

Traumatic and Acquired Brain Injury Legal Needs Assessment

Final Report

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Executive Summary

In the United States, Traumatic Brain Injury (TBI) is a major cause of death and disability (CDC, 2017). A TBI is “caused by a bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain” (CDC, 2019). An acquired brain injury is caused by “damage to the brain by internal factors, such as a lack of oxygen, exposure to toxins, pressure from a tumor, etc.,” which affects the normal function of the brain (Brain Injury Association of America, 2019). In Alaska the rate of identified TBI is 28% greater than the national average, however “little has been done to address and treat the cognitive, emotional, and behavioral manifestations of a traumatic brain injury in the affected population” (Alaska Division of Behavioral Health, 2017). There is a need in Alaska to understand why people with brain injuries are not receiving benefits and services for which they are eligible. Further, an examination has not been completed in Alaska to investigate the civil legal needs of people who experience brain injury, and the connection of these legal needs to obtaining services and benefits.

The University of Alaska Anchorage (UAA) Center for Human Development (CHD) was contracted by the Disability Law Center (DLC) of Alaska to conduct a statewide needs assessment on the legal needs of adults with traumatic and acquired brain injuries (TABI). The purpose of this study was two-fold, one, to gather information on the legal needs of adults with TABI, and two, to better understand the experience of adults with TABI in accessing services and benefits. The needs assessment consisted of three activities: key informant interviews, an online survey of adults with TABI, and focus group interviews with adults with TABI. Data collected through the needs assessment activities will inform the DLC, and the State, about the legal needs of adults with TABI and why people with brain injuries are not receiving the benefits and services they need.

Key Informant Interviews

The purpose of the key informant interviews was to gather information to develop the question sets for the online survey and the focus group interviews for the remaining needs assessment activities. Key informant interviews were conducted with professionals in the TABI field and represented state agencies and councils, non-profits, military clinics, and medical professionals. The key informant interviews identified multiple barriers and legal challenges for adults with TABI related to the following areas: employment; housing; education; access to state, federal and/or veterans’ benefits; benefit application assistance; and DLC services. This information provided a contextual framework and was used to develop both the online survey questions and focus group question guides for the needs assessment.

TABI Legal Needs Assessment Online Survey

The Legal Needs Assessment Survey gathered information from adults with TABI, across the state, about obtaining housing, employment, education, benefits, services, and legal needs. Eighty-eight (88) adults with TABI completed the online survey. On average, respondents were approximately 50 years old at the time of completing the survey. The average age at which survey participants experienced their first brain injury was 27 years old and on average had experienced 3 head injuries. Sixty-nine percent (69.0%) of respondents lived in urban locations.

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Key findings from the survey concluded that individuals with TABI most commonly applied for Social Security and Medicaid benefits. The data showed that people with TABI had the most success obtaining Veterans Benefits, Medicare, and Medicaid benefits. Social Security and Adult Public Assistance had the highest denial rates. Across all benefit and services categories, care coordinators and case managers were the most relied upon support people to help complete applications. Unfortunately, this study documented that community-based services, such as physical therapy or occupational therapy, were not being utilized by adults with TABI; on average adults received only one community-based service. A significant association was found between receiving education and training and positive employment outcomes. Lastly, while over two-thirds of the study sample had heard of the DLC, it did not translate into people understanding the mission of the DLC or seeking legal assistance.

Focus Group Interviews

The focus group interviews gathered information from individuals with TABI about their experiences with legal services in Alaska. Three focus groups were offered at various locations across Anchorage with adults with TABI. At one location individuals did not wish to participate in the focus group interview, so individual interviews were conducted instead with interested participants. Researchers used the same focus group interview guide during the individual interviews. A total of 22 people participated in focus group activities; 16 people in focus group interviews (14 individuals with TABI and 2 family members) and 6 people in individual interviews (5 individuals with brain injury and 1 family member).

Based upon the analysis of the focus group and individual interviews, six key findings emerged from the data:

1. TABI is a complex life experience, unique to each individual, that impacts the way a person interacts with the world around them.
2. Robust TABI systems, services, and the connections between them are critical to ensure positive outcomes for survivors.
3. Legal rights and needs are not well understood by people with TABI and their natural supports.
4. Legal help received or sought by people with TABI is usually in relation to another system.
5. The Disability Law Center's mission is not clearly understood by the TABI community.
6. The Disability Law Center can customize their service delivery and expand their outreach to better meet the needs of the TABI community.

The focus group and individual interviews highlighted the complexity of TABI and the challenges people with TABI face as they seek services, benefits, assistance, and legal supports. The DLC can play an important role in the recovery process for adults with TABI to help them access services and benefits. From a larger perspective, individuals with brain injury are an underserved population and gaps exist in the current service system. TABI services need to be better coordinated across the system to improve outcomes for survivors.

Conclusion

Given the overall findings of this needs assessment, there is much work to be done in Alaska to address the needs of adults with TABI. Two sets of recommendations emerged throughout the needs assessment; a set specific to the DLC and a set for the broader TABI service system in

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Alaska. Both sets of recommendations need to be addressed in order to enhance the TABI service system and improve the quality of life for Alaskans with TABI.

Recommendations for the DLC:

1. The DLC should educate people with TABI on its mission, available services, and when and how to access those services.
2. The DLC should provide training to community-based providers on DLC services and referral processes to increase providers' knowledge and capacity about legal assistance.
3. DLC staff would benefit from professional development on TABI, best practices, and what to expect when working with survivors.
4. The DLC would benefit from a review of their own materials, policies, procedures, and practices, through the lens of a person with a TABI, and make adjustments to enhance services.

Recommendations for the AK TABI service system:

5. Alaska would benefit from coordinating TABI systems and services to strengthen positive recovery outcomes for TABI survivors.
6. The TABI service system should examine unemployment, underemployment, and legal concerns in the workplace to improve employment outcomes for people with TABI.
7. The TABI service system should assess housing to address the disparities around homelessness, gaps in housing assistance services, and precarious housing (i.e., those who may have a home, but are consistently in danger of losing their housing).
8. The TABI service and support system should increase educational efforts to increase public understanding of TABI.

Introduction

In the United States, Traumatic Brain Injury (TBI) is a major cause of death and disability (CDC, 2017). A TBI is “caused by a bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain” (CDC, 2019). An acquired brain injury is caused by “damage to the brain by internal factors, such as a lack of oxygen, exposure to toxins, pressure from a tumor, etc.,” which affects the normal function of the brain (Brain Injury Association of America, 2019). Individuals with traumatic and acquired brain injury (TABI) can experience changes from their injury for the rest of their lives. “Despite the fact that the incidence rate of identified TBIs in Alaska is 28% higher than the national rate, little has been done to address and treat the cognitive, emotional, and behavioral manifestations of a traumatic brain injury in the affected population” (Alaska Division of Behavioral Health, 2017). There is a need in Alaska to understand why people with brain injuries are not receiving benefits and services for which they are eligible. Further, an examination has not been completed in Alaska to investigate the civil legal needs of people who experience brain injury, and the connection of these legal needs to obtaining services and benefits.

The University of Alaska Anchorage (UAA) Center for Human Development (CHD) was contracted by the Disability Law Center (DLC) of Alaska to conduct a statewide needs assessment about the legal needs of adults with brain injuries. The purpose of this study was two-fold, one, to gather information on the legal needs of adults with brain injury, and two, to better understand the experience of adults with TABI in accessing services and benefits. The needs assessment consisted of three activities: key informant interviews, an online survey of adults with TABI, and focus group interviews with adults with TABI.

Data collected through the needs assessment activities will inform the DLC, and the State, about why people with brain injuries are not receiving the benefits and services they need. It will also inform the DLC about legal needs for adults with TABI. Further, the DLC will have a better understanding of the experience of people with TABI to expand and enhance their services to better assist this population.

Key Informant Interviews

Method

The purpose of the key informant interviews was to gather information to develop the question sets for the online survey and the focus group interviews. Key informant interviews were conducted with individuals identified by the project partners and staff. Questions for the key informant interviews were decided upon in collaboration with the DLC and focused on legal needs related to the following areas: employment; housing; education and transition services; access to state, federal and/or veterans benefits; access to community events and other opportunities; issues for veterans with TABI; and other areas of concern.

Results

A total of five key informant interviews were conducted with professionals in the field of TABI. Individuals interviewed represented state agencies and councils, non-profits, military clinics, and medical professionals. An invitation to participate was extended to an individual with a brain

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injury, however that individual did not complete an interview. The following is a summary of the key informants' responses.

Employment

Key informants discussed several challenges related to employment. These challenges included people not knowing how to disclose their head injury, workplace accommodations, job retention, workers compensation cases, and inconsistent assistance from DVR. One key informant shared that people with TABI do not always know how to present in an interview regarding disclosure. Another noted cognitive issues related to TABI could interfere with the ability to retain employment. One key informant shared that there needs to be more training and information available to both the employer and employee about their rights and how to exercise them.

Housing

Housing services can present barriers for some adults with TABI as noted by the key informants. Key informants brought up a few challenges related to housing. One spoke about the capacity to enter into complex contractual agreements, both written and verbal agreements, and questioned how well some people with brain injury may understand such agreements. Another noted that housing is expensive and not always accessible to adults with TABI. Issues with service animals were also brought up under housing.

Education and Transition Services

Key informants discussed how education and transition services can be challenging for individuals with TABI. One key informant stated, "individuals with TABI have difficulty accessing education." Key informants discussed the challenge created when people do not want to disclose their head injury or seek assistance from disability support services. As a result, non-disclosure can prevent individuals from being successful in their education. One informant stated, "education and transition can be difficult to impossible" for individuals with TABI.

Access to State, Federal, and/or Veteran Benefits

Key informants talked about difficulties related to accessing state, federal and veterans' benefits. As noted by one key informant, "there are lots of barriers to getting benefits." Key informants identified that people with TABI need assistance with applying for all benefits. One noted, "the paperwork alone is daunting to extremely difficult." Another pointed out it is a barrier to "just prove one has a head injury." A few talked about the challenge of getting a diagnosis; without a diagnosis accessing benefits and services is even more of an obstacle.

Access to Community Events and Other Opportunities

Not all key informants spoke to needs related to accessing community events and other opportunities. For the few who did, their comments focused on the lack of transportation for people with TABI to access community events, doctors, schools, etc. One key informant commented "transportation is a huge barrier to accessing services, employment, and following up with any referrals for continued treatment, rehabilitation, and employment." It was also noted that physical, cognitive, and/or emotional symptoms of a TABI could prevent people from fully engaging with their communities.

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Concerns for Veterans' with TABI

A few key informants discussed barriers veterans with TABI may experience. One noted, veterans are told “not to disclose while in the service and then once out, told to disclose” and this creates contradictions for service members. Another noted mental health issues can worsen and previously undiagnosed co-occurring conditions may require further medical/mental health care. Coordination between Veterans' Administration benefits and Social Security Disability benefits can be a challenge.

Other Concerns Addressed

Key informants also discussed other areas of concern for individuals with TABI. Several spoke about the lack of attorneys in Alaska with training “on brain injuries and the lifelong implications of a brain injury.” Further, interviewees shared that the lack of attorneys with brain injury training is a challenge for people with TABI who are trying to access benefits and services because they need legal assistance and cannot find it. One key informant suggested the DLC advertise to let individuals with brain injury know they are able to assist them with benefit applications and to develop informational or training videos. One key informant shared simply that people with TABI need legal representation.

One key informant discussed that there is a lack of training and information on TABI for primary care providers in rural Alaska. This results in few services for individuals with TABI and little to no legal support within rural communities. Another discussed the challenge of not having a statewide-standardized assessment tool for brain injury at points of entry into the TABI service system.

Key informants also touched on the complexities of TABI. One discussed the feelings of loneliness and isolation people with TABI may experience when they do not disclose to those around them. Another commented that people with TABI have good days and bad days and these variations can impact the services they receive. Another spoke of medical professionals viewing TABI survivors as drug seeking and other negative stereotypes.

Discussion

Key informants discussed many of the barriers and legal challenges people with TABI experience when trying to access services and benefits. This information provided a contextual framework and was used to develop both the online survey questions and focus group question guide for the needs assessment. These interviews provided the direction to more fully explore the civil legal needs of adults with brain injury in Alaska. The **TABI Legal Needs Assessment Survey** included specific questions regarding:

- housing;
- benefits such as Social Security, Adult Public Assistance, Medicaid/Medicare, and Veteran's Affairs benefits;
- employment;
- education;
- application assistance, and
- DLC services.

The **question guide for focus groups** with people with brain injuries centered on:

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- legal assistance needed by individuals with TABI,
- knowledge about the DLC,
- information dissemination about the DLC, and
- improvements to legal assistance and services.

See Appendix A for copies of the TABI Legal Needs Assessment survey question set and focus group question guide.

TABI Legal Needs Assessment Survey

Method

Based upon the findings of the key informant interviews, CHD developed the TABI Legal Needs Assessment Survey. The online survey solicited information from adults who have experienced TABI about obtaining housing, employment, education, benefits, and other services. The survey also asked specific questions about the role of the DLC in obtaining services and benefits. The TABI Legal Needs Assessment Survey was an open-choice format (i.e., multiple-choice questions) with a few open-ended questions, making for a short survey with minimal typing necessary for completion. The survey data was collected using the web-based SurveyMonkey.com. A toll-free telephone number was provided as an alternative to the web-based survey. An incentive was offered for completing the survey. Participants were eligible to receive a \$10 gift card to a store of their choice at the completion of the survey. The TABI Legal Needs Assessment Survey methods and protocol were reviewed and approved by the UAA Institutional Review Board.

Recruitment and Sample

CHD distributed the TABI Legal Needs Assessment Survey through email and listserv invitations. The invitation explained the project, reviewed research participants' rights, and provided a link to the survey. The online survey invitation was distributed using a convenience sample of listservs that included: CHD, Alaska Brain Injury Network (ABIN), the Statewide Independent Living Council (SILC), Governor's Council on Disabilities and Special Education, the Alaska Mental Health Trust Authority, Access Alaska, the Disability Law Center (DLC), Joint Base Elmendorf-Richardson (JBER) TBI Clinic, and the State of Alaska Rural Veteran Health Access Program. A snowball sample was used to disseminate the email invitation with the online survey link; people were encouraged to share the survey invitations with others to increase the number of responses.

The use of a convenience sample with a snowball sample does not lend itself to an accurate count of email invitations distributed. The survey collected data from October 19, 2017 through February 23, 2018. Responses were analyzed from a total of 88 surveys collected over the four-month period.

Analysis

Depending on the characteristics of the data, statistical analyses included frequency distributions, chi-square tests, and Pearson's correlation tests. Any additional tests used during the analyses are clearly noted in the report. The level of significance for all tests was $\alpha = 0.05$. In cases where a chi-square test or Pearson's correlation test had significant results, the report identifies the one or

two factors that most contributed to the association. All statistical analyses were conducted using SPSS 25.0 for Windows (SPSS Inc., Chicago, IL).

Results

Participant Demographics

Demographic information was gathered from participants who completed the online survey. See Table 1 for the demographic results. The mean (i.e., average) age of a person who responded to the survey was 49 years old ($M = 49$, $SD = 13.4$), with a participant age range of 18 to 76 years old. The majority of participants (69.0%, $n = 58$) lived in urban areas (i.e., Anchorage, Juneau, or Fairbanks). About a third of participants lived alone (33.3%, $n = 28$), while a quarter reported living with a spouse (26.2%, $n = 22$). When asked to describe their living situation, the two most frequent responses were lived in their own home (42.4%, $n = 36$) or in an apartment (29.4%, $n = 25$). A little over a third of the participants reported that they were single (40.0%, $n = 34$), while about a quarter were married (28.2%, $n = 24$).

Table 1. Participant Demographics

Demographic Variable	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	<i>Mdn</i>
Participant age	-	49.6 (13.4)	-
Age at first head injury	-	27.3 (19.2)	20.0
Number of head injuries	-	3.1 (3.3)	2.0
Participant location			
Urban	58 (69.0%)	-	-
Rural	26 (31.0%)	-	-
Who participant lives with			
Alone	28 (33.3%)	-	-
With a spouse	22 (26.2%)	-	-
With parents	10 (11.9%)	-	-
With another family member	9 (10.7%)	-	-
With a roommate	5 (6.0%)	-	-
With a significant other	3 (3.6%)	-	-
Other	7 (8.3%)	-	-
Where participant lives			
Own home	36 (42.4%)	-	-
An apartment	25 (29.4%)	-	-
Parent's home	6 (7.1%)	-	-
Supported housing	5 (5.9%)	-	-
Relative's home	2 (2.4%)	-	-
Other	11 (12.9%)	-	-
Participant marital status			
Single	34 (40.0%)	-	-
Married	24 (28.2%)	-	-
Divorced	23 (27.1%)	-	-
Separated	3 (3.5%)	-	-
Widowed	1 (1.2%)	-	-

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The mean age at which participants received their first head injury was 27 years old ($M = 27.3$, $SD = 19.2$) and a median age of 20 years old ($Mdn = 20.0$) (Table 1). In this study, the highest number of head injuries occurred between 5-14 years of age, 15-24 years of age, and 45-64 years of age, see Figure 1. Additionally, the mean number of total head injuries was 3 ($M = 3.02$, $SD = 3.3$) (Table 1), but the median was 2 total head injuries ($Mdn = 2.00$, $SD = 3.3$). The difference between the mean and median could be explained by a few participants who experienced a very high number of head injuries, which increases the overall mean number of head injuries. See Figure 2 for a chart of the total number of head injuries reported by participants.

Figure 1. Age of First Head Injury

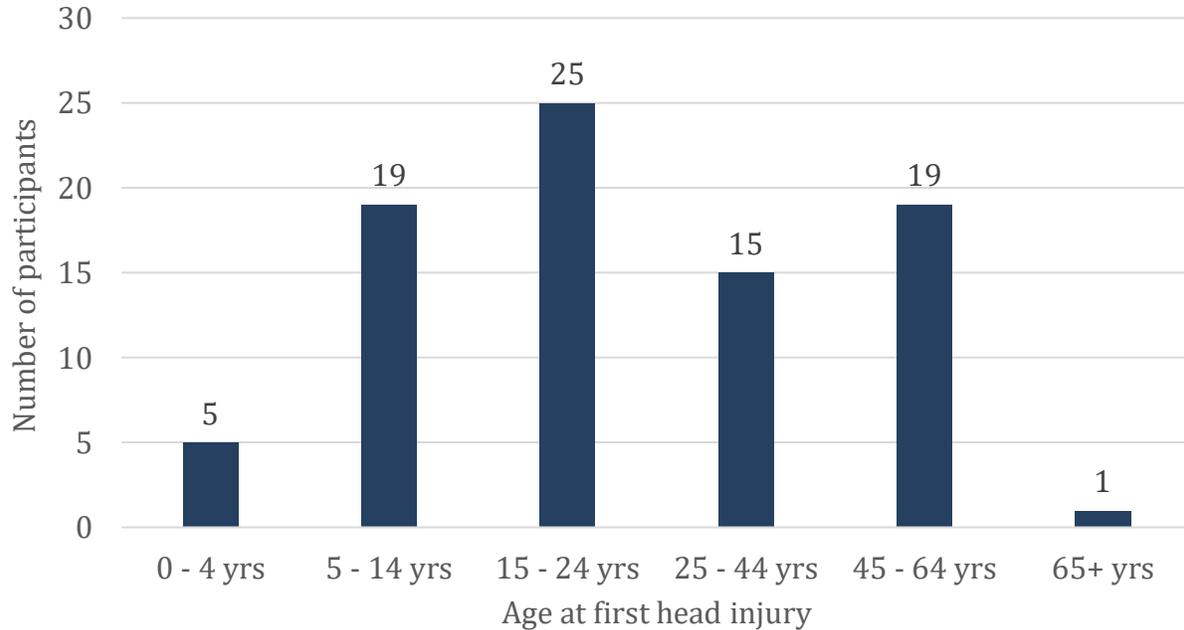
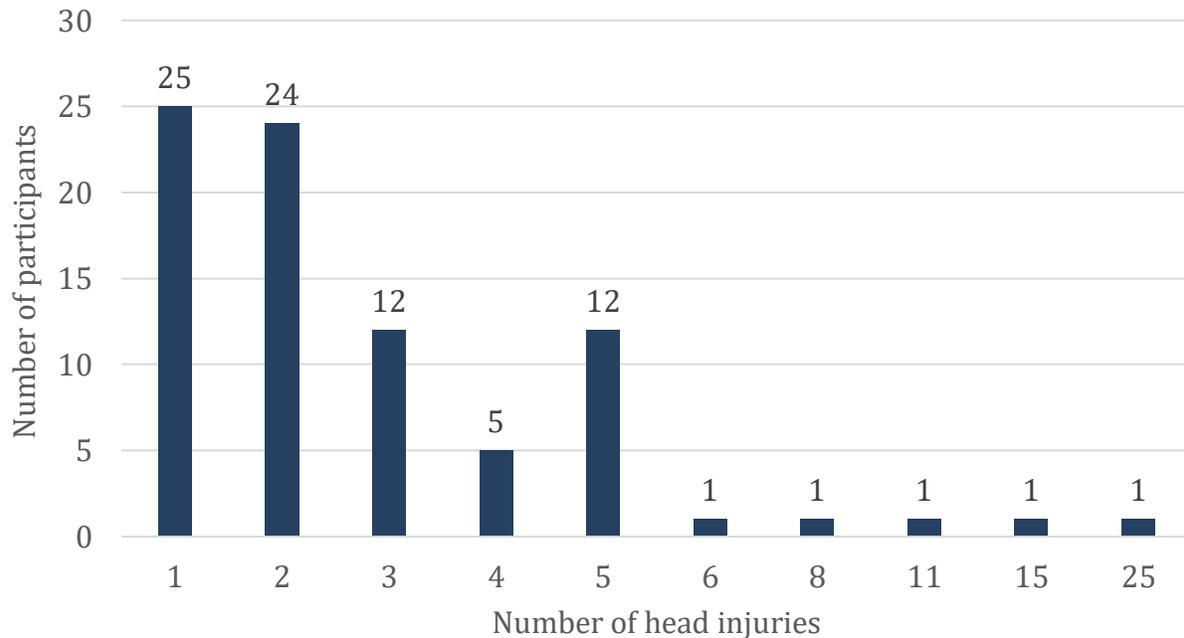


Figure 2. Reported Number of Head Injuries



Supports and Services

Housing

Nearly 40% of the participants (37.8%, $n = 31$) reported difficulties related to housing. Only 13.6% of the total surveyed participants ($n = 11$) reported receiving housing assistance, such as Section 8 Housing, rent, or utilities assistance. Out of those who were receiving assistance, five (45.4%) reported encountering difficulties obtaining housing assistance. When asked how many times people applied for housing assistance, five participants reported they had applied at least twice ($Mdn = 2.00$). Most people had someone assist them with their housing application (81.8%, $n = 9$); usually a friend or family member, or care coordinator/case manager. However, there was no association between having received help with the application and having difficulty in obtaining housing assistance. Meaning that having help with housing applications did not impact whether or not a person reported having difficulty obtaining housing assistance.

Most of the survey participants (86.4%, $n = 70$) reported they were not receiving housing assistance and one-third of participants ($n = 21$) reported they had never applied for housing assistance. Eight participants (16.3% or 8/49), who were not receiving assistance, reported they had been denied housing assistance. Six of those eight individuals (75%) had applied at least twice ($Mdn = 2.00$) for housing assistance. A few participants (17.1% or 12/70) who were not receiving housing assistance reported having help with housing applications. Care coordinators/case managers, or friends or family members were most often cited as helping with housing assistance applications. Having any kind of help filling out a housing application did not impact whether participants obtained or were denied housing services.

The data showed that having help with a housing assistance application did not make it easier to obtain housing assistance nor were individuals less likely to be denied. However, individuals who applied for housing assistance more than once and up to seven times were more likely to report obtaining assistance according to a Pearson's correlation test ($r = 0.465$, $p = 0.001$).

Social Security (SS)

Over half of the survey participants had applied for Social Security benefits (56.4%, $n = 44$) and of the 44 participants who applied, 24 (55.8%) were currently receiving Social Security benefits. Approximately 70.0% ($n = 16$) of the participants receiving benefits reported applying only once to obtain their benefits ($Mdn = 1.00$, $min = 1$, $max = 6$), but 7 participants applied at least twice, and 3 reported applying more than 4 times. One participant did not share how many times they applied.

Almost half of the 44 participants (47.7%, $n = 21$) who applied for Social Security benefits had been denied at some point. The majority of those who had been denied applied only once (66.7%, $n = 12$), but almost 30% ($n = 5$) of those who had been denied applied three or more times. Three participants did not share how many times they applied for Social Security benefits.

The three most frequently cited sources of assistance in completing the Social Security application were family or friends, a care coordinator/case manager, and Social Security office staff. One participant indicated the DLC was their source of assistance.

Having any kind of assistance on the Social Security benefits application was not associated with receiving benefits. Meaning that having assistance with an application, at least in this sample, did not impact whether the participants obtained or were denied Social Security benefits.

Adult Public Assistance (APA)

A little over a third of survey participants (38.2%, $n = 29$) had applied for Adult Public Assistance (APA) and 58.6% of those participants were currently receiving benefits. The mean number of times people with TABI filled out an APA application was twice ($M = 2.00$, $SD = 2.17$), while the median number of applications was one ($Mdn = 1.00$). The difference between the median and mean number of applications is likely due to a few individuals who applied multiple times. Of those who reported applying for APA benefits, 41.6% were denied at some point. Over half of those who applied (62.1%, $n = 18$) reported that someone assisted them with the application. Family members or friends and care coordinators/case managers were reported most frequently as sources of assistance when completing the application.

There was no association between receiving assistance with the application and receiving benefits. In this sample, even though over half of the participants reported that someone assisted them with completing the APA application, that did not impact whether or not they received benefits.

Health Care (Medicaid/Medicare)

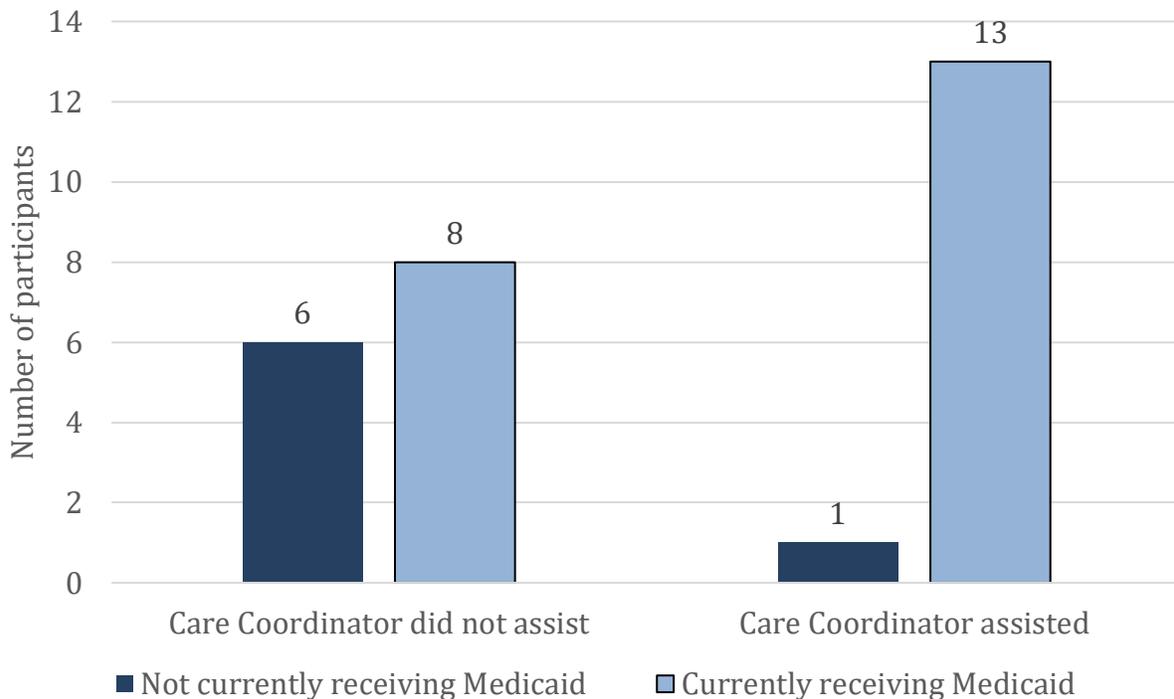
Medicaid

Half of the participants (50.6%, $n = 39$) had applied for Medicaid. Of those participants, 74.3% were receiving Medicaid benefits and had applied a mean of 2.2 times ($M = 2.19$, $SD = 2.19$). About a third of participants who applied for Medicaid (32.4%, $n = 12$) reported they had been denied at some point. Almost three quarters of participants (71.8%, $n = 28$) had some kind of assistance filling out the Medicaid application. Family members, friends, and care coordinators/case managers were the most commonly reported sources of help.

A Pearson's correlation test illustrated that when a care coordinator/case manager assisted with a Medicaid application, there was a significant association with the individual receiving Medicaid benefits ($r = 0.412$, $p = 0.029$). Meaning, when a care coordinator assisted someone with a TABI on a Medicaid application, the person with TABI was more likely to receive those benefits. See

Figure 3 for a comparison of care coordinator/case manager assistance with a Medicaid application.

Figure 3. Care Coordinator Assistance with Medicaid Application



Medicare

Fewer than half of the participants had applied for Medicare (40.3%, $n = 31$). Most participants who shared their benefits status reported they were receiving benefits ($n = 24$, 85.7%) and 10.7% ($n = 3$) reported they had been denied Medicare at some point. The mean number of times participants had applied for Medicare benefits was 1.5 ($M = 1.46$, $SD = 1.53$). Most participants (79.3%, 23/29) received some kind of application assistance, mostly from family members or friends or care coordinators/case managers. There was no association between receiving Medicare application assistance and an individual receiving Medicare benefits.

Veteran Status and Benefits

Only a few participants were eligible for Veteran’s Affairs (VA) benefits (9.3%, $n = 7$). Of those who were eligible, 71.4% ($n = 5$) applied for benefits and all who applied (100.0%) reported receiving benefits. A little less than half of the participants receiving VA benefits had to appeal an eligibility decision (40.0%, $n = 2$). Most people (80.0% or 4/5) received assistance with the application, primarily from VA staff members.

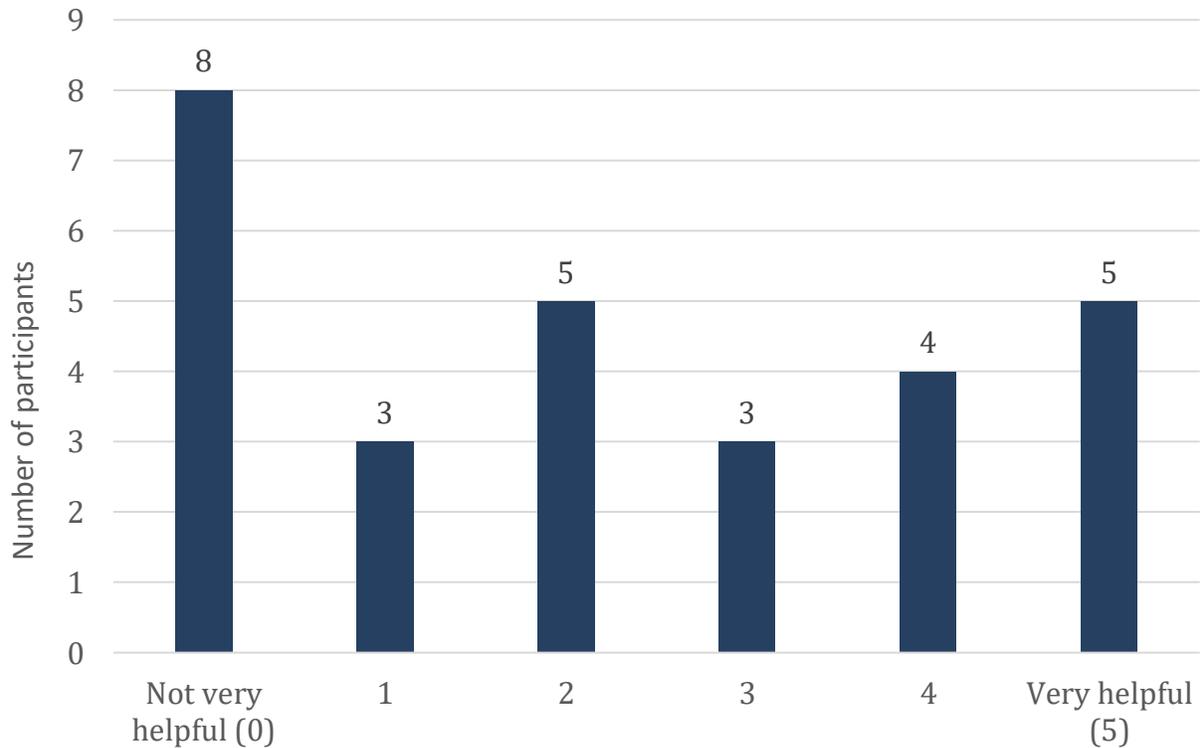
Employment, DVR, Education and Accommodation

Participants were split almost evenly with regards to employment status; 52.1% were unemployed, and 47.9% were employed. In this sample, there were no associations between the participant’s age when they had their first brain injury and their employment status. That is, the age at which someone experienced their first injury did not impact their employment status. Further, the number of head injuries also did not impact employment status.

Only about a third of participants (37.5%, 27/72) were able to return to the work they had done before their brain injury. Slightly more than half of the participants (52.1%, $n = 38$) indicated they were unable to find and keep a job for more than one year after their brain injury. About a third of the participants (38.4%, $n = 28$) reported working with the Division of Vocational Rehabilitation (DVR) to re-enter the work force.

Participants who had worked with DVR were asked to rate how helpful DVR was on a scale of 0 to 5 (with 0 being ‘not very helpful’ and 5 being ‘very helpful’). The median response was 2 ($Mdn = 2.00$, $SD = 1.90$), see Figure 4.

Figure 4. Helpfulness of DVR in Re-entering Workforce



According to a chi-square test, there were significant negative associations between working with DVR and being currently employed ($\chi^2 = 4.592$, $df = 1$, $p = 0.032$) and between working with DVR and being able to return to the work the participant had done before the injury ($\chi^2 = 4.619$, $df = 1$, $p = 0.032$). Participants who worked with DVR were less likely to be employed and were less likely to be able to return to their previous work. See Figures 5 and 6 for employment outcomes. However, it should be noted, the severity of the head injury was not reported in this study. Previous research has shown people with more severe head injuries are less likely to return to work and are less likely to be employed (Saltychev, Eskola, Tenovuo & Liami, 2013). Further, DVR tends to work with more severe cases. Therefore, these findings should be interpreted with caution.

Figure 5. Return to Previous (Pre-Injury) Employment and DVR Involvement

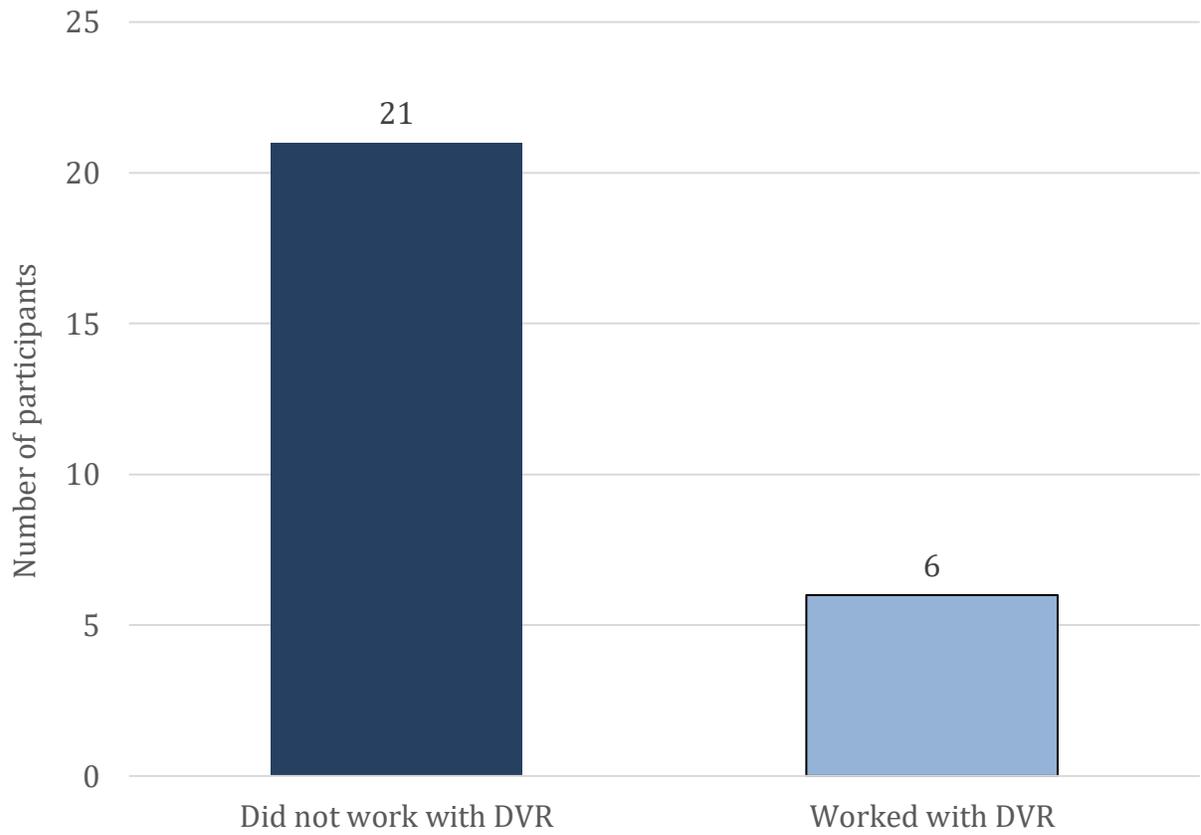
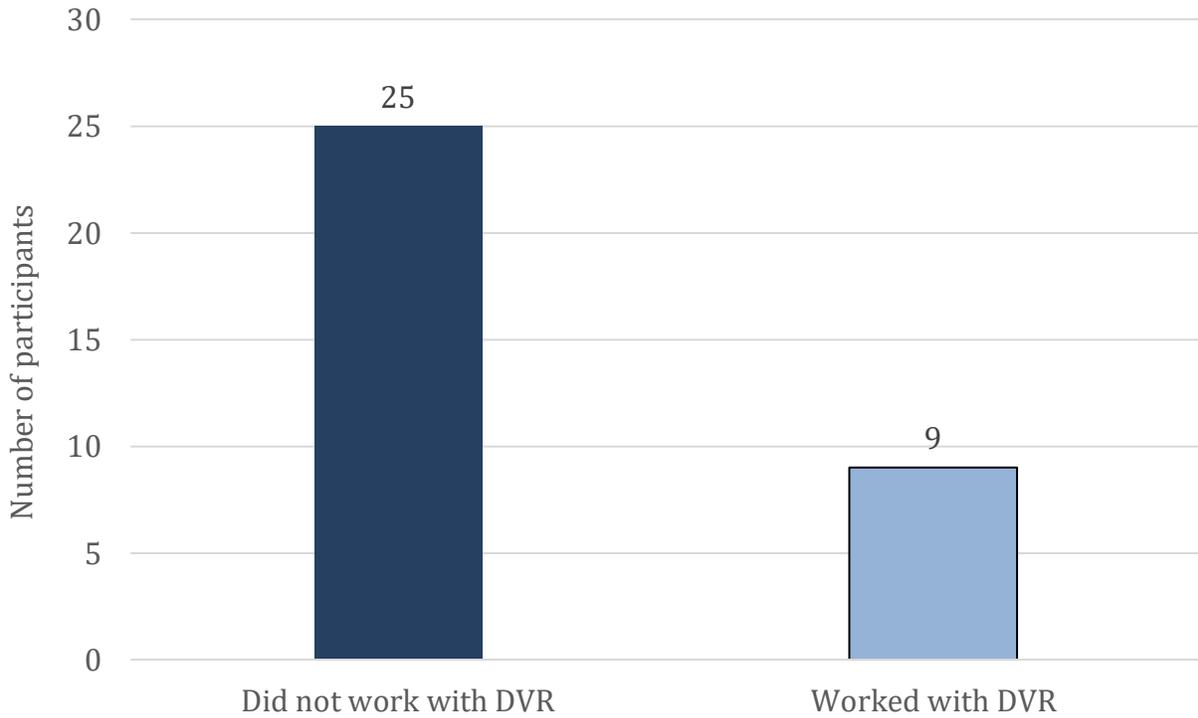


Figure 6. Currently Employed and DVR Involvement



Participants were asked to provide feedback on what would have improved their experience with DVR. Several participants encountered DVR staff who lacked an understanding about TABI and the challenges faced by people with TABI. For example, participants stated, “I don’t know that they knew how to work with someone with a head injury...I process things slowly and they wanted to do everything fast,” and “because I wasn’t responding fast enough they just wiped me off the list.” One participant specifically suggested training in trauma informed care and TABI noting, “they are awful with PTSD/trauma informed care, and women professionals with TBI. [They] need an overhaul and training in those areas before they harm more consumers.” Several participants noted that compassionate DVR professionals would have made the experience better. They stated that, “there was no compassion; I tried to talk with her (boss) about it and she got very mad, got right in my face, that my head injury was too bad and I just needed to go home,” and having “people who care” would be beneficial.

School/Training

Since their brain injury, over half of the participants have attended some type of school or training (61.6%, $n = 45$). Less than one fourth of participants who attended school or training had DVR assistance with that training (22.2%, $n = 10$). A chi-square test indicated statistically significant associations between attending some type of training or education post-head injury and: (1) being currently employed ($\chi^2 = 8.420$, $df = 1$, $p = 0.004$), (2) being able to return to previous work ($\chi^2 = 7.982$, $df = 1$, $p = 0.005$), and (3) being able to find and keep a job for more than one year ($\chi^2 = 8.89$, $df = 1$, $p = 0.003$). If a person with a TABI had attended some type of training or schooling post-injury, they were more likely to be currently employed, more likely to be able to return to the work they did before their injury, and were more likely to be able to find and keep a job for more than one year. See Figures 7 through 9 for a comparison of attending schooling or training post brain injury and employment outcomes. There was a statistically significant negative association with DVR assisting with the training and being employed according to a Pearson’s correlation test ($r = -0.321$, $p = 0.034$); that is, participants who reported DVR assisted them with training were also more likely to report being unemployed, see Figure 10.

Figure 7. Currently Employed and School/Training Attendance

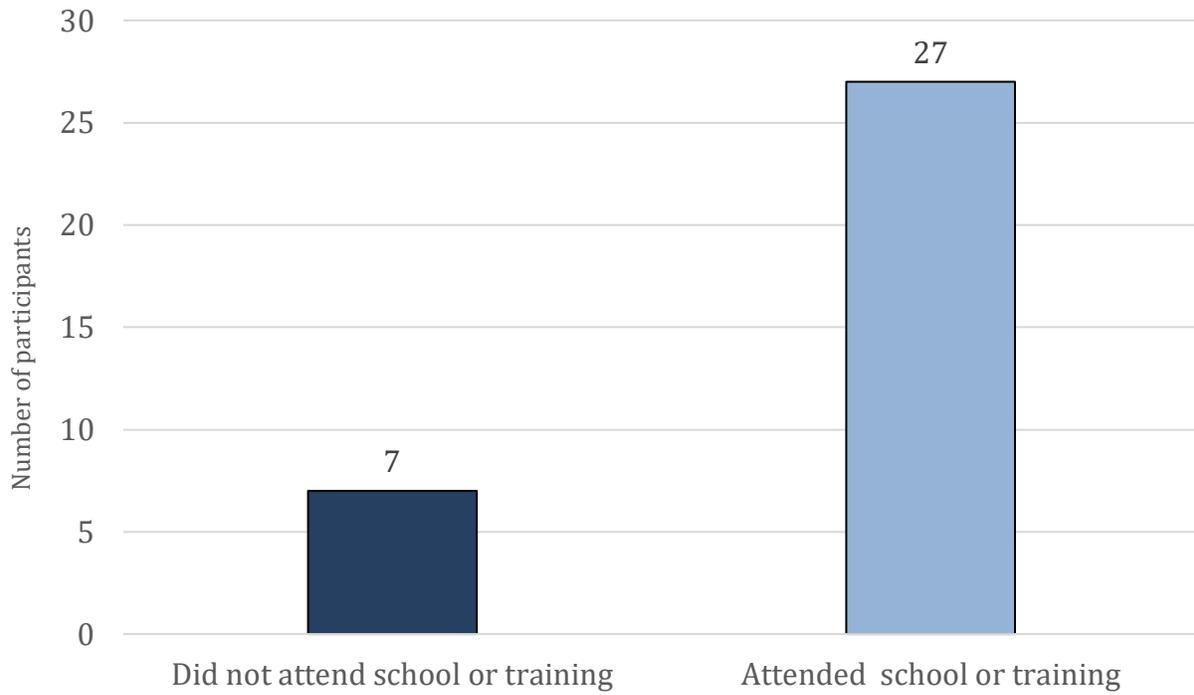


Figure 8. Job Retention for At Least One Year and School/Training Attendance

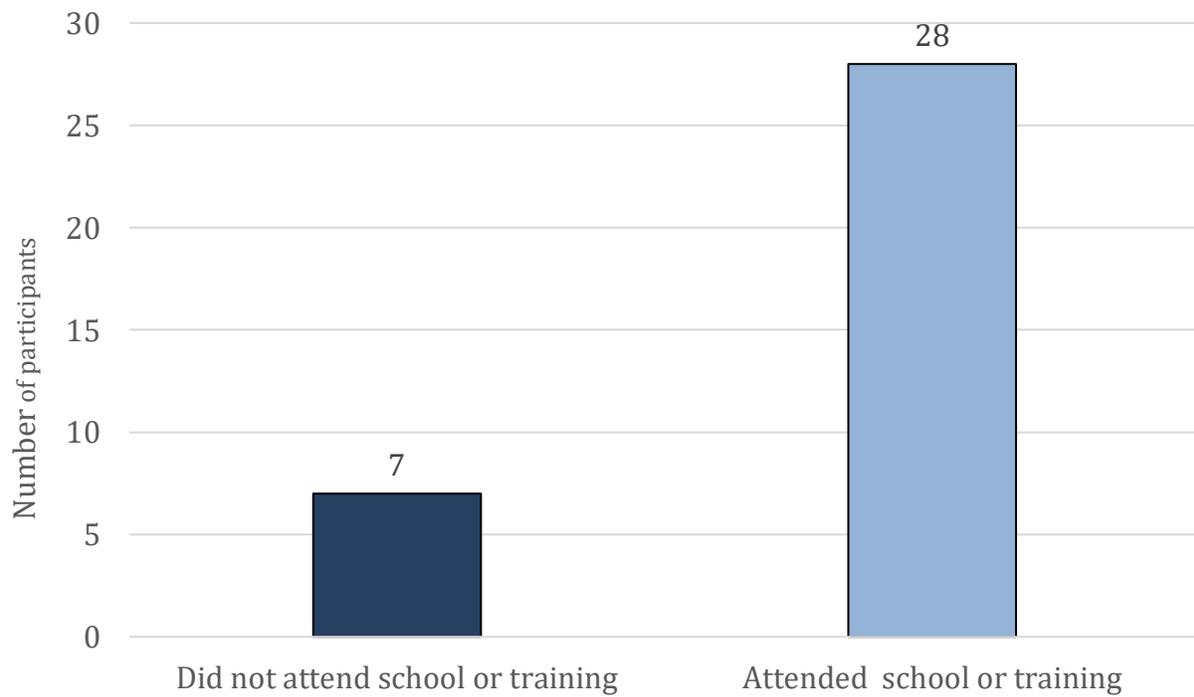


Figure 9. Return to Previous (Pre-Injury) Employment and School/Training Attendance

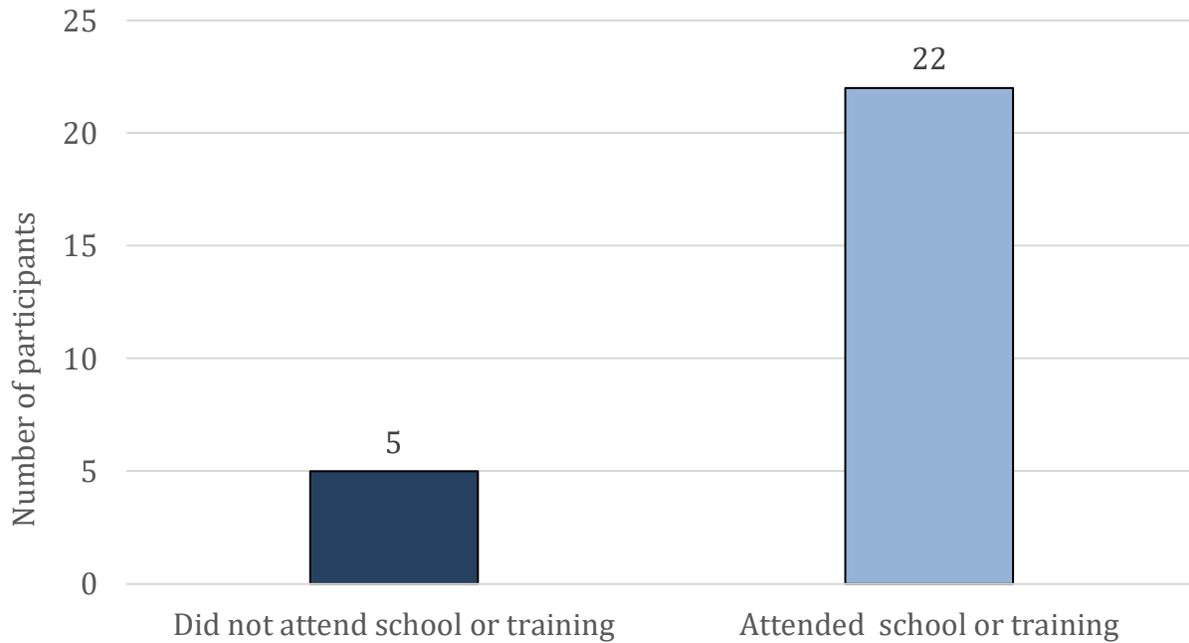
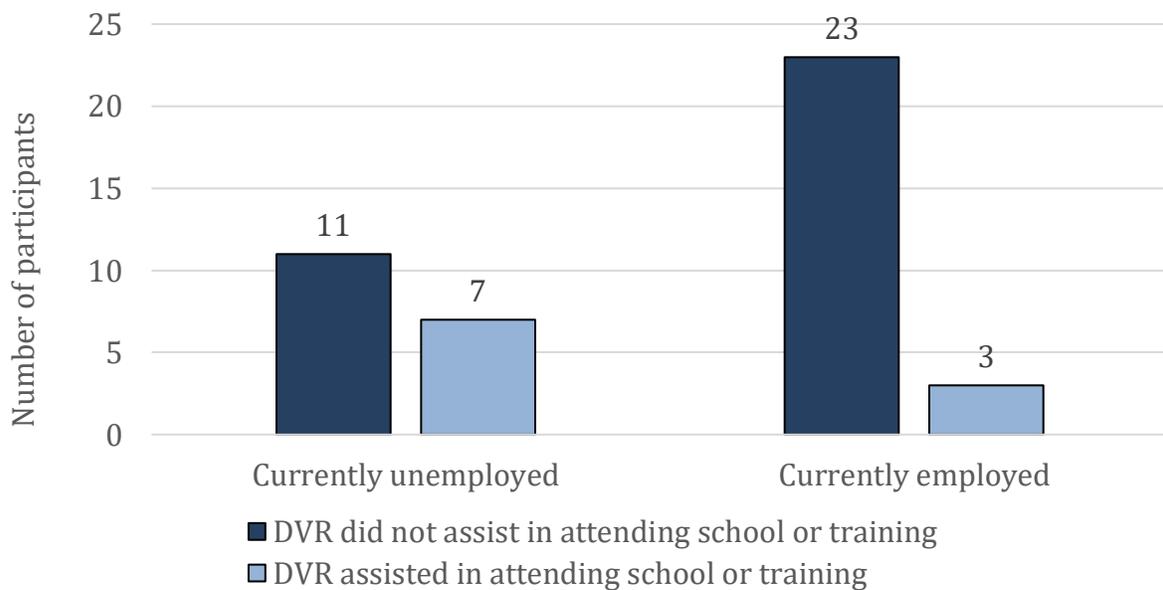


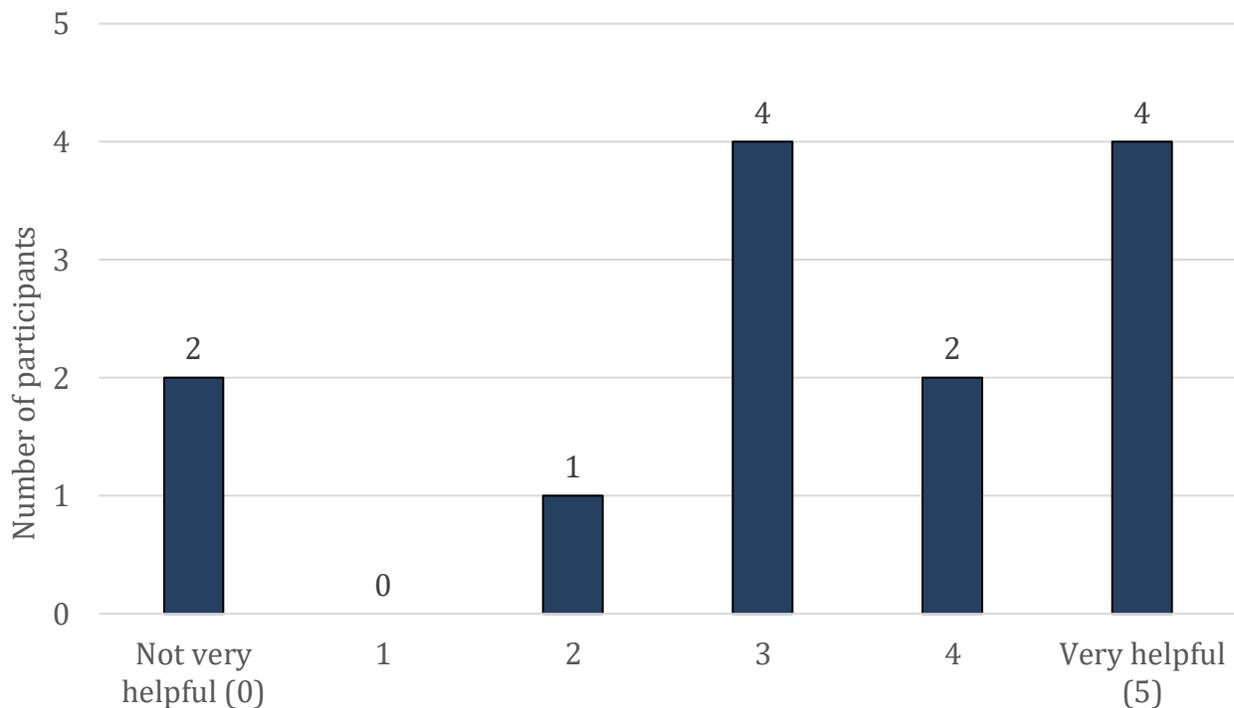
Figure 10. DVR Assistance with School and Employment Outcomes



Note: One participant did not share their employment status.

About one-quarter of participants sought disability accommodation during their schooling or training (28.3%, 13/46). Of those who sought accommodation, 57.1% ($n = 8$) went through a formal process. Participants rated how helpful that process was on a scale of 0 to 5 (with 0 being 'not very helpful' and 5 being 'very helpful'). Figure 11 shows the median rating was 3 ($Mdn = 3.00$, $SD = 1.74$, $s^2 = 3.03$).

Figure 11. Helpfulness of Accommodation Process for School and/or Training



Survey participants were asked to describe what would have made their education, training, or accommodations experiences better. Several participants found they needed more support. For instance, one participant noted, “to have one person to help understand assignments, assistance with classroom notes” would have been beneficial. Someone else stated, “another counselor to assist and more tutoring” would have helped. Another participant shared that they needed more time because of “severe physical [limitations] and problems staying focused on subject matter for long periods of time. [Fifteen to twenty] minutes was my max.” One participant noted that having more information about what they personally needed to succeed would have been helpful, specifically “an evaluation to more clearly identify my functional deficits.” While not a suggestion about how to improve education, training, or accommodation processes, one participant remarked that “services have been cut from a lot of resources or agencies; some agency staff are not paid for the added services that they provide [like occupational therapy] to do what is needed to help others. Therefore, we are not getting the help we need.”

Community Services

Participants reported utilizing a broad array of services in their communities. The most frequently utilized services were behavioral health services (21.2%, $n = 18$), physical therapy (16.5%, $n = 14$), and medication management (11.8%, $n = 10$). Participants also listed cognitive therapy, assistive technology, eye therapy, follow up screenings, neurological services, speech and language therapy, osteopathic manipulation treatment, massage therapy, acupuncture, TABI support groups, and Alaska Native Traditional Healing as additional services they were receiving. Participants most often reported receiving only one community-based service (mode = 1.00) and a mean of just over one service ($M = 1.19$, $SD = 1.52$). This difference may be

explained by a few individuals who reported receiving multiple community-based services, which increased the mean. Whereas, the mode illustrates the most common response given by participants, which was one community-based service. Three-quarters of the participants (75.0%, n = 63) received only one or no community-based services.

Participants received community-based services from medical providers, behavioral health providers, physical therapy providers, the University of Alaska, community support services, benefits services, Alaska Native organizations, or through private providers and work insurance. See Appendix B for a detailed list of community-based service providers.

To investigate the relationship between services and benefits, the percentages of respondents who reported receiving both community-based services and applying for benefits were examined, see Table 2. Only the three most commonly reported services (i.e., behavioral health, physical therapy, and medication management) and the four most often reported benefits (i.e., Social Security, Adult Public Assistance, Medicaid, and Medicare) were examined. A small percentage, less than 15% of the study sample, reported receiving both community-based services and benefits. It is important to note, over 85% of the study sample received only benefits, only community-based services, or no assistance. These findings potentially indicate a gap between receiving benefits and services for adults with TABI.

Table 2. Percentage of Participants Receiving Both Benefits and Community Services

Benefit	Service		
	Behavioral Health	Physical Therapy	Medication Management
Social Security	14.1% (11)	11.5% (9)	7.69% (6)
Adult Public Assistance	14.5% (11)	9.21% (7)	5.26% (4)
Medicaid	14.3% (11)	10.4% (8)	5.19% (4)
Medicare	10.4% (8)	7.79% (6)	2.60% (2)

In an attempt to determine where the gap lies, that is do benefits lead to services or do services lead to benefits, the number of participants who both applied for benefits and were receiving community based services out of the total number of those who had applied for benefits (Figure 12, Scenario A) were compared to the number of those who both applied for benefits and were receiving community based services out of the total number of those receiving services (Figure 12, Scenario B).

Figure 12. Benefits and Community Service Scenario Comparison

Scenario A		Scenario B
# applied for benefits AND received services	compared to	# applied for benefits AND received services
Total # applied for benefits		Total # received services

Through this comparison, the proportions of Scenario B were greater than Scenario A for all community service and benefit categories. Meaning, if an individual received services, they probably had applied for benefits, yet someone who had applied for benefits may not have necessarily received community services. For example, 61.1% of the individuals with TABI who received behavioral health services had also applied for Social Security, compared to 25.0% of individuals with TABI who applied for Social Security received behavioral health services.

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These comparisons are illustrated in Tables 3a-3c; percentages for Scenario A are in column D and percentages for Scenario B are in column E.

Table 3. Number of Participants Who Applied for Benefits and Received Community Services

3a. Receiving Behavioral Health (BH) Services

Comparison	A. Total Number Accessing both BH and SS	B. Total Number Applied for Benefit	C. Total Number receiving BH	D. Scenario A (A/B) %	E. Scenario B (A/C) %
BH and SS	11	44	18	25.0%	61.1%
BH and APA	11	29	18	37.9%	61.1%
BH and Medicaid	11	39	18	28.2%	61.1%
BH and Medicare	8	31	18	25.8%	44.4%

3b. Receiving Physical Therapy (PT) Services

Comparison	A. Total Number Accessing both PT and SS	B. Total Number Applied for Benefit	C. Total Number receiving PT	D. Scenario A (A/B) %	E. Scenario B (A/C) %
PT and SS	9	44	14	20.5%	64.3%
PT and APA	7	29	14	20.5%	50.0%
PT and Medicaid	8	39	14	28.2%	57.1%
PT and Medicare	6	31	14	19.4%	42.9%

3c. Receiving Medication Management (MM) Services

Comparison	A. Total Number Accessing both MM and SS	B. Total Number Applied for Benefit	C. Total Number receiving MM	D. Scenario A (A/B) %	E. Scenario B (A/C) %
MM and SS	6	44	10	13.6%	60.0%
MM and APA	4	29	10	13.8%	40.0%
MM and Medicaid	4	39	10	10.3%	40.0%
MM and Medicare	2	31	10	6.5%	20.0%

This may indicate a few different gaps. First, without benefits, individuals may not be able to pay for community-based services. In this case, being denied benefits could act as a barrier to receiving community-based services. Secondly, there may also be gaps in community knowledge about what services are available to people with TABI. If many people do not know, for instance, that medication management services are available to them, they will not seek these services. There were no statistically significant findings with any of the most commonly accessed services (behavioral health, physical therapy and medication management) and applying (or not applying) for services, with one exception: participants who received behavioral health services were more likely to also report they applied for Adult Public Assistance according to a chi-square test ($\chi^2 = 5.266, df = 1, p = 0.022$).

Benefit Application Rates and Denial Rates

As shown in Table 4, Social Security and Medicaid were the most sought after benefit categories for people with TABI; over 50% of the study sample reported applying for Social Security and/or Medicaid. The most commonly obtained benefits included Veterans’ Affairs benefits (100.0%), Medicare (85.7%), and Medicaid (74.4%).

Table 4. Percentage of TABI Survivors who Applied for Benefits and Received Benefits

Benefit Type	% of Respondents Who Applied (n Applied)	% of Applications Who Received Benefit
Social Security	56.4% (44)	55.8%
Medicaid	50.6% (39)	74.4%
Medicare	40.3% (31)	85.7%
Adult Public Assistance	38.2% (29)	58.6%
Housing	28.4% (23)	47.8%
VA	9.3% (7)	100.0%

Denial of services is a significant barrier for survivors of TABI. The denial rates for benefits were examined to identify which type of benefits are the most challenging for participants to obtain, see Table 5. Social Security, Adult Public Assistance, and Medicaid were the three most common types of benefits denied at any point in time to individuals with TABI. Many people with TABI, roughly one third of this sample, applied more than once for benefits and were

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denied services initially, but obtained them upon re-application. Table 6 illustrates the number of participants who reported receiving benefits and also reported ever being denied. Social Security, Adult Public Services, and Medicaid were the three most likely benefits individuals received after applying more than one time. It is interesting to note the similarity between denial rates and reapplication recipient rates for Social Security and Adult Public Assistance. That is, over 40% of the first-time applications for Social Security and Adult Public Assistance were denied and upon reapplication one-third obtained benefits. On the other end of the scale, Medicare and VA benefits had the lowest denial rates, and Medicare had the highest rate of individuals later receiving services after a denial. For some of the benefit categories, like VA benefits and Medicare, the eligibility criteria to obtain services (e.g., veteran status or age) may narrow the pool of potential applicants and thus decrease the number of denials for such benefits.

Table 5. Initial Denial Rates of Benefits

Benefit	# People Who Applied (% of total sample)	# People Reporting Denial	Denial Rate (Total # Denied/ Total # Applied)
Social Security	44 (56.4%)	21	47.7%
Adult Public Assistance	29 (38.2%)	12	41.4%
Medicaid	39 (50.6%)	12	30.7%
Medicare	31 (40.3%)	3	9.68%
VA	7 (9.3%)	0	0.0%

Table 6. Receiving Benefits after Denial

Benefit	# People Reporting a Denial*	# People Reporting Receiving Benefits After At Least One Denial	% People Receiving Benefits After a Denial
Social Security	20	7	35.0%
Adult Public Assistance	12	4	33.3%
Medicaid	12	3	25.0%
Medicare	2	1	50.0%**

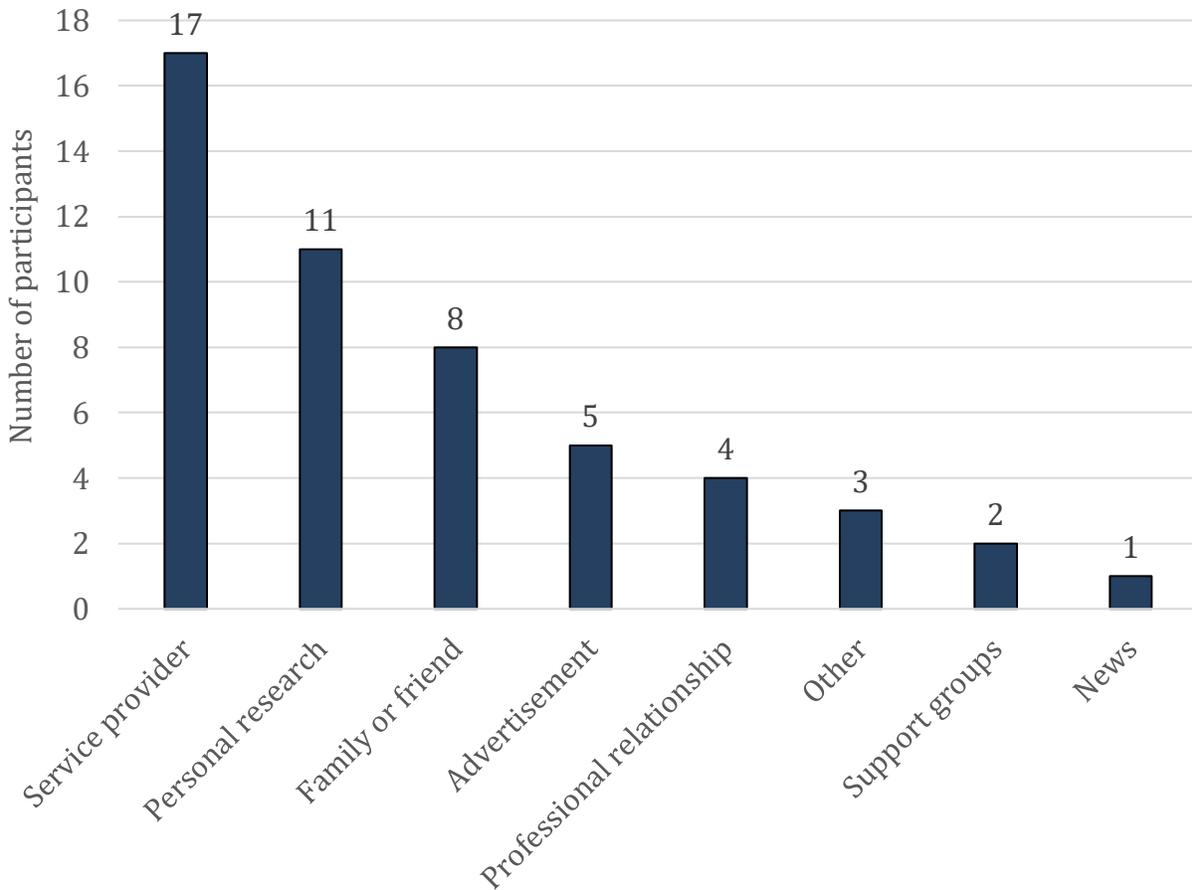
* Participants who did not answer whether or not they were receiving services were excluded from this analysis

** This was based on a sample size of two

Knowledge of and Experiences with the Disability Law Center

Over two-thirds of the survey participants had heard of the DLC (68.0%, $n = 51$). Most often, people with TABI heard about the DLC through service providers (32.7%, $n = 17$), personal research (21.2%, $n = 11$), or through a family member or friend (15.4%, $n = 8$). See Figure 13 for sources of knowledge about the DLC, note individuals were able to report only one source of information for this question. Fewer than half of participants (47.3%, $n = 35$) knew the DLC assists people with disabilities who are denied access to services or benefits.

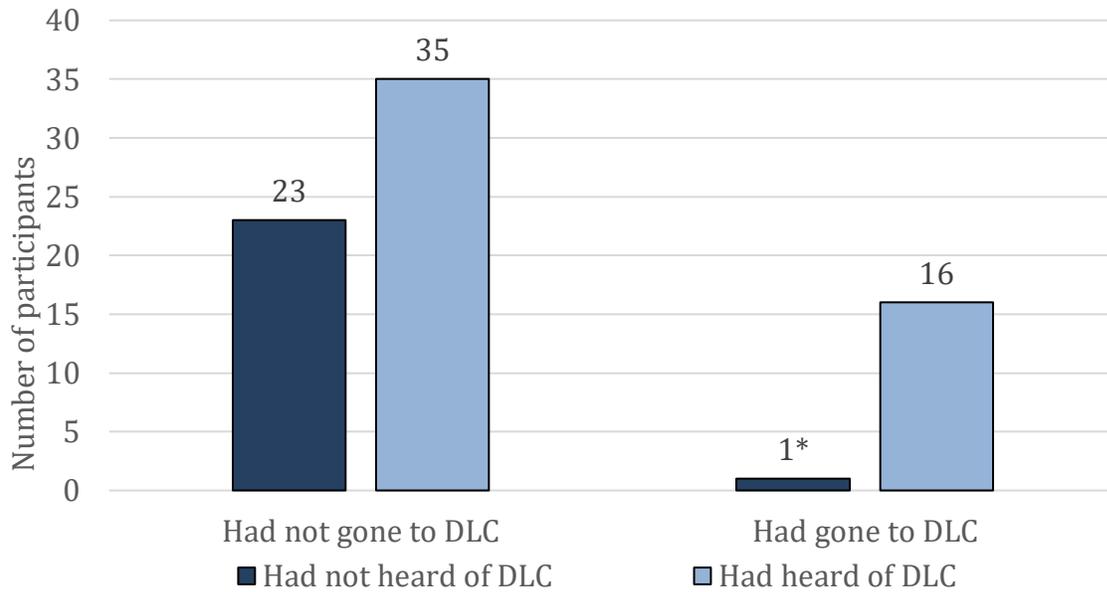
Figure 13. Sources of Information About the Disability Law Center



Only about a third of participants had visited the DLC for assistance (31.2%, $n = 16$). People with TABIs who accessed DLC services reported seeking assistance for the following concerns: benefits (56.3%, $n = 9$), services (43.8%, $n = 7$), housing (29.4%, $n = 5$), education (18.8%, $n = 3$), community access (18.8%, $n = 3$), employment (12.5%, $n = 2$), and insurance (12.5%, $n = 2$). Other concerns for which people with TABIs were seeking assistance included filing grievances ($n = 2$), seeking assistance for others ($n = 2$), and receiving a training on benefits ($n = 1$). Participants could report seeking assistance for more than one area of concern. A chi-square test revealed individuals with TABI who knew of the DLC were statistically more likely to have sought assistance from the DLC ($\chi^2 = 6.891$, $df = 1$, $p = 0.009$), see Figure 14. Knowing the mission of the DLC was associated with seeking assistance from them according to chi-square test ($\chi^2 = 7.535$, $df = 1$, $p = 0.006$) and with thinking about seeking assistance, but ultimately not doing so ($\chi^2 = 7.090$, $df = 1$, $p = 0.008$), see Figure 15. In other words, if an individual knew the mission of the DLC, they were more likely to seek assistance. They were also more likely to think about seeking assistance but ultimately deciding to not seek assistance. There were no statistically significant relationships between the different ways participants learned about the DLC and seeking assistance, meaning that no one way of communicating about the DLC was

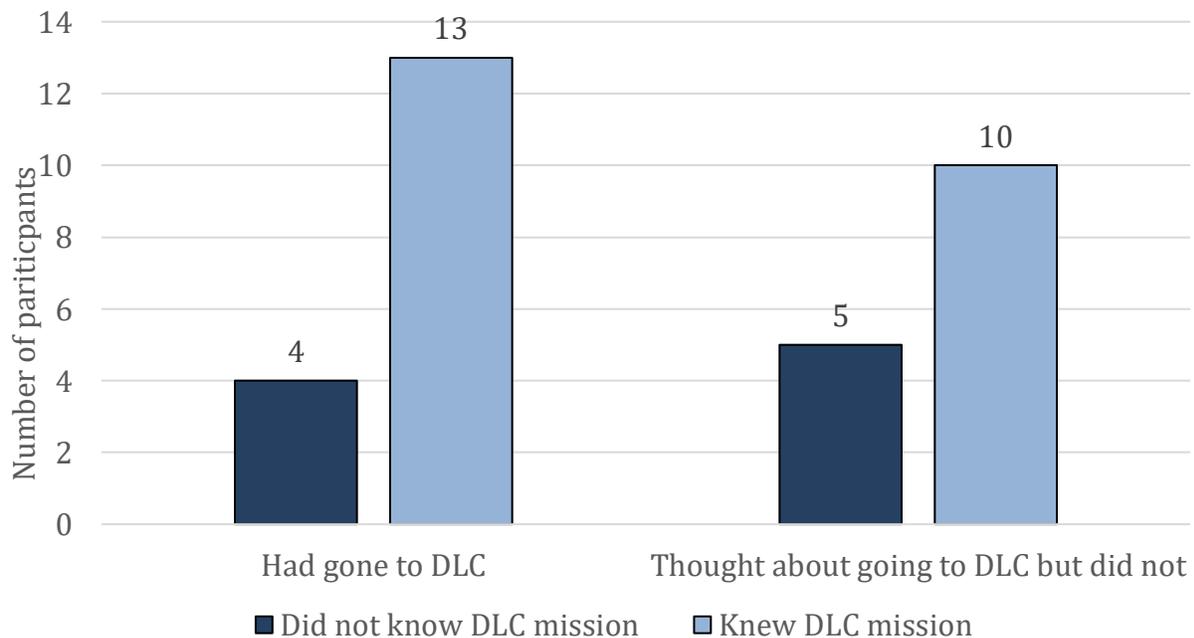
more likely to bring people to the Center than another. Whether participants lived in a rural or urban area of Alaska did not influence their decision to seek, or not seek, help from the DLC.

Figure 14. Knowing About and Accessing the Disability Law Center



* One participant reported they had not heard of the DLC, yet had gone to the DLC

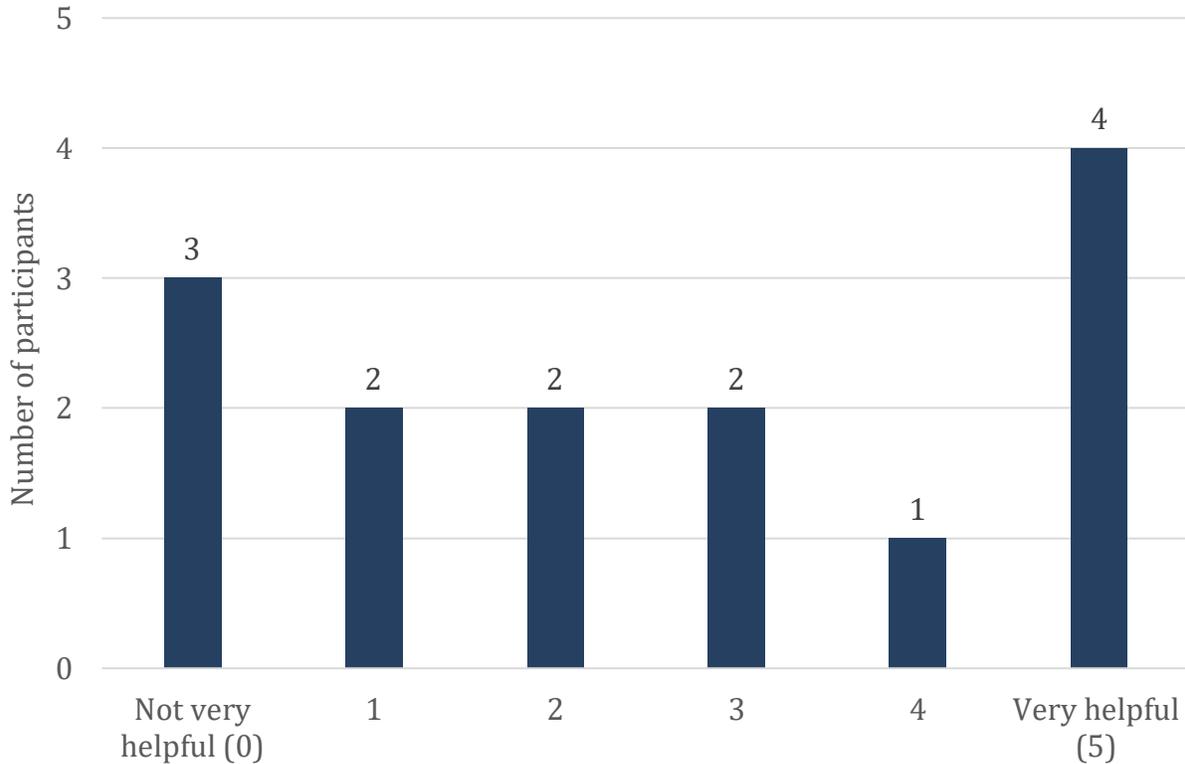
Figure 15. Knowing Disability Law Center Mission and Seeking Assistance



Individuals with TABI were asked to rate how helpful the DLC was in assisting them on a scale

of 0 to 5 (with 0 being ‘Not very helpful’ and 5 being ‘Very helpful’). As shown in Figure 16, 14 participants who had sought DLC assistance gave a median rating of 2.5 ($Mdn = 2.50$, $SD = 1.99$).

Figure 16. Helpfulness of the Disability Law Center



Of those who did not seek out assistance from the DLC, over a quarter (26.8%, 15/56) had thought about going at one point but ultimately did not. When asked why they did not seek assistance from the DLC, three major themes emerged. First, several participants expressed a lack of awareness about the DLC and its mission. One participant shared that they “couldn’t figure out where they were and case workers did not talk about [the DLC].” Another said, “I didn’t know anything about them.” With regards to not understanding the mission, one participant stated, “I didn’t think they would fight disability for me or help me.”

Next, second-hand information about the DLC influenced why some participants did not seek assistance. For example, one participant stated, “I heard they were short staffed.” Another said, “in the past I saw what they did or did not do for others. They pick and choose.”

Lastly, negative past experiences and confusion related to receiving benefits or services also played a role in whether people sought assistance from the DLC. One participant offered, “I’m never eligible for anything.” Another person stated, “not sure what assistance I need or qualify for or where to begin.”

Barriers to a Quality Life

Finally, the survey asked participants to describe their biggest barrier to a quality life after their brain injury. Very few participants listed only one barrier; many described several obstacles.

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One barrier mentioned by many people was the interconnectivity between memory loss, organizational skills, and the ability to complete tasks quickly. For example, one participant noted “short term memory loss. The loss of organization in my life. Big tasks that used to take half a day to complete now take days, sometimes weeks.” Another said, “I also have difficulty with quickly processing directions, or really any type of communication.” It was further explained by another, “I am unable to remember much information short term or long term. I used to work as [occupation] and there is no way I could do that type of work again at this time.” Lastly, one individual stated, “I still have a hard time understanding my memory and that I need to slow down and give myself more process time. It’s also difficult to explain this to friends, my SO, and employer.”

Participants also pointed to physical and mental health issues as barriers to living their lives. Participants shared their specific experiences such as, “I’ve lost some vision, and I need more sleep (naps during the day and more hours at night) daily,” “physical limitations stemming from my stroke (partial paralysis/impair balance),” and “the extreme fatigue...never hitting restful sleep.” Anxiety, isolation, and depression were mental health challenges specifically mentioned by multiple participants.

Participants also described barriers in terms of dealing with stigma, preconceived notions about TABIs, and general lack of knowledge around TABI. One participant described their experience this way:

It’s invisible...if I go to the grocery register and I’m having a hard time...I’m slow...sometimes I’ll have someone trying to hurry me up and say something mean...and I wasn’t like that before...I have to be very careful with money and when they try to rush me in line, it’s hard with all the noise and everything it’s hard to focus and do things and they don’t understand why I’m having a hard time. There’s a reason why I’m struggling and people don’t have a clue why it is that way.

Another said:

I’m expected to function like everyone else but when convenient [people] have used my TBI to say I can’t/shouldn’t do certain things like apply for a promotion [because] I’m ‘too injured’ or they’ll say I’m functioning too well to need help e.g., relearning my job or getting help from [support services organization].

Lastly, participants identified financial barriers to living their lives after brain injury. Participants addressed financial barriers in both a personal sense and a structural sense. Examples of personal financial barriers were “not able to pay my bills” and “no income other than social security, no job.” Participants described several structural financial barriers, including “[trying] to get my SSDI benefits approved has been very stressful and is a ongoing battle...the fight for benefits,” “health insurance has denied addition PT and speech”, “applying for Medicaid,” and “our financial system is changing in this current political era; services are not so plentiful as they used to be.”

Limitations

There are certainly some limitations to the survey that should be considered when examining the data. There were several associations the statistical tests determined to be significant that may have been influenced by a small sample size or other factors. These associations may in fact actually be false positives and should be interpreted with some caution.

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The first association that should be interpreted cautiously is working with DVR and employment outcomes. In the analysis, working with DVR was associated with being less likely to be employed and less likely being able to return to participant's previous work. There are two factors to consider with this finding. First, there was a statistically smaller sample size that worked with DVR according to a chi-square test ($\chi^2 RS = 8.5, p = 0.047$). Secondly, this association may be explained by unemployment and poor job retention prompting people with more complex and severe TABIs to seek assistance from DVR, rather than DVR driving unemployment and poor job retention.

The second association was also related to DVR; participants who reported that DVR assisted them with their education or training were more likely to report unemployment. Like the previous association, this finding may be influenced by the statistically smaller number of participants who worked with DVR. It may also be indicative of the possibility that people with TABIs who are unemployed and seek educational or vocational training from DVR may have more complex symptoms related to their brain injury.

An additional limitation with the survey instrument itself was that it captured data from a single point in time. While it did ask respondents to report past experience, for example denial of a service, it did not allow us to determine the amount of time between events. Continuing with the denial of a service example, an individual may have not met eligibility criteria at time point A, but at time point B applied again and received the benefit. Knowing the length of time between point A (denial) and point B (receipt of benefits after reapplication) may have provided useful information about reapplication success. Gathering data from a single point in time also limits our ability to determine any order of events leading to gaps in service systems.

Another limitation of the study is the use of an online survey. All survivors of TABI may not have access to a computer. Others may not be able to complete the lengthy survey. It is important to note that how data was collected may have influenced the outcomes of the survey. For example, if someone does not have housing they most likely do not have access to a computer. Hopefully, the focus groups provided a more accessible format for all individuals with TABI to participate in the needs assessment.

Conclusion

Overall, the TABI Legal Needs Assessment Online Survey was helpful in gathering information about the benefits and services people with TABI are receiving in Alaska. It also explored how the DLC can assist to fill the gaps in benefits and services for people with TABI.

Social Security and Medicaid were the most sought after and commonly applied for benefits by people with TABI. They had the most success obtaining benefits related to Veterans Benefits, Medicare, and Medicaid. Unfortunately, there is a large gap around the denial of benefit services, particularly Social Security and Adult Public Assistance. These two benefit categories had the highest denial rates from the survey responses.

Care coordinators and case managers seem to be bridges that most often helped people with TABIs complete applications for benefits and connecting folks with the DLC. Across all benefit and services categories, care coordinators and case managers were the most relied upon support people to help complete applications. Participants who reported that a care coordinator or case manager assisted them with the Medicaid application were statistically more likely to receive services. It seems that care coordinators and case managers play an integral role in assisting

people with TABI to access benefits. The DLC should build and strengthen relationships with care coordinators or case managers to increase likelihood that people with TABIs will be able to get the services for which they are eligible.

In regard to services, 60% of the study sample reported accessing community-based services, yet on average individuals accessed only one service. Given the complexity of TABI, this indicates a huge gap in service delivery for people with TABI. Brain injuries are complex and survivors need access to a wide-range of services to aid in their recovery. From the results of this study, it does not appear TABI survivors may be aware of and/or access the supports and services they need.

Further, 61.6% of people with TABI had accessed training and education services since their injury and 38.4% had worked with DVR. It is important to note that there was a significant association with receiving education/training and being employed, returning to previous work, and/or retaining a job for more than one year. However, survey respondents reported gaps in employment, education, and/or vocational training quality. It appears more services related to school and training would be beneficial for survivors and those offering the services need more education and resources about how to best work with individuals with TABI to better support them. It could be beneficial for the DLC to coordinate and/or participate in trainings with disability support service organizations (e.g., ABIN, SILC, CHD) to learn more about TABI and share resources with community providers.

It was promising that over two-thirds of the respondents had heard of the DLC. Unfortunately, this did not translate into people understanding the mission of the DLC or seeking assistance. Knowing the mission of the Center was a stronger predictor of people with TABI seeking assistance than just simply knowing that the DLC exists. In future messaging about the DLC, the mission and purpose should be more prominently and clearly highlighted.

Focus Group Interviews

Method

Based upon the findings of the key informant interviews, and with the objectives of the project in mind, CHD developed the focus group interview guide (see Appendix A). The focus group interviews solicited information from adults with brain injuries regarding their experiences with legal services in Alaska. The focus groups utilized standardized open-ended interviews where the question wording and the sequence of questions were predetermined. The standardized interview format allowed all respondents to answer the same questions and increased comparability of responses. This format also helped to reduce interviewer bias as more than one interviewer conducted the focus group interviews.

Three focus groups were offered at various locations across Anchorage. Focus groups were limited to 10 people per group interview. Two CHD research team members were present at each focus group interview, one to facilitate the discussion and the other to assist and take notes. At one location, after a review of the project, not all individuals wished to participate in the focus group interview and instead individual interviews were conducted with interested participants. Researchers used the same focus group interview guide during the individual interviews. A passive consent process was used for all the focus group activities to help ensure confidentiality of the participants. Focus group and individual interviews were recorded after consent was

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obtained and written notes were also taken for analysis purposes. Participants were offered a \$25 gift card as a thank you for their time. The focus group methods and protocol were reviewed and approved by the UAA Institutional Review Board.

Recruitment and Sample

CHD distributed an email invitation to participate in the focus group interviews intended for adults with brain injuries in Anchorage. The invitation was distributed using a convenience sample through the CHD listserv, the Governor's Council on Disability and Special Education (GCDSE) listserv, Alaska Statewide Independent Living Council (SILC) listserv, Alaska Brain Injury Network (ABIN) listserv, Access Alaska, DLC, and the Alaska Mental Health Trust Authority e-newsletter. A snowball method was used to disseminate the email invitation. The invitation explained the project, reviewed research participant rights, and outlined the schedule for interviews. If people were interested in participating in the focus group interviews, they were asked to contact CHD. CHD gathered information relating to accommodation requests and answered any questions participants had about the focus group interviews.

A total of two focus groups and six individual interviews were conducted. Focus group interviews were approximately 120 minutes long and individual interviews were approximately 20 minutes long. A total of 22 people participated in research activities; 16 people in focus group interviews (14 individuals with TABI and 2 family members) and 6 people in individual interviews (5 individuals with brain injury and 1 family member). The three family members who asked to participate in the focus groups/individual interviews provided support to individuals with TABI. Researchers felt their experience would not deter from the data being collected and allowed them to answer the questions.

Analysis

A Consensual Qualitative Research Model (Hill, Thompson, & Williams, 1997; Hill, Knox, Thompson, Williams, Hess, & Ladany, 2005) was used to analyze the feedback gathered during focus group interviews. Consensual Qualitative Research (CQR) involves multiple researchers working together to code and analyze the data through a consensual process. The two researchers involved in conducting the interviews comprised the primary team. A third researcher who had not participated in the interview process served as an auditor to the CQR. Data analysis consisted of three steps: 1) identification of domains; 2) construction of core ideas; and 3) interpretation of key findings through a cross analysis. During the first stage, team members each independently reviewed two transcriptions from the focus group interviews and assigned domains to the transcripts. After independently assigning domains, the team met to discuss the coding. The goal was to reach consensus about the coding of the data. Once a clear criterion was established for the domains, the researchers divided the work to finish coding the remaining six transcriptions. The second stage of CQR was to summarize the content of the domains into clear, concise core ideas. Team members worked together using the abstraction process to summarize the data for each domain. In the final stage, similarities and variations were examined across transcripts and domains to draw conclusions about the data. The auditor reviewed the work of the primary team at the end of each stage and provided feedback.

Results

After the first round of coding two transcriptions (i.e., one focus group and one individual interview), researchers developed a list of 40 domains, which they provided to an external

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auditor for feedback. Based on the auditor's review, researchers collapsed or removed 16 duplicative domains and added 9 new domains, resulting in a list of 33 domains. With a finalized domain list, researchers then coded the remaining transcripts.

During the second stage of analysis, through the consensual process researchers reviewed the comments within each domain to identify the core ideas discussed by the focus group and interview participants. The process of developing core ideas helped researchers to distill the comments into clear, concise concepts. Researchers reviewed the comments, focusing on the original intent of the participants' statements and tried to avoid adding assumptions or interpretations of the data. Next, researchers reexamined the domains. Two domains were eliminated and combined within more appropriate domains. One domain was broken out into two domains. At the end of the second stage 32 domains remained.

Researchers then moved into the final stage of analysis, cross-analysis. The frequency of domains across the focus group interviews were examined to identify patterns, relationships, discrepancies, and essential themes. Using the total number of eight events (i.e., two focus group interviews and six individual interviews), domains were placed into three categories based on the commonality of their use - general, typical, and variant. General domains applied to all or most all of the focus group or individual interviews (6 to 8 focus groups/interviews), typical applied to more than half (4 to 5 focus groups/interviews), and variant included at least two and up to half (2 to 4 focus groups/interviews). See Figure 17 for the list of domains categorized into general, typical, and variant categories.

Figure 17. Final Interview Domains

General	Typical	Variant
<ul style="list-style-type: none">• Disability Law Center suggestions• Finances• Legal services• TBI self-experience	<ul style="list-style-type: none">• Access to services• Advocacy• Aware of Disability Law Center• Disability Law Center experience• Disability/SSDI• Employment• Housing• Information dissemination• Lack of TBI knowledge• Legal rights• Navigation of system• No contact with Disability Law Center• Support services	<ul style="list-style-type: none">• Discharge issues• Disability Law Center perceptions• Denial of services• Division of Vocational Rehabilitation• Name of Disability Law Center• Natural supports• Ombudsman• Own help/research• TBI evaluation/diagnosis• Unmet needs

Based upon the analysis of the focus group and individual interviews, six key findings emerged from the data:

1. TABI is a complex life experience, unique to each individual, that impacts the way a person interacts with the world around them.
2. Robust TABI systems, services, and the connections between them are critical to ensure positive outcomes for survivors.

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3. Legal rights and needs are not well understood by people with TABI and their natural supports.
4. Legal help received or sought by people with TABI is usually in relation to another system.
5. The Disability Law Center's mission is not clearly understood by the TABI community.
6. The Disability Law Center can customize their service delivery and expand their outreach to better meet the needs of the TABI community.

Complexity of TABI

Participants of the focus groups and individual interviews revealed that TABI is a complex life experience that is unique to the individual. Many stressed that “everyone’s injury is different” and “not all TABIs are the same.” While “everyone’s situation is different” after a TABI, survivors discussed a few similar challenges they each experienced as they learned to live with a cognitive disability. Many of the participants shared how their lives had changed as a result of their brain injuries and they now required more time to complete tasks, had a harder time remembering things, struggled with sequencing, combatted stigma about “looking normal” but having difficulty processing information, and struggled with other preconceived notions around TABI. One participant shared,

It’s hard to remember to make appointments. I make notes but then I forget where my notes are. I set my alarm but I have to make sure I put what I’m supposed to be doing with that alarm [because] if I don’t, it’s just an alarm going off and I’m like ‘well I know I’m supposed to be doing something.’

Others stated that people around them “operate with a mindset that [people with TABI/head injury] know and function like they did before” and fail to recognize that people and “their personalities change.” In addition to cognitive challenges, participants also discussed the drastic changes related to other areas of their lives such as employment, medical insurance, housing, education, and relationships. One participant shared, “This is devastating because we go from working, a tax paying individual, to something different. You worked your whole life, then have limited income. Medical is not available because of insurance.”

People with TABI face a vastly different life experience after their injury. One participant summarized that the impact of their brain injury “affects me every day of my life.” In order to best aid those in recovery, it is critical for those working with survivors to understand that TABI is a complex, highly individualized experience for each person. See Figure 18 for additional quotes about the complexity of TABI.

Figure 18. Complexity of TABI – Quotes

Complexity of TABI
<ul style="list-style-type: none">• "I remember one day dialing up numbers, I have no idea who I'm calling, I don't know why I'm calling them, I don't know who's calling me back. I mean, this is the life in the day of a person with a brain injury."• "You do get exhausted mentally just trying to make a phone call...that might be your day's energy right there just trying to find that out... and it's like, what do you do then? It's disheartening."• "Because I can't express myself doesn't mean I don't know something. Don't treat me like I don't have a brain."• "Each brain injury is different. Each will be different in how you respond or help that person."• "Huge stigma around TBI and being excluded from work, life, losing everything."

TABI Systems and Services

Focus group and individual interview participants discussed the importance of TABI systems and services at great length. TABI systems and services refer to the system of care people with brain injuries become a part of after their injury. This system can include hospitals, medical providers, community agencies, case managers, care coordinators, Division of Vocational Rehabilitation, Social Security, Medicaid, Veterans Administration, legal advocacy, independent living centers, support groups, peer supports, natural supports (e.g., family members, religious organizations), etc.

A few participants shared their experiences when they were able to connect with systems and services that were in place. One participant shared:

Luckily, I have [a case manager] that knows me, knows my background, and we work pretty decently together. She's helped me go to a couple food pantries recently and that was something that before when I was short on money I wouldn't do because I had so much anxiety.

Another participant discussed their experience with the VA and how "the social worker was the person that guided me in the right direction because she gave me a wealth of information. When you're in the hospital, they have that information available when you depart." A few spoke about experiencing their injury as a child and the critical role their family played in their recovery stating, "If I didn't have my parents there's no way I would be where I am now without their support and having a brain injury." Another stated, "I was a child at the time and thank goodness my mom and dad were there... and did all the work." From the comments made, it seems it is easier to enter into TABI service system as a child with the natural support of a family than as an adult.

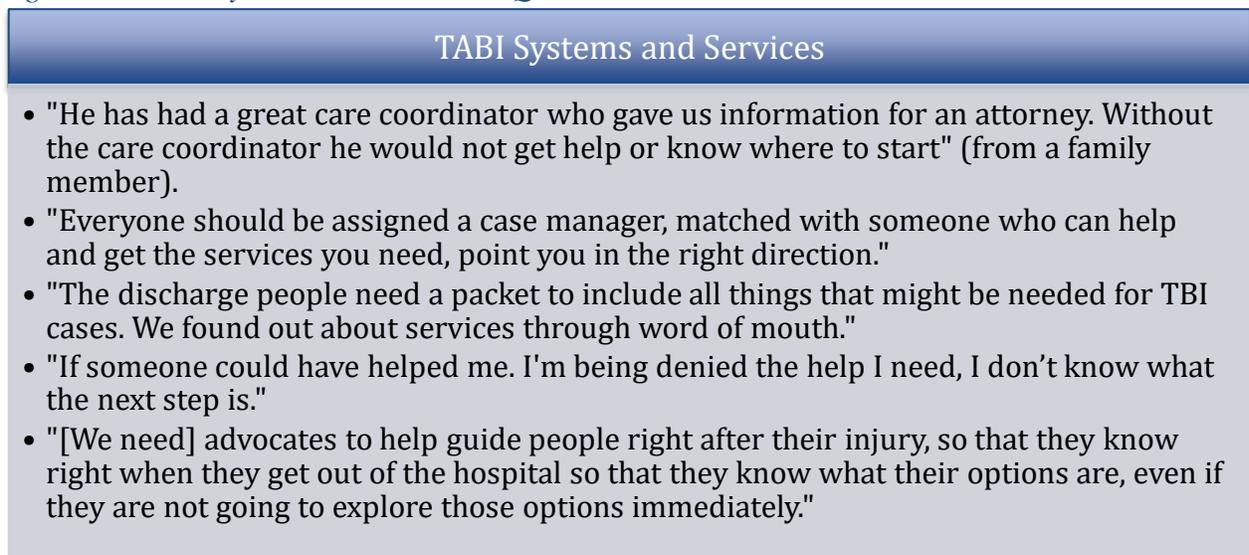
Unfortunately, many of the participants relayed examples of not connecting with the TABI system and services. For example, one person shared that after their injury "there was nothing, absolutely nothing. Anything would have been better than what I had. I had no house, I had no income, I had no resources, I had no clothes, nothing. I had no care coordinator, I had no case worker, nothing." Several individuals discussed the difficulty of getting a TABI diagnosis and

without it “you are turned away” and are unable to access the system and services. The lack of a TABI diagnosis can become a significant barrier to accessing services.

Many suggested hospitals as being a natural entry point for individuals with TABI to become connected with the system and services related to brain injury. One person shared, “when I got out of the hospital, I could’ve used some help to steer me in the directions of what I was supposed to do next. I got released and streeeted and said ‘have a nice life’ there was no [supports or services put into place].” Another participant shared, “it would have been nice to have been met at the door and said ‘Here, let us walk you through this.’ Whether that’s legal or social or whatever.” Others also reiterated the complexity of TABIs, especially as you are newly diagnosed and leaving the hospital, and the need to make sure family supports have access to information about services, supports, and systems. One person stated “I’m all for the first line on the health side of it getting folks right when they get out of the hospital even though as [a] brain injury person ... you’re out of it. At least get [information] in the hands of the family.” Additional suggestions included peer navigators and resource packets on available services and how to access them.

Without connections to systems and services, many people with TABI “go without the help” they often need. Without support, individuals rely upon “Google searches” to do their own research and try to “figure it out.” Robust TABI systems and services, and the connection between them are critical to ensure positive outcomes for survivors. Recovery experiences differ dramatically based on an individual’s level of access to the TABI system and services. See Figure 19 for additional quotes about TABI systems and services.

Figure 19. TABI Systems and Services - Quotes



Legal Rights and Needs

People with TABIs reported a wide range of legal needs, including settlements from automobile accidents, advocacy, workman’s compensation and injury claims, financial problems, Social Security Disability income applications, housing, employment, workplace discrimination, and workplace accommodations. Workman’s compensation in particular is a challenge for Alaskans with TABIs, as several focus group members discussed their experiences. Many shared they “don’t understand the legal system” and had questions about their rights. One person

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summarized that the legal system is “a big black box. I don’t know how to get into the legal system. There is more I could do but I’m clueless.”

Some of the focus group and interview participants were able to rely upon family members or friends in the legal system to advise them along the way. One person reported, “my wife asked a friend who was an attorney what to expect while I was in a coma. He advised her wisely.” Another shared, “luckily we had a lawyer in the family, so it worked out.” Several participants shared that they hired private attorneys to seek help, but doing so added a financial burden, “I had to hire a private attorney I can’t afford to,” “I went to a private attorney and paid a lot of money,” and “I had to pay out of my own pocket.” For others, the financial barrier kept them from seeking the assistance they needed.

Participants of the focus groups and individual interviews had diverse legal experiences, but many reported not completely understanding their legal needs and rights and felt they were “not educated on [their] legal rights and need help with that.” Even when access to legal services was available, the complexities of brain injuries make the legal system difficult to navigate. A few participants talked about the challenges they faced when those in the legal system did not understand the complexity of a brain injury. One person shared:

To me, whether at Disability Law Center or whether you’re hiring a private attorney, if the [attorneys] don’t have a concept of what happens to a person when they have a head injury, then we’re, the person with the head injury, is working at a deficit. The attorney without the knowledge of head injuries is working on understanding or assumption without training. They make assumptions that my brain is processing the same way as their brain and my brain does not process the same as their brain.

See Figure 20 for additional quotes regarding legal needs and rights.

Figure 20. Legal Rights and Needs - Quotes

Legal Rights and Needs

- "Trying to find legal services without having a compass. I had no compass. I had no idea about disability law services."
- "It wasn't good or bad – but didn't have the money to pay. [The lawyer] didn't devote too much time to it."
- "I was like a fish out of water. I was very confused, didn't know what to do. Wish I had more guidance along the way. I ended up not using local attorneys. No one was helping me."

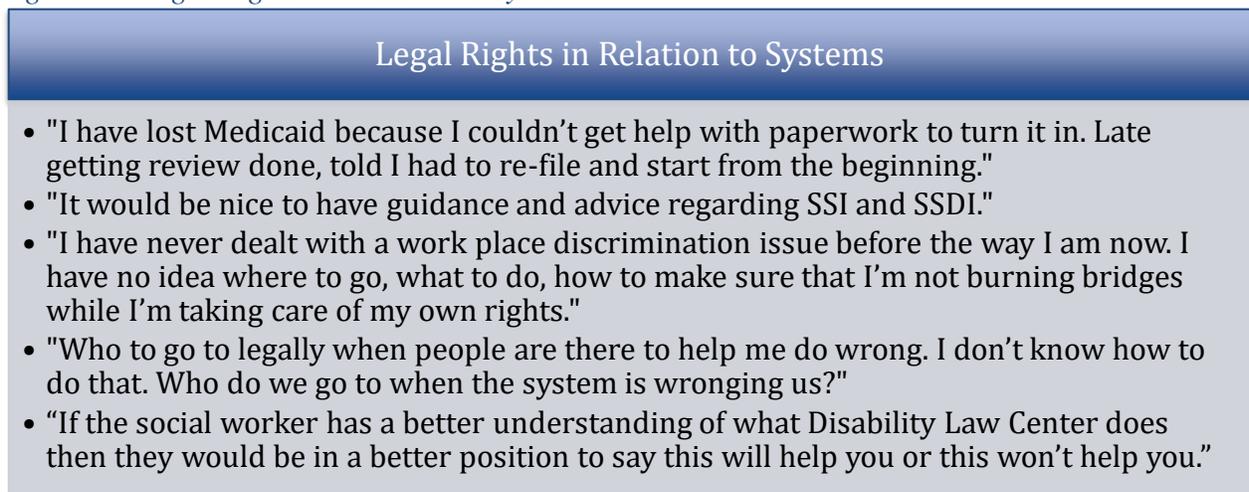
Legal Rights in Relation to Systems

As participants of the focus groups and individual interviews discussed legal rights and needs, a pattern emerged that much of the legal help wanted by people with TABIs was in relation to other systems and services. Many commented on the need for legal assistance with accessing services, and some expressed they did not know when or how to access these services. For example, one person shared they, “needed help and could still use guidance regarding Social Security rules so I can keep my medical benefits and go to work.” Concerns regarding the denial of services and the needed legal advocacy and assistance to dispute such denials were common among participants. One shared, “I applied for disability but was denied,” and took no further

actions to dispute the denial. Another person noted, “I know people who have gotten benefits because of the DLC. [Alaska’s] denial rate for disability benefits is higher, highest in the country.” As mentioned previously, most did not have a firm understanding of their legal rights, and therefore did not know how to go about navigating applications, service denials, and accessing legal assistance and support.

Several people shared legal needs regarding employment concerns, such as worker compensation, workplace discrimination, and workplace accommodations. Some expressed they did not know what types of supports and assistance were necessary in order to resolve these concerns. One person stated, “I was dropped from workman’s compensation, I probably need help with that – I don’t know.” By not knowing where to turn for assistance, many people with TABI go without the legal help they need. Others, however, were able to connect with legal supports to meet their needs. One participant shared, “I have a friend who was able to do some type of workplace accommodation and she was able to get assistance from the DLC.” See Figure 21 for more comments on legal rights in relation to systems.

Figure 21. Legal Rights in Relation to Systems



Disability Law Center Mission

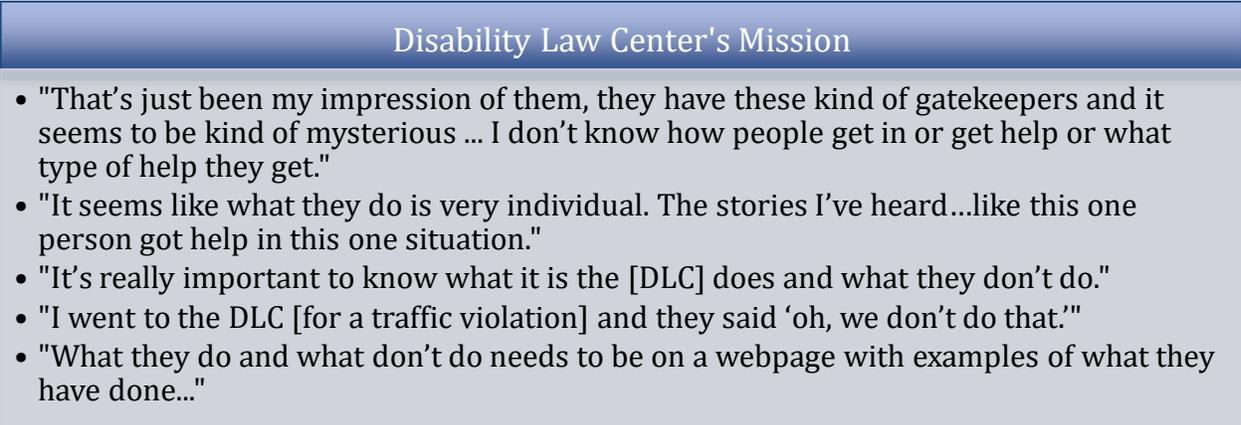
Throughout the focus group and individual interviews, it became apparent many people with TABI were unfamiliar with the DLC in general or did not understand its mission. Statements included, “I haven’t heard of the DLC and don’t know how they apply to me,” “I do know who they are, but I don’t know exactly what they do,” and “never heard of them until I got the email [about the focus groups].” Others talked about not knowing that people with TABI could access the services of the DLC. One person stated, “I have never thought to go there as a person with a TBI.”

Several other participants shared their perceptions of the scope of work of the DLC, such as, “I don’t know if it’s true, my perception, I have never contacted them because it is for people with ADA stuff, like ‘I need a ramp,’” “I thought it was for parents to advocate for kids with the school district,” or “I thought that it was for folks with disabilities, on Disability - not me.” It seems unless people with TABI directly had experience with the DLC, they did not know the mission or services offered by the DLC.

Participants also discussed how the name of the DLC is confusing. One person shared, “you have this wonderful name, Disability Law [Center], but it doesn’t fit from what I’ve seen and there’s a lot of disappointment” when people seek assistance for issues beyond the scope of the DLC’s mission. Another participant similarly stated, “I think a lot of it is half the problem is we . . . want people to know we’re a law center and we work with disabilities so Disability Law Center sounds like a great name, but it’s too big.” Many suggested the DLC “give people an idea of what actually they can and can’t do” because as one person shared, “I didn’t know anything about them until I needed their services.”

A few of the focus group and individual interview participants were more familiar with the work of the DLC. They noted that the DLC “funding is so small and . . . what they’re federally mandated to do is so large, that they can’t do everything.” Again, these individuals suggested the need to “increase the visibility” of the DLC as Alaska’s protection and advocacy agency. See Figure 22 for additional quotes about the DLC mission.

Figure 22. DLC's Mission - Quotes



Disability Law Center's Mission

- "That’s just been my impression of them, they have these kind of gatekeepers and it seems to be kind of mysterious ... I don’t know how people get in or get help or what type of help they get."
- "It seems like what they do is very individual. The stories I’ve heard...like this one person got help in this one situation."
- "It’s really important to know what it is the [DLC] does and what they don’t do."
- "I went to the DLC [for a traffic violation] and they said ‘oh, we don’t do that.’"
- "What they do and what don’t do needs to be on a webpage with examples of what they have done..."

DLC Customization and Expansion Suggestions

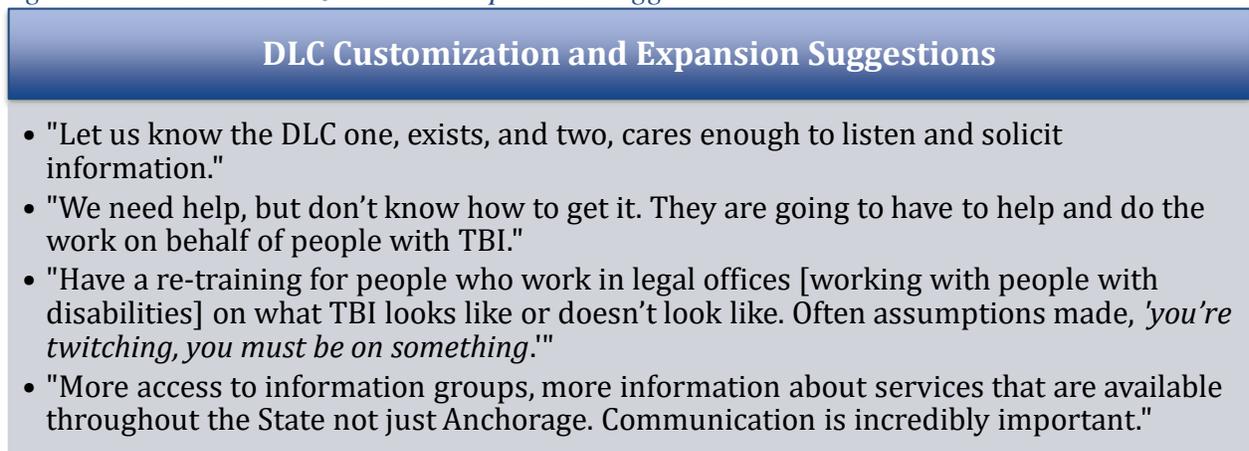
Over the course of the focus group and individual interviews, participants made suggestions on how the DLC can customize their services and expand their outreach to better meet the needs of the TABI community. Several individuals shared they did not know that the DLC worked with TABI survivors and suggested the need to clarify who the DLC supports. One person commented, “if you don’t believe they have services for you, you don’t look.”

Many mentioned the desire to know what types of legal support and advocacy are available through the DLC. A survivor commented, “what they do and what they don’t do needs to be on a webpage.” Suggestions for disseminating information regarding DLC services included social media (e.g. Facebook, LinkedIn); through presentations and outreach to other support service organizations; pamphlets on DLC services in grocery stores, laundromats, medical office waiting rooms; health fairs; open houses; and visiting support groups in-person to talk about the DLC. One person shared their experience and encouraged the need to “increase [the DLC’s] visibility somehow, because I didn’t know anything about them until I needed their services.” TABI survivors also discussed the need for accessible outreach from the DLC about services and shared barriers they faced when trying to access DLC services. One participant described an experience in which they were trying to attend a free legal clinic but because the event was held on a holiday and the buses were not running, they had to take a cab to attend the event.

Some of the focus group and interview participants discussed universal ways the DLC can improve the experience for those they serve. Several discussed the importance to “understand the population, be accessible, be sensitive,” and “talk with people about their learning styles.” Others mentioned assistance understanding legal terminology would be helpful. One person shared their experience applying for SSI with a support and said “there’s a lot of jargon in there that I don’t get, and the other folks that I work with don’t understand, but [we] had to jump through a lot of hoops just to figure it out.”

More specific suggestions related to TABI services included staff understanding the challenges that accompany having a TABI. One survivor explained, “because of my TBI people think I am drunk” and this creates a poor first impression. Others talked about presenting information in more than one format, allowing extra time for comprehension, and being clear with timelines and expectations. Suggestions for services and procedures included legal advocacy, hosting educational events specific to TABI survivors and family members, and collaborating with existing support service organizations as part of a coordinated system of care. See Figure 23 for additional quotes regarding DLC suggestions from focus group and individual interview members.

Figure 23. DLC Customization and Expansion Suggestions



Conclusion

Individuals with TABI have complex, diverse experiences and needs. As stated by focus group participants, “not all TBIs are the same.” Yet, individuals shared similar challenges they faced when seeking services, benefits, assistance, and legal supports. Individuals with brain injury are an underserved population and gaps exist in the current service system; this combination impedes the recovery process for adults in Alaska.

From the information gathered in the focus group and individual interviews, people who experienced their injury as a child seemed to face fewer obstacles as adults. These individuals pointed to the role families, other supports, and services played to aid their path to recovery and, because they were established when they were children, eased their transition to adulthood. However, as comments from the focus group and individual interviews revealed, people who experienced their brain injury as an adult faced more barriers, did not have the same support systems as individuals who experienced TABI as children, and had a more difficult time accessing services and benefits. Comments from participants suggest this is more problematic because people may not have strong natural supports to assist in the process in adulthood and

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there is an expectation that adults should be able to navigate life on their own. Additionally, TABI is an invisible disability and people “look fine.” One person shared, “we operate with the mindset that [people with TABI] know and function like they did before.” Entry into the service system as an adult is more difficult and additional support is needed for individuals to successfully recover.

People with TABI need better access into the TABI service system. Several individuals discussed the difficulty of obtaining a diagnosis and how, without a diagnosis, people are not eligible for services. Many conveyed frustrations with trying to access the system, but not knowing where to start or who to talk to. The challenges trying to navigate these unfamiliar systems are compounded by the cognitive, physical, and psychological effects of a TABI. TABI services need to be better coordinated across the system. Community providers need to know and understand what other services exist and how to access them to better support the people with whom they work. When adults with TABI have knowledgeable support staff, they have better access to the services and benefits for which they are eligible.

The DLC can play an important role in the recovery process for adults with TABI to help them access services and benefits. Unfortunately, in this study, many adults with TABI had little information about the DLC and its mission. From the feedback gathered in the focus groups and individual interviews, people did not know when or how to access the DLC or that they could receive assistance from the DLC. TABI survivors, organizations working with people with TABI, and the general public need more information and education about the role and mission of the DLC. Further, suggestions provided by participants should be reviewed by the DLC to determine how to enhance services for adults with TABI (see DLC Customization and Expansion Suggestions section on pages [38-39](#) of this report).

Overall Conclusion and Recommendations

Conclusion

A comprehensive needs assessment of the legal needs of adults in Alaska who experience a TABI was conducted utilizing a variety of methods. Throughout this process, common findings emerged across the needs assessment results. These included: 1) the complexity of TABI, 2) difficulty accessing benefits, 3) the legal needs of people with TABI, and 4) the role of the DLC.

Complexity of TABI

Throughout the needs assessment activities, stakeholders and individuals with TABI spoke about the complexity of TABIs. It was noted that a TABI can happen to anyone at any stage of their life and their experience will be unique. The survey also highlighted that individuals may experience more than one injury in their lifetime. Individuals with TABI face different symptoms and complications as a result of their injury and several discussed difficulties with tasks, organizational skills, memory loss, light sensitivity, twitching or shaking, depression, anxiety, etc. Many also mentioned difficulty with disclosing their invisible disability and the stigma associated with both disclosure and their disability. These challenges impact their quality of life and recovery process. When examining the TABI system, it is important to keep these experiences and challenges in mind, because they will impact how people with TABI interact with systems, services, support staff, family members, and others around them.

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Accessing Benefits

Results from all three data collection methods identified difficulty gaining access to critical state, federal, and veteran's benefits as a barrier to the well-being of adults with TABI. Social Security benefits and Medicaid benefits were both identified as the most difficult benefits to obtain. The number of people applying for or in need of Social Security or Medicaid benefits is much larger than the number of people who were able to successfully receive those benefits. In fact, on their first application, almost half of those who applied for Social Security were issued a denial (47.7%) and about a third of those who reported applying for Medicaid had been denied (32.4%). Many of those who were receiving Social Security or receiving Adult Public Assistance had to apply more than one time.

When a care coordinator or case manager assisted a person in filling out the Medicaid benefits application they were more likely to receive benefits than someone who did not have that support. This was echoed in the focus groups by someone who stated, "the social worker was the person that guided me in the right direction because she gave me a wealth of information." In this way, care coordinators, case managers, or other supports can act as a bridge between services and the people who need them. This, however, requires that the care coordinators or other supports understand and are connected with services and systems themselves, or at least have a way to get information about services and systems. For people with TABI to have the best positive outcomes overall, robust TABI systems, services, and connections between those systems are necessary.

Serving Legal Needs of People with a TABI

Navigating the world as an individual with a TABI is fraught with complexities. Legal systems are in themselves complex entities. That complexity is magnified if individuals seeking counsel have trouble with memory, focusing for long periods of time, or face mental fatigue as many (but not all) people with TABIs experience. According to stakeholders and individuals with TABIs, there are not enough attorneys with the necessary knowledge, skills, and abilities in working with this community to effectively serve them. Participants provided examples of opportunities where and how these skills and abilities could be cultivated. For example, training DLC staff about TABI could improve the Center's ability to work with clients who experience a TABI. These trainings could then help create customized service delivery systems to better meet the needs of the community. Examples of customized service delivery could include providing extra time to complete forms or providing alternate formats (e.g., flow charts, graphics) to explain a process. Another suggestion was to expand outreach to ensure that all members of the TABI community have access to the resources available to them at the DLC. Participants shared that they wanted legal help that clarified expectations, clearly laid out processes and walked them through each step, and educated them on all of their legal rights and options. This sort of individualized, flexible legal help would be most beneficial for people with TABI as they navigate the legal aspects of their lives.

The Role of the DLC

The online survey and focus groups revealed one additional finding that was not found in the stakeholder interviews: many members of the TABI community do not completely understand the mission of the DLC and the scope of services provided. Many participants stated they had

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never heard of the DLC. Others knew of the DLC, but were unclear as to what kinds of services the Center offered. A few shared they did not even realize they were eligible for legal help from the DLC and thought that it was primarily for ADA compliance or disability benefit recipients. Some other participants knew of the DLC and described experiences in which they had gone to the Center to seek assistance, only to learn once they were there that their issue was beyond the scope of services, which left them very frustrated. Participants who did understand the mission, however, were more likely to go seek legal help from the DLC. Targeted education to the TABI community on the mission of the DLC could improve outreach and increase the number of people with TABI served by the DLC. Further, education efforts should define the scope of services so people with TABI know quickly whether the DLC is an avenue for assistance or if they need to seek a different resource. The ability to know which resources had the greatest chance of successfully helping them was important to several individuals with TABI. Suggestions for communicating the mission and scope of the DLC included updating the website and providing examples of services offered.

Recommendations

Two sets of recommendations emerged throughout the needs assessment; a set specific to the DLC and a set for the broader TABI service system in Alaska.

For DLC:

1. The DLC should educate people with TABI on its mission, available services, and when and how to access those services.
2. The DLC should provide training to community-based providers on DLC services and referral processes to increase providers' knowledge and capacity about legal assistance.
3. DLC staff would benefit from professional development on TABI, best practices, and what to expect when working with survivors.
4. The DLC would benefit from a review of their own materials, policies, procedures, and practices, through the lens of a person with a TABI, and make adjustments to enhance services.

For the AK TABI service system:

5. Alaska would benefit from coordinating TABI systems and services to strengthen positive recovery outcomes for TABI survivors.
6. The TABI service system should examine unemployment, underemployment, and legal concerns in the workplace to improve employment outcomes for people with TABI.
7. The TABI service system should assess housing to address the disparities around homelessness, gaps in housing assistance services, and precarious housing (i.e., those who may have a home, but are consistently in danger of losing their housing).
8. The TABI service and support system should increase educational efforts to increase public understanding of TABI.

Given the findings of this needs assessment, there is much work to be done in Alaska to address the needs of adults with TABI. Understanding the complexity of TABI is critical when providing legal and other services. Addressing this concern through training staff, improving processes, and modifying and enhancing policies, procedures and practices to be more brain injury friendly would go a long ways towards improving the systems experience for people with TABI. Tackling the high denial rate of Medicaid and Social Security benefits at a systems level is critical in improving the lives of Alaskans with TABI. Also, determining and providing the

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support needed to be successful in obtaining needed benefits would be helpful. At the legal level, individuals with TABIs need individualized help from staff and attorneys trained in the complexity of brain injury to be able to successfully address their legal needs. Finally, the Disability Law Center would do well to create a marketing plan outlining the services they provide in a manner accessible to individuals with brain injury.

References

- Alaska Division of Behavioral Health. (2017). Initiatives: Traumatic Brain Injury. Retrieved from <http://dhss.alaska.gov/dbh/pages/initiatives/tbi/default.aspx>. Accessed June 2017.
- Brain Injury Association of America. What is the Difference Between an Acquired Brain Injury and a Traumatic Brain Injury? Retrieved from <https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury>. Accessed March 2019.
- Centers for Disease Control and Prevention. (2019). Basic Information about Traumatic Brain Injury and Concussion. Retrieved from <https://www.cdc.gov/traumaticbraininjury/basics.html>. Accessed March 2019.
- Centers for Disease Control and Prevention. (2017). TBI: Get the Facts. Retrieved from https://www.cdc.gov/traumaticbraininjury/get_the_facts.html. Accessed January 2019.
- Hill, C. E., Thompson, B. J., & Williams, E. N. (1997). A guide to conducting consensual qualitative research. *The Counseling Psychologist*, 25(4), 517–572.
- Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess S. A., & Ladany N. (2005). Consensual Qualitative Research: An update. *Journal of Counseling Psychology*, 52(2), 196-205.
- Saltychev, M., Eskola, M., Tenovuo, O., & Laimi, K. (2013). Return to work after traumatic brain injury: Systematic review. *Brain Injury*, 27(13-14), 1516 – 1527.

Appendix A. TABI Legal Needs Assessment Survey Question Set and Focus Group Question Guide

Survey Question Set

1. Have you experienced a brain injury?
 - a. Yes (*Continue to Question 2*)
 - b. No (*Show disqualification page*)
2. How old are you?
3. What city/town/village do you live in?
4. Who do you live with?
 - a. Alone
 - b. With parents
 - c. With a spouse
 - d. With a roommate
 - e. With another family member
 - f. With a significant other
 - g. Other (please specify)
5. Do you live in:
 - a. An apartment
 - b. Parent's home
 - c. Own home
 - d. A relative's home
 - e. A shelter
 - f. A halfway house
 - g. Supported housing
 - h. A motel
 - i. Homeless
 - j. Other (please specify)
6. What is your marital status?
 - a. Single
 - b. Married
 - c. Separated
 - d. Divorced
 - e. Widowed
7. How old were you when the first head injury occurred?
8. How many head injuries have you experienced (total number)?
9. Since your brain injury, have you had difficulty finding housing?
 - a. Yes
 - b. No
10. If yes, did any of the following help you find housing (Check all that apply)
 - a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. Other (please specify)

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11. Are you receiving housing assistance (for example, Section 8 Housing or assistance paying for rent or utilities)?
 - a. Yes (*Skip to Question 15*)
 - b. No (*Continue to Questions 12 – 14 then skip to Question 18*)
12. Were you denied housing assistance?
 - a. Yes
 - b. No
13. How many times have you applied for housing assistance?
14. Did any of the following help you complete the housing assistance application? (Check all that apply)
 - a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. Housing assistance staff member
 - f. Other (please specify)
15. Did you have a hard time obtaining housing assistance?
 - a. Yes
 - b. No
16. How many times have you applied for housing assistance?
17. Did any of the following help you complete the housing assistance application? (Check all that apply)
 - a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. Housing assistance staff member
 - f. Other (please specify)
18. Since your brain injury, have you applied for Social Security benefits?
 - a. Yes (*Continue to Question 19*)
 - b. No (*Skip to Question 23*)
19. Are you currently receiving Social Security benefits?
 - a. Yes
 - b. No
20. How many times have you applied for Social Security benefits?
21. Were you ever denied Social Security benefits?
 - a. Yes
 - b. No
22. Did any of the following help you complete the Social Security benefits application? (Check all that apply)
 - a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. Social Security staff member
 - f. Other (please specify)

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23. Since your brain injury, have you applied for Alaska Adult Public Assistance?
 - a. Yes (*Continue to Question 24*)
 - b. No (*Skip to Question 28*)
24. Are you currently receiving Alaska Adult Public Assistance benefits?
 - a. Yes
 - b. No
25. How many times have you applied for Alaska Adult Public Assistance benefits?
26. Were you ever denied Alaska Adult Public Assistance?
 - a. Yes
 - b. No
27. Did any of the following help you complete the Alaska Adult Public Assistance benefits application? (Check all that apply)
 - a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. Alaska Adult Public Assistance staff member
 - f. Other (please specify)
28. Since your brain injury, have you applied for Medicaid?
 - a. Yes (*Continue to Question 29*)
 - b. No (*Skip to Question 33*)
29. Are you currently on Medicaid?
 - a. Yes
 - b. No
30. How many times have you applied for Medicaid?
31. Were you ever denied Medicaid?
 - a. Yes
 - b. No
32. Did any of the following help you complete the Medicaid application? (Check all that apply)
 - a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. Medicaid staff member
 - f. Other (please specify)
33. Since your brain injury, have you applied for Medicare?
 - a. Yes (*Continue to Question 34*)
 - b. No (*Skip to Question 38*)
34. Are you currently on Medicare?
 - a. Yes
 - b. No
35. How many times have you applied for Medicare?
36. Were you ever denied Medicare?
 - a. Yes
 - b. No
37. Did any of the following help you complete the Medicare application? (Check all that apply)

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- a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. Medicare staff member
 - f. Other (please specify)
38. Are you eligible to receive VA benefits for disabled veterans?
- a. Yes (*Continue to Question 39*)
 - b. No (*Skip to Question 43*)
39. Have you ever applied for VA benefits for disabled veterans?
- a. Yes (*Continue to Question 40*)
 - b. No (*Skip to Question 43*)
40. Are you currently receiving VA benefits for disabled veterans?
- a. Yes
 - b. No
41. Did any of the following help you complete the VA benefits application? (Check all that apply)
- a. Family or friend
 - b. Care coordinator or case manager
 - c. Attorney
 - d. Disability Law Center
 - e. VA staff member
 - f. Other (please specify)
42. Did you have to appeal the decision?
- a. Yes
 - b. No
43. Are you currently employed?
- a. Yes
 - b. No
44. Were you able to return to the work you did before your brain injury?
- a. Yes
 - b. No
45. Have you been able to find and keep a job for more than one year since your brain injury?
- a. Yes
 - b. No
46. Have you worked with the Division of Vocational Rehabilitation (DVR) to re-enter the workforce?
- a. Yes (*Continue to Question 47*)
 - b. No (*Skip to Question 49*)
47. Please rate how helpful was DVR in assisting you to re-enter the workforce? (*Rated on scale of 1 – 6 stars with 1 star being 'Not very helpful' and six stars being 'Very helpful'*)
48. What could have made your experience better?
49. Since your brain injury, have you attended any school or training?
- a. Yes (*Continue to Question 50*)
 - b. No (*Skip to Question 55*)
50. Did DVR assist you in attending school or a training?

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- a. Yes
 - b. No
51. Did you seek accommodations for your disability from the school or training center?
- a. Yes (*Continue to Question 52*)
 - b. No (*Skip to Question 55*)
52. Did you go through a formal process to obtain accommodations?
- a. Yes
 - b. No
53. Please rate how helpful the accommodation process was in assisting you to complete your schooling or training? (*Rated on scale of 1 – 6 stars with 1 star being 'Not very helpful' and six stars being 'Very helpful'*)
54. What could have been done to make your experience better?
55. Are you receiving any of the following services in your community? (Check all that apply)
- a. Behavioral health (for example, individual or group counseling)
 - b. Case management
 - c. Transportation
 - d. Occupational therapy
 - e. Physical therapy
 - f. Respite
 - g. Daily living skills support
 - h. Substance abuse treatment
 - i. Medication management
 - j. Recreation or leisure support
 - k. Other (please specify)
56. From what agencies are you receiving the above services?
57. Have you ever heard of the Disability Law Center of Alaska?
- a. Yes
 - b. No
58. If yes, where did you hear about them?
- a. Personal research
 - b. Family or friend
 - c. Advertisement
 - d. News
 - e. Service provider
 - f. Other (please specify)
59. Did you know the Disability Law Center of Alaska is there to assist people with disabilities who are denied access to services or benefits?
- a. Yes
 - b. No
60. Have you ever gone to the Disability Law Center of Alaska for assistance?
- a. Yes (*Continue to Questions 61 – 62 then skip to Question 65*)
 - b. No (*Skip to Question 63*)
61. What areas of assistance were you seeking help for? (Check all that apply”)
- a. Benefits (Federal, State, or VA)
 - b. Housing
 - c. Employment

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- d. Education
 - e. Insurance
 - f. Services
 - g. Community access
 - h. Other (please specify)
62. Please rate how helpful the Disability Law Center was in helping you? *(Rated on scale of 1 – 6 stars with 1 star being ‘Not very helpful’ and six stars being ‘Very helpful’)*
63. Has there ever been a time when you thought about talking with the Disability Law Center of Alaska, but did not?
- a. Yes
 - b. No
64. If yes, please describe why you did not seek out assistance from the Disability Law Center.
65. Please describe the biggest barrier to living the life you want after your brain injury.

Focus Group Question Guide

1. What is your first name and what is your favorite thing to do in Anchorage and why?
2. Since your head injury, have you needed help with legal problems or help from an attorney for anything other than a crime?
 - a. If so, what was it for?
 - b. Tell me about your experience getting the help you needed OR your experience if you did not get the help you needed.
3. What types of legal help would you or someone else with a head injury want access to?
4. What do you know about the Disability Law Center in Alaska?
 - a. Describe any help you have received from the Disability Law Center in the past.
5. How can the Disability Law Center get information about their services to you and other people with head injuries?
6. What could be done to improve legal help for people with head injuries in Alaska?
7. Anything else you’d like to add?

Appendix B. Table of Community Services Utilized by Participants

<i>Medical Providers</i>
Anchorage Neighborhood Health Center
Anchorage Neurosurgical Associates
Anchorage Oncology LLC
Alaska Imaging Associates
Mat-Su Health Services
Peninsula Community Health Services
PEAK Neurology
Alaska Neurology Center
Tanana Valley Clinic
<i>Behavioral Health Providers</i>
Greatland Clinical Counseling
Alliance Behavioral
Juneau Alliance for Mental Health, Inc.
Providence Behavioral Health Medical Group
Mat-Su Behavioral
<i>Physical Therapy Providers</i>
Providence Physical Therapy
Alyeska Therapy Center
Alaska Physical Therapy
Algone Physical Therapy
<i>Community Support Services</i>
Anchor Rides
ResCare
Foodbanks
2-1-1
Consumer Direct
Daybreak
Mat-Su Services for Children and Adults, Inc.
Office of Child Services
Providence Senior Services
Access Alaska
Southeast Alaska Independent Living
Support groups
Mary Siah Recreation Center
Wildflower Court
<i>Benefits Services</i>
Division of Vocational Rehabilitation
Workman's Compensation
Medicaid
Department of Labor Job Service
Temporary Assistance for Needy Families

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Veteran's Affairs
Joint Base Elmendorf-Richardson
<i>Alaska Native Organizations</i>
Alaska Native Medical Center
Alaska Native Tribal Health Consortium
Indian Health Service
Cook Inlet Tribal Council
Kikiktagruk Inupiat Corporation
SouthCentral Foundation
Tanana Chiefs Conference
<i>Additional Organizations</i>
Legal guardian or Trustee
Church
University of Alaska
Employer-provided insurance
National Counselor Examination Board (for legal services)
Private entities, firms or practices