months. Specifically, they were asked, “Please explain, why their six-month recovery was [option caregiver provided]?” Among those who selected *poor* or *very poor*, responses included that the injury was severe ($n = 3$). Among those who selected *acceptable*, responses included there being a slow recovery ($n = 2$). Among those who selected *good* or *very good*, responses included that the individual with TBI learned basic life skills (walking, talking, etc.) ($n = 6$). For a full list of responses, see Appendix 18. Caregivers – Why Their Six-Month Recovery Was *Poor* or *Very Poor*, Appendix 19. Caregivers – Why Their Six-Month Recovery Was *Acceptable*, and Appendix 20. Caregivers – Why Their Six-Month Recovery Was *Good* Or *Very Good*.

Caregivers were also asked about current recovery: “How would you rate their TBI recovery **currently**?” When rating current recovery, fewer caregivers stated that the recovery was *very poor* (5.8%), thus indicating some individuals with TBI were making improvements over time. However, there were still many caregivers stating that the recovery is currently *poor* (28.8%) or *acceptable* (26.9%). On the positive side, nearly a quarter (23.1%) reported that the current recovery is *good*, and some reported *very good* (15.4%).

While TBI survivors rated their recovery progress favorably, caregivers were less optimistic about recovery, and indicated that their current recovery was “acceptable” (26.9%), “poor” (28.8%), or “very poor” (5.8%). The discrepancy between these two reports may be due to several factors: for example, the level of reliance on the caregiver may not have declined, which leads the caregiver to feel a lack of improvement or progress in recovery. However, the TBI survivor may experience cognitive and behavioral improvements, such as regaining balance, memory, emotional control, or speech, and therefore feel they have made tremendous progress in their recovery. The invisibility of many of the effects of TBI is one of the many reasons why support groups play a significant role for TBI survivors in their recovery; it is impossible to measure what cannot be seen in others unless you can “see it” as well.

Figure 50. Recovery Currently



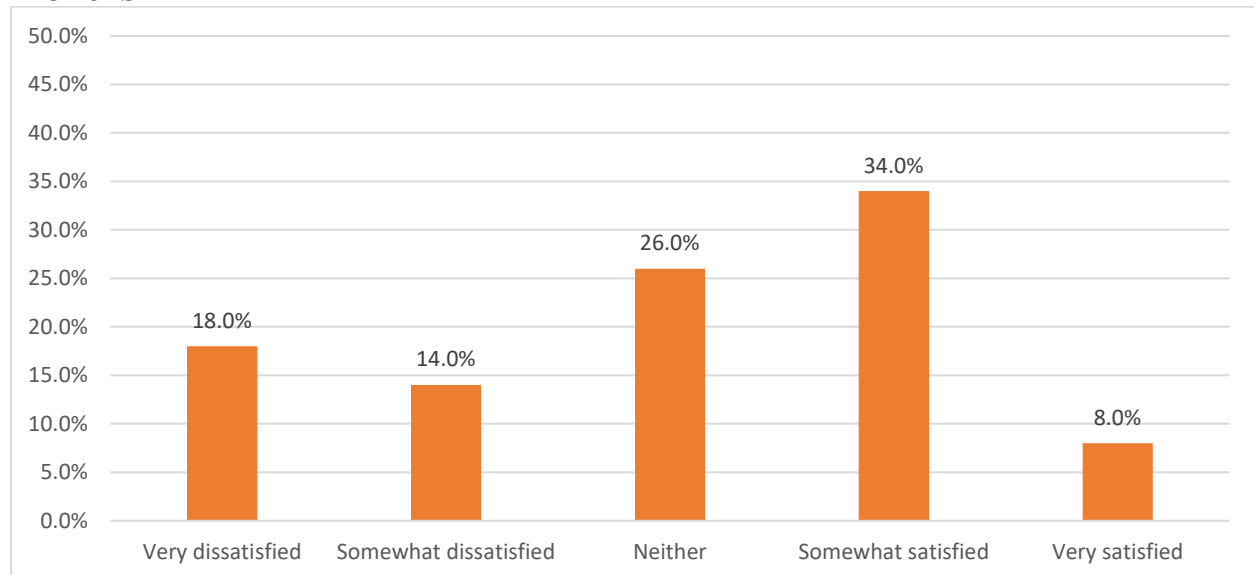
Note: $n = 52$.

Caregivers were asked to elaborate on the rating that they provided for current recovery. Specifically, they were asked, “Please explain, why their current recovery is [option the caregiver selected]?” Among those who selected *poor* or *very poor*, responses included that the individual with TBI still needs 24-hour care ($n = 3$) and that their condition is starting to worsen ($n = 2$) or it has been worsening over many years ($n = 2$). Among those who selected *acceptable*, responses included the individual with TBI having “reached a plateau” in their recovery ($n = 2$). Among those who selected *good* or *very good*, responses included that the individual with TBI has relearned how to talk ($n = 3$) and that they are now working ($n = 3$). For a list of all responses, see Appendix 21. Caregivers – Why Their Current Recovery Is *Poor* or *Very Poor*, Appendix 22. Caregivers – Why Their Current Recovery Is *Acceptable*, and Appendix 23. Caregivers – Why Their Current Recovery Is *Good* or *Very Good*.

Satisfaction with TBI Care

Caregivers were asked, “Overall, how satisfied are you with the services/care the person with TBI has received from health care providers (doctors, nurses, therapists, etc.) in the last six months?” As illustrated in the figure below, satisfaction with medical services in the last six months appears to be mixed. That is, 32.0% reported being *somewhat/very dissatisfied*, whereas 42.0% stated they were *somewhat/very satisfied*.

Figure 51. Satisfaction with Person’s Medical Services/Care in Last Six Months

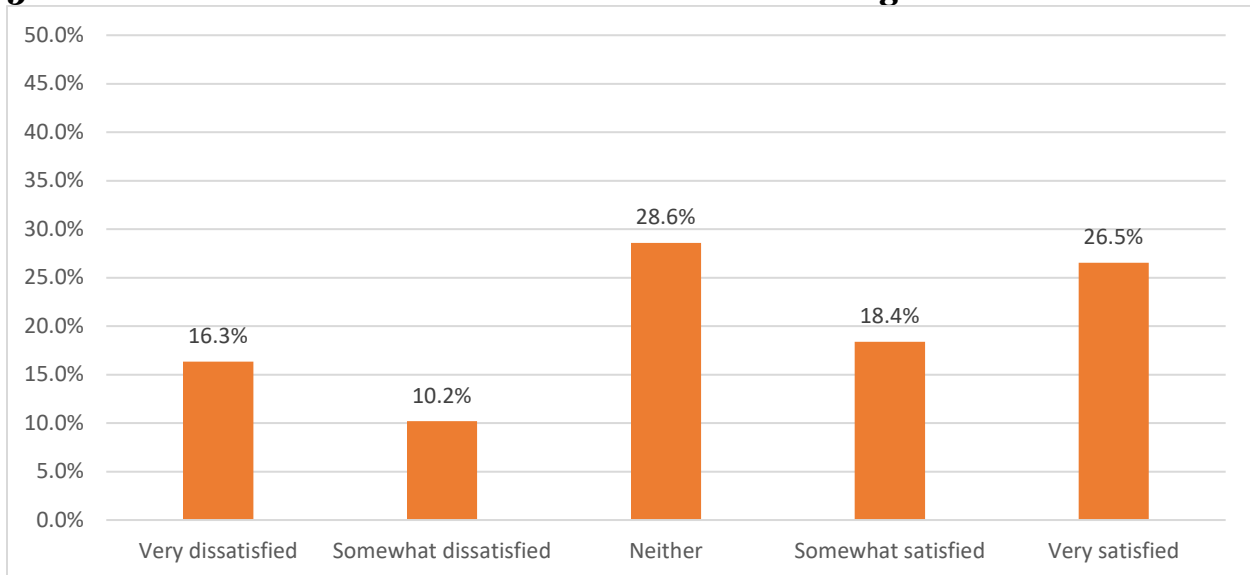


Note: $n = 50$.

Caregivers were given an opportunity to elaborate and were asked, “Please explain why you were [option they selected earlier] with their services/care?” Among those who selected *somewhat* or *very satisfied*, responses included a lack of adequate health insurance coverage ($n = 4$) and a lack of medical help or services ($n = 3$). Among those who selected *neither*, responses included that the individual with TBI is not receiving services/care for their TBI ($n = 2$) and that it has been difficult to get services/care because of COVID-19 ($n = 2$). Among those who selected *somewhat* or *very satisfied*, responses included difficulty finding/paying for mental health care ($n = 2$). For a list of all responses, see Appendix 24. Caregivers – Why Their Health Care/Services Are *Somewhat* or *Very Poor*, Appendix 25. Caregivers – Why Their Health Care/Services Are *Neutral*, and Appendix 26. Caregivers – Why Their Health Care/Services Are *Somewhat* or *Very Good*.

Caregivers were also asked to rate their healthcare providers' knowledge of TBI: "How satisfied are you with health care providers' (doctors, nurses, therapists, etc.) knowledge of TBI?" As illustrated in the figure below, ratings slightly leaned positive but were still mixed. A larger number of caregivers reported being *somewhat/very satisfied* (44.9%), whereas others reported being *somewhat/very dissatisfied* (26.5%).

52. Satisfaction with Health Care Providers' Knowledge of TBI



Note: $n = 49$.

“They didn't bother to do speech therapy; they didn't know that my daughter wasn't understanding the commands because they were getting messed up in her head. They thought she just wasn't listening, wasn't focusing, wasn't paying attention, but she was hearing every word, she just wasn't understanding the words properly. They need to get out[side] the box, and it would be nice if the medical community would just continue in some way, but for anybody who's two or three years out, they're done with the insurance paying for things.”

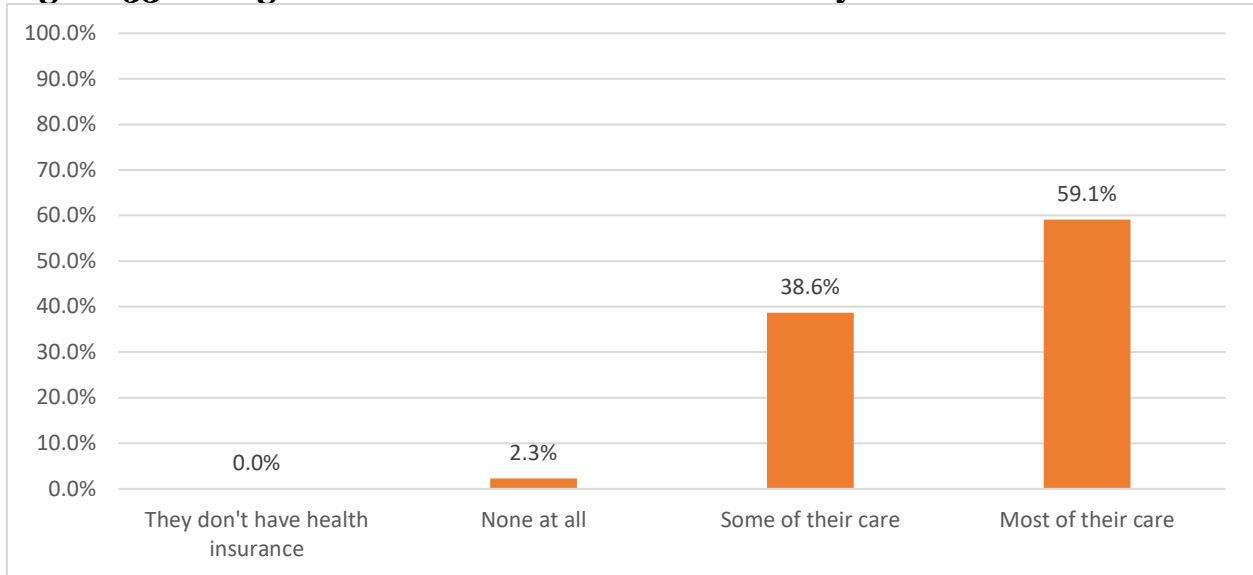
- Caregiver of Person with TBI

Health Insurance Coverage

Access to both health care and specialized TBI care is vital for the recovery process.⁴⁰

Caregivers were asked, “In thinking about the person with TBI, how much of their care has their health insurance covered?” Caregivers report that most individuals with TBI have most of their care covered by their health insurance (59.1%). Another 38.6% reported that some of their care is covered. See the figure below for additional details.

Figure 53. Caregiver - Person’s TBI Care Covered by Health Insurance



Note: $n = 44$.

⁴⁰ Recovery from a Moderate or Severe TBI. (2021). Centers for Disease Control and Prevention. <https://www.cdc.gov/traumaticbraininjury/moderate-severe/recovery.html>

Caregivers who stated, “most of their care”, “some of their care”, or “none at all” were asked, “What services or treatments does the person with TBI need insurance to help with more?” Common responses included mental health care such as psychologists, psychiatrists, and neuropsychologists ($n = 8$), therapy ($n = 5$), speech therapy ($n = 5$), physical therapy ($n = 5$), and occupational therapy ($n = 4$). See the table below for the full list of responses.

Table 10. Caregivers – Services/Treatments Individual with TBI Needs Insurance to Help with More

Response	<i>n</i>
Psychologist/psychiatrist/neuropsychology/mental health care	8
Therapy/more therapy/longer therapy sessions	5
Speech therapy	5
Physical therapy	5
Occupational therapy	4
TBI vision care	3
Assistive devices/equipment (e.g., speech synthesizer, walker)	3
Transportation	2
Cognitive therapy	2
Surgeries	2
I don't know	2
Switched from private to public insurance, which is more difficult to get timely services/care	1
Mobility therapy	1
Cerebral therapy	1
Mobility devices	1
Care for seizures	1
Neurologist	1
General practitioner who is knowledgeable of TBI	1
Out-of-pocket expenses	1
Music therapy	1
Hand therapy	1
Vision therapy	1
None	1
Alternative therapies	1
Short-term treatment centers	1
Autoimmune therapies	1
Training for use of white cane	1
Training for use of phone apps for the blind	1
Placement in long-term care facility	1
Information on severity of their TBI	1
Legal help	1
Assistance with ADL	1

Help with walking	1
Housing	1
Personal one-on-one assistant	1
Hospital care	1
Dental care	1
100% coverage of health care	1
Prognosis for recovery	1
Help with "everything"/learning ADL	1
Rehabilitation	1
Ambulance	1
Support after hospital discharge	1
Help switching health insurers	1
Total	74

Impact of Being a Caregiver

Caregivers are faced with unique and ongoing challenges that can have an impact on their health.⁴¹ To understand some of these areas of impact, caregivers were asked, “Which of the following has your role as a caregiver negatively affected? Select all that apply.” Common areas negatively affected include the caregivers’ relationship with spouse/partner (64.6%), friendships (58.3%), access to community events/services/activities (56.3%), activities of daily living (56.3%), and being able to leave the house (50.0%).

See the table below for additional areas negatively affected.

Table 11. Impact of Being a Caregiver

Category	Percentage	N
Relationship with spouse/partner	64.6%	31
Friendships	58.3%	28
Access to community events/services/activities	56.3%	27
Activities of daily living (for example, going shopping, doing chores around home, etc.)	56.3%	27
Being able to leave the house	50.0%	24
Family	45.8%	22
Managing my health care	45.8%	22
Employment	43.8%	21
Living arrangements	37.5%	18
Getting access to health care	27.1%	13
School	20.8%	10
Total		48

Note: Total percentage does not add to 100% as caregivers could select all that apply.

⁴¹ Caregiving (2019). Centers for Disease Control and Prevention. <https://www.cdc.gov/aging/caregiving/index.htm>

“We kiss, hug, and cuddle. It’s not the same, but I’ve learned to say, ‘This is okay because there’s a real love and intimacy.’ I’ve had to work at that. Not as far as my age is a good thing because I’m not 30 and I’m not really wanting. What we had before, that can be very painful for couples. I feel for couples when that’s really where a couple counseling needs to be specialized because you can’t put them under any pressure. Medications also now lessen his desire. You’re like, ‘Yes, your libido. It’s gone,’ because you have to take this medication.”

-Caregiver of Person with TBI

Needs of Caregivers

To better understand the unmet needs of caregivers, as well as different perspectives, all groups (caregivers, professionals, and individuals with TBI) were asked the same question regarding unmet needs.

Specifically, caregivers were asked, “Which of the following resources or services do you currently need? Select all that apply.” Most caregivers need help finding TBI resources (71.1%). More than half also reported needing mental health counseling (51.1%), whereas others need support groups (46.7%) or respite care (44.4%).

See the table below for additional unmet needs.

Table 12. Caregivers’ Unmet Needs as Reported by Caregivers

Unmet Needs	Percentage	N
Help finding TBI resources, such as therapists, support programs, etc.	71.1%	32
Mental health counseling	51.1%	23
Support groups	46.7%	21
Respite care (having someone help for a few hours or a day so that you can take a break)	44.4%	20
Legal assistance	37.8%	17
Help with how to communicate with health professionals	37.8%	17
Financial support	35.6%	16
Help with transportation	28.9%	13
Education on what TBI is and what to expect	28.9%	13
Housing assistance	26.7%	12
Food assistance	20.0%	9
Total		45

Note: Total percentage does not add to 100% as caregivers could select all that apply.

As illustrated above, the top unmet need of caregivers is help finding TBI resources. This was also a common theme in caregiver interviews. Caregivers were often in the position

of orchestrating their loved one's care, sometimes necessitating a specialized familiarity with the various programs, insurance requirements, and treatment options available to individuals with TBI. Some caregivers expressed a need for a person they could turn to—such as a case manager—who could offer this help to both find resources and coordinate care.

Caregivers were then asked, “What other needs do you have that are not being met?” Caregivers gave a variety of answers which included two mentions each of help with long-term care plans (especially important for aging parent caregivers), health care providers who understand TBI, mental health care of individuals with TBI, mental health care for caregivers, and an IHSS worker. For a list of all responses, see Appendix 15. Caregivers – “What other needs do you have that are not being met?”

“I think the case manager situation that you mentioned of having a resource to connect to or lean on. If you don't know your taxes, you lean on a CPA. If you don't know the law, you have a lawyer. I don't know this TBI or what to do today—I don't know how to fix this. I don't know how to support this.... These are all different things now. What is that? Who fulfills that role? Like you said, it's a case manager to connect to resources.”

-Caregiver of Person with TBI

“Unfortunately, the people who support in the medical field, they mean well, but they don't know what it feels like to be on the receiving end, so it's this weird [dynamic]—They give you tons of pamphlets. When you check out of rehab or you check out of the hospital after a stroke, they give you a stack of stuff this big, like half an inch, quarter of an inch thick. All these flyers. ‘Here's all the services.’ You are so tired at the end of the day, you just put them aside. It was months before I could wade my way through them. I could have used someone to say, ‘Hey, this could help you. This could help you. Stop and think about that.’”

-Caregiver of Person with TBI

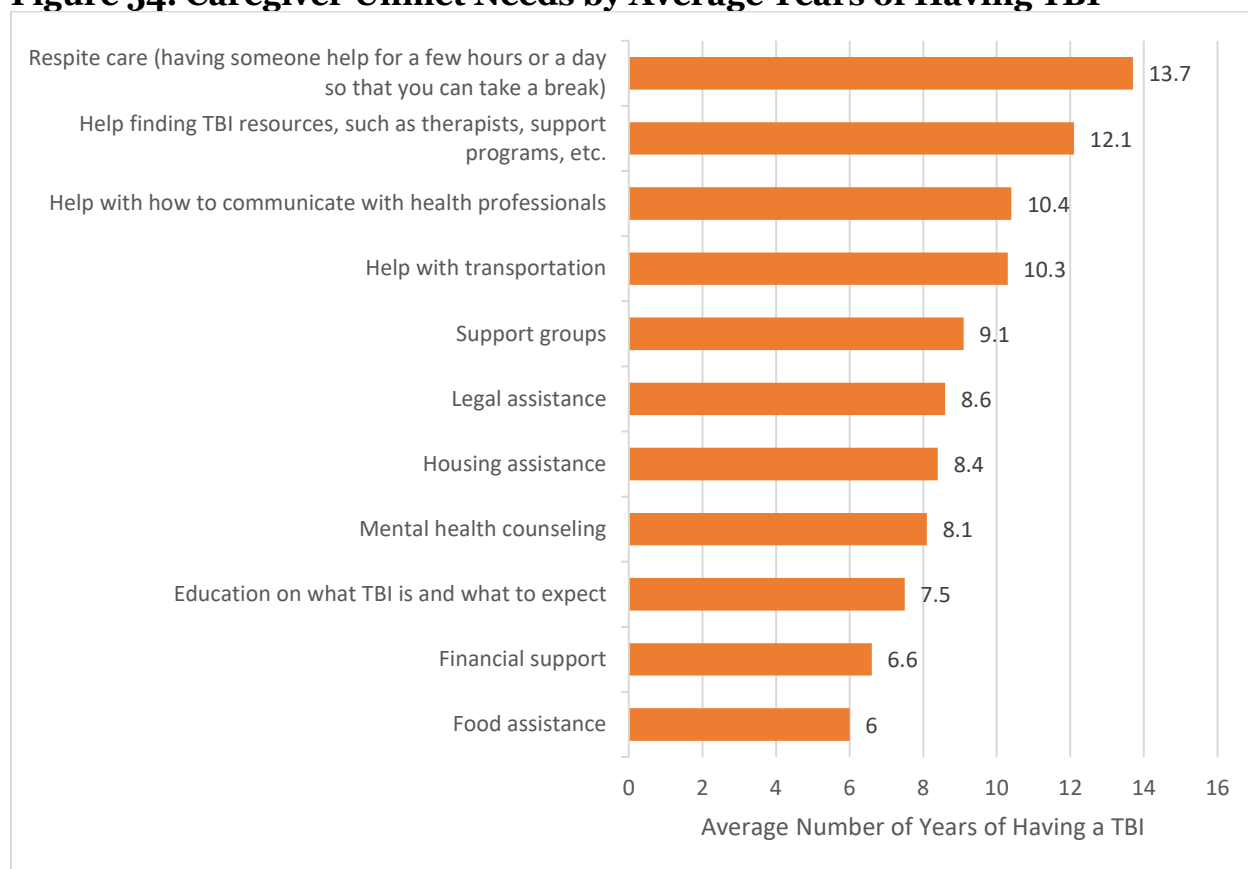
Caregiver Needs by Number of Years Individual Had TBI

The needs illustrated previously can vary as a function of other demographics. For this reason, the unmet needs of caregivers were analyzed by the average number of years the individual with TBI has had the TBI. That is, the figure below illustrates this analysis with each unmet need, and the corresponding average number of years for having a TBI.

As illustrated in the figure below, the average number of years for the individual with the TBI is higher for needs such as respite care (average = 13.7 years), help finding TBI resources (average = 12.1 years) and help with how to communicate with health professionals (average = 10.4 years). Conversely, the average number of years for the individual with TBI is lower for needs such as food assistance (average = 6 years), financial support (average = 6.6 years), and education on what TBI is and what to expect (average = 7.5 years).

See the figure below for additional details.

Figure 54. Caregiver Unmet Needs by Average Years of Having TBI



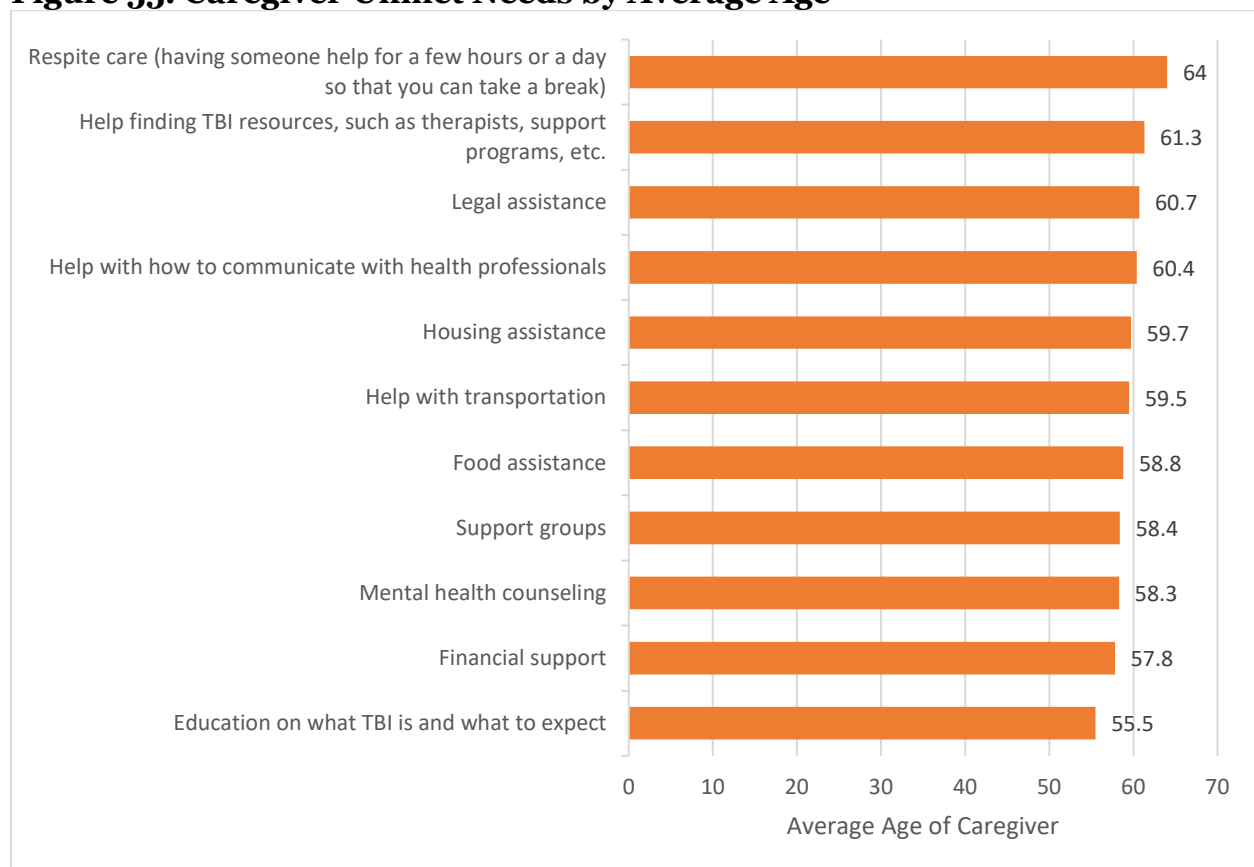
Note: $n = 45$.

Caregiver Needs by Age

Unmet needs were also analyzed as a function of caregiver age. As illustrated in the figure below, there is some slight variation in the average age of a caregiver by need. For instance, older caregivers reported needing respite care (average = 64.0 years), help finding TBI resources (average = 61.3 years), legal assistance (average = 60.7 years), and help with how to communicate with health professionals (average = 60.4 years). Conversely, younger caregivers report needing education on what a TBI is and what to expect (average = 55.5 years), financial support (average = 57.8 years), and mental health counseling (average = 58.3 years).

See the figure below for additional details.

Figure 55. Caregiver Unmet Needs by Average Age



Note: $n = 45$.

An analysis of caregiver needs by TBI severity was also performed. However, nearly all caregivers reported caring for a person with a severe TBI; one reported “mild”, three reported, “moderate” and the remaining reported “severe” ($n = 37$) or “not sure” ($n = 3$). Thus, an analysis of need by TBI severity was unwarranted.

Also, caregivers were given a few more follow-up, open ended questions based on the needs they stated. For instance, caregivers who stated they need help finding more TBI resources were asked, “What kind of TBI resources do you need help finding?” Three responses were for mental health care providers who specialize in TBI. There were two responses each for care manager/social worker, alternative therapies, mental health care for the individual with TBI, transportation, physical therapist, and social activities/programs. For a full list of responses, see Appendix 28. Caregivers – “What kind of TBI resources do you need help finding?”

Caregivers who selected the need for financial support were further asked, “In what areas of your life do you need financial support?” Only a handful of responses were provided. The most common response was help paying for medical treatments/therapies ($n = 6$). There were also two mentions each of extra/supplemental income, rent/housing, and transportation. For a full list of responses, see Appendix 29. Caregivers – “In what areas of your life do you need financial support?”

To understand the needs of caregivers from multiple perspectives, individuals with TBI were asked the same question regarding caregiver need: “Which of the following resources does your caregiver need? Select all that apply.” Individuals with TBI reported that their caregiver needs help finding TBI resources (56.3%). Many individuals with TBI also reported that their caregiver needs financial support (47.9%), help with transportation (45.8%), and mental health counseling (45.8%).

See the table below for additional areas of need.

Table 13. Caregivers’ Unmet Needs as Reported by Individuals with TBI

Unmet Needs	Percentage	N
Help finding TBI resources, such as therapists, support programs, etc.	56.3%	27
Financial support	47.9%	23
Help with transportation	45.8%	22
Mental health counseling	45.8%	22
Respite care (having someone help for a few hours or a day so that your caregiver can take a break)	41.7%	20
Food assistance	37.5%	18
Support groups	33.3%	16
Housing assistance	31.3%	15
Help with how to communicate with health professionals	31.3%	15
Education on what TBI is and what to expect	27.1%	13
Legal assistance	16.7%	8
Total		48

Note: Total percentage does not add to 100% as individuals with TBI could select all that apply.

Lastly, professionals were asked the same question regarding caregiver need: “Which of the following resources and services are most needed by the **caregivers of your patients/clients** with TBI? Select all that apply.”

Like the feedback given by caregivers and individuals with TBI, professionals also reported that caregivers need help finding TBI resources (82.9%). Professionals also stated that caregivers need education on what TBI is and what to expect (81.4%), support groups (80.0%), and help with how to communicate with health professionals (75.7%).

See the table below for additional areas of unmet needs.

Table 14. Caregivers’ Unmet Needs as Reported by Professionals

Unmet Needs	Percentage	N
Help finding TBI resources, such as therapists, support programs, etc.	82.9%	58
Education on what TBI is and what to expect	81.4%	57
Support groups	80.0%	56
Help with how to communicate with health professionals	75.7%	53
Respite care	71.4%	50
Mental health counseling	68.6%	48
Help with transportation	62.9%	44
Financial support	58.6%	41
Housing assistance	47.1%	33
Legal assistance	42.9%	30
Food assistance	32.9%	23
Total		70

Note: Total percentage does not add to 100% as professionals could select all that apply.

Professionals were then asked, “What other needs do the caregivers of clients/patients with TBI have that are not being met?” Other needs that professionals have identified for caregivers include encouragement of self-care ($n = 2$), an understanding of the long term process of TBI ($n = 2$), better pay ($n = 1$), access to culturally sensitive caregivers ($n = 1$), support groups ($n = 1$), job opportunities ($n = 1$), legal support for social security benefits ($n = 1$), mental health support ($n = 1$), respite care ($n = 1$), a collaborative with a team to report daily life issues ($n = 1$), and medical support at home.

PROFESSIONALS

Professionals serving individuals living with a TBI.

Professionals

There were a total of 79 survey participants who indicated they are professionals serving individuals living with a TBI. All professionals completed the survey in English (100.0%). In addition, a total of 13 professionals participated in the key informant interviews.

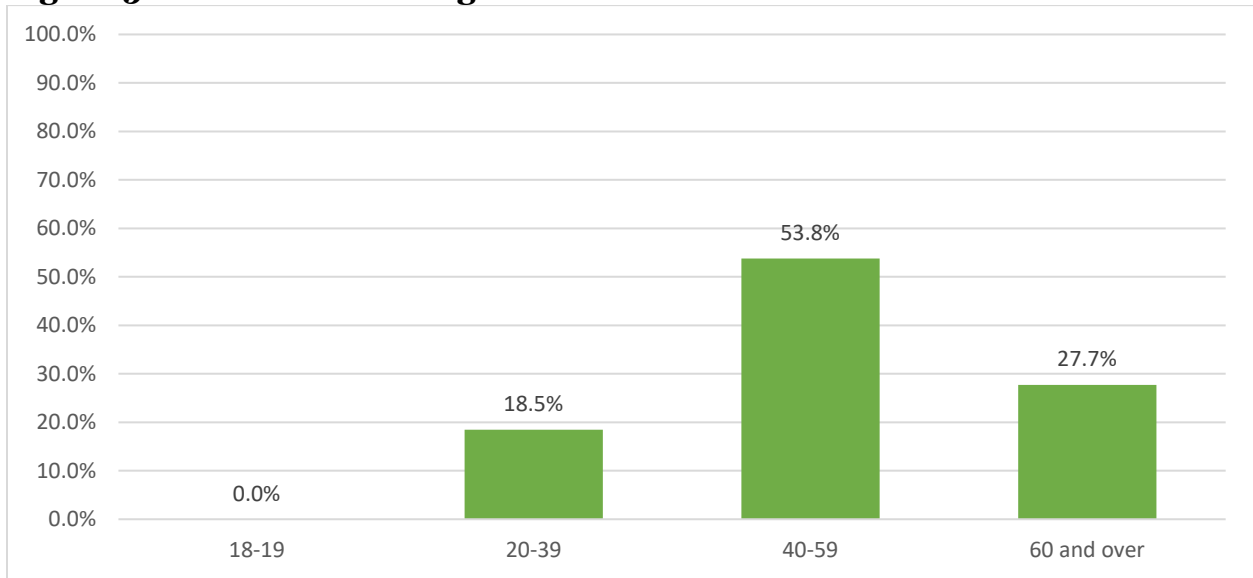
Demographics

Age

Professionals who participated in the survey were often in the middle age group. The mean (average) age of professionals was 50.4 years old (standard deviation = 12.3 years). The age groups were as follows:

- 18.5% were 20-39 years old (adult).
- 53.8% were 40-59 years old (middle-aged adult).
- 27.7% were 60 years old and over (senior adult).

Figure 56. Professionals - Age

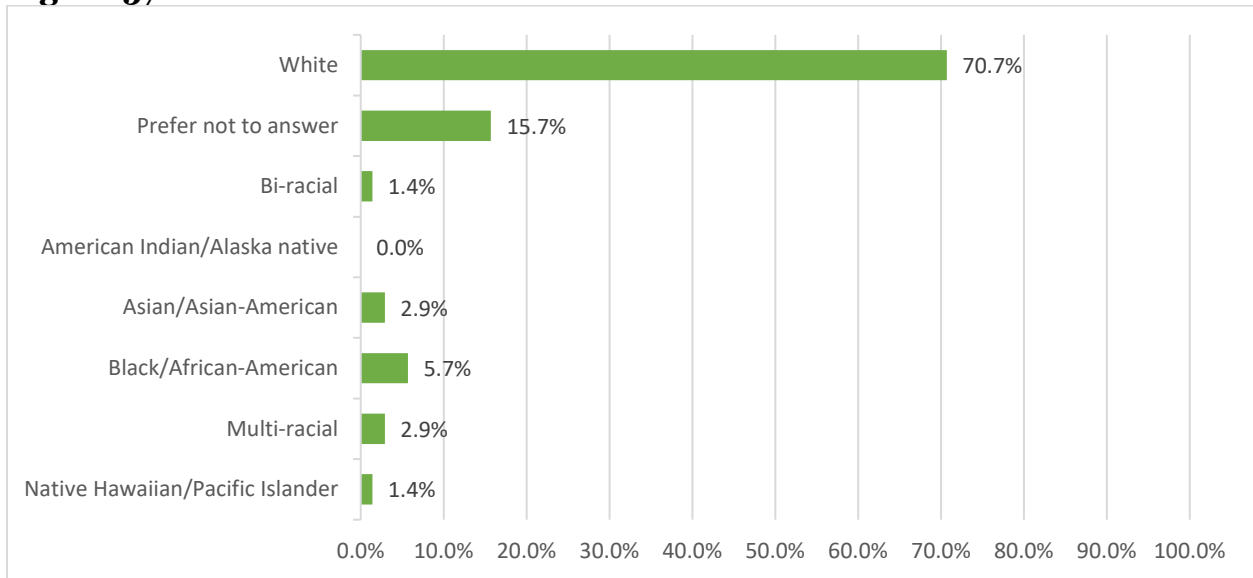


Note: $n = 65$.

Race and Ethnicity

Most professionals specified their race as White (70.7%), as illustrated below. There were also a high percentage of professionals who preferred not to disclose their race (15.7%).

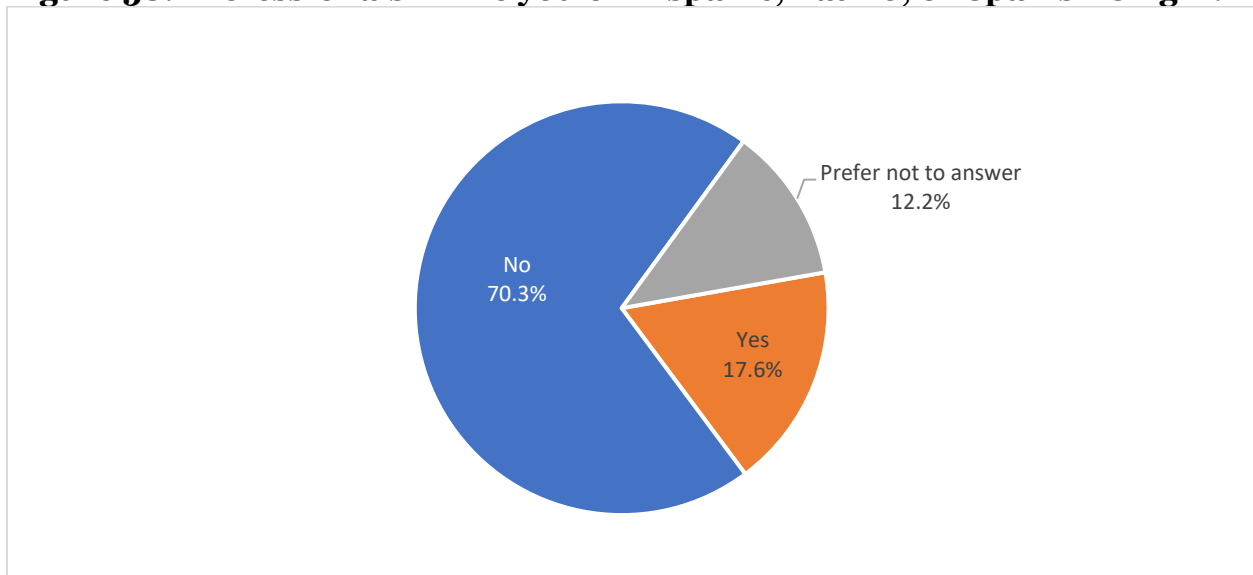
Figure 57. Professionals – Race



Note: $n = 70$.

Most professionals indicated they are not of Hispanic, Latino, or Spanish origin (70.3%). Approximately 17.6% are of Hispanic, Latino, or Spanish origin, and a smaller percentage (12.2%) would prefer not to answer.

Figure 58. Professionals - “Are you of Hispanic, Latino, or Spanish Origin?”

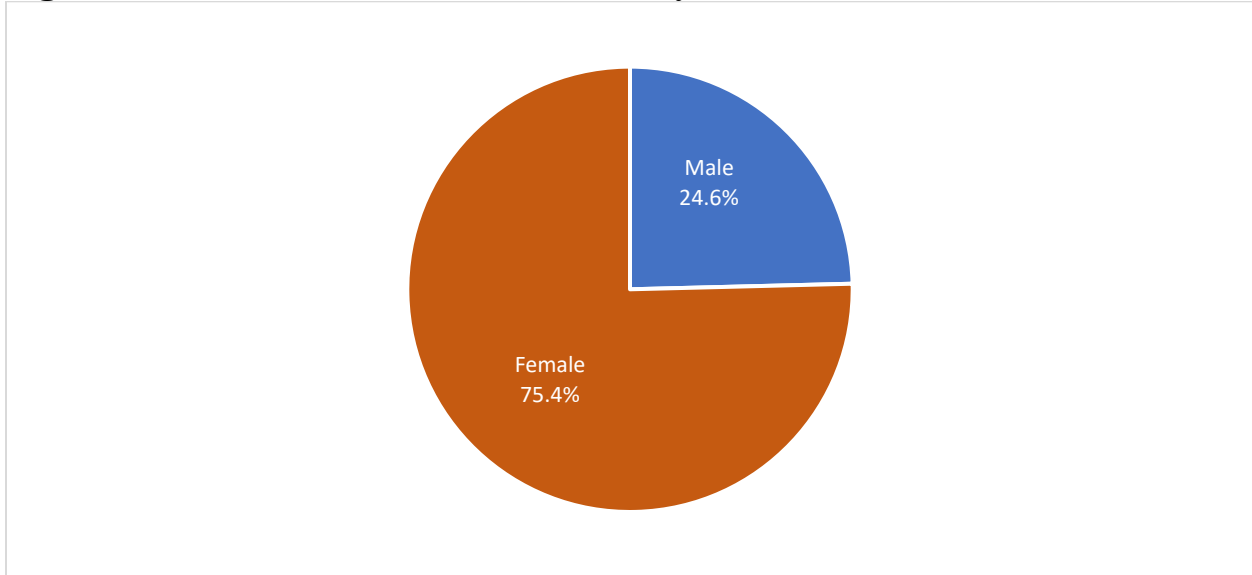


Note: $n = 74$.

Gender Identity

The majority of professionals indicated they are female (75.4%), while a quarter indicated they are male (24.6%).

Figure 59. Professionals - Gender Identity



Note: $n = 69$.

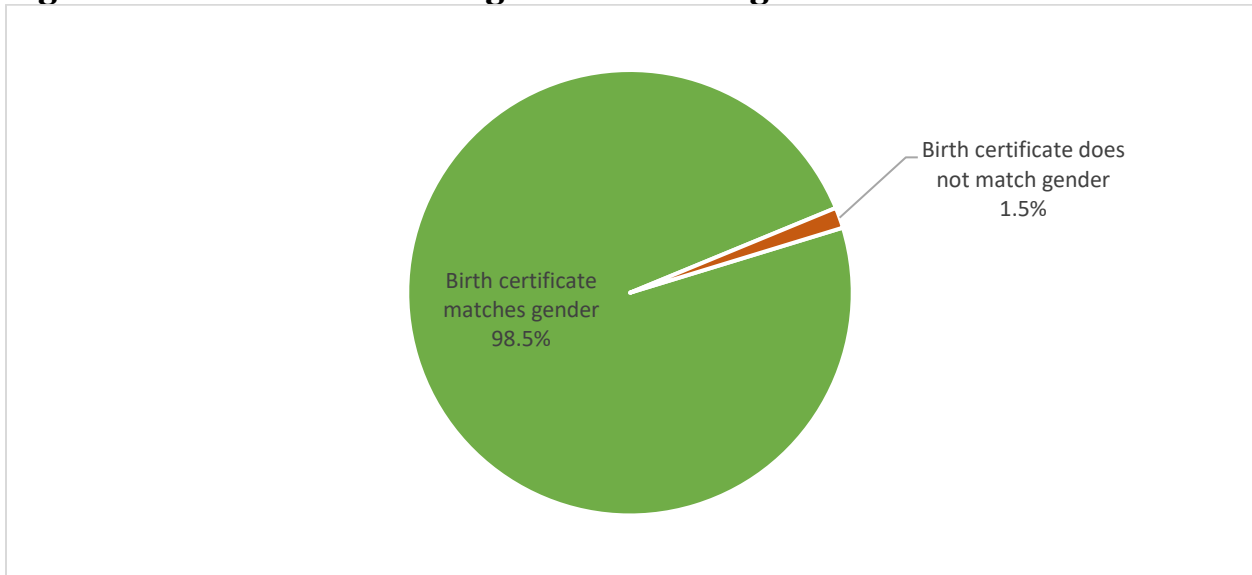
Professionals who identified as either White (70.7%), non-Hispanic (70.3%), or female (75.4%) were likely overrepresented in the dataset, given that, in California, the general adult population is 43.6% White, 64.0% non-Hispanic, and 50.7% female.⁴²

⁴² U.S. Census (2020) United States Census Bureau <https://data.census.gov/cedsci/>

Participants were asked, “What sex were you assigned at birth, on your original birth certificate?” These answers were compared to stated gender identity to determine how many participants have a gender that matches the sex they were assigned at birth. This method of measurement helps to identify people with a different gender identity from birth, as recommended by the UCLA William’s Institute.⁴³

The vast majority of professionals indicated their birth certificate matches their gender identity (98.5%). One professional (1.5%) has a gender identity that does not match their birth certificate.

Figure 60. Professionals - Cisgender or Transgender Status



Note: $n = 68$.

⁴³ UCLA School of Law Williams Institute (2020). Sexual Orientation and Gender Identity (SOGI) Adult Measures Recommendations FAQs. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Measures-FAQ-Mar-2020.pdf>

Professionals were asked “In which city do you live in California?” The most common cities professionals live in include San Diego (10.0%) and Sacramento (5.0%). The most commonly reported counties of residence were San Diego County (13.3%), Los Angeles County (10.0%), and Sacramento County (8.3%). Because these percentages are disproportionate to the counties’ general populations, it is likely that individuals who live in these counties are overrepresented in the survey sample. For a list of all reported cities and counties of residence, see Appendix 31. Professionals’ Cities of Residence and Appendix 32. Professionals’ Counties of Residence.

The most common profession of participating professionals is vocational rehabilitation counselor (37.2%). There were also a high percentage of participants who indicated they have another profession not listed here (26.9%).

Those who selected “Other” profession included two educators and two non-profit leaders as well as one service coordinator, day program coordinator, post-secondary disability services professional, IHSS caregiver, instructor/therapist for a computer-based program (Neuropsychonline), disabled student programs and services academic counselor, director of rehabilitation, craniosacral/bodywork therapist, and art therapist. Less common professions included occupational therapist (5.1%), case manager/administrator (5.1%), physician/medical doctor (3.8%), physical therapist (3.8%), speech therapist (3.8%), psychologist (3.8%), independent living center employee (3.8%), and neuropsychologist (2.6%).

The specialties of the surveyed physician/medical doctors were neurosurgery, pediatric rehabilitation, and physical medicine and rehabilitation.

Table 15. Professions of Professional Survey Participants

Profession	Percentage	n
Vocational rehabilitation counselor	37.2%	29
Other	26.9%	21
Occupational therapist	5.1%	4
Case manager/administrator	5.1%	4
Physician/medical doctor (not psychiatrist)	3.8%	3
Physical therapist	3.8%	3
Speech therapist	3.8%	3
Psychologist	3.8%	3
Independent Living Center employee	3.8%	3
Neuropsychologist	2.6%	2
Psychiatrist	1.3%	1
Social worker	1.3%	1

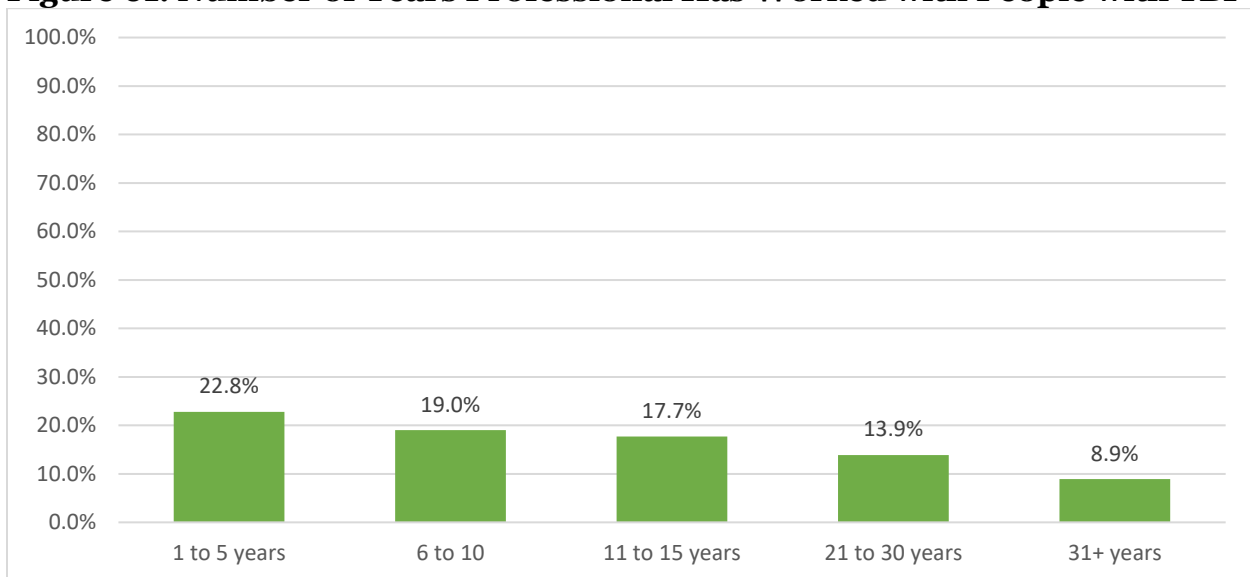
Lawyer/legal advocate	1.3%	1
Total		78

Professionals were asked “For how many years have you, as a professional, been working with people with a TBI?” As illustrated in the Figure below, nearly a quarter (22.8%) have worked with people with a TBI for less than five years.

There were also a fair portion of professionals who have worked with people with a TBI for 31 or more years (8.9%).

The mean (average) number of years surveyed professionals have been working with people with TBI is 15.1 years.

Figure 61. Number of Years Professional Has Worked with People with TBI



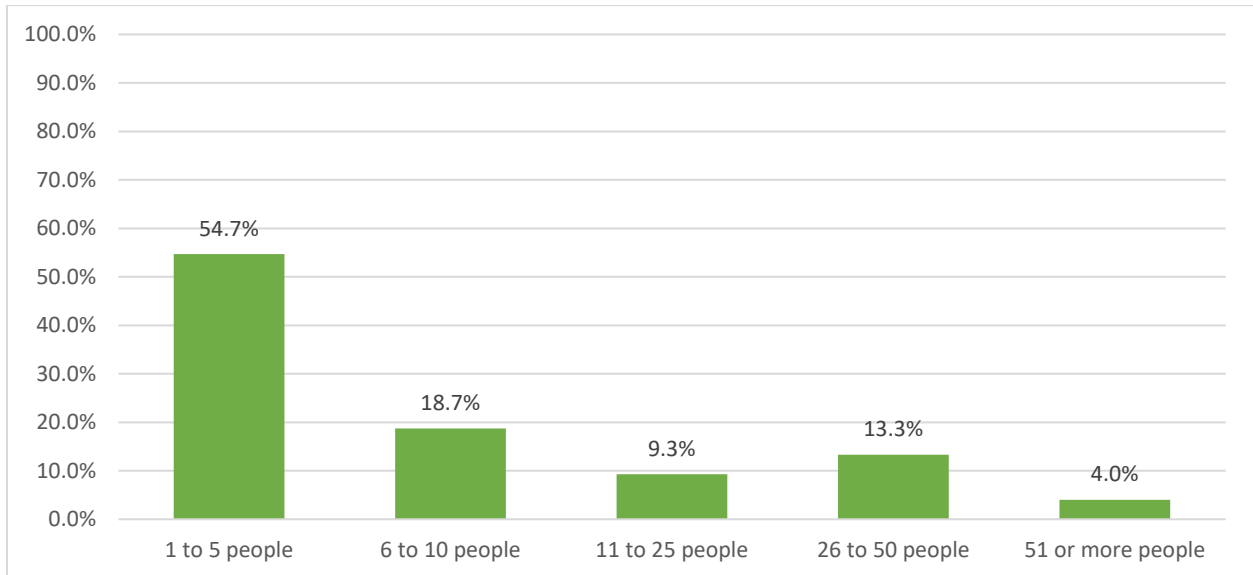
Note: $n = 79$.

Care/Services for People with a TBI

Professionals were asked, “Approximately how many people with a TBI have you provided care/services for in the past six months?” Most professionals (54.7%) provided care for one to five people in the last six months. Few professionals (4.0%) have provided care for 51 or more people with TBI in the past six months.

The mean (average) number of people with TBI cared for in the past six months by surveyed professionals is 13.2 people.

Figure 62. Number of People with TBI That Professionals Provided Care for in the Last Six Months

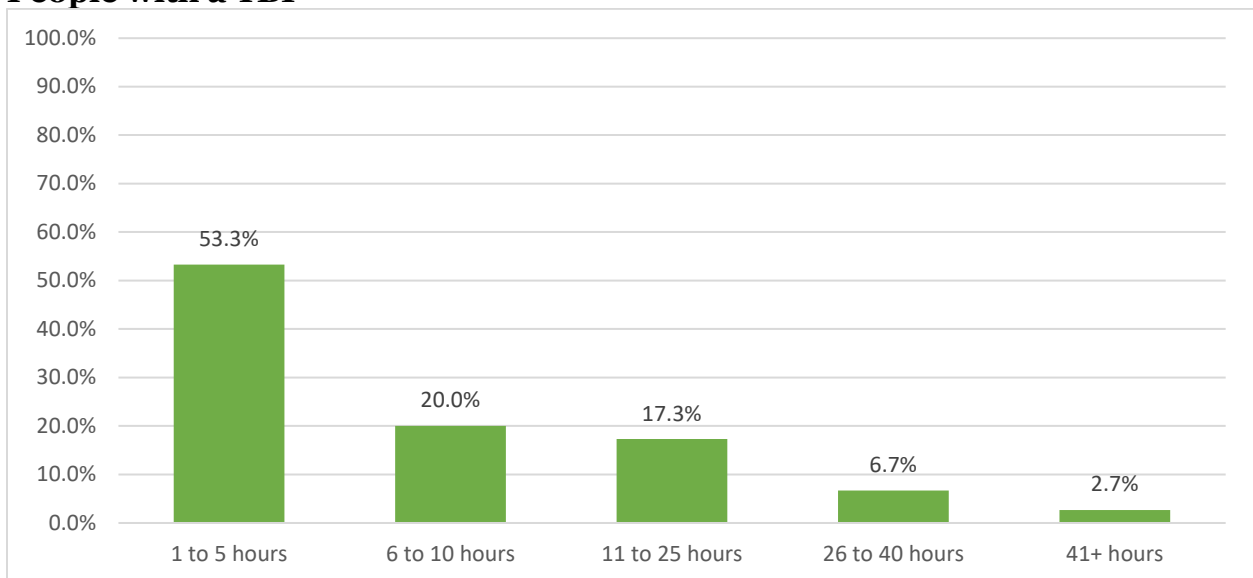


Note: $n = 75$.

Professionals were asked, “In the past six months, in an average week, how many hours are you providing care/services to all your patients/clients with TBI?” More than half of professionals (53.3%) provide care/services for people with a TBI for one to five hours per week. Very few professionals (2.7%) provide care/services to people with a TBI for 41 or more hours per week.

The mean (average) number of weekly hours that surveyed professionals provided services/care to people with TBI in the last six months is 10.2 hours per week.

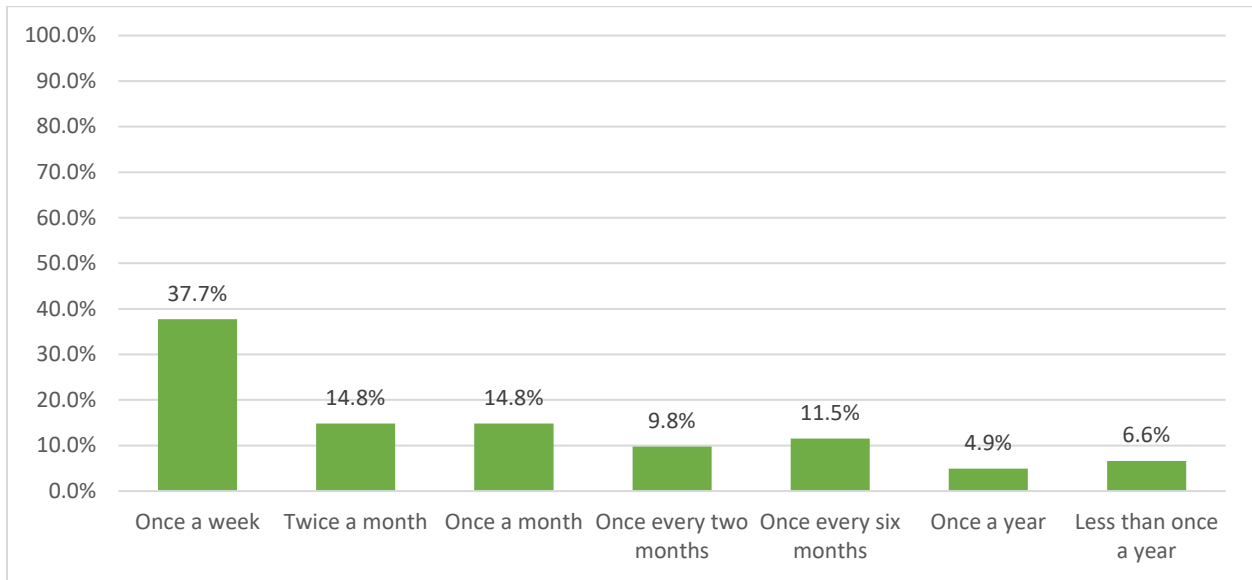
Figure 63. Number of Weekly Hours Professionals Provide Care/Services to People with a TBI



Note: $n = 75$.

Professionals were asked “On average, how often do you see each patient/client with a TBI?” The most common response from professionals is that they see clients, on average, once a week (37.7%). Conversely, 6.6% see patients/clients less than once per year. How often professionals see clients/patients is likely highly affected by their specific profession; thus, the variety of responses to this question is as expected.

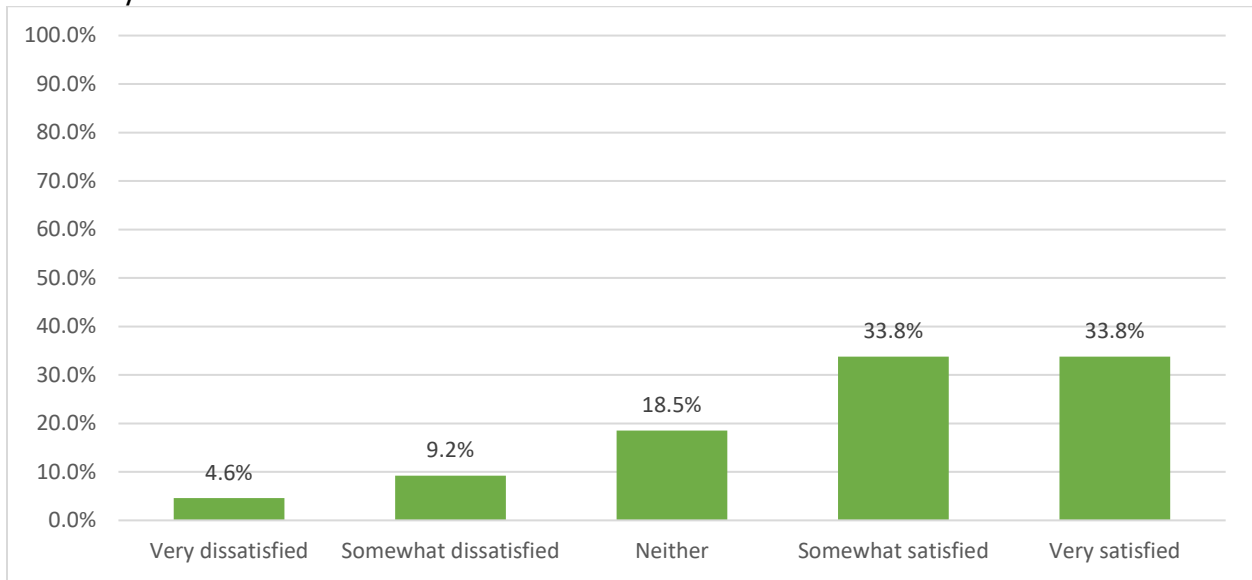
Figure 64. “On average, how often do you see each patient/client with a TBI?”



Note: $n = 61$.

Professionals were asked, “How satisfied are you with the average number of visits for each of your patients/clients with TBI?” For the most part, professionals are either *satisfied* or *very satisfied* with the average number of visits for each TBI patient/client (67.6%). On the other hand, 13.8% of professionals are either *somewhat* or *very dissatisfied*.

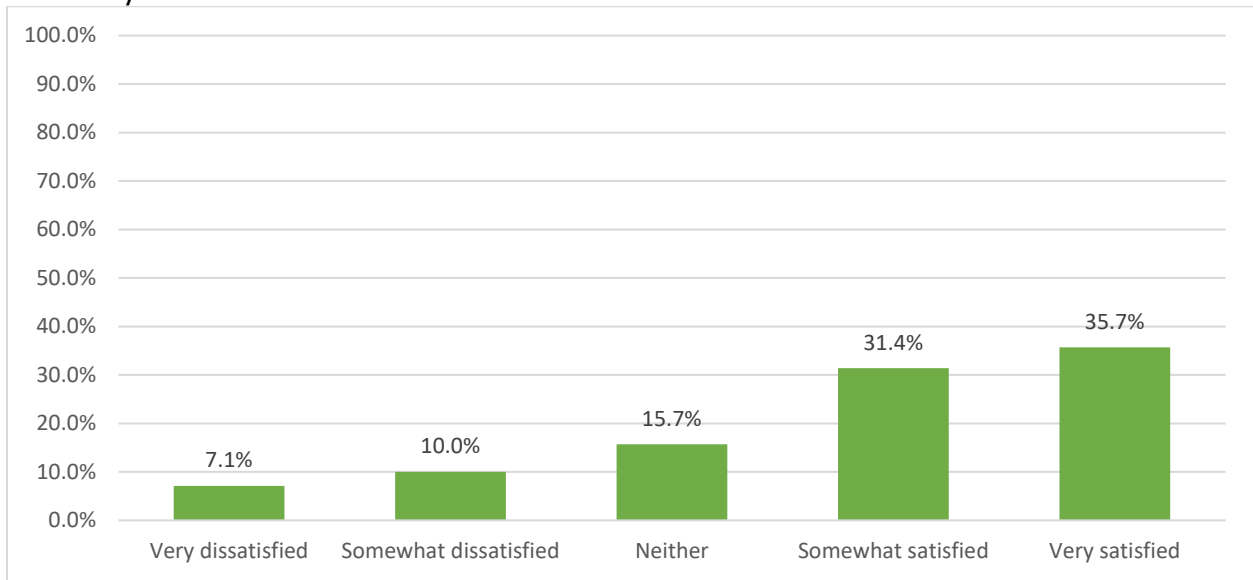
Figure 65. Satisfaction with Average Number of Visits for Each TBI Patient/Client



Note: $n = 65$.

Professionals were asked, “How satisfied are you with the amount of time you have, on average, during each visit with your patients/clients with TBI?” Professionals were mostly *satisfied* or *very satisfied* with the average amount of time with each TBI patient/client (67.1%). On the other hand, 17.1% of professionals were either *somewhat* or *very dissatisfied* with the average amount of time with each TBI patient/client.

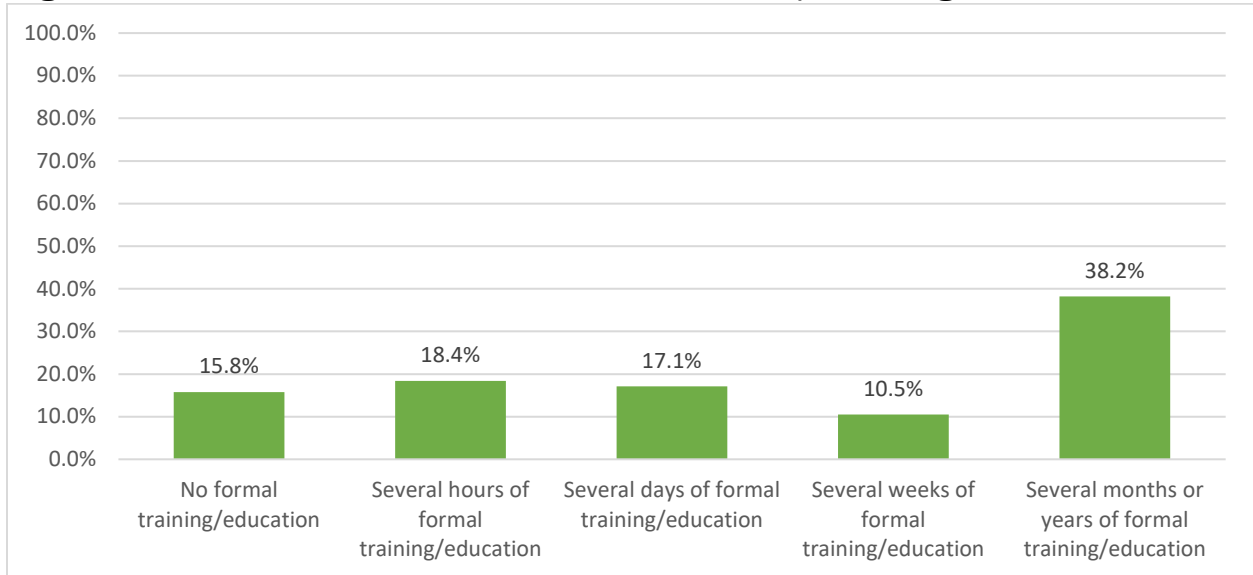
Figure 66. Satisfaction with Average Amount of Time with Each TBI Patient/Client



Note: $n = 70$

Professionals were asked, “How much formal education/training have you received about people with TBI?” The most common response from professionals is that they have received several months or years of formal training/education (38.2%). That said, 15.8% of professionals have received no formal education/training about people with TBI.

Figure 67. Professionals - Formal TBI Education/Training Received

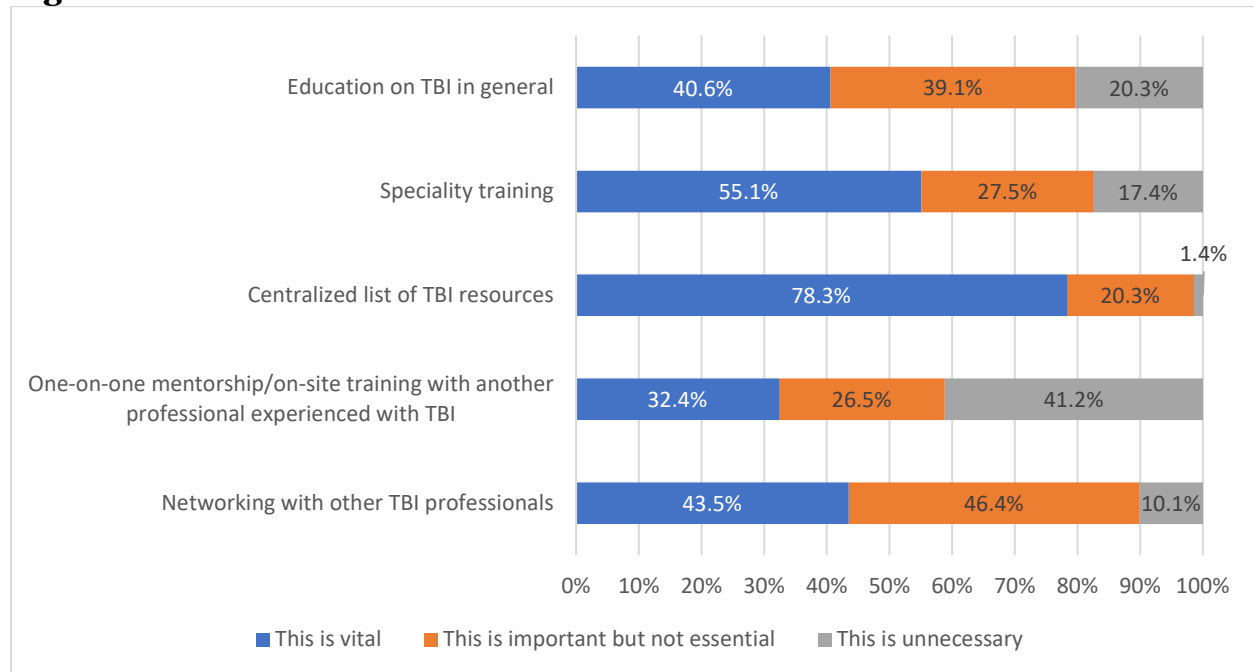


Note: $n = 76$.

Needs of Surveyed Professionals

Professionals were asked, “Which of the following do **you** need to better meet the needs of people with a TBI?” A centralized list of TBI resources was viewed by most professionals as vital (78.3%). More than half of professionals also rated specialty training as vital (55.1%).

Figure 68. Resources Needed for Professionals - Self



Note: $n = 69$, $n = 69$, $n = 69$, $n = 68$, $n = 69$, respectively.

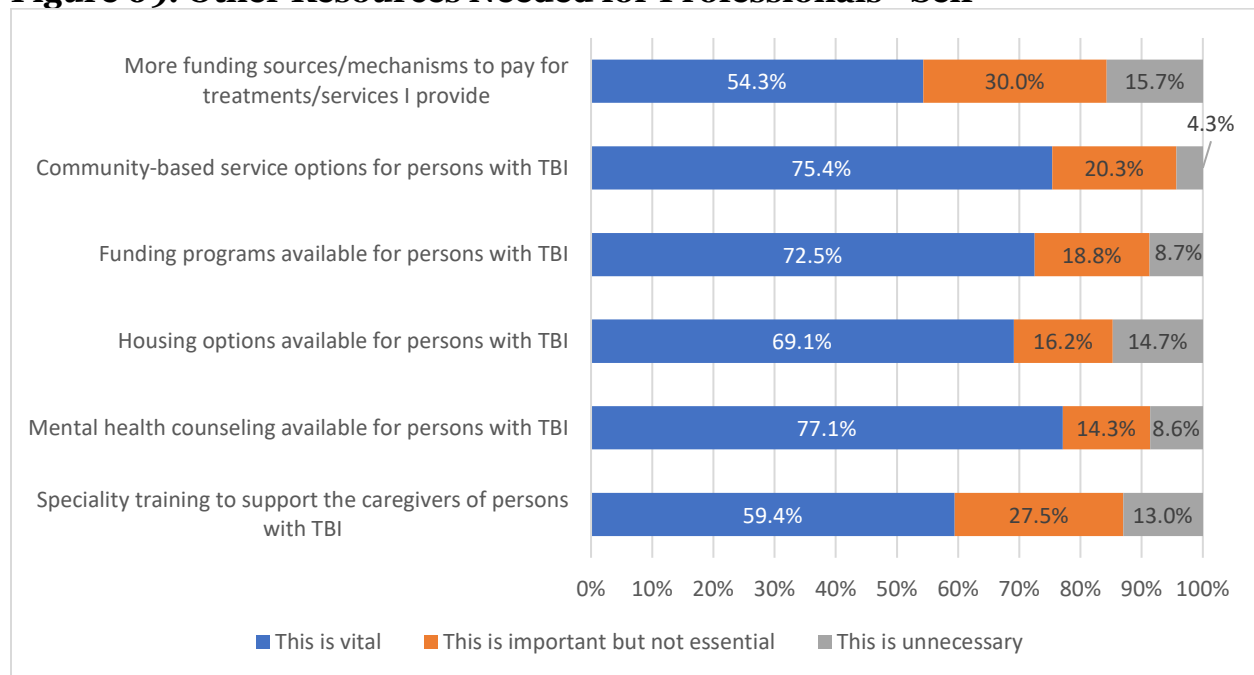
As illustrated above, the highest unmet need reported by professionals is a centralized list of TBI resources. This is consistent with the needs of individuals with TBI and caregivers to have help finding TBI resources. This was also a common theme in interviews with professionals. Professionals expressed the need to connect to resources—such as therapists, state programs, and community organizations—to refer patients/clients to.

“It’d be great to have... from DOR a network of to be linked up to refer people to other providers... Otherwise, we use our personal network (who we know), but now people are in the digital world. It would be great to have access to the best available care.... if DOR had a listserv or a listing of that, then it would be helpful.”

-Neuropsychologist

Professionals were asked about other resources they might need. Mental health counseling available for persons with TBI was rated by many professionals as vital (77.1%). Other resources viewed as vital include community-based service options for persons with TBI (75.4%) and funding programs available for persons with TBI (72.5%).

Figure 69. Other Resources Needed for Professionals - Self



Note: $n = 70$, $n = 69$, $n = 69$, $n = 68$, $n = 70$, $n = 69$, respectively.

Professionals were then asked, “In thinking about your work with people who have a TBI, what else would you need to improve your services?” Responses included funding for TBI programs and organizations ($n = 6$), ongoing training/seminars for providers/other professionals ($n = 4$), meeting/networking with other professionals ($n = 3$), and community resources ($n = 3$). For a full list of responses, see Appendix 33. Professionals – Additional Professional Needs.

The above survey responses reflect themes that arise in interviews, such as the need for community-integrated services. For example, one response was as follows: “I’ve got the neurosurgical diagnostic piece well established... [but] the challenge for myself and my colleagues is the paucity of therapists with specialized training and the lack of easy access to community resources. [There’s a] need for a navigator for patients with TBI because they can’t do it themselves due to the TBI.”

A major theme in interviews was the need for community-integrated services that meet the full needs of the individual with TBI. In addition to medical treatment, this approach would include social support, assistance with housing, or vocational training, among other services. One major barrier is simply funding, as these community-integrated services are usually offered by non-profit organizations with unstable and insufficient funding sources.

“Now we’re still working with those people in our community to try to create a community of individuals with brain injury so they know each other. If nothing else, they socialize; we do a book club, we do educational conferences, we do music therapy. [We’re] trying to create opportunities for them to live in the community and to be socially accepted.”

-Brain injury nonprofit leader

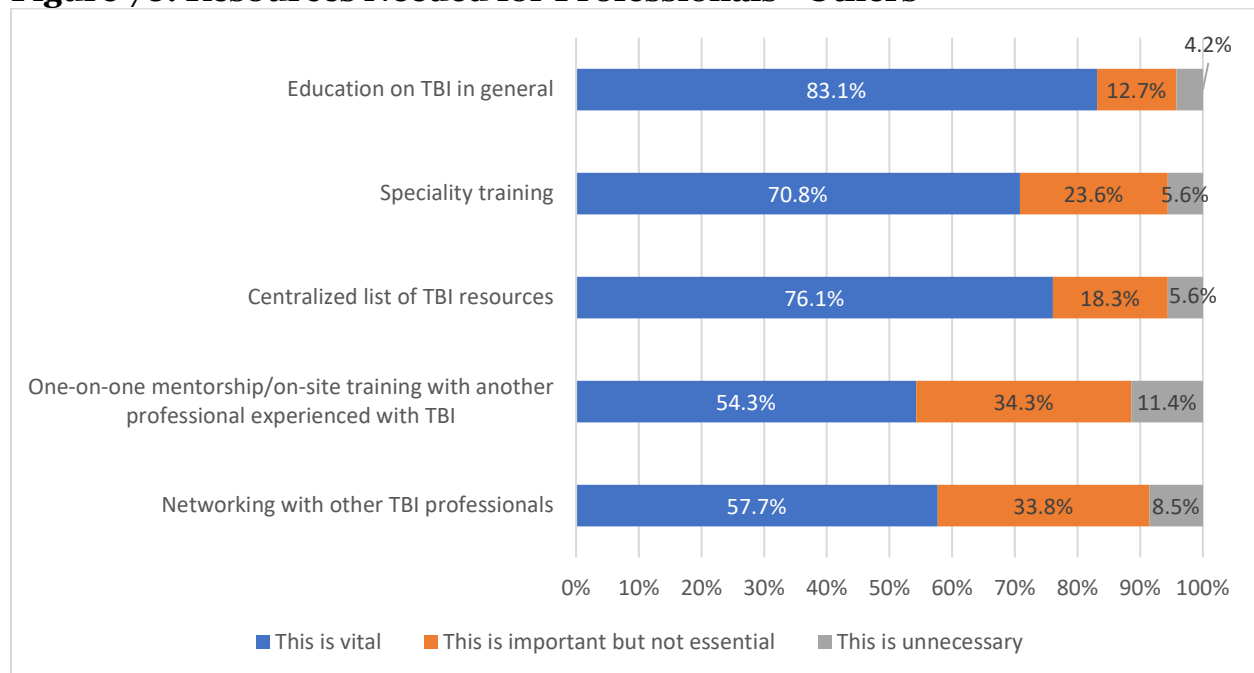
“I think support services and community-based services, like what the Schurig Center provides, I think are really needed. Services that address some things that [health] insurance doesn't necessarily address. Art therapy, socialization, those kinds of things. It's a real need for that kind of stuff.”

-Neuropsychologist

Needs of Other Professionals

Professionals were asked, “Which of the following do **other professionals** need to better meet the needs of people with a TBI?” The majority of professionals (83.1%) rate education on TBI in general as vital for other professionals. Other resources rated vital for other professionals include a centralized list of TBI resources (76.1%) and specialty training (70.8%).

Figure 70. Resources Needed for Professionals - Others



Note: $n = 71$, $n = 72$, $n = 71$, $n = 70$, $n = 71$, respectively.

In interviews, professionals spoke of how different types of care and services for individuals with TBI are connected. For example, psychological counseling or community-integrated services can help only so far if a client/patient does not have adequate housing, income, or medical treatment. Support must be made available to the client/patient that meets all of their needs.

“I think it’s something that needs to be at the forefront of research and development because the longer they go undiagnosed or not treated, the worse the person’s going to get and the higher the likelihood of somebody else with the same injury is suffering through it without any idea of what’s going on.”

-Personal Injury Attorney

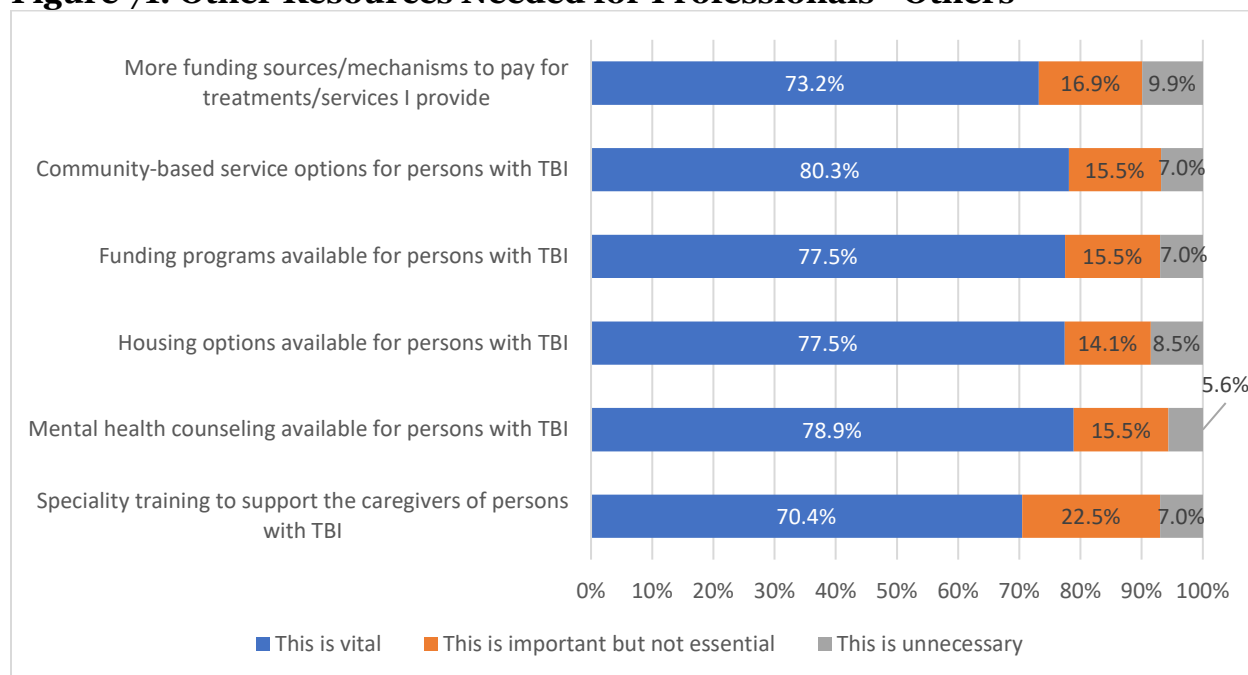
“One of the things I’ve struggled with as a provider, for people in later stages of rehabilitation, is supportive access to return to the highest level of functioning. Some people return to their work in an adaptive format. There seems to be a lot of—inequalities in work—There should be more support in OT [occupational therapy] and vocational support, which are important for those with TBI who have the capacity and will.”

-Neuropsychologist

Professionals were asked about what other resources other professionals need to better meet the needs of individuals with TBI. All the other resources were rated as vital for other professionals.

The majority of professionals (80.3%) rated community-based service options for persons with TBI as a vital resource. Other items rated by many as vital include mental health counseling available for persons with TBI (78.9%), funding programs available for persons with TBI (77.5%), and housing options available for persons with TBI (77.5%).

Figure 71. Other Resources Needed for Professionals - Others



Note: n = 71 for all items.

Professionals were asked if they had any other comments they would like to share. Seven professionals provided additional comments, which are listed in Appendix 34. Professionals – Additional Comments.

Conclusion

Recommendations

The needs expressed by individuals with TBI, caregivers, and professionals are wide in scope and complex in nature, but these needs can be simply summarized. Individuals with TBI need, in addition to necessities like health care and income, ways to reintegrate themselves into their communities. Caregivers need social support and respite care. Professionals emphasize the need for mental health and community-based services to refer patients/clients to. And all three groups need help finding TBI resources. Below are summaries of the needs for each group, followed by several suggestions for meeting those needs.

Individuals with TBI need help finding TBI resources, funding for treatments (including for mental health), greater economic support (both for employment and disability benefits), and services that reintegrate them into their communities. To meet these needs, individuals with TBI would need tools or a form of guidance that list or explain available programs, therapies, and other resources; requirements for health insurance to cover needed TBI therapies; improved vocational training/job placement and expansion of disability income (SSI or SSDI); and services that prioritize community reintegration (such as support groups, adult daycare, and assistance with employment). Caregiver and professional needs are similar to those of individuals with TBI. Caregivers need help finding TBI resources, along with mental health counseling and respite care. To meet these needs, caregivers would need access to caregiver support groups, mental health counseling, and respite care as well as tools to help find TBI resources.

Professionals also need help finding TBI resources, as well as the ability to refer patients/clients to mental health counseling and community-based service options. In interviews, professionals often expressed a strong need to have a list or record of all available TBI resources (such as employment programs, disability income assistance, in-home care support, non-profit community organizations, therapies, advocates, etc.). To meet the needs of professionals, it would be valuable to have a list of statewide resources and educational seminars/workshops on TBI care and resources. These educational forums could fulfill requirements for continuing education or continuing medical education.

Help Finding TBI Resources

Across all three survey groups, “help finding TBI resources” was the top unmet need for individuals with TBI (selected by 61.6% of individuals with TBI, 62.5% of caregivers, and 84.9% of professionals). Additionally, help finding TBI resources was the top unmet need for caregivers (selected by 56.3% of individuals with TBI, 71.1% of caregivers, and 82.9% of professionals). Likewise, for professionals, the top unmet need was a “centralized list of TBI resources” (78.3% of professionals).

Educational materials on TBI resources for individuals with TBI and caregivers should be made available in languages other than English. Most professionals attested to a need for non-English educational materials for their TBI clients/patients. While this need for non-English resources was not stressed by individuals with TBI or caregivers, participants in this project were disproportionately White and non-Hispanic and thus likely underrepresented the need for non-English materials.

TBI resources would be most beneficial to individuals with TBI and caregivers in the early stages of recovery. Individuals with TBI and caregivers ranked satisfaction with TBI recovery lower for the first six months of recovery than for their current recovery. Both individuals with TBI and caregivers spoke of the difficulty of obtaining information about TBI programs, therapies, and other resources in the first months of recovery. Further, two-fifths (21.1%) of individuals with TBI reported never having been given information or resources about TBI, either in the early or current stages of recovery. For professionals, educational materials about TBI resources were requested by several key informants in the format of a centralized list of state and private services or seminars/workshops that could be incorporated into existing continuing education programs.

For individuals with TBI and caregivers, data suggest the preferred format for educational materials would be interpersonal, either through peers or providers. When asked what would help them to find/get resources, survey participants most mentioned having providers who are educated or trained in TBI. In interviews, individuals with TBI and caregivers reported finding TBI resources through either support groups, community-based organizations, or recommendations/suggestions by health care providers.

Help with Employment

Survey data make clear that although individuals with TBI can be well educated (56.4% with a college degree or higher), their injury can readily lead to financial hardship (27.5% under the federal poverty level). Most individuals with TBI (51.7%) said they need a well-paying job. A common theme in interviews was that individuals with TBI have career goals that ambitiously yet practically seek to make full use of an individual's abilities. Several interviewees (individuals with TBI and caregivers) articulated the need for job training that considered a person's background, skills, and potential. Vocational training and job placement should support individuals with TBI who are seeking fulfilling, meaningful, and well-paying work.

Expansion of Disability Income

A plurality of individuals with TBI want to work but are not able to work because of their injury (41.5%). Nearly one-third (29.3%) said they do not have disability income (SSI or SSDI) but they need it, and a majority (55.2%) said they have disability income, but it is not enough. To meet these needs, disability income (SSI or SSDI) would need to be expanded and made more accessible.

Improvement of Mental Health Care Access

The vast majority (94.6%) of individuals with TBI said that mental health care is either *somewhat* or *very important*. A large majority of professionals (84.9%) selected mental health care as a major need of individuals with TBI. Most caregivers (51.1%) also selected mental health counseling as a caregiver need. One interview theme was the importance of mental health care, and some key informants had difficulty finding suitable therapists (e.g., with experience treating TBI or covered by insurance). Mental health care access could be expanded, perhaps by increasing the number of available therapists (especially neuropsychologists) or promoting mental health care for both TBI patients and caregivers.

Requirements for Health Insurance to Cover TBI Medications/Treatments

Over two-fifths of individuals with TBI (43.1%) said their health insurance covered “some” of their TBI care, and another two-fifths (42.3%) said their health insurance covered “most” of their TBI care. A conservative reading of these data would conclude that a sizable portion (over 40%) do not have sufficient coverage for all their TBI care. In interviews, several key informants said their health insurance did not cover enough of their treatment or their insurance did not have enough specialists with experience treating TBI. This included two mentions of Medi-Cal. Further investigation would be necessary to determine which TBI medications and treatments could be required to be covered by Medi-Cal and private health insurance companies.

Funding of Support Groups and Other Community-Based Services

Social support was a clear need articulated by survey participants. Three-quarters (74.4%) of individuals with TBI said their injury negatively affected friendships, and 60.5% reported it negatively affected access to community events/services/activities. In addition, about half (49.6%) of individuals with TBI and half of caregivers (46.7%) reported they need support groups. In interviews, support groups were by far the resource that was most often mentioned as being helpful. Support groups meet multiple needs: finding friendships, validation of one’s emotions, education about TBI, connection to resources, and a vital “sense of community.”

Key informants explained that virtual support groups (e.g., on Zoom) are more accessible, especially for isolated individuals (those in rural areas or those confined to home). Nearly two-thirds (59.0%) of individuals with TBI said they would prefer support groups that are hybrid (both in-person and virtual).

Efforts would need to be made to fund and replicate support groups (for individuals with TBI and caregivers) and the community-based programs that facilitate them. Several key informants also stressed the pressing need for such community-based services in rural areas.

Assessment and Action

The above data clarify the varied yet vital needs of individuals with TBI, caregivers, and professionals. To meet these needs, several actions can be taken. These include creating tools or forums to help find TBI resources, devising well-tailored vocational training/job placement, augmenting disability income, improving mental health care access, funding and replicating support groups (and other community-based services), and possibly requiring Medi-Cal and private health insurance companies to cover some TBI medications/treatments. Future research can help guide these actions.

First, an authoritative body (with knowledge of TBI patients' medical needs) could conduct a review of TBI medications/treatments to determine which should be covered by Medi-Cal and private health insurance companies.

Second, further investigation could explore different methods of conveying information about TBI resources. Key informant interviews and survey data suggest that interpersonal formats, such as TBI-trained professionals (e.g., health care providers) and peer-to-peer channels (e.g., support groups) are the most common (if not most effective) method for connecting people to resources. Other education and outreach models, yet to be uncovered, might exist among the informal networks of support groups and community-based organizations.

Third, further investigation could also explore vocational training and job placement practices that have been most effective for individuals with TBI. This could also include documenting common workplace accommodations needed for individuals with TBI and creating state standards or guidelines for workplaces to comply with these accommodations.

Fourth, further investigation could also explore existing curricula for professional TBI education/training and identify what curricula are still needed. These might be in the form of workshops, seminars, or conferences that fit into continuing education or continuing medical education programs.

Fifth, further investigation could identify mechanisms or routes to increase disability income and make the application process of disability income more accessible.

This evaluation has illustrated that with support, individuals with TBI can achieve stability as well as a renewed sense of meaning and life purpose. These positive outcomes—that meet both the basic and most essential human needs—are possible only when adequate social support, medical care, and economic resources are made available and accessible. Meeting these needs can help people not only survive but flourish.

Appendices

Appendix 1. Individuals' with TBI Cities of Residence

City	Percentage	n
San Diego city	21.5%	23
Sacramento city	5.6%	6
Oceanside city	4.7%	5
San Marcos city	3.7%	4
Chico city	2.8%	3
El Cajon city	2.8%	3
Carmichael	1.9%	2
Chula Vista city	1.9%	2
Escondido city	1.9%	2
Fullerton city	1.9%	2
Garden Grove city	1.9%	2
Long Beach city	1.9%	2
Santa Ana city	1.9%	2
Santa Rosa city	1.9%	2
Santee city	1.9%	2
Antelope	0.9%	1
Aptos	0.9%	1
Brea city	0.9%	1
Buena Park city	0.9%	1
Cathedral City	0.9%	1
Citrus Heights city	0.9%	1
Crescent City	0.9%	1
Del Mar city	0.9%	1
East Los Angeles	0.9%	1
East Quincy	0.9%	1
Encinitas city	0.9%	1
Fallbrook	0.9%	1
Glendale city	0.9%	1
Gold River	0.9%	1
Grass Valley city	0.9%	1
Irvine city	0.9%	1
Laguna Woods city	0.9%	1
La Mesa city	0.9%	1
Los Angeles city	0.9%	1
Lynwood city	0.9%	1
Marina city	0.9%	1
Mission Viejo city	0.9%	1
Norwalk city	0.9%	1
Novato city	0.9%	1
Oakland city	0.9%	1
Paramount city	0.9%	1
Pismo Beach city	0.9%	1

Pleasanton city	0.9%	1
Ramona	0.9%	1
Red Bluff city	0.9%	1
Redlands city	0.9%	1
Rio Linda	0.9%	1
Salinas city	0.9%	1
San Buenaventura (Ventura) city	0.9%	1
San Francisco city	0.9%	1
San Jose city	0.9%	1
Santa Barbara city	0.9%	1
Santa Cruz city	0.9%	1
Shasta Lake city	0.9%	1
Solana Beach city	0.9%	1
Vallejo city	0.9%	1
Wallace	0.9%	1
Watsonville city	0.9%	1
Whittier city	0.9%	1
Yuba City	0.9%	1
Total	100.0%	107

Appendix 2. Individuals' with TBI Counties of Residence

County	Percentage	n
San Diego County	43.9%	47
Sacramento County	11.2%	12
Orange County	10.3%	11
Los Angeles County	8.4%	9
Butte County	2.8%	3
Santa Cruz County	2.8%	3
Sonoma County	1.9%	2
Marin County	1.9%	2
Alameda County	1.9%	2
Riverside County	0.9%	1
Del Norte County	0.9%	1
Plumas County	0.9%	1
Nevada County	0.9%	1
Monterey County	0.9%	1
San Luis Obispo County	0.9%	1
Tehama County	0.9%	1
San Bernardino County	0.9%	1
Ventura County	0.9%	1
San Francisco County	0.9%	1
Santa Clara County	0.9%	1
Santa Barbara County	0.9%	1
Shasta County	0.9%	1
Solano County	0.9%	1
Calaveras County	0.9%	1
Sutter County	0.9%	1
Total	100.0%	107

Appendix 3. Individuals with TBI – “Other” TBI Symptoms

Symptom	n
Balance/vertigo	3
Cannot multitask	3
Pain	2
Aphasia/word recall	2
Overwhelmed	1
No smell/taste	1
Visual discrimination issue	1
PTSD	1
Nervous system challenge	1
Loss of hand function	1
Executive functioning	1
Ringing ears	1
Non-symptoms	1
Poor eye convergence	1
Autonomic dysfunction	1
Digestive issues	1
Lack of focus	1
Apraxia	1
Change in taste/smell	1
Info processing problem	1
Frustrated/difficulty controlling emotions	1
"Not being accepted"	1
"Difficulty feeling emotions"	1
Isolation	1
Proprioception impairment	1
Impulsivity	1
Racing thoughts	1
Total	36

Appendix 4. Individuals with TBI – Why Six-Month Recovery Was *Poor* or *Very Poor*

Category	Percentage	n
No help or not enough help/support/services	19.0%	15
Wasn't referred to TBI treatment/specialists	11.4%	9
Severe/acute symptoms (e.g., being in a coma)	11.4%	9
I was undiagnosed/misdiagnosed	10.1%	8
TBI symptoms (e.g., cognitive fatigue)	7.6%	6
No providers with TBI experience/professionals were unhelpful	6.3%	5
I was abused	3.8%	3
Not enough information on TBI recovery/resources	3.8%	3
I had no income	2.5%	2
Family didn't understand TBI	2.5%	2
No health insurance/health care	2.5%	2
I didn't get hospital care	2.5%	2
I didn't understand what was happening	2.5%	2
Hard to keep track of time	1.3%	1
TBI not taken seriously by others	1.3%	1
I forgot appointments	1.3%	1
I had to work to support my family	1.3%	1
I couldn't work	1.3%	1
My condition worsened	1.3%	1
Symptoms limited ability to begin therapy	1.3%	1
Unable to continue school	1.3%	1
Panic attacks	1.3%	1
Slow recovery progress	1.3%	1
Sporadic/inconsistent therapy	1.3%	1
Total	100.0%	79

Appendix 5. Individuals with TBI – Why Six-Month Recovery Was Acceptable

Category	Percentage	n
Good recovery progress	10.3%	7
I can walk/walk better	8.8%	6
I didn't get enough help/support	5.9%	4
I was in a comprehensive program/rehab center	4.4%	3
I returned to school	4.4%	3
I can talk now	4.4%	3
Good support of family/friends	4.4%	3
I returned to work	2.9%	2
Marriage ended	2.9%	2
Acceptable recovery progress	2.9%	2
I can drive again	2.9%	2
I had other injuries (e.g., broken neck)	2.9%	2
Learning to speak again	2.9%	2
TBI symptoms	2.9%	2
Stable recovery period	1.5%	1
I can manage symptoms, but they're getting worse	1.5%	1
I don't know	1.5%	1
I don't know what to expect	1.5%	1
Financial hardship	1.5%	1
I couldn't drive	1.5%	1
I can't walk	1.5%	1
I can't work	1.5%	1
Slow recovery	1.5%	1
In ICU for first 6 months	1.5%	1
Good physical therapy	1.5%	1
A lot of support	1.5%	1
I exceeded the Dr.'s expectations	1.5%	1
I was undiagnosed	1.5%	1
Still have severe problems	1.5%	1
Medical care was acceptable	1.5%	1
I had psychiatric medication	1.5%	1
Not enough recovery progress	1.5%	1
I can read again	1.5%	1
I survived	1.5%	1
I had to return to combat	1.5%	1
Cognitive recovery was after 6 months	1.5%	1
I was discharged from the hospital	1.5%	1
Social isolation	1.5%	1
Relied on caregiver for activities of daily living	1.5%	1

Total	100.0%	68
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Appendix 6. Individuals with TBI – Why Six-Month Recovery Was *Good* or *Very Good*

Category	Percentage	n
Lots of improvement/progress	22.9%	8
Great treatment/therapies/providers	20.0%	7
I survived	11.4%	4
I focused on recovery full time	8.6%	3
Rehabilitation program	8.6%	3
Could do activities of daily living again	5.7%	2
Support from friends/family	5.7%	2
Short-term state disability	2.9%	1
Symptoms manageable	2.9%	1
I was motivated by other survivors	2.9%	1
Got time off from work	2.9%	1
I have strong will power	2.9%	1
School counseling services	2.9%	1
Total	100.0%	35

Appendix 7. Individuals with TBI - Why Current Recovery Is Poor or Very Poor

Category	Percentage	n
Symptoms/symptoms persist	25.4%	15
My symptoms/condition worsened	11.9%	7
Can't work	5.1%	3
Chronic pain	5.1%	3
No medical care	3.4%	2
No housing	3.4%	2
Unable to find help/resources	3.4%	2
Difficulty with activities of daily living	3.4%	2
Little or no improvement	3.4%	2
"Loosing my grip"	1.7%	1
Other health challenges	1.7%	1
No social support	1.7%	1
Abused	1.7%	1
No access to good nutrition	1.7%	1
No income	3.4%	2
No caregiver	1.7%	1
I don't know if I'm improving	1.7%	1
"Not eligible for support"	1.7%	1
Still doing rehab	1.7%	1
I now use a wheelchair	1.7%	1
Hard to find good IHSS caregivers	1.7%	1
I'm still learning about what happened to me/what my TBI means	1.7%	1
Insurance doesn't cover treatment	1.7%	1
I regularly encounter new limits/obstacles	1.7%	1
I never received treatment	1.7%	1
I can't find a provider	1.7%	1
My employer doesn't know about my TBI	1.7%	1
Returning to work is very challenging	1.7%	1
Improvement has slowed	1.7%	1
Total	100.0%	59

Appendix 8. Individuals with TBI – Why Current Recovery Is Acceptable

Category	Percentage	n
Making progress but slowly	6.4%	3
Still have symptoms	6.4%	3
Insurance won't cover needed treatment	6.4%	3
Symptoms have improved	4.3%	2
Good support from providers	4.3%	2
I can't work	4.3%	2
Depression/anxiety	4.3%	2
I have a wonderful caregiver/family support	4.3%	2
I have more knowledge on TBI but lack social support	2.1%	1
I have been very disciplined in my rehab	2.1%	1
I educated myself about TBI	2.1%	1
I'm able to work	2.1%	1
I'm in a safe/non-abusive environment	2.1%	1
I'm in a TBI program	2.1%	1
I'm afraid to socialize/be stigmatized by others	2.1%	1
I'm able to function in society, but still need help	2.1%	1
I still need help, but I know where to find help	2.1%	1
Hard to find providers who treat TBI	2.1%	1
I work but it's difficult	2.1%	1
Just living day to day	2.1%	1
I'm able to do this survey without assistance	2.1%	1
Help of TBI community organization (Brain Injury Coalition)	2.1%	1
I still need other services/treatment	2.1%	1
I've learned to live with the symptoms	2.1%	1
I can function in society	2.1%	1
Lost relationships with family	2.1%	1
I'm continuing therapy/treatment	2.1%	1
I live alone	2.1%	1
Some symptoms improved, some worsened	2.1%	1
Still can't drive	2.1%	1
I can't explain here	2.1%	1
I still need a walker	2.1%	1
Still recovering	2.1%	1
I don't want any more symptoms	2.1%	1
Consistently making progress	2.1%	1
Didn't receive treatment	2.1%	1
Total	100.0%	47

Appendix 9. Individuals with TBI - Why Current Recovery Is Good or Very Good

Category	Percentage	n
I'm making progress in recovery	16.7%	13
I'm able to live independently	14.1%	11
I can drive	7.7%	6
Brain injury classes	5.1%	4
I'm working	5.1%	4
I found good resources/educated myself on TBI	5.1%	4
Learned to walk/talk again	3.8%	3
Working part time	3.8%	3
Symptoms are manageable	3.8%	3
Help from capable professionals	2.6%	2
I do better caring for myself/functioning	2.6%	2
Completed my schooling	2.6%	2
Found a suitable career	2.6%	2
Coping with symptoms	2.6%	2
I found good providers/therapies	1.3%	1
I've adjusted to "TBI lifestyle"	1.3%	1
I learned to love myself	1.3%	1
I can run again	1.3%	1
I have a lot of support	1.3%	1
I've grateful for what I have	1.3%	1
"My day to day is good"	1.3%	1
I have an apartment	1.3%	1
I'm improving but will always have challenges	1.3%	1
I have healthcare but still difficult getting access to testing	1.3%	1
My condition is fine when managed well	1.3%	1
Getting now ideal medication dosage	1.3%	1
I am lucky to have survived/be as independent as I am	1.3%	1
I can work with accommodations	1.3%	1
Taking college classes	1.3%	1
TBI support groups	1.3%	1
Worst symptoms are gone	1.3%	1
Total	100.0%	78

Appendix 10. Individuals with TBI – “What would help you to better find/get TBI resources you need?”

Category	Percentage	n
Providers/professionals who understands/are educated about TBI	14.1%	11
Not sure/nothing	11.5%	9
Updated "central access point"/"one-stop shop" or website with "all information"	11.5%	9
Support group	7.7%	6
Case manager/caseworker/mentor/patient advocate	5.1%	4
Money/financial assistance	5.1%	4
Worker/personal assistant in person, on Zoom, or by phone	3.8%	3
Transportation help	3.8%	3
Education on TBI/resources for survivors	3.8%	3
Insurance that covers TBI care	2.6%	2
TBI education for health insurers	2.6%	2
Universal health care	1.3%	1
Gov employees with TBI training	1.3%	1
List/outline of treatment options	1.3%	1
List of people who specialize in TBI	1.3%	1
Vocational retraining	1.3%	1
A brain injury center or department	1.3%	1
Weekly/monthly email newsletter	1.3%	1
Statewide TBI guidebook listing all available resources	1.3%	1
TBI resource packet upon hospital discharge	1.3%	1
Telehealth	1.3%	1
Rental assistance	1.3%	1
"Automatic SSDI"	1.3%	1
Legal/employment protections	1.3%	1
Help finding mental health professionals	1.3%	1
"Mental stability"	1.3%	1
More time with doctors	1.3%	1
Assistive technology (e.g., laptop)	1.3%	1
Legal representation	1.3%	1
Enforcement of ADA and Civil Rights"	1.3%	1
Attendant care 24/7	1.3%	1
"Agencies with funding"	1.3%	1
"More information available"	1.3%	1
Total	100%	78

Appendix 11. Other Unmet Needs of Individuals with TBI as Reported by Caregivers

Response	n
Education	2
Transportation	2
Social groups/activities for adults with disabilities	2
Training on using white cane	1
Assistive technology	1
Help for when caregiver is no longer around	1
Making friends	1
Dating	1
Group therapy	1
Employment services	1
Help to assist them in recovering	1
Help finding a good caregiver	1
Mental health counseling	1
Housing	1
Job retraining	1
Neurologist evaluation	1
Help understanding TBI/what to expect	1
Nothing	1
A better wheelchair	1
Aid monitoring	1
Total	23

Appendix 12. Caregivers' Cities of Residence

City	Percentage	n
San Diego city	25.6%	10
Chico city	7.7%	3
San Marcos city	5.1%	2
California City	2.6%	1
Carlsbad city	2.6%	1
Clovis city	2.6%	1
Crescent City	2.6%	1
Duarte city	2.6%	1
Dublin city	2.6%	1
El Cajon city	2.6%	1
Fairfield city	2.6%	1
Forestville	2.6%	1
Grass Valley city	2.6%	1
Irvine city	2.6%	1
Los Angeles city	2.6%	1
Merced city	2.6%	1
Mission Viejo city	2.6%	1
Novato city	2.6%	1
Oroville East	2.6%	1
Paradise	2.6%	1
Penryn	2.6%	1
Riverside city	2.6%	1
San Andreas	2.6%	1
San Diego Country Estates	2.6%	1
Santa Rosa Valley	2.6%	1
Spring Valley (San Diego County)	2.6%	1
Yreka city	2.6%	1
Total	100.0%	39

Appendix 13. Caregivers' Counties of Residence

City	Percentage	n
San Diego County	41.0%	16
Butte County	12.8%	5
Los Angeles County	5.1%	2
Orange County	5.1%	2
Kern County	2.6%	1
Fresno County	2.6%	1
Del Norte County	2.6%	1
Alameda County	2.6%	1
Solano County	2.6%	1
Sonoma County	2.6%	1
Nevada County	2.6%	1
Merced County	2.6%	1
Marin County	2.6%	1
Placer County	2.6%	1
Riverside County	2.6%	1
Calaveras County	2.6%	1
Ventura County	2.6%	1
Siskiyou County	2.6%	1
Total	100.0%	39

Appendix 14. Caregivers – “Other” Reported Symptoms

Response	n
Decrease in their happiness	1
Difficulty with recent memories	1
Dissociation	1
Extreme sensory issues	1
Hypermania	1
Lack of toilet training	1
Loss of smell	1
Loss of taste	1
Resistance to care	1
Severe anxiety	1
Short temper and violent outbursts when frustrated	1
Total	10

Appendix 15. Caregivers – “What other needs do you have that are not being met?”

Response	<i>n</i>
Long-term care plan and implementation	2
Mental health care for individuals with TBI	2
Mental health care for caregivers	2
Health care provider who understands TBI	2
IHSS worker	2
Insurance that covers treatment	1
Local services/training for those who are blind/memory challenged	1
Mobility assistance devices	1
Adult day care	1
More funding for TBI resources such as advocates, transportation, etc.	1
Social security benefits	1
Speech therapy	1
Technical support, a laptop, and office supplies	1
Business management course	1
Prayer	1
Help navigating rehab/ongoing care	1
Nursing homes that provide better care	1
Physical therapy	1
Occupational therapy	1
Cerebral therapy	1
Rehabilitation	1
Mobility therapy	1
Total	26

Appendix 16. Caregivers – How Helpful Was TBI Information Provided Upon Hospital Discharge?

Response	n
Very helpful	6
Adequate/OK	4
Helpful	3
Great info provided during rehab	2
Information was basic	2
Excellent resources which I still use	1
I don't know	1
Helped me know who to call for help	1
No helpful info after rehab	1
“It was the first 10% of what I needed, with absolutely no follow-up or additional help”	1
Programs were offered, but not always for TBI	1
We learned more from our own experience and from friends	1
Total	24

Appendix 17. Caregivers – How Helpful Was TBI Information Provided at Any Other Time?

Response	n
Very helpful	7
Helpful	3
I did a lot of research on my own	2
Not too helpful	2
Somewhat helpful	2
Adequate	1
I have done my own research, but it has been only marginally helpful.	1
I have not found much help from "official" agencies.	1
Information from local non-profit has been more helpful than other institutions	1
Not given information specific for TBI; only given information for people with disabilities in general	1
I am on my own to figure out what to do	1
Very helpful but information was provided five years after the injury	1
Very helpful but not in-depth	1
A book on TBI provided by the San Diego Brain Injury Foundation	1
Yes	1
Family doctor got them into TBI classes	1
Provided both in-home and out-patient rehabilitation	1
Total	27

Appendix 18. Caregivers – Why Their Six-Month Recovery Was *Poor* or *Very Poor*

Response	n
Injury was severe	3
Difficult symptoms	2
Recovery slow/harder than expected	2
Hospitalized for 1 year or more	2
They experienced a lot of confusion	2
They were refused therapy	1
"Because they will not ever recover"	1
There are no local suitable resources	1
I had to do everything for them (teach how to eat, talk, walk)	1
Discharged from hospital without TBI information, resources, or follow-up	1
"Assessment by Casa Colina"	1
"No treatment provided from traditional allopathic medicine"	1
Severe complications while in hospital	1
Individual with TBI remained uncooperative and angry	1
"No medical assistance"	1
Denied medical treatment in Marine Corps	1
They were in a coma	1
Delay in speech impediment recovery	1
Their condition has worsened	1
Total	26

Appendix 19. Caregivers – Why Their Six-Month Recovery Was Acceptable

Response	n
Slow recovery	2
I don't know	2
We didn't know what to expect	1
Recovery support could have been better	1
Delayed diagnosis	1
Good physical recovery, but poor mental/emotional recovery	1
They are good physically	1
They are having difficulty finding a job	1
We are grateful they survived and have made any type of progress	1
They had a comprehensive occupational/physical therapy team	1
9-month coma and rehab started 6 months after injury	1
Their needs were met (therapy, friends)	1
Total	14

Appendix 20. Caregivers – Why Their Six-Month Recovery Was *Good Or Very Good*

Response	n
Relearned basic life skills (walking, talking, etc.)	6
Recovery progress far better than prognosis	2
Progress made with therapies, but regressed after therapy ended	1
Regained control of right-side of body	1
They were able to come home	1
They are fine, except for feeling depressed	1
They did physical/occupational therapy	1
I became a full-time caregiver	1
"Physical functions returned very quickly"	1
Total	15

Appendix 21. Caregivers – Why Their Current Recovery Is *Poor* or *Very Poor*

Response	n
They still need 24-hour care	3
Their condition has worsened over the years	2
They feel extremely depressed/anxious	2
Their condition is starting to worsen	2
They have no desire to interact socially	1
No assistance from any agencies or doctors	1
They don't have any therapy	1
They refuse to tell their doctor about their TBI, for fear the doctors won't understand	1
They have memory loss and are wheelchair bound	1
"Have not found appropriate treatment because nothing is found in testing"	1
Their behavior "is becoming more mean"	1
They will soon turn 21 and won't be eligible anymore for California Children Services program	1
They have not recovered	1
No ongoing therapy, only periodic therapy	1
Total	19

Appendix 22. Caregivers – Why Their Current Recovery Is Acceptable

Response	n
They have "reached a plateau" (no longer improving)	2
They are "able to do some things on their own"	1
They are being discharged and admitted to acute rehab	1
"Learning to accept new/permanent limitations"	1
They still have problems with memory, communication, and confusion	1
They are physically normal	1
Resources outside the house have been limited because of COVID; but they are still recovering	1
Mental health (depression) not being addressed	1
Total	9

Appendix 23. Caregivers – Why Their Current Recovery Is *Good* or *Very Good*

Response	n
They are now working	3
They have learned to talk	3
They are making slow but steady progress	2
They can walk	2
They are in very helpful TBI classes	1
They are self-sufficient now	1
They finished college and have a job counseling at DOR	1
Communication skills have improved markedly	1
Made significant improvements	1
They can work part time and attend classes, but still struggle with mental health	1
They can live independently	1
It has not gotten worse	1
We have sought all types of resources	1
They have far surpassed their prognosis	1
Total	20

Appendix 24. Caregivers – Why Their Health Care/Services Are *Somewhat or Very Poor*

Response	n
Lack of adequate insurance coverage	4
There is no medical help/services	3
Not enough resources/information	2
Providers were not educated on TBI	1
Providers misdiagnosed TBI	1
Providers only provided medication/no education on TBI	1
There is no case worker/follow-up	1
No speech therapy offered	1
No mental health counseling offered	1
No help for rehabilitation	1
No help for physical therapy	1
No help for occupational therapy	1
Providers don't help when we go to the ER	1
No referral to neurological help	1
No coordination of care	1
No advocate	1
Provider turn-over	1
No contact for further assistance	1
Lack of opportunities for socialization	1
Lack of proper care in nursing facility	1
Little to no TBI-specific care	1
Providers don't spend enough time with patient	1
Providers don't know how to communicate/listen	1
Total	29

Appendix 25. Caregivers – Why Their Health Care/Services Are *Neutral*

Response	n
They are not receiving services/care for TBI	2
Difficult to get services/care because of COVID	2
I don't know	1
Caregivers play major role in securing services/care	1
There are not enough TBI services	1
No TBI services/care received for 5 years	1
No TBI services/care received for 6 months	1
TBI information/services need to be tailored to individual patient	1
Total	10

Appendix 26. Caregivers – Why Their Health Care/Services Are *Somewhat* or *Very Good*

Response	n
Difficult to find/pay for mental health care	2
Services/care is ongoing, but I'm satisfied	1
Providers in rehab are wonderful	1
They had neglectful care that led to life-threatening complications	1
Caregiver needs to be "fighting" to advocate for them	1
I want more help to maintain their current health status	1
Most providers not educated about TBI	1
No referrals to resources or follow up	1
Response time is often delayed	1
Negative impacts of COVID staffing shortages	1
Standard care/unexceptional	1
They will soon age out of current rehab program (California Children Services)	1
Therapists are very good	1
Good care/rehab team	1
We can't find a caregiver to take them to physical fitness classes	1
Fortunate health insurance covers high-equality care	1
Total	17

Appendix 27. Caregivers – “What other needs do you have that are not being met?”

Response	n
Long-term care plan and implementation	2
Mental health care for individuals with TBI	2
Mental health care for caregivers	2
Health care provider who understands TBI	2
Insurance that covers treatment	1
Local services/training for blind/memory challenged family member	1
Mobility assistance devices	1
Adult day care	1
More funding for TBI resources such as advocates, IHSS workers, transportation, etc.	1
Social security benefits	1
Speech therapy	1
Technical support, a laptop, and office supplies	1
Business management course	1
Prayer	1
Help navigating rehab/ongoing care	1
Nursing homes that provide better care	1
Physical therapy	1
Occupational therapy	1
Cerebral therapy	1
Rehabilitation	1
Mobility therapy	1
IHSS worker	1
Total	26

Appendix 28. Caregivers – “What kind of TBI resources do you need help finding?”

Response	n
Mental health care specializing in TBI	3
Care manager/social worker	2
Alternative treatments/therapies	2
Mental health care for individual with TBI	2
Transportation	2
Physical therapist	2
Social activities/programs for individuals with TBI (events, camps, groups, etc.)	2
Activities	1
Adaptive sports	1
Advocacy	1
Legal assistance	1
Career counseling	1
Help finding a job	1
Housing	1
Mental health care for caregiver	1
Diet/food-related services	1
Cognitive behavioral services	1
Help with care/management of TBI	1
DOR	1
"Help with resources"	1
Long-term care plan for when caregiver can no longer provide care	1
Convincing the individual with TBI that they need help	1
Navigating health insurance	1
Neurologist	1
Getting an MRI to evaluate individual with TBI	1
Professionals with experience treating TBI	1
Support groups for individuals with TBI	1
Long-term care facilities that are suited for TBI patients	1
Eye specialist with experience treating TBI	1
Respite care	1
"TBI clinic availability"	1
Neurological therapy	1
Occupational therapy	1

Rehabilitation	1
Therapy	1
ADL assistance (e.g., bathroom use) at school	1
Knowing what resources are available	1
Total	26

Appendix 29. Caregivers – “In what areas of your life do you need financial support?”

Response	<i>n</i>
Medical treatments/therapies	6
Extra/supplemental income	2
Rent/housing	2
Transportation	2
Cost of living	1
I do not receive any financial support	1
Help for son to live on his own	1
Long-term planning	1
Food	1
Support for caregivers who are unable to work	1
School	1
Utilities	1
Life insurance	1
Total	21

Appendix 30. Caregivers – “What kind of social support would be most help for you?”

Response	n
Counseling	7
Support group/Support group for individuals with TBI	5
Meeting other TBI caregivers	4
People who understand survivor's limitations	2
Having someone to talk to	1
Any support	1
Contact with other individuals with TBI	1
Help getting medical care	1
Finding new hobbies	1
Getting together in-person or on Zoom	1
Group therapy	1
Long-term care for individual with TBI	1
Places where TBI survivors can meet others	1
Knowledge of what TBI is/what to expect	1
Peer support	1
Online resources	1
Legal guidance/resources	1
Respite care	1
Social activities	1
Social/medical home visits	1
Helping individual with TBI be social	1
Education	1
Job counselor	1
Total	37

Appendix 31. Professionals' Cities of Residence

City	Percentage	n
San Diego city	10.0%	6
Sacramento city	5.0%	3
Anaheim city	3.3%	2
Camarillo city	3.3%	2
Chico city	3.3%	2
Los Angeles city	3.3%	2
Oakland city	3.3%	2
Oroville city	3.3%	2
Rocklin city	3.3%	2
Santa Barbara city	3.3%	2
Acalanes Ridge	1.7%	1
Auburn city	1.7%	1
Beaumont city	1.7%	1
Berkeley city	1.7%	1
Carmichael	1.7%	1
Clovis city	1.7%	1
Commerce city	1.7%	1
Costa Mesa city	1.7%	1
Diamond Bar city	1.7%	1
El Cajon city	1.7%	1
Fairfield city	1.7%	1
Hanford city	1.7%	1
Joshua Tree	1.7%	1
Ladera	1.7%	1
Larkspur city	1.7%	1
Lincoln city	1.7%	1
Long Beach city	1.7%	1
Merced city	1.7%	1
Midway City	1.7%	1
National City	1.7%	1
Oxnard city	1.7%	1
Palm Springs city	1.7%	1
Placerville city	1.7%	1
Rancho Cordova city	1.7%	1
Rancho Cucamonga city	1.7%	1
Riverside city	1.7%	1
San Luis Obispo city	1.7%	1
San Pablo city	1.7%	1
San Rafael city	1.7%	1
Santa Maria city	1.7%	1
Santa Rosa city	1.7%	1
South Pasadena city	1.7%	1
Taft city	1.7%	1
Ukiah city	1.7%	1
Watsonville city	1.7%	1

Total	100.0%	60
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Appendix 32. Professionals' Counties of Residence

City	Percentage	n
San Diego County	13.3%	8
Los Angeles County	10.0%	6
Sacramento County	8.3%	5
Orange County	6.7%	4
Butte County	6.7%	4
Placer County	6.7%	4
Alameda County	5.0%	3
Santa Barbara County	5.0%	3
Riverside County	5.0%	3
Ventura County	5.0%	3
Contra Costa County	3.3%	2
San Bernardino County	3.3%	2
Marin County	3.3%	2
Fresno County	1.7%	1
Solano County	1.7%	1
Kings County	1.7%	1
San Mateo County	1.7%	1
Merced County	1.7%	1
El Dorado County	1.7%	1
San Luis Obispo County	1.7%	1
Sonoma County	1.7%	1
Kern County	1.7%	1
Mendocino County	1.7%	1
Santa Cruz County	1.7%	1
	100.0%	60
Total	100.0%	60

Appendix 33. Professionals – Additional Professional Needs

Response	n
Not applicable/Nothing	10
Funding for TBI programs and organizations	6
Ongoing training/seminars for professionals	4
Time to meet/network with other professionals	3
Community resources	3
Resources for clients	2
More local resources for rural areas	2
Resources to cover out-of-network TBI services/treatment	2
Transportation/accessible wheelchair vehicles	2
Day programs providing socialization for TBI survivors	2
Job placement/training	2
Housing	2
TBI case manager/navigator	2
Assistive technology with follow-up training for individuals with TBI	1
Post-recovery services for referring TBI clients to	1
More TBI diagnoses/referrals from providers	1
Regular updates on latest medical research and treatment methods	1
Technology options to use apps/devices for support	1
Understanding all potential TBI resources that are available	1
Remove vaccine mandates for classes	1
Webinars/seminars for clients in the community	1
Training/support to start a TBI support group at my facility	1
More psychiatrists familiar with TBI	1
Life skill trainers/life coaches for TBI survivors	1
Formal training in LMS at DOR	1
Access to brain function assessment workbooks to better advocate for TBI clients	1

Training in best ways to progress their care plan	1
Community-based mental health care	1
Understanding of TBI among wider community	1
Education	1
Ability to provide services according to regulations and not local management goals	1
Funding for equipment needed for retraining	1
Immediate provision of approved DOR vendors for TBI in geographic areas of importance	1
More time for counseling in post-secondary education	1
Therapists with TBI specialty	1
Mentors and tutors	1
Collaboration between centers	1
More recognition of individuals with TBI who lie in the middle, between high functioning and severely disabled	1
Public outreach for/raising awareness of TBI programs	1
More time with clients	1
Total	68

Appendix 34. Professionals – Additional Comments

Additional Comments
“Important for DOR BFS to identify this specialty and pay for expertise”
“More medical facilities in the area needed”
“Neuro rehabilitative optometry is underrepresented as a part of the treatment team”
“Thank you for creating this initiative.”
“Thanks for doing this survey. I hope to hear more about the services you provide.”
“Thanks for your efforts!”
“This survey is not valid; the formatting excluded some answers from being able to be seen and/or selected”

Appendix 35. “Other” Symptoms Reported by Individuals with TBI

Symptom	n
Balance/Vertigo	3
Cannot multitask	3
Chronic or physical pain	2
Aphasia/word recall	2
“Overwhelmed and I shut down”	1
No smell/taste	1
Visual discrimination issue	1
PTSD	1
Nervous system challenges	1
Loss of hand function	1
Challenges with executive functioning	1
Ringing ears	1
Poor eye convergence	1
Autonomic dysfunction	1
Digestive issues	1
Lack of focus	1
Apraxia	1
Change in taste/smell	1
Info processing problem	1
Feeling frustrated/difficulty controlling emotions	1
"Not being accepted"	1
"Difficulty feeling emotions"	1
Isolation	1
Proprioception impairment	1
Impulsivity	1
“Racing thoughts”	1

Appendix 36. “Other” Areas Financial Support Is Needed Most – Individuals with TBI

Response	<i>n</i>
Housing	3
Legal representation	3
Food	2
SSI income is not enough	1
Help with financial management	1
Funding for case manager/advocate	1
Transportation	1
My disability insurance was canceled	1
A job that is not too demanding/overwhelming	1
Dental insurance	1
Long-term loan/financing	1
Time to heal	1
To support my family	1

Appendix 37. Needs of Individuals with TBI – “What other needs do you have that are not being met?”

Response	Percentage	n
Not sure/none/NA	15.2%	12
Transportation	5.1%	4
Work/school/ADA accommodations	5.1%	4
Finding practitioners with experience treating TBI	3.8%	3
Therapy/medications	3.8%	3
Patient advocate	3.8%	3
Legal assistance/protection	3.8%	3
Housing	3.8%	3
Help with daily tasks	2.5%	2
Increased income	2.5%	2
Employment	2.5%	2
"Information about case management services"	2.5%	2
Physical therapy	2.5%	2
Financial planning	2.5%	2
Healthy, affordable food	2.5%	2
A caregiver	2.5%	2
Technology/IT help	1.3%	1
Caregiver respite care	1.3%	1
Preparing meals	1.3%	1
A computer	1.3%	1
“A sense of purpose”	1.3%	1
Nutritional education	1.3%	1
Dental care	1.3%	1
Higher education	1.3%	1
Physical exercise	1.3%	1
Auditory/hearing help	1.3%	1
Help controlling emotions	1.3%	1
TBI education for nursing facilities	1.3%	1
Liaison between patient and employers	1.3%	1
"Automatic SSD"	1.3%	1
Rehabilitative therapy	1.3%	1
Mental health counseling	1.3%	1
"Education on coping skills"	1.3%	1
Friends	1.3%	1
Help learning how to drive	1.3%	1
Help with memory retention	1.3%	1
Finding providers in a rural area	1.3%	1
Recreation opportunities	1.3%	1
Help to live independently	1.3%	1

Hyperbaric chamber therapy	1.3%	1
Disability income	1.3%	1
Protection from elder abuse	1.3%	1
Affordable phone/internet service	1.3%	1
Help filling out paperwork	1.3%	1
Total	100.0%	79

Appendix 38. “Other” Reasons for Needs Not Being Met as Reported by Individuals with TBI

Response	<i>n</i>
I was undiagnosed/misdiagnosed	3
I need guidance	3
Being isolated	1
Anxiety	1
Support group meetings went virtual since COVID-19	1
Housing	1
Agencies don't have enough funding	1
Discrimination	1
No support groups for younger people like me	1

Appendix 39. Degree of Difficulty Working in Same Job

People who selected “I am currently working in the same job I had before my injury” were asked, “How hard has it been to continue working in the same job you had before your injury?”

Category	Percentage	<i>n</i>
Very difficult	42.9%	3
Difficult	28.6%	2
Neutral	28.6%	2
Easy	0.0%	0
Very easy	0.0%	0
Total	100%	7

Appendix 40. Degree of Difficulty Working in New Job

People who selected “I am currently working in a new job” were asked “How hard was it to find your new job?”

Category	Percentage	<i>n</i>
Very difficult	37.5%	12
Difficult	21.9%	7
Neutral	28.1%	9
Easy	12.5%	4
Very easy	0.0%	0
Total	100%	32

Appendix 41. Degree of Difficulty Finding a Job

People who selected “I want to work, and I’m trying to” were asked “How hard is it for you to currently find a job?”

Category	Percentage	<i>n</i>
Very difficult	42.1%	8
Difficult	36.8%	7
Neutral	15.8%	3
Easy	0.0%	0
Very easy	5.3%	1
Total	100%	19

Appendix 42. Individuals with TBI Interview Themes

Caregiver role (“My caregiver is my...”)	<i>n</i>
Spouse/partner	7
Parent	2
Sibling	1
Child	1
Professional caregiver	1
Friend	1

Support received from caregiver	<i>n</i>
Help with house chores	4
Daily activities	4
Help with documents	4

Resources Needed for Caregivers	<i>n</i>
Educational materials	7
Caregiver support groups/someone to talk to	6

Changes in relationships	<i>n</i>
Lost relationships/family/friendships	15
Family/friends do not understand TBI	8
More isolated/less social	4

Mental health challenges	<i>n</i>
Anxiety	17
Depression	16
Difficulty controlling emotions	10
Post-traumatic stress disorder (PTSD)	8

Other changes due to TBI	<i>n</i>
Difficulty with memory	16
Cognitive fatigue/deficits	12
Sensitivity to light	8
Sensitivity to noise	6
Migraines	6

Goals	<i>n</i>
Go back to work	6

Be more social	5
Serve others with TBI	3

Impact of TBI on Work	<i>n</i>
Stopped working	16
Returned to work	4

Resources/services that have been helpful	<i>n</i>
Support groups	19
Physical therapy	9
Speech therapy	7
Mental health counseling	6

Unmet needs	<i>n</i>
Financial support	5
Adequate health insurance coverage	4
Social support	3

What resources could be provided to meet needs	<i>n</i>
More information about resources	5
Professionals who understand TBI	5
Better health insurance coverage	4
Help finding a job	3

Appendix 43. Caregivers Interview Themes

Caregiver role (“As a caregiver, I’m their...”)	<i>n</i>
Spouse/partner	5
Parent	4

Type of support caregiver provides	<i>n</i>
Paying bills	5
Meals	5
Taking medication	4
Transportation	4

Greatest unmet needs of individual with TBI	<i>n</i>
Socialization	6
Adult day care	3
Provider/therapist who understands TBI	3

Greatest unmet needs of Caregiver	<i>n</i>
Mental health care	4

Resources needed for caregivers	<i>n</i>
Respite care/someone else who can care for them	6

Caregiver mental health challenges	<i>n</i>
Stress	5
Anxiety	5
Depression	4

Appendix 44. Professional Interview Themes

Helpful resources/services for individuals with TBI	<i>n</i>
Support groups/community-based services	5
Mental health care	3
Education/connecting to resources	3

Unmet needs of individuals with TBI	<i>n</i>
Occupational therapy/vocational rehab	5
Housing for TBI patients	3
Professionals who are familiar with TBI	3

Barriers to meeting the needs of individuals with TBI	<i>n</i>
Language/speech barriers	3
Not understanding TBI needs/resources	3

How to improve care	<i>n</i>
Education/outreach about TBI resources	3
Better trained staff	3
Make resources more affordable (accessible)	3

Unmet needs of caregivers	<i>n</i>
Respite care	4
Understanding TBI/TBI resources	3
Social and financial support	3

Barriers for professionals	<i>n</i>
Funding of services/insurance restrictions	6
Finding clients/connecting clients to resources	3

Services/resources for professionals	<i>n</i>
Funding	4
Access to TBI client registry/list of providers	3

Networking for TBI professionals	3
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Professional Education or Training	<i>n</i>
Continuing education (CE)	3
Training on concussions	3

Appendix 45. Individual with TBI Survey (English Version)

Note that the survey was administered via online software. The survey provided below includes the exact question text/response, and notes on skip-logic. This document was used during the survey deployment phase between DOR and HARC staff.

Section	Notes	Question	Response
Information for potential respondent		<p>Thank you for your interest in our survey!</p> <p>The California Department of Rehabilitation and HARC are working together to conduct a community health needs assessment about people with a traumatic brain injury (also known as TBI).</p> <p>This survey is designed for adults with a TBI. Your input on this survey will help to inform us of the greatest needs that exist.</p> <p>If you are not an individual with a TBI, you may take the survey for caregivers here or the survey for professionals here.</p> <p>This survey is expected to take no more than 20 minutes but please take as long as you need. The survey can be saved and completed at another time.</p> <p>If you have any questions/concerns, you may contact HARC at dpolk@HARCdata.org</p>	
Qualification		<p>1. Traumatic brain injury (TBI) is defined as an alteration in brain function or other evidence of brain pathology caused by an external force such as a jolt, blow, or penetration to the head. Most non-fatal TBIs are</p>	<p>Yes (proceeds to next question) No (disqualified)</p>

Section	Notes	Question	Response
		<p>caused by falls, motor vehicle accidents, or being struck by a person or an object, such as in sports.</p> <p>Do you have a TBI?</p>	
Qualification		2. Do you live in California?	Yes (proceeds to next question) No (disqualified)
Qualification		3. Are you 18 years or older?	Yes (proceeds to start of survey) No (disqualified)
Caregiver Information		1. Do you have a caregiver who helps you?	Yes No (skip to #4) I don't know (skip to #4)
Caregiver Information		2. What relationship do you have with your caregiver? If you have more than one caregiver, think about the caregiver who provides you the MOST amount of care.	My caregiver is... My spouse/partner My parent My child My sibling Other family member My friend A professional caregiver (no personal relationship) Other (please specify)
Caregiver Information		3. Which of the follow resources does your caregiver need? Select all that apply.	Help with transportation Help finding TBI resources, such as therapists, support programs, etc. Education on what TBI is and what to expect Respite care (having someone help for a few hours or a day so that your caregiver can take a break) Mental health counseling Support groups Financial support Housing assistance Food assistance Legal assistance Help with how to communicate with health professionals
TBI General Information		4. How was your TBI characterized as?	Mild Moderate Severe

Section	Notes	Question	Response
			Not sure
TBI General Information		5. In what year did you get your TBI?	Drop down of years [I don't know as an option as well]
TBI General Information		6. When were you told by a health care provider that you had a TBI?	Drop down of years [I don't know] [I never was]
TBI General Information		7. When were you provided with information or resources about your TBI?	Drop down of years [I don't know] [I never was]
TBI General Information		8. What are the most challenging symptoms you've experienced because of your TBI? Select all that apply	Difficulty controlling emotions Mental health (depression, anxiety, etc.) Difficulty speaking Difficulty walking Difficulty with daily living tasks Difficulty with memory Sensitivity to light Sensitivity to noise Discomfort in public/crowds Difficulty thinking or being mentally overwhelmed (Cognitive fatigue) Difficulty maintaining concentration Difficulty solving problems Difficulty with sexual function Hearing loss Headaches Feeling physically tired or fatigued Difficulty sleeping Experiencing seizures Less social Difficulty with balance or feeling dizzy Difficulty visualizing images in your mind Poor eyesight Other (Please specify)
TBI Cause	Condensed list to ease respondent burden	9. What was the cause of your TBI?	Accidental fall Injury purposely inflicted by other persons Injury resulting from operations of war Motor vehicle accident Self-inflicted injury

Section	Notes	Question	Response
			Other accident/injury: _____
TBI Recovery Information		10. How would you rate your TBI recovery during the first six months of recovery?	Very good Good Acceptable Poor Very poor
		11. Please explain, why your six-month recovery was [option they selected on #18 earlier will appear here]?	Open-ended
TBI Recovery Information		12. How would you rate your TBI recovery currently ?	Very good Good Acceptable Poor Very poor
TBI Recovery Information		13. Please explain why your recovery currently is [option they selected on #11 will appear here]?	Open-ended
Satisfaction with care		14. Overall, how satisfied are you with the medical services/care you have received for your TBI in the last six months ?	Very satisfied Somewhat satisfied Neither Somewhat dissatisfied Very dissatisfied
Satisfaction with care		15. Please explain why you were [option they selected earlier will appear here, i.e., satisfied] with your services/care?	Open-ended
Satisfaction with care	Mentioned during interviews	16. How satisfied are you with your health care providers' (doctors, nurses, therapists, etc.) knowledge of TBI?	Very satisfied Somewhat satisfied Neither Somewhat dissatisfied Very dissatisfied
Insurance	Mentioned during interviews	17. How much of your care for your TBI has your health insurance covered?	Most of my care Some of my care None at all I don't have health insurance
	Modified from California Health Interview Survey	18. [those who selected any option other than "I don't have insurance"] What kind of health	Medicare Medicaid/Medi-Cal Employment-based insurance Privately purchased insurance

Section	Notes	Question	Response
		insurance do you currently have? Select all that apply	Insurance through the U.S. Department of Veterans Affairs (the VA) Insurance through the military Other: specify
Insurance	Mentioned during interviews	19. [Those who selected some of my care, not at all, or I don't have insurance see this question] What services or treatment for your TBI do you need insurance to help with more?	Open-ended
		20. [Those who selected "I don't have insurance"] You indicated that you don't have health insurance. How do you pay for health care for your TBI?	Open
Impact of TBI	Modified from a study on long-term TBI outcomes. ⁴⁴	21. Which of these has your TBI negatively affected? Select all that apply.	Access to community events/services/activities Activities of daily living (for example, going shopping, doing chores around home, etc.) Being able to leave the house Employment Family Friendships Getting access to health care Living arrangements Managing my health care School Relationship with spouse/partner
Needs	List of needs pulled from existing DOR questionnaires as well as areas mentioned during interviews	22. Which of the following services and resources do you currently need? Select all that apply	Adult day programs (for example, a place you go to and spend the day doing supervised activities) Assistive technologies Education on what TBI is and what to expect Educational materials in Spanish Educational materials in languages other than Spanish or English Financial support Food assistance Help accessing community events/services/activities

⁴⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3064530/>

Section	Notes	Question	Response
			Help finding TBI resources, such as therapists, support programs, etc. Help with activities of daily living (for example, going shopping, doing chores around home, etc.) Help with transportation Home modifications Housing assistance Legal assistance Medical treatments and services Mental health counseling Substance use counseling Help returning to pre-injury employment Help with finding employment Help with developing and maintaining friendships Help with dating Sexuality counseling Help with medication management Support groups
		23. What other needs do you have that are not being met? These could be services, information, education, or any kind of resource to help you.	Open-ended
		24. Of your top unmet needs, what were the reasons for these needs not being met? (Select all that apply)	Limited health insurance Limited personal finances The resource was not available I didn't know about the resource Lack of family/social support Lack of transportation Other (please specify)
Needs	Areas mentioned during interviews	25. [If help finding resources is selected above] What would help you to better find/get TBI resources you need?	Open-ended
Needs	Areas mentioned during interviews	26. [If support groups is selected above] Support groups for people with TBI provide the chance to learn from others and share your own experience. How	Virtual In-person Both

Section	Notes	Question	Response
		would you like support groups set up?	
Needs	Areas mentioned during interviews	27. [If financial support is selected above] What areas do you need financial support most? (Select all that apply.)	<p>I need a well-paying job</p> <p>I have disability income (SSI or SSDI), but it isn't enough</p> <p>I do NOT have disability income (SSI or SSDI), and I need it</p> <p>I have Workers' Compensation insurance income, but it isn't enough</p> <p>I have personal disability insurance income, but it isn't enough</p> <p>I have income through an injury settlement or court decision, but it isn't enough</p> <p>I need better health insurance coverage</p> <p>Other (please specify)</p>
		28. How important would you say mental health care is for your recovery (for example, seeing a counselor or psychological therapist)?	<p>Very important</p> <p>Somewhat important</p> <p>Neither</p> <p>Somewhat unimportant</p> <p>Not important at all</p>
Employment		29. What goals do you have for working?	<p>I am currently working in the same job I had before my injury</p> <p>I am currently working in a new job</p> <p>I want to work, and I'm trying to find a job</p> <p>I want to work, but I am unable to work because of my TBI</p> <p>I don't want to return to work</p>
Employment		30. [People who selected "I am currently working in the same job I had before my injury" see this question] How hard has it been to continue working in your same job you had before your injury?	<p>Very difficult</p> <p>Difficult</p> <p>Neutral</p> <p>Easy</p> <p>Very Easy</p>
		31. [People who selected "I am currently working in a new job" see this question] How hard was it to find your new job?	<p>Very difficult</p> <p>Difficult</p> <p>Neutral</p> <p>Easy</p> <p>Very Easy</p>

Section	Notes	Question	Response
		32. [People who selected “I want to work, and I’m trying to” see this question] How hard is it for you to currently find a job?	Very difficult Difficult Neutral Easy Very Easy
Employment		33. [People who selected “I am working in the same job I had before my injury,” “I am currently working in a new job”, or “I want to work, and I’m trying to” see this question] What resources would best help you with working? Select all that apply	Changes in the workplaces so that it’s easier for me to work Part-time work schedule Training in new skills Help finding a new job Help finding a new career/field Having co-workers who understand TBI California Department of Rehabilitation Support from family Support from friends Private rehabilitation agency/company Other (please specify)
Geography		34. In which city do you live in California?	Auto-populating list
Demographics		35. Are you of Hispanic, Latino, or Spanish origin?	Yes No Prefer not to answer
Demographics		36. Which one of these groups would you say best represents your race? For the purposes of this survey, Hispanic is not a race.	White Black/African-American Asian/Asian-American American Indian/Alaska native Native Hawaiian/Pacific Islander Bi-racial Multi-racial Other (please specify) Prefer not to answer
Demographics		37. What is your age?	_____ years
Demographics		38. What sex were you assigned at birth, on your original birth certificate?	Male Female
Demographics	William’s Institute recommendation for measuring	39. How do you describe yourself?	Male Female Transgender Do not identify as female, male, or transgender

Section	Notes	Question	Response
	gender identity. ⁴⁵		
Demographics		40. Are you currently...? (Select all that apply.)	Employed for wages Self-employed Out of work (unemployed) Homemaker Student Retired Unable to work
Demographics	Can be used to calculate poverty level	41. How many people, including yourself, reside in your household?	____ adults (ages 18 or older) ____ children (under age 18)
Demographics	Can be used to calculate poverty level	42. Last year, what was your household income from all sources before taxes?	Open-ended
Demographics	A proxy to track socio-economic class	43. What is your highest level of education?	Some high school High school graduate Vocational apprenticeship completion Some college College graduate Postgraduate or professional degree
Demographics	Taken from a study on long-term TBI outcomes. ⁴⁶	44. What is your current living arrangement? Select all that apply.	Alone Living with spouse/partner Living with other family member(s) Living with roommate(s) Living in military housing Living in an assisted living facility Living in a nursing home Unhoused (no permanent place of residence) Other: specify
Demographics	From DOR questionnaires	45. When you got your TBI, were you serving in the military?	Yes No I don't know
End of survey		That concludes the survey! Thank you so much for your time and responses. We truly appreciate it.	

⁴⁵ <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Measures-FAQ-Mar-2020.pdf>

⁴⁶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3064530/>

Section	Notes	Question	Response
		If you have any questions or concerns regarding the survey and/or the needs assessment, you may contact dpolk@HARCdata.org .	

Appendix 46. Caregiver Survey (English Version)

Note that the survey was administered via online software. The survey provided below includes the exact question text/response, and notes on skip-logic. This document was used during the survey deployment phase between DOR and HARC staff.

Section	Notes	Question	Response
Information for potential respondent		<p>Thank you for your interest in our survey!</p> <p>The California Department of Rehabilitation and HARC are working together to conduct a community health needs assessment about people with traumatic brain injury (also known as TBI).</p> <p>This survey is designed for caregivers of people with a TBI. Your input on this survey will help to inform us of the greatest needs that exist.</p> <p>If you are not a caregiver, you may take the survey for individuals with a TBI here or the survey for professionals here.</p> <p>This survey is expected to take no more than 20 minutes but please take as long as you need. The survey can be saved and completed at another time.</p> <p>If you have any questions/concerns, you may contact HARC at dpolk@HARCdata.org</p>	
Qualification		<p>1. Traumatic brain injury (TBI) is defined as an alteration in brain function or other evidence of brain pathology caused by an external force such as a jolt, blow, or penetration to the head. Most non-fatal TBIs are caused by falls, motor vehicle accidents, or being struck by a person or an object, such as in sports.</p> <p>Do you provide care to someone who has a TBI?</p>	<p>Yes (proceeds to next question) No (disqualified)</p>
Qualification		<p>2. Do you live in California?</p>	<p>Yes (proceeds to next question) No (disqualified)</p>
Qualification		<p>3. Are you 18 years or older?</p>	<p>Yes (proceeds to start of survey)</p>

Section	Notes	Question	Response
			No (disqualified)
Caregiver Information		1. What relationship do you have with the person you care for? If you care for more than one person, think about the person for whom you provide the MOST amount of care.	The person I care for is... My spouse/partner My parent My child My sibling Other family member My friend A client (no personal relationship) Other (please specify)
		2. When did you start caring for this person?	Less than a month after they got their TBI 1-5 months after they got their TBI 6 months to a year after they got their TBI More than a year after they got their TBI
Caregiver Information		3. How many people with a TBI have you provided care for in the past 30 days?	Drop-down list of numbers
Caregiver Information		4. In the past 30 days , in an average week, how many hours are you providing care to people with TBI?	Drop-down list of numbers
Caregiver Information		5. In the past six months , in an average week, how many hours are you providing care/services to people with TBI?	Drop-down list of numbers
Caregiver Information		6. Where do you usually care for the person with TBI?	Their home Our home (I live with them) Somebody else's home Assisted living facility Nursing home Hospital Other: specify
Caregiver needs	List of needs pulled from existing DOR questionnaires as well as areas	7. Which of the following resources or services do you currently need? Select all that apply.	Help with transportation Help finding TBI resources, such as therapists, support programs, etc. Education on what TBI is and what to expect

Section	Notes	Question	Response
	mentioned during interviews		Respite care (having someone help for a few hours or a day so that you can take a break) Mental health counseling Support groups Financial support Housing assistance Food assistance Legal assistance Help with how to communicate with health professionals
Caregiver needs		8. What other needs do you have that are not being met?	Open-ended
Caregiver needs	Mentioned during interviews	9. [If they selected Help finding TBI resources] What kind of TBI resources do you need help finding?	Open-ended
Caregiver needs		10. [If they selected financial support] In what areas of your life do you need financial support?	Open-ended
Caregiver needs	Mentioned during interviews	11. How important would you say social support is for you as a caregiver (for example, seeing a counselor, going to support groups, having a circle of friends, etc.)?	Very important Somewhat important Neither important nor unimportant Somewhat unimportant Not important at all
Caregiver needs	Mentioned during interviews	12. [If they selected very important or somewhat important above] What kind of social support would be most help for you?	Open-ended
TBI General Information		13. For the person you care for the most, how was their TBI characterized as?	Mild Moderate Severe Not sure
TBI General Information		14. For the person you care for the most, what year did they get their TBI?	Drop down of years [I don't know as an option as well]
TBI Cause	Condensed list to ease respondent burden	15. What was the cause of their TBI?	Accidental fall Injury purposely inflicted by other persons

Section	Notes	Question	Response
			Injury resulting from operations of war Motor vehicle accident Self-inflicted injury Other (please specify) : _____
TBI General Information		16. For the person you care for the most, what are the most challenging symptoms they've experienced because of their TBI? Select all that apply.	Difficulty controlling emotions Mental health (depression, anxiety, etc.) Difficulty speaking Difficulty walking Difficulty with daily living tasks Difficulty with memory Sensitivity to light Sensitivity to noise Discomfort in public/crowds Difficulty thinking or feeling mentally overwhelmed (Cognitive fatigue) Difficulty maintaining concentration Difficulty solving problems Difficulty with sexual function Hearing loss Headaches Feeling physically tired or fatigued Difficulty sleeping Experiencing seizures Less social Difficulty with balance or feeling dizzy Difficulty visualizing images in their mind Poor eyesight Other (please specify)
TBI General Information		17. For the person you provide care for the most, upon their discharge from the hospital , were you ever provided information/resources about caring for the person with TBI?	Yes No I don't know

Section	Notes	Question	Response
		18. [If selected “yes” above] How helpful was this information?	Open-ended
		19. For the person you provide care for the most, at any time later in their recovery , were you ever provided information/resources about caring for the person with TBI?	Yes No I don’t know
TBI General Information		20. [If selected “yes” above] How helpful was this information?	Open-ended
TBI Recovery Information		21. How would you rate their TBI recovery during the first six months of recovery?	Very good Good Acceptable Poor Very poor
		22. Please explain, why their six-month recovery was [option they selected on #18 earlier will appear here]?	Open-ended
TBI Recovery Information		23. How would you rate their TBI recovery currently ?	Very good Good Acceptable Poor Very poor
TBI Recovery Information		24. Please explain, why their current recovery is [option they selected on #20 earlier will appear here]?	Open-ended
Satisfaction with care		25. Overall, how satisfied are you with the services/care the person with TBI has received from health care providers (doctors, nurses, therapists, etc.) in the last six months ?	Very satisfied Somewhat satisfied Neither satisfied nor dissatisfied Somewhat dissatisfied Very dissatisfied I don’t know
Satisfaction with care		26. Please explain why you are [option they selected earlier will appear here, i.e., satisfied] with their services/care received from health care providers?	Open-ended
Satisfaction with care	Mentioned during interviews	27. How satisfied are you with health care providers’ (doctors, nurses, therapists, etc.) knowledge of TBI?	Very satisfied Somewhat satisfied Neither satisfied nor dissatisfied Somewhat dissatisfied Very dissatisfied I don’t know

Section	Notes	Question	Response
Insurance	Mentioned during interviews	28. In thinking about the person with TBI, how much of their care has their health insurance covered?	Most of their care Some of their care None at all They don't have health insurance I don't know
Insurance	Mentioned during interviews	29. [Those who selected Most of their care, some of their care, or none at all see this question] What services or treatments does the person with TBI need insurance to help with more?	Open-ended
		30. You indicated that they don't have health insurance. How do they pay for health care for their TBI?	Open-ended question
Impact of TBI	Modified from a study on long-term TBI outcomes. ⁴⁷	31. Which of the following has your role as a caregiver negatively affected? Select all that apply.	Access to community events/services/activities Activities of daily living (for example, going shopping, doing chores around the home) Being able to leave the house Employment Family Friendships Getting access to health care Living arrangements Managing my health care School Relationship with spouse/partner
Needs of people with TBI	List of needs pulled from existing DOR questionnaires as well as areas mentioned during interviews	32. Thinking of the person with TBI you provide care for the most, which of the following resources and services do they currently need? Select all that apply.	Adult day programs (for example, a place they go to and spend the day doing supervised activities) Assistive technologies Education on what TBI is and what to expect Educational materials in Spanish Educational materials in languages other than Spanish or English Financial support Food assistance

⁴⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3064530/>

Section	Notes	Question	Response
			Help accessing community events/services/activities Help finding TBI resources, such as therapists, support programs, etc. Help with activities of daily living (for example, going shopping, doing chores around home, etc.) Help with transportation Home modifications Housing assistance Legal assistance Medical treatments and services Mental health counseling Substance use counseling Help returning to pre-injury employment Help with finding employment Help with developing and maintaining friendships Help with dating Sexuality counseling Help with medication management Support groups
Needs of people with TBI		33. What other needs does the person with TBI have that are not being met? These could be services, information, education, or any kind of resource to help them.	Open-ended
Demographics		34. Are you of Hispanic, Latino, or Spanish origin?	Yes No Prefer not to answer
Demographics		35. Which one of these groups would you say best represents your race? For the purposes of this survey, Hispanic is not a race.	White Black/African-American Asian/Asian-American American Indian/Alaska native Native Hawaiian/Pacific Islander Bi-racial Multi-racial Prefer not to answer Other (please specify):

Section	Notes	Question	Response
Demographics		36. What is your age?	_____ years
Demographics		37. What sex were you assigned at birth, on your original birth certificate?	Male Female
Demographics	William's Institute recommendation for measuring gender identity. ⁴⁸	38. How do you describe yourself?	Male Female Transgender Do not identify as female, male, or transgender
		39. In which city do you live in California?	Auto-populating list
Demographics		40. Are you currently...? Select all that apply.	Employed for wages Self-employed Out of work (unemployed) Homemaker Student Retired Unable to work
Demographics	Can be used to calculate poverty level	41. How many people, including yourself, reside in your household?	_____ adults (ages 18 or older) _____ children (under age 18)
Demographics	Can be used to calculate poverty level	42. Last year, what was your household income from all sources before taxes?	Open-ended
Demographics	A proxy to track socio-economic class	43. What is your highest level of education?	Less than high school Some high school High school graduate Vocational apprenticeship completion Some college College graduate Postgraduate or professional degree
Demographics	Taken from a study on long-term TBI outcomes. ⁴⁹	44. What is your current living arrangement? Select all that apply.	Alone Living with spouse/partner Living with other family member(s) Living with roommate(s) Living in military housing

⁴⁸ <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Measures-FAQ-Mar-2020.pdf>

⁴⁹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3064530/>

Section	Notes	Question	Response
			Living in an assisted living facility Living in a nursing home Unhoused (no permanent place of residence) Other (please specify)
Demographics	From DOR questionnaires	45. For the person you care for the most, when they got their TBI, were they serving in the military?	Yes No I don't know
End of survey		That concludes the survey! Thank you so much for your time and responses. We truly appreciate it. If you have any questions or concerns regarding the survey or the community health needs assessment, you may contact dpolk@HARCdata.org .	

Appendix 47. Professional Survey (English Version)

Note that the survey was administered via online software. The survey provided below includes the exact question text/response, and notes on skip-logic. This document was used during the survey deployment phase between DOR and HARC staff.

Section	Notes	Question	Response
Information for potential respondent		<p>Thank you for your interest in our survey!</p> <p>The California Department of Rehabilitation and HARC are working together to conduct a community health needs assessment about people with traumatic brain injury (also known as TBI).</p> <p>This survey is designed for professionals who work with people who have a TBI. Your input on this survey will help to inform us of the greatest needs that exist.</p> <p>If you are not a professional, you may take the survey for individuals with a TBI here or the survey for caregivers here.</p> <p>The survey is expected to take no more than 20 minutes but take as long as you need. The survey can be saved and completed at another time.</p> <p>If you have any questions/concerns, you</p>	

Section	Notes	Question	Response
		may contact HARC at dpolk@HARCdata.org	
Qualification		<p>1. Traumatic brain injury (TBI) is defined as an alteration in brain function or other evidence of brain pathology caused by an external force such as a jolt, blow, or penetration to the head. Most non-fatal TBIs are caused by falls, motor vehicle accidents, or being struck by a person or an object, such as in sports.</p> <p>Are you a professional who works with people who have a TBI?</p>	<p>Yes (proceeds to next question)</p> <p>No (disqualified)</p>
Qualification		2. Do you live and work in California?	<p>Yes (proceeds to next question)</p> <p>No (disqualified)</p>
Qualification		3. Are you 18 years or older?	<p>Yes (proceeds to start of survey)</p> <p>No (disqualified)</p>
Provider characteristics		1. What is your profession?	<p>Physician/medical doctor (not psychiatrist)</p> <p>Psychiatrist</p> <p>Physician Assistant</p>

Section	Notes	Question	Response
			Physical therapist Speech therapist Occupational therapist Registered Nurse (R.N.) Psychologist Neuropsychologist Mental health therapist Case manager/administrator Social worker Vocational rehabilitation counselor Independent Living Center employee Peer/community advocate Lawyer/legal advocate Other (please specify)
		2. [If Physician/medical doctor selected above] What is your medical specialty (e.g., internal medicine, neurology, etc.)?	Open-ended
		3. [If Physician/medical doctor, Psychiatrist, Physician Assistant, Physical Therapist, Speech Therapist, Occupational Therapist, Psychologist, Neuropsychologist, or Mental Health Therapist selected above] Generally speaking, how satisfied are you with the authorized number of sessions to provide	Very satisfied Somewhat satisfied Neither Somewhat dissatisfied Very dissatisfied I don't know Not applicable

Section	Notes	Question	Response
		treatment for your patients with TBI?	
Provider characteristics		4. For how many years have you, as a professional, been working with people with a TBI?	Drop-down list of numbers of years
Provider characteristics		5. Approximately how many people with a TBI have you provided care/services for in the past six months?	Drop-down list of numbers
Provider characteristics		6. In the past six months, in an average week, how many hours are you providing care/services to all your patients/clients with TBI?	Drop-down list of numbers
Provider characteristics		7. On average, how often do you see each patient/client with a TBI?	Once a week Twice a month Once a month Once every two months Once every six months Once a year Less than once a year Other: please specify
Provider characteristics		8. How satisfied are you with the average number of visits for each of your patients/clients with TBI?	Very satisfied Somewhat satisfied Neither Somewhat dissatisfied Very dissatisfied I don't know
Provider characteristics		9. How satisfied are you with the amount of time you	Very satisfied Somewhat satisfied Neither

Section	Notes	Question	Response			
		have, on average, during each visit with your patients/clients with TBI?	Somewhat dissatisfied Very dissatisfied I don't know			
Provider characteristics		10. How much formal education/training have you received about people with TBI?	No formal training/education Several hours of formal training/education Several days of formal training/education Several weeks of formal training/education Several months or years of formal/training education			
Needs of providers	People with TBI in interviews expressed concern with providers not having enough knowledge of TBI	11. Which of the following do you need to better meet the needs of people with a TBI?		This is vital. I greatly need this.	This is important but not essential. I kind of need this	This is unnecessary. I don't need this
			Education on TBI in general			
			Specialty training on treating TBI/serving the needs of people with TBI			
			A centralized list of TBI resources (providers, centers, programs, etc.)			
			One-on-one mentorship/on-site training with another professional experienced with TBI			
			Networking with other TBI professionals			

Section	Notes	Question	Response			
			More funding sources/mechanisms to pay for treatment/services I provide			
			Community-based service options for persons with TBI			
			Funding programs available for persons with TBI			
			Housing options available for persons with TBI			
			Mental health counseling available for persons with TBI			
			Specialty training to support the caregivers of persons with TBI			
Needs of providers	People with TBI in interviews expressed concern with providers not having enough knowledge of TBI	12. Which of the following do other professionals need to better meet the needs of people with a TBI?		This is vital. Other professionals greatly need this.	This is important but not essential. Other professionals kind of need this	This is unnecessary. Other professionals don't need this
			Education on TBI in general			
			Specialty training on treating TBI/serving the needs of people with TBI			
			A centralized list of TBI resources (providers, centers, programs, etc.)			
			One-on-one mentorship/on-site training with another professional			

Section	Notes	Question	Response																																
			<table border="1"> <tr> <td>experience with TBI</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Networking with other TBI professionals</td> <td></td> <td></td> <td></td> </tr> <tr> <td>More funding sources/mechanisms to pay for treatment/services I provide</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Community-based service options for persons with TBI</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Funding programs available for persons with TBI</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Housing options available for persons with TBI</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Mental health counseling available for persons with TBI</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Specialty training to support the caregivers of persons with TBI</td> <td></td> <td></td> <td></td> </tr> </table>	experience with TBI				Networking with other TBI professionals				More funding sources/mechanisms to pay for treatment/services I provide				Community-based service options for persons with TBI				Funding programs available for persons with TBI				Housing options available for persons with TBI				Mental health counseling available for persons with TBI				Specialty training to support the caregivers of persons with TBI			
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Mental health counseling available for persons with TBI																																			
Specialty training to support the caregivers of persons with TBI																																			
Needs of providers	People with TBI in interviews expressed concern with providers not having enough knowledge of TBI	13. In thinking about your work with people who have a TBI, what else would you need to improve your services?	Open-ended																																
Needs of patients/clients		14. Some people have poor health insurance or	Open-ended																																

Section	Notes	Question	Response
		difficulty paying for treatment or services. Among patients/clients like this, what treatment or services could health insurance pay more for?	
Needs of patients/clients	List of needs pulled from existing DOR questionnaires as well as areas mentioned during interviews	15. Which of the following resources and services do your patients/clients with TBI need? Select all that apply.	<ul style="list-style-type: none"> Adult day programs (for example, a place you go to and spend the day doing supervised activities) Assistive technologies Education on what TBI is and what to expect Educational materials in Spanish Educational materials in languages other than Spanish or English Financial support Food assistance Help accessing community events/services/activities Help finding TBI resources, such as therapists, support programs, etc. Help with activities of daily living Help with transportation Home modifications Housing assistance Legal assistance Medical treatments and services Mental health counseling Substance use counseling Help returning to pre-injury employment Help with finding employment Help with developing and maintaining friendships Help with dating Sexuality counseling Help with medication management Support groups
Needs of patients/clients		16. What other needs do your clients/patients	Open-ended

Section	Notes	Question	Response
		with TBI have that are not being met?	
Needs of caregivers	List of needs pulled from existing DOR questionnaires as well as areas mentioned during interviews	17. Which of the following resources and services are most needed by the caregivers of your patients/clients with TBI? Select all that apply.	<ul style="list-style-type: none"> Help with transportation Help finding TBI resources, such as therapists, support programs, etc. Education on what TBI is and what to expect Respite care Mental health counseling Support groups Financial support Housing assistance Food assistance Legal assistance Help with how to communicate with health professionals
		18. What other needs do the caregivers of clients/patients with TBI have that are not being met?	Open-ended
Demographics		19. Are you of Hispanic, Latino, or Spanish origin?	<ul style="list-style-type: none"> Yes No Prefer not to answer
Demographics		20. Which one of these groups would you say best represents your race? For the purposes of this survey, Hispanic is not a race.	<ul style="list-style-type: none"> White Black/African-American Asian/Asian-American American Indian/Alaska native Native Hawaiian/Pacific Islander Bi-racial Multi-racial Other (please specify): Prefer not to answer
Demographics		21. What is your age?	_____ years
Demographics		22. What sex were you assigned at birth, on your original birth certificate?	<ul style="list-style-type: none"> Male Female
Demographics	William's Institute	23. How do you describe yourself?	<ul style="list-style-type: none"> Male Female

Section	Notes	Question	Response
	recommendation for measuring gender identity. ⁵⁰		Transgender Do not identify as female, male, or transgender
Geography		24. In which city do you live in California?	Auto-populating list
Final comments		25. Do you have any other comments you'd like to share?	No Yes: Please specify
End of survey		That concludes the survey! Thank you so much for your time and responses. We truly appreciate it. If you have any questions or concerns regarding the survey and/or needs assessment, you may contact dpolk@HARCdata.org .	

⁵⁰ <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Measures-FAQ-Mar-2020.pdf>

Appendix 48. Individual with TBI Interview Script (English Version)

Hello! Thank you for taking the time for this interview. My name is _____ and I work for a research nonprofit called HARC. We conduct research to improve community health. We have been hired by the California Department of Rehabilitation to help them better understand the needs of people with traumatic brain injury (also known as TBI).

For this interview, we will be talking about your experience as a person with TBI. I'll ask you about 12 questions to structure the conversation. It should take about 45 minutes to complete, though it could be a bit shorter or longer.

We are conducting interviews with not only people with TBI but also caregivers of people with TBI and professionals who serve people with TBI. We will write a report based on these interviews and also based on a separate survey. This report will help the State of California in their effort to improve services. Your input is important and very much appreciated.

Your responses to these questions are completely confidential – your name will never be shared with others. We may pull quotes from you and others, for the report, but no one will know who you are from the quotes. I would also like to record our conversation so that I can accurately capture the ideas that you share. Is it okay with you if I record our conversation?

Before we begin, do you have any questions?

Interview Guide for People with TBI

1. To begin, would you like to share a little about yourself and your injury?
 - a. How severe was your injury (mild, moderate, or severe)?
2. I'd like to get an idea of where you're at in your recovery. How long has it been since your traumatic brain injury?
3. Where are you currently living?
 - a. [For example, in a nursing home, in a rehabilitation facility, at home alone, at home with a caregiver, etc.]
4. Is there anyone in your life who helps take care of you or helps you with life responsibilities?
 - a. [If yes] Who are they and how do they help you?
 - b. [If yes] Thinking about your caregiver, what resources or services do you think would be most helpful to them?
5. A common experience for people with TBI is changes in relationships, such as with friends or family. Would you say that your relationships have changed in any significant ways since your injury?
 - a. [If yes] How have your relationships changed?
6. It's very common for people with TBI to experience challenges such as depression, anxiety, PTSD, or difficulty controlling emotions. Have you experienced any such challenges with mental health since your injury?
 - a. [If yes] What have those challenges been like for you?
7. Have you experienced any other changes, since your injury, that you haven't yet mentioned?
 - a. [For example, people with TBI often have different changes such as in perception of time, sensitivity to light, or difficulty remembering.]
8. People with TBI have different goals for their recovery process. What would you say are your goals for your recovery?
 - a. [For example, resuming daily activities, living independently, adjusting to a "new normal," etc.]
9. It's very common for people with TBI to have to stop working or for work to be greatly impacted. Did you work before your injury?
 - a. [If yes] How has your injury impacted work?

- b. [If stopped working] Some people with TBI have the goal of trying to find a job or return to work. What goals do you have regarding finding a job or working?
- 10. Thinking about your recovery process so far, what resources or services have been most helpful and how have they helped you?
 - a. [For example, physical therapy, counseling, housing assistance, etc.]
- 11. Are there any needs you have that are not being met?
 - a. [For example, help with transportation, good health insurance, social support, finding work, etc.]
- 12. What do you think could be done, or what resources could be provided, to help you meet those needs?
- 13. Do you have any other comments that you would like to share?

Appendix 49. Caregiver Interview Script (English Version)

Hello! Thank you for taking the time for this interview. My name is _____ and I work for a research nonprofit called HARC. We conduct research to improve community health. We have been hired by the California Department of Rehabilitation to help them better understand the needs of people with traumatic brain injury (also known as TBI).

For this interview, we will be talking about your experience as a caregiver of a person with TBI. I'll ask you about 10 questions to structure the conversation. It should take about 45 minutes to complete, though it could be a bit shorter or longer.

We are conducting interviews with not only caregivers but also people with TBI and professionals who serve people with TBI. We will write a report based on these interviews and also based on a separate survey. This report will help the State of California in their effort to improve services. Your input is important and very much appreciated.

Your responses to these questions are completely confidential – your name will never be shared with others. We may pull quotes from you and others, for the report, but no one will know who you are from the quotes. I would also like to record our conversation so that I can accurately capture the ideas that you share. Is it okay with you if I record our conversation?

Before we begin, do you have any questions?

Interview Guide for Caregivers

1. To begin, could you tell me a little about the person you care for and their injury?
 - a. How severe was their injury (mild, moderate, or severe)?
2. I'd like to get an idea of where the person is in their recovery process. How long has it been since their TBI?
3. Where are they currently living?
 - a. [For example, in a nursing home, in a rehabilitation facility, at home alone, at home with a caregiver, etc.]
4. Could you tell me a little about your role as a caregiver? What relationship do you have with the person with TBI beyond that of caregiving?
 - a. [For example, are you a spouse, parent, etc.?)
5. What kind of help or support do you provide for them?
 - a. [For example, meal preparation, help with medication, emotional support, etc.]
6. People with TBI often have different needs. What are some of the greatest unmet needs of your client/friend/family member?
 - a. [For example, help with transportation, good health insurance, social support, finding work, etc.]
7. What do you think could be done, or what resources could be provided, to help meet those needs?
8. Caregivers also have needs. What would you say are some of your greatest unmet needs as a caregiver?
 - a. [For example, help finding healthcare providers, help understanding TBI, social support, etc.]
9. What resources or services would be most helpful to you as a caregiver?
10. It's common for caregivers to experience challenges such as anxiety, depression, or feeling overwhelmed and stressed. Have you experienced any challenges with mental health because of your role as a caregiver?
 - a. [If yes] What have those challenges been like for you?
11. Do you have any other comments that you would like to share?

Appendix 50. Professional Interview Script (English Version)

Hello! Thank you for taking the time for this interview. My name is _____ and I work for a research nonprofit called HARC. We conduct research to improve community health. We have been hired by the California Department of Rehabilitation to help them better understand the needs of people with traumatic brain injury (also known as TBI).

For this interview, we will be talking about your experience as a professional who serves people with TBI. I'll ask you about 10 questions to structure the conversation. It should take about 45 minutes to complete, though it could be a bit shorter or longer.

We are conducting interviews with not only professionals but also people with TBI and caregivers of people with TBI. We will write a report based on these interviews and also based on a separate survey. This report will help the State of California in their effort to improve services. Your input is important and very much appreciated.

Your responses to these questions are completely confidential – your name will never be shared with others. We may pull quotes from you and others, for the report, but no one will know who you are from the quotes. I would also like to record our conversation so that I can accurately capture the ideas that you share. Is it okay with you if I record our conversation?

Before we begin, do you have any questions?

Interview Guide for Professionals

1. First, could you tell me a bit about your professional background? What types of services do you provide and in what settings?
2. What are the services or resources that are most helpful to people with TBI?
3. What would you say are some of the major unmet needs of people with TBI?
4. What are some of the major barriers to meeting those needs?
5. How do you think care for people with TBI could be improved in your specific field?
6. People with TBI often rely on family or other caregivers. What do you think are some of the major unmet needs of caregivers of people with TBI?
7. What services or resources would help support caregivers of people with TBI?
8. What are some of the greatest barriers for you, as a professional, to serving and caring for people with TBI?
9. What services or resources would most help you to better serve and care for people with TBI?
10. What additional education or training would be useful to help you serve people with TBI?
 - a. [For example, workshops, training seminars, etc.]
11. Do you have any other comments that you would like to share?