

Living with a Brain Injury in Maine: Individual Experiences, Perceptions, and Needs

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**UNIVERSITY OF
SOUTHERN MAINE**

Individual Experiences & Perceptions

“When we come together as a group, we have done some pretty amazing things. With lots of support and plenty of time and pacing and strategies, and when things come together, we can contribute to the world.”

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Executive Summary

Introduction

Maine has been recognized for its recent progress in improving the lives of person with brain injury within the state. This report is the third brain injury report over the past ten years as Maine continues in its efforts to understand the service needs of persons with brain injury, broaden awareness of the impact of a brain injury, improve treatment options, and ultimately prevent brain injuries, especially in vulnerable populations. The information gained through a survey and through focus group discussions provides further context for upcoming brain injury policy decisions and resource allocation. While the causes and consequences of brain injuries have gained greater public attention, the information gathered in this report reveals that additional work is needed. The survey used in this report requested comment on a broad range of topics. For ease of understanding, the survey information has been categorized according to brain injury diagnoses, brain injury effects, and brain injury services and supports.

Survey and Focus Groups – Information Gathered

The survey respondents and focus group participants provided detailed, candid feedback on many aspects of their daily lives. The experiences and perceptions of these individuals, most of whom have been living with a brain injury for many years, dramatize the loss that results from a brain injury and the risks that an injury presents for significant additional medical and mental health diagnoses. The individuals represented here manage complex health conditions and physical and cognitive function. They consider their brain injury to be a chronic health condition that requires ongoing follow-up health and rehabilitative care, continuing access to services and supports and assistance with social activities and transportation. Many respondents reported delays in diagnosis which resulted in treatment delay and may have caused greater than necessary impairment.

The experiences of the individuals represented in this report are particularly poignant when expressing the impact their injuries have had on how they see themselves, how others perceive them, and the effect of injury on their closest relationships, and their work status. Their expressions of loss, sadness, and frustration are compelling evidence of the urgency for continued commitment to understanding their needs and the allocation of resources in ways that are most meaningful for these individuals and their family members.

Conclusions

- ◆ Survey respondents and focus group participants perceive that the healthcare and social service communities lack adequate awareness of brain injury diagnosis and treatment.
- ◆ Many individuals had a substantial delay in the diagnosis of their brain injury.
- ◆ Eighty percent of survey respondents have other diagnoses, many include multiple mental health diagnoses.
- ◆ Over 60% of respondents have had more than one brain injury.
- ◆ Persons with brain injury must manage complex health conditions, even while they have serious physical and mental functional limitations.

- ◆ Persons with brain injury consider themselves to have a chronic health condition that has lifelong impact in many domains of daily life.
- ◆ Their chronic health condition requires ongoing assistance with care management and with locating and accessing services and supports.
- ◆ A brain injury has a significant and negative impact on an individual's feelings of self-worth and competence, as well as on relationships, education, and employment.
- ◆ Many individuals feel isolated and need help with transportation and other supportive services in order to access social activities.
- ◆ Many individuals feel disconnected from regular life and from the services and supports that might be able to assist them. Most are uncertain where to go for help.

Next Steps

The final page of the report provides several suggestions for further study in order to expand knowledge in key areas that could not be addressed with the current survey. For instance, the success of several recent brain injury initiatives may not be well reflected in the current study because they are so new. In addition, young children and older adults are not represented in the survey and warrant further study. Recent recommendations of The National Centers for Disease Control and Prevention for improved tracking of brain injury incidence and prevalence and for future research focus areas will provide opportunities for states to use that information for more detailed analyses of brain injury causes, treatment, prevention, and service needs. Maine's Traumatic Brain Injury State Implementation Partnership Grant has offered the opportunity for the development of a robust network of brain injury healthcare and social service providers and brain injury advocates who have been working hard on many fronts. These stakeholders may benefit from a comprehensive, longer term strategic plan that incorporates information from recent reports and anticipates expanded data collection and research at the state and national levels.

Introduction

BACKGROUND AND CONTEXT

There has been increased focus on brain injury in the past decade, particularly over the past several years as we gain greater awareness of the risks of sport-related concussions¹, the experiences of veterans with brain injuries², the emerging science on the likelihood of brain injury in domestic and other episodes of violence,^{3,4} and as we seek to gain a better understanding of the lived experiences of persons with brain injuries.⁵ This year, an Academy award-nominated film on concussions⁶ and multiple mainstream media articles on brain injury and its devastating effects on individuals and families⁷ will further broaden societal awareness.

Maine has been recognized for its efforts in furthering awareness of brain injury and its support of the community of persons with brain injury and their families, and those who provide care and services to them. In 2013 Maine received the *Big Strides Award* from the federal Health Resources and Services Administration (HRSA) for its achievements in several brain injury-related areas such as the creation of a brain injury Medicaid waiver program⁸, encouraging participation by middle schools and high schools in concussion management programs, tracking data from those programs, and supporting neurorehabilitative clinical and direct service staff in obtaining Certified Brain Injury Specialist (CBIS) certifications.

Maine's participation in the Traumatic Brain Injury State Partnership grant funded by HRSA has provided the financial support for initiatives on several other fronts in order to improve brain injury screening, educate providers and other healthcare workers, and improve access to needed services (See Appendix D). As part of the grant activity, a Maine chapter of the Brain Injury Association of America (BIAA) has been recently established. It is partnering closely with the New Hampshire chapter and it is currently moving forward with a plan of outreach to every Maine hospital as well a plan for a series of public forums to disseminate critical information about brain injury facts and available services. The BIAA Maine Chapter publishes a monthly newsletter with an expanding database of recipients and it is currently

¹ CDC. (2016). Heads up. *Centers for Disease Control and Prevention, National Center for Injury Prevention and Control*. Accessed 20 Jan. 2016. www.cdc.gov/headsup/index.html

² US Department of Veterans Affairs. (2015). Polytrauma/TBI system of care. Accessed 20 Jan. 2016. www.polytrauma.va.gov/understanding-tbi/

³ Shields, L. B., Corey, T. S., Weakley-Jones, B., & Stewart, D. (2010). Living victims of strangulation: a 10-year review of cases in a metropolitan community. *The American journal of forensic medicine and pathology*, 31(4), 320-325.

⁴ Snyder, R. (2015, December). No visible bruises: domestic violence and traumatic brain injury. *The New Yorker*. Retrieved from: www.newyorker.com

⁵ Levack, W. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability and rehabilitation*, 32(12), 986-999.

⁶ Scott, R., Scott, G., Wolthoff, D., Shuman, L., and Cantillon, E (Producers). Landesman, P. (Director). (2015). *Concussion*. [Motion Picture]. United States: Sony Pictures.

⁷ For example, <http://www.npr.org/2015/08/09/430877562/is-football-worth-the-brain-injury-risk-for-some-the-answer-is-no>

⁸ Section 18 Home and Community Based Services for Adults with Effective Brain Injury. MaineCare Benefits Manual Chapter II, §§101-10-144 (2014).

compiling a much sought after comprehensive resource directory that will be readily available across the state for patients, families, and healthcare providers.

The Acquired Brain Injury Advisory Council (ABIAC) was formed in 2002 under a federal grant. In 2007 the Maine Legislature enacted 34-B M.R.S.A §19001, et seq, which permanently established the Council. The ABIAC consists of a broad stakeholder group that provides independent oversight, advice, and recommendations to the Legislature, the Commissioner of the Department of Health and Human Services, the Office of Aging and Disability, the Office of MaineCare Services, and to the Maine Center for Disease Control and Prevention. The Council holds public hearings and forums to gather information from persons with brain injury and other stakeholders and it files annual reports to the Legislature outlining priority issues and making recommendations for action. The Council's 2014 and 2015 reports⁹, for instance, cite a long list of its activities and accomplishments, many of which involve collaboration with other agencies and initiatives, including Maine's Disability Rights Center, the Veteran's Administration and its Maine Military Family Coalition, Maine Employment First, and the Maine Concussion Management Initiative. Through its consistent outreach, collaborative efforts, and annual recommendations, the ABIAC significantly contributes to brain injury awareness and improvement of brain injury services throughout the state and its progress-reporting provides critical accountability for continued advances.

REPORT PURPOSE AND FRAMEWORK

Despite the extraordinary work by many individuals in recent years, there remain gaps in brain injury awareness, services, education, and policy that ultimately result in diagnosis, treatment, and service delays, diminished quality of life, and increased burden for persons with brain injuries and their loved ones. This report provides data collected from a paper survey mailed to persons with brain injuries in Maine receiving MaineCare services and from focus groups of individuals with brain injury and some of their family members. It identifies several key themes that can inform brain injury policy and decision-makers and other stakeholders in ongoing efforts to provide meaningful services and supports to this community of individuals.

This report seeks to capture the individual experiences and perceptions of those individuals who have had to manage the repercussions from brain injuries. The survey and focus groups captured a wealth of information across a wide spectrum of needs within several domains of everyday life. In order to provide a framework for evaluating survey responses and focus group comments, and highlight the more noteworthy survey results, this report groups the information into the three broad areas of **1) brain injury diagnoses; 2) the effects of brain injury on relationships, education, and employment;** and **3) the services and supports that are most important to the injured person**, both at the time of the injury, in the years following the injury, and those that might be needed or desired in the future. The report includes the charts reflecting the paper survey responses as well as individual quotes taken from the open-ended survey responses and from focus group discussions. Where helpful and informative, this

⁹ Acquired Brain Injury Advisory Council of Maine (ABIAC). (2015, 2016). Brain injury in Maine: a growing public health issue. *Annual report*.

report makes comparisons to information and conclusions highlighted in either or both of the two previous brain injury reports in 2005 and 2010.

The report concludes with a summary of the most noteworthy messages from the survey and focus group data as well as several suggestions for future study that might address gaps in our current knowledge. The three focus areas are briefly described as follows:

Brain Injury Diagnoses

Information about brain injury diagnoses, including the timing of the initial diagnosis as well as the number and type of subsequent diagnoses, provides helpful context for understanding the health complexity that many individuals and family members face in the wake of a brain injury. Challenges resulting from delays in diagnoses, or confusion or uncertainties surrounding these diagnoses, and extensive co-occurring or related diagnoses are the norm for many persons with brain injury. This troubling reality significantly impacts quality of care, and quality of life in ways that remain in large part misunderstood and unaddressed by the health care community, from the perspective of persons living with brain injury.

Brain Injury Effects

We are just beginning to study and understand the lived experience of persons with brain injury. It is critical to do so in order to craft policy, manage service delivery, and ultimately be responsive and accountable to individuals and family members who have brain injury-related health and service needs. Hearing directly from persons with a brain injury and learning from their difficulties enables us to chart a course towards improvement not only for their lives, but for those who will need brain injury services and supports in the future. The survey responses and the focus group discussions underscore the heartbreaking consequences of a brain injury. Most study participants indicated that their injury has had a substantial ongoing negative impact on their relationships, on their ability to learn and to work, on their living situation, and on their physical and mental health status. These survey findings call attention to the continuing need for support and assistance for these individuals in the most important domains of their daily existence.

Brain Injury Services and Supports

Those involved with supporting the community of persons with brain injury and their families and colleagues must gain a greater understanding of the type and extent of service utilization as well as the appropriate timing of brain injury services in order to make measureable progress in fulfilling service needs. There is work to be done in improving access to services, filling gaps in services, expanding existing insufficient services, and trimming services that are underutilized so that resources are appropriately allocated in ways that are most meaningful to individuals, family members, and service providers. A better understanding of service needs, access, and utilization will inform decision-making, enhance collaboration, and support the growth of service-related networks to improve access. Accurate information about services in Maine will also facilitate use of national data as the National Centers for Disease Control and

Prevention focus increased attention on brain injury services and the associated human and financial costs.

The current survey responses and focus group discussions are persuasive evidence that we do not yet have the right combinations and levels of services in Maine to fully meet the needs of this population. The survey data, however, also provide an opportunity to make adjustments, recommit, and forge ahead armed with knowledge from the most reliable source: the experience of those with brain injuries and the persons closest to them.

PREVIOUS STUDIES

This current study is the third needs-related brain injury report in the past ten years. The first study in 2005, *The Silent Epidemic: Traumatic Brain Injury Services, Experiences and Expectations in Maine*¹⁰, outlined a comprehensive list of policy, education, and collaboration recommendations based on a survey of persons with brain injury in Maine, providers of brain injury services, and several focus group sessions with persons with brain injury and their family members. The second study in 2010, *Brain Injury in Maine: A Needs Assessment*, reviewed the current policies and programs in Maine that serve persons with brain injury and identified significant gaps in brain injury awareness, data, and services and offered several suggestions for addressing those gaps. The 2010 study did not survey individuals affected by brain injury, but instead provided a comprehensive review of policies and services in place at that time. In the intervening five years since the 2010 study, there have been policy changes and ongoing efforts in Maine that have contributed to raising awareness, expanded services, and increased caregiving competency to persons with brain injury.

2005 Report

The 2005 brain injury report resulted from an extensive paper survey of persons with brain injury and providers of services to persons with brain injuries. Several focus groups of persons with brain injury and their family members were held around the state and the session content was analyzed and included in the report. One of the “overarching theme[s] from all participants was the pressing need for education...that increases awareness, understanding and expertise” about brain injury and its impact on patients and their families. (*The Silent Epidemic*, p. 5). This theme was echoed in the 2010 report which identified several strategies for “closing the [brain injury] awareness gap in light of the evidence that brain injury “is under-identified in Maine’s schools, jails and prisons, and the mental health and substance abuse service systems”.¹¹

Many of the concerns raised by participants in the 2005 study remain primary concerns in 2015. For instance, the 2005 report stated that “[f]inding appropriate help did not necessarily follow once a proper diagnosis was provided...Participants assert the increasing need for professionals trained in the recognition, diagnosis and management of TBI”. (*The Silent Epidemic*, p. 21). Similarly, a 2015 focus group

¹⁰ The Silent Epidemic: Traumatic Brain Injury Services, Experiences and Expectations in Maine, Survey Findings, (2005).

¹¹ Griffin, E. (2010). Brain injury in Maine: a needs assessment. *University of Southern Maine Muskie School of Public Service*.

participant stated that “lack of education for brain injury professionals and families” was a barrier to receiving services that were needed. Many in the group nodded in agreement. In 2005 “[m]any participants of the focus groups expressed the need to access information and resources at the time of the injury”; and in 2015 one focus group participant mentioned, with many agreeing, “How do you get information? Primary care providers don’t know. How do you connect people with information? There is no clearinghouse for brain injury information.”

While several of the recommendations made in the 2005 report have been implemented in the intervening years and have been highlighted in the ABIAC annual reports, the similar survey results in 2005 and in 2015 may indicate that more time is needed to reach targeted persons and to expand initiatives and services recently begun as well as to track progress from more recent efforts. Other recommendations, such as tracking incidence through use of a registry, remain on the “to-do” list at both the state and national levels¹² and others, such as the development of a comprehensive brain injury resource guide, are currently underway.

2010 Report

The 2010 brain injury report offered recommendations on closing some of the policy gaps related to brain injury information, awareness, and services. It highlighted the disparities in access to services as a result of insurance coverage limits, geographic remoteness, and lack of specialized brain injury knowledge, as well as the societal costs of brain injuries resulting from undiagnosed or misdiagnosed injuries, and physical and mental health impairment related to brain injuries. Some of the service access issues are being addressed by the new MaineCare Brain Injury Waiver program and gaps in awareness are slowly closing as brain injury prevention and treatment continue to appear at the top of many lists of recommended actions for states, advocates, and other stakeholders. However, many of the data collection recommendations remain a challenge. As the National Centers for Disease Control and Prevention make progress toward their own goals of improved data collection across several brain injury-related metrics to gain more accurate incidence and prevalence estimates (CDC, 2015), states will also be able to leverage use of this information to advance state and local brain injury service and outreach objectives.

As with the 2005 report, several themes highlighted in 2010 remain concerns in 2015. For instance, the disparity in care resulting from the availability, or lack thereof, of insurance coverage or access to MaineCare funded services is an ongoing issue that was highlighted in the 2010 report. “The lack of adequate financing for needed services has major public policy implications” (Griffin, 2010, p. 6). In 2015, a focus group participant complained, for instance, that “capping therapy treatments at \$1700 per year requires us to ration our therapy. Some of us need all of the different types of therapy: speech, physical, and OT”. These issues remain on the national agenda as well; the National CDC recommends “enhance[d]

¹² Centers for Disease Control and Prevention. (2015). Report to Congress on Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation. National Center for Injury Prevention and Control; Division of Unintentional Injury Prevention. Atlanta, GA.

understanding of cost effectiveness” of TBI rehabilitation and examination of “the optimal timing, intensity, and dose of rehabilitation interventions” (CDC, 2015).

Both previous reports brought valuable information to the ongoing discussion around brain injury needs assessment and needs fulfillment. The current report is a continuation of prior work and provides further context for decisions around where to concentrate brain injury efforts and resources in Maine and how best to prioritize the upcoming work on the many goals that have already been identified.

REPORT METHODS

Survey Instrument

For ease of comparison, a survey instrument was drafted that was similar, though not identical, in content to the survey distributed in 2005. The identity of the survey recipients was obtained from the list of persons receiving MaineCare benefits related to brain injury services since Maine does not have access to the identity of persons diagnosed with a brain injury unless they are approved for MaineCare services. The decision was made to avoid a broad internet request for survey participation in order to avoid duplication of responses. It is acknowledged that those persons with brain injury who pay privately for healthcare and social services related to their injuries are not represented in the paper survey responses; they were, however, well represented in both of the focus group discussions. The paper survey was mailed by the Office of Aging and Disability Services to service recipients in May, 2015 and survey responses were collected throughout the following months. Each returned survey was numbered in order to avoid duplication.

As survey responses were received, the numbered documents were scanned into Remark Optical Mark Recognition (OMR) software program by Muskie School staff, analyzed in SPSS statistics software, and graphs were created in Microsoft Office PowerPoint. Due to rounding, percentages on the graphs throughout the report may not add up to 100%. Open-ended responses were typed into SPSS, exported to Word, and further exported to NVivo software program. Those survey questions with extensive open-ended questions were coded in NVivo according to appropriate categories and frequency of references. For those open-ended responses that could have been included in a designated response category, every effort was made to do so while still preserving the nuance in the respondent’s choice of words. A close review of the surveys reveals that some respondents entered a close-ended response as well as an open-ended response; in those instances, both responses are accounted for.

Focus Groups

The focus groups were comprised of persons currently attending existing brain injury support groups. Existing support groups were identified using the Brain Injury Association of America Maine Chapter website. Contact was made with support group facilitators and the scope of the project was explained. Support group facilitators announced the project at a group session and volunteer participants were identified. Support group facilitators obtained written informed consent, the contents of which were reviewed again at the time of the focus group. A focus group protocol (Appendix C) was drafted with several open-ended questions in order to invite free-flowing conversation. The focus group discussion

was recorded and handwritten notes were taken by focus group facilitators. Focus group audio files were transcribed in order to insure accuracy of quotes used in the report. The focus group sessions were held in the same locations as the regular support group sessions to ease anxiety and encourage meaningful participation.

Literature Review

A brief literature review was conducted to find the most recent brain injury statistics and to identify trends in national brain injury research from the perspective of the experiences of the injured person. Much of the available brain injury data is older than five years; however, Maine data from 2011 was located.

REPORT LIMITATIONS

Survey Instrument

The paper survey was mailed by the Office of Aging and Disability staff members in order to preserve the confidentiality of the persons receiving the survey. No reminder follow up notice was sent, which may have impacted the final response rate for the survey. The modest response rate for this survey may be a limiting factor in identifying trends and conclusions based on the data.

Although the survey preparers contemplated that some recipients would need the assistance of others in order to fully complete the survey, there is no way to tell which respondents received help and which did not. As a result, it is possible that some of the questions were misinterpreted or misunderstood. Where possible, however, every effort was made to honor the spirit of the responses and to place them in appropriate categories so that the experiences of each person could be considered.

Several of the survey questions related to second brain injuries. Forty percent of survey respondents indicated they had more than one brain injury; however, due to the skip patterns in the survey instrument, many respondents did not answer all of the questions about second brain injuries. As a result of the low response rate to the second brain injury follow up questions, these data are not included within the body of the report, although the survey responses for those questions are included at Appendix B.

Several survey questions ask respondents to “check ALL that apply” without ranking. While this method provides an excellent snapshot of information relevant to the question, it does not allow for close examination of a specific issue or problem. For example, survey question number 24 asks “Have any of the following stopped you from finding or using needed services (please check ALL that apply)?” Many respondents checked several answers and this provides a picture of all of the types of barriers to service utilization. It does not, however, allow one to identify the *primary* barriers to use of services.

Many of the survey questions included an opportunity for “Other” responses and provided space for an open-ended answer. Several of the graphs for these questions include notable patterns in the “Other” responses or a tally of similar open-ended responses in order to provide a fuller picture of the overall response to the survey question. The open-ended responses are not included in the Appendix in their entirety in order to preserve the privacy of the survey respondents. In addition, the inherent variation in

open-ended responses contributes to potential misinterpretation. As stated, we have made every effort to preserve the accuracy and integrity of the responses while still using the information for reporting purposes.

Focus Groups

The two focus groups, held in Portland and Augusta respectively, were comprised of persons already attending established brain injury support groups in those communities. While it was critical to receive the input provided by these participants, their views may be less representative of persons with brain injury who may be more isolated and receive less peer support than those attending regular support group meetings. Further, since the focus groups were held in more urban settings, the views of the participants may not reflect the views of persons with brain injuries who reside in more rural parts of the state.

Brain Injury Definitions

There is often confusion about brain injury terminology which can lead to misunderstandings about the nature of the diagnosis, the resulting disability risks, or the services needed to support the injured person. The Brain Injury Association of America provides the following information on its website:

Acquired Brain Injury (ABI) - *An acquired brain injury is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth.*¹³ *Examples of acquired brain injury would include stroke, tumor, neurotoxins, electric shock, or lightning strike.*

Traumatic Brain Injury (TBI) - *Traumatic Brain Injury is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force.*¹⁴ *Traumatic brain injuries include concussion, contusion, penetrating brain injury, and shaken baby syndrome.*

Traumatic brain injuries are further classified on a scale of “mild, moderate, and severe”, based on indicators involving structural imaging criteria, loss of consciousness, post traumatic amnesia, Glasgow Coma Scale¹⁵ score, and Abbreviated Injury Scale score: Head¹⁶. In its Report to Congress, The National Centers for Disease Control and Prevention National Center for Injury Prevention and Control explain that classification of TBI is challenging as a result of “the complexity of TBI and limitations of available assessment tools”. The CDC Report includes the table to the right with detail on the classification criteria for each category.

The brain injury community emphasizes that the classification of the brain injury may not necessarily align with the life impact of the injury.¹⁷ Many persons diagnosed with even a mild brain injury may still be debilitated as a result of post-injury symptoms that interfere with function and quality of life.

Table 2. Criteria used to classify TBI severity

| Criteria | TBI SEVERITY | | |
|---|--------------|------------------------|--------------------|
| | Mild | Moderate | Severe |
| Structural imaging | Normal | Normal or abnormal | Normal or abnormal |
| Loss of consciousness | <30 minutes | 30 minutes to 24 hours | >24 hours |
| Post traumatic amnesia | 0-1 day | >1 and <7 days | >7 days |
| Glasgow Coma Scale score (best available score in 24 hours) | 13-15 | 9-12 | 3-8 |
| Abbreviated Injury Scale score: Head | 1-2 | 3 | 4-6 |

Source: Brasure et al., 2012

¹² Brain Injury Association of America (BIAA). (2012). About brain injury. Accessed 20 Jan. 2016. www.biausa.org/about-brain-injury.htm#definitions.

¹³ Brain Injury Association of America (BIAA). (2012). About brain injury. Accessed 20 Jan. 2016. www.biausa.org/about-brain-injury.htm#definitions.

¹⁵ Teasdale, Sir G. (2014). The Glasgow structured approach to assessment of the Glasgow coma scale. *Glasgow Coma Scale*. Accessed 20 Jan. 2016. www.glasgowcomascale.org. Copy is included at Appendix E.

¹⁶ See generally, <http://www.aaam.org/about-ais.html>

¹⁷ In-person conversation with Kirsten Capeless, MS, Program Manager for Brain Injury Services, January 12, 2016.

The survey respondents and focus group participants had injuries resulting from many different events and the injuries spanned the range of mild, moderate, and severe. While much of the recent societal discussion has been around traumatic brain injury, the data gathered in this study evidence that while injury symptoms vary considerably among the type and severity of injuries, there is much common ground in personal experiences and perceptions, and in individual health and social service needs.

Brain Injury Statistics

It is estimated that during 2010 and 2011 there were 497 traumatic brain injury deaths in Maine and almost 2,000 hospital discharges related to traumatic brain injury.¹⁸ Every week there are, on average, nearly 200 TBI-related hospital emergency department visits. Recent data show that visits to emergency departments (EDs) related to TBI are increasing nationwide.¹⁹ ED visits for TBI increased by about 29% from 2006 and 2010 (Marin, 2014). As a comparison, total ED visits for all reasons increased by only 3.6% between 2006 and 2010. In 2011, it was estimated that the number of ED visits for nonfatal traumatic brain injuries was approximately 770 per 100,000 people in the U.S.²⁰ The National Centers for Disease Control and Prevention (CDC) estimate that 90% of annual hospital admissions for TBI are persons 16 years and older.²¹ There were about 380,000 ED visits for TBI in 2010 nationally.²² In Maine, the number of ED visits related to TBI was 81.4 per 10,000 population in 2011²³ which equates to approximately 10,500 ED visits related to TBI for Maine's 2011 population of 1.3 million persons.

These statistics likely underestimate the extent of brain injuries in the United States. The National CDC has recommended improving TBI incidence and prevalence estimates for brain injuries that are diagnosed outside of the hospital setting, as increasing numbers of patients look to primary care physicians and specialists for advice and information about TBI-related health effects.

Another recommendation of the National CDC is to improve understanding of the effectiveness of brain injury rehabilitation and to create service models to optimize care and for the provision of ongoing follow-up care for persons with TBI. While the CDC Report recognizes the gains made in brain injury interventions over the past twenty years, it also emphasizes the need for evaluation of "delivery models of rehabilitation and long-term medical care for TBI". National data also show that TBI has persistent health effects that "contribute to potential impairment, functional limitation, disability, and reduced quality of life"²⁴ and repeated TBIs can result in "prolonged and long-term effects". At five years post-injury, almost 4 in 10 individuals with TBI will have lost functionality that was regained at an earlier time after the injury (Corrigan, 2014). It is estimated that almost 50% of persons with TBI require rehospitalization within 5

¹⁸ Mervis, C., and Zwicker, K. (2014). 2010-2011 Maine injury data book: Maine CDC injury prevention program. *Maine Center for Disease Control and Prevention*.

¹⁹ Marin, J. R., Weaver, M. D., Yealy, D. M., & Mannix, R. C. (2014). Trends in visits for traumatic brain injury to emergency departments in the United States. *Jama*, *311*(18), 1917-1919.

²⁰ Health Indicators Warehouse. (n.d.) Traumatic brain injury ED visits (per 100,000). *National center for health statistics*. Accessed: 6 Jan. 2016.

²¹ Corrigan, J., Cuthbert, J., Harrison-Felix, C., Whitneck, G., Bell, J., Miller, C., et al. (2014). US population estimates of health and social outcomes 5 years after rehabilitation for traumatic brain injury. *J Head Trauma Rehabil.* *29*(6). doi: 10.1097/HTR.000000000000020.

²² Marin, J. R., Weaver, M. D., Yealy, D. M., & Mannix, R. C. (2014). Trends in visits for traumatic brain injury to emergency departments in the United States. *Jama*, *311*(18), 1917-1919.

²³ Maine Shared Health Needs Assessment and Planning Process (SHNAPP). (2015). *State report*.

²⁴ Centers for Disease Control and Prevention. (2015). Report to congress on traumatic brain injury in the United States: epidemiology and rehabilitation. *National Center for Injury Prevention and Control*. Division of Unintentional Injury and Prevention. Atlanta, GA.

years after the injury and approximately one-third require supervision or assistance during some part of their day. More than half of individuals with TBI are classified as moderately disabled or worse (Corrigan, 2014). Persons aged 30-59 at age of injury showed the most dissatisfaction with their lives five years after their TBI, with almost half of individuals aged 40-49 expressing life dissatisfaction (Corrigan, 2014).

Survey

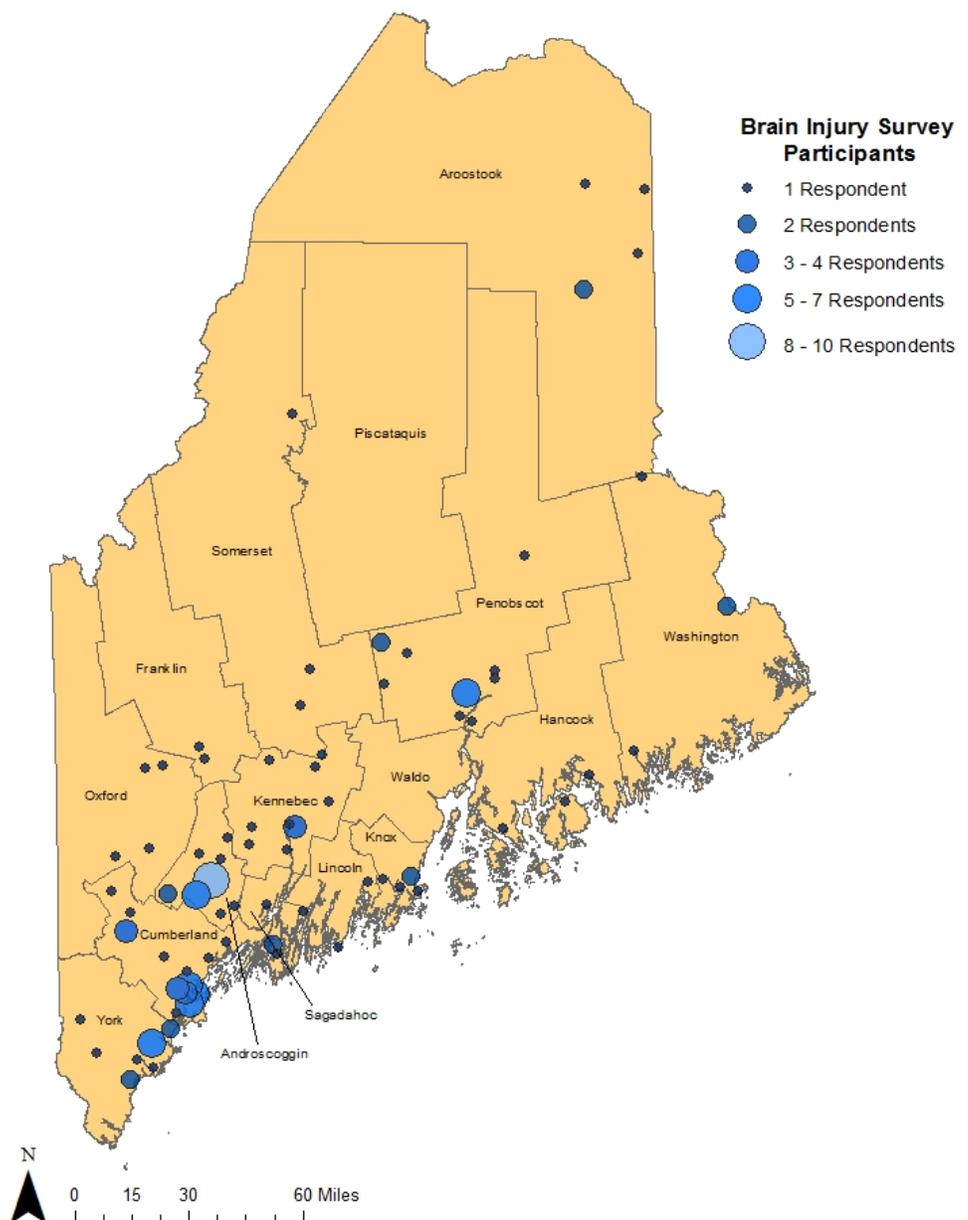
SURVEY RESPONSE RATE

A total of 845 Surveys were mailed in May 2015 to individuals who received MaineCare services related to brain injury, their family members, or representatives.

- ◆ 16% n = 132 returned filled out
- ◆ 3% n = 28 have no current address
- ◆ 2% n = 15 are deceased
- ◆ .3% n = 3 returned blank

A total of 178 surveys accounted for.

NOTE: Re-mailed 14%, n = 117, due to undeliverable addresses.



SURVEY RESPONDENT DEMOGRAPHICS

Survey respondents were primarily the person with the brain injury. Survey responses were received from all but two Maine counties. Respondents were well distributed between the genders, though less well distributed across the age spectrum. Most live on their own or with family members.

Brain Injury Demographics

Brain injuries occur across the age spectrum as a result of the many ways by which someone can receive a brain injury.²⁵ Young adults and the elderly are, however, most at risk. Very few survey responses were received from persons over the age of 60 years and, as a result, the survey does not reflect the increased risk of brain injury for older adults nor does it capture the experiences of living with a brain injury as an older adult. As the number of older Mainers continues to grow, the focus of future studies might include identifying the particular needs of older adults with respect to prevention of brain injuries, awareness of brain injury symptoms and disabilities, and access to brain injury services.

No survey responses were received from, or on behalf of persons under the age of 20 because MaineCare brain injury services are adult services. The current survey does suggest, however, the elevated risk of brain injury for young persons. 60% of survey respondents suffered their brain injury when they were 19 years or younger (Figure 8). This statistic demonstrates that parents and family caregivers of young children and adolescents with brain injuries may be particularly in need of information and support. As one focus group participant stated, “there needs to be someone available to talk with the family of a person with a brain injury.” And another, “there are no services for the family of a person with brain injury.”

Nearly 60% of respondents were between the ages of 40 and 59 years old and most had received their brain injury when younger and have, therefore, been living with the effects of their brain injury for many years. Their experiences provide a unique perspective on living with brain injury over an extended period of time, but they may not entirely reflect recent additions and improvements in services in Maine nor the greater levels of awareness and brain injury knowledge in the provider and caregiving communities.

Survey respondents were spread across Maine and all but two counties were represented. The majority of respondents were, however, from the more urban counties of Cumberland, Androscoggin, Penobscot, and York (Figure 2). Rural Mainers have greater challenges accessing many healthcare services, and brain injury services are likely no exception. Future reports might focus on more effective ways to support rural Mainers with brain injuries. As one focus group participant offered: “There are really no services north of Bangor; services are really lacking. People come down from Aroostook to get services here.”

Most survey respondents and focus group participants are living in their own homes or living at home with family members or other relatives (Figure 5). Many of the responses to later questions about service needs reveal how much individuals rely on these family members for assistance accessing services and obtaining transportation for daily life.

²⁵ <http://www.traumaticbraininjury.com/understanding-tbi/what-are-the-causes-of-tbi/>

I am a/an:

n = 126

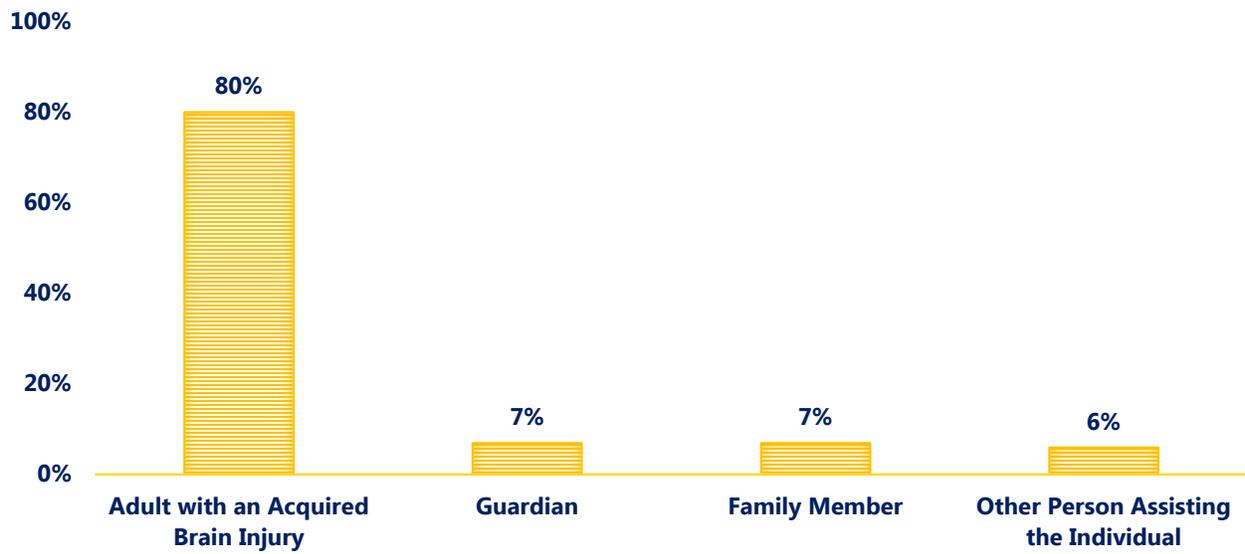


Figure 1 – Survey Question #1

- ◆ The primary responders to the survey were the persons with the brain injury.

I live in:

n = 132

| | Frequency | Valid Percent |
|---------------------|------------|---------------|
| Cumberland | 32 | 24% |
| Androscoggin | 23 | 17% |
| Penobscot | 17 | 13% |
| York | 15 | 11% |
| Kennebec | 11 | 8% |
| Aroostook | 6 | 5% |
| Knox | 5 | 4% |
| Sagadahoc | 4 | 3% |
| Washington | 4 | 3% |
| Somerset | 4 | 3% |
| Hancock | 3 | 2% |
| Oxford | 3 | 2% |
| Franklin | 3 | 2% |
| Lincoln | 1 | 1% |
| Unknown | 1 | 1% |
| Total | 132 | 100% |

Figure 2 – Survey Question #2

- ◆ There were no survey responses from Piscataquis and Waldo counties. Piscataquis County is the least populated county in Maine. Waldo County has a population that approximates Knox County.
- ◆ The number of survey responses from each county is approximately representative of current population estimates for Maine’s counties,²⁶ with the most populated counties providing the most survey responses, with the exception of Lincoln County, which has a population similar to Sagadahoc County.

²⁶ <http://www.census.gov/popest/data/index.html>

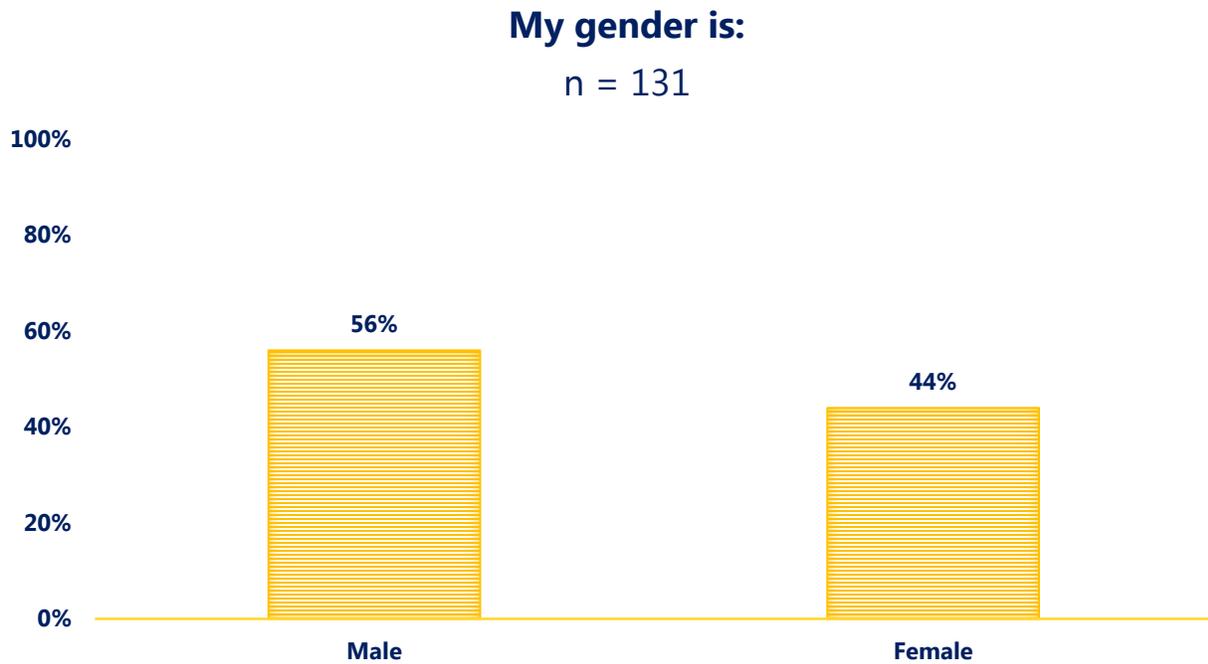


Figure 3 – Survey Question #3

- ◆ Survey respondents were well distributed between the genders.
- ◆ Focus group participants were also nearly equally distributed between the genders.

Age at time of survey based on Date of Birth (DOB)

n = 132

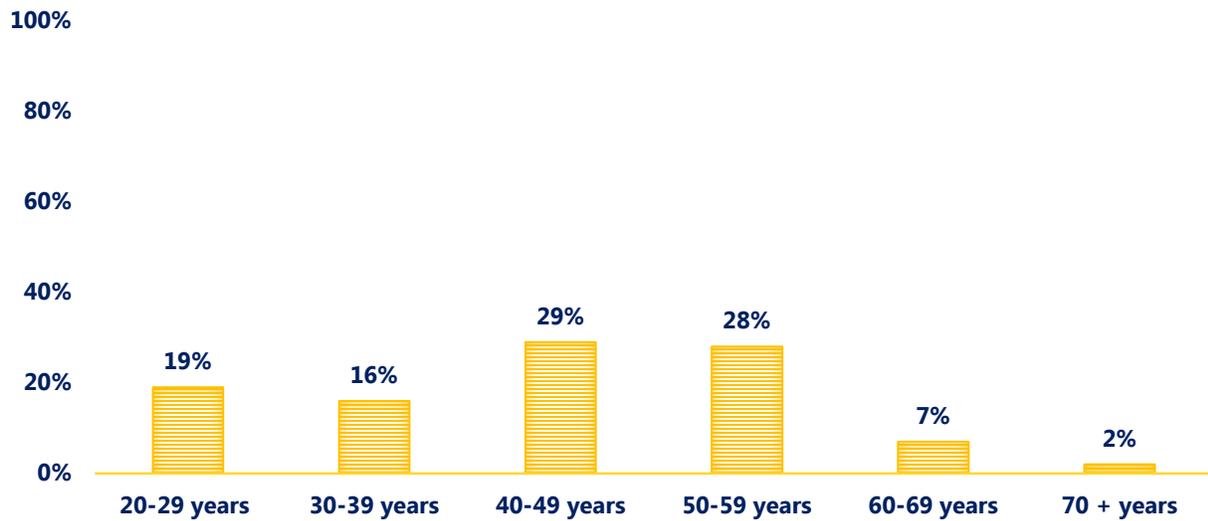


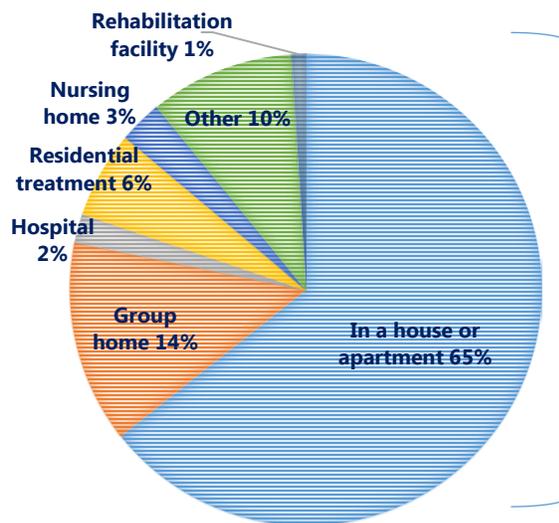
Figure 4 – Survey Question #4

- ◆ The majority of survey respondents received their brain injury under the age of 19 (See Figure 8); this means that most respondents have been living with their brain injury for many years.
- ◆ There were no survey respondents under the age of 20 because MaineCare services are adult services.²⁷

²⁷ Many brain injury services and supports for children are received through the school systems.

Where are you currently living?

n = 118



Respondents Living In a House or Apartment:

n = 82

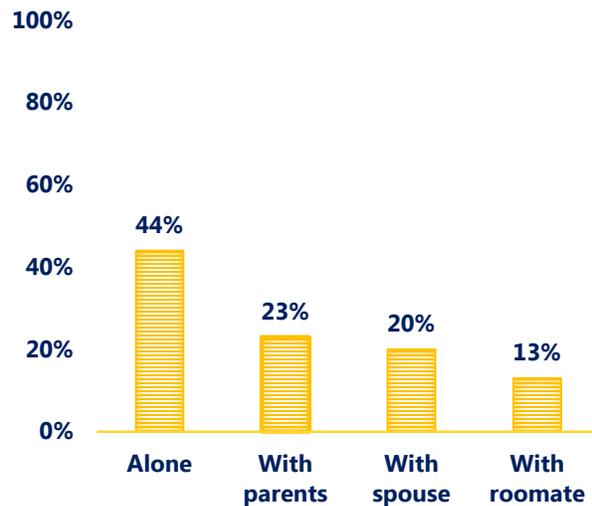


Figure 5 – Survey Question #43

- ◆ Of the 65% who responded that they lived “In a house or apartment”, they indicated that they live:
 - Alone - 44%
 - With a parent - 23%
 - With a spouse - 20%
 - With a roommate - 13%
- ◆ Of the 10% of “Other” responses, most indicated they were living with various other family members, e.g., sister, aunt and uncle, “ex- in laws.”

BRAIN INJURY DIAGNOSES

Many individuals have had more than one brain injury and most have secondary diagnoses that they did not have before their brain injury. This fact highlights the health complexity and related challenges for this population. Delays in diagnosis of brain injury are common.

Brain Injury Diagnoses

Age at Time of Injury

The majority of survey respondents received their brain injury under the age of 19 years (Figure 8). This is consistent with national statistics. Very young children, adolescents between the ages of 15-19, and older adults are the populations most at risk for traumatic brain injury and the most likely to have emergency department visits as a result of injury. (CDC Report, 2015).

Multiple Brain Injuries and Causes

Sixty-one percent of survey respondents have had more than one brain injury. This suggests the increased risk of additional injuries once an individual has had one brain injury. Many brain injuries are caused by falls, motor vehicle accidents, and sports-related blows to the head and almost 40% of survey respondents indicated that a vehicle accident was a contributing cause of their brain injury. The survey results do not reflect the most recent statistics on the frequency of sports-related brain injuries, and only 2% of persons surveyed indicated they had a sports-related injury. This may be because the majority of survey respondents are middle aged and received their brain injuries several years ago when sports concussions were less likely to be referred for treatment or result in a brain injury diagnosis. Follow up studies that include persons with brain injuries that are not on MaineCare services may show recent successes in the reporting and diagnosis of sports-related concussions. Similarly, this survey does not reflect the risk of brain injury for older adults since many with brain injuries sustained earlier in life may not have been diagnosed as having a brain injury. In addition, it is possible that some of the older adults with a brain injury diagnosis who are currently on MaineCare may have dementia and already be living in nursing or residential care facilities and may have received or been able to fill out the survey.

Delay in Diagnosis

The data also show that over 40% of survey respondents received their diagnosis of brain injury more than three months after their injury, with a full 22% receiving their diagnosis *five or more years* after their injury. This delay in diagnosis reveals that some persons currently living with the often disabling consequences of a brain injury may not realize they have an injury and are likely not receiving appropriate treatment or services to support them in recovery. While nearly all survey respondents found out that they had a brain injury from someone in the health professions, this diagnosis was untimely for many. We do not yet know the cause of the delays in diagnosis nor whether or how the delays may contribute to diminished physical or cognitive function or quality of life.

In their 2015 Report to Congress, *Traumatic Brain Injury in the United States*²⁸ (hereinafter "CDC Report"), the Centers for Disease Control and Prevention describe some of the challenges related to brain injury diagnosis, several of which may be reflected in our current survey and focus group responses. For

²⁸ Centers for Disease Control and Prevention (2015). Report to congress on traumatic brain injury in the United States: epidemiology and rehabilitation. *National Center for Injury Prevention and Control*. Division of Unintentional Injury and Prevention. Atlanta, GA. p. 21.

instance, for young children, “some of the common behavioral manifestations of TBI in children and adolescent such as lack of inhibition, difficulty reading social cues, and emotional lability, might be mistakenly attributed to other causes” (CDC Report, 2015, p. 21). When asked about the barriers to receiving “needed services”, a full 16% of survey respondents indicated that “I didn’t know I had a brain injury”. Since 60% of our survey respondents received their brain injury when they were under the age of 19, a question for future study may be to better understand how confusion about challenging behaviors contributes to delays in diagnosis despite increased societal awareness of brain injury in children and adolescents as a result of sports-related injuries, falls, motor vehicle accidents, and similar events.

Nearly 30% of survey respondents ultimately received their diagnosis from someone other than, or in addition to, a physician at a hospital. The CDC Report also mentions that persons residing in rural geographical areas have reduced access to specialized services and transportation challenges and are therefore more vulnerable to diagnosis and treatment delay. Since “primary care physicians are more likely to be the single source of care” for persons with brain injury in rural areas, lack of “advanced training” may interfere with the timely diagnosis of TBI-related conditions (CDC Report, 2015, p. 21).

Multiple Diagnoses

Advances in medical technologies and treatments have resulted in a significantly improved survival rate for brain injuries in recent decades.²⁹ The consequence, however, is that more individuals are living with disabling and complex health conditions. Over half of the survey respondents indicate that they have had more than one brain injury and a full 80% have diagnoses in addition to their brain injury, most of which they did not have prior to their brain injury. One of the most common themes in the open-ended questions to the survey as well as in the focus group discussions, was how challenging it is to manage one’s daily affairs and complex health circumstances with limited cognitive and physical function. Individuals report that understanding and patience from family members, friends, and healthcare providers is desperately needed, as well as support and assistance with access to care and care coordination. Several focus group participants noted that the healthcare system is challenging to navigate -- “imagine having to do so with a brain injury” and its attendant cognitive and other limitations.

²⁹ Zink, B. J. (2001). Traumatic brain injury outcome: concepts for emergency care. *Annals of emergency medicine*, 37(3), 318-332.

Have you had more than one brain injury?

n = 130

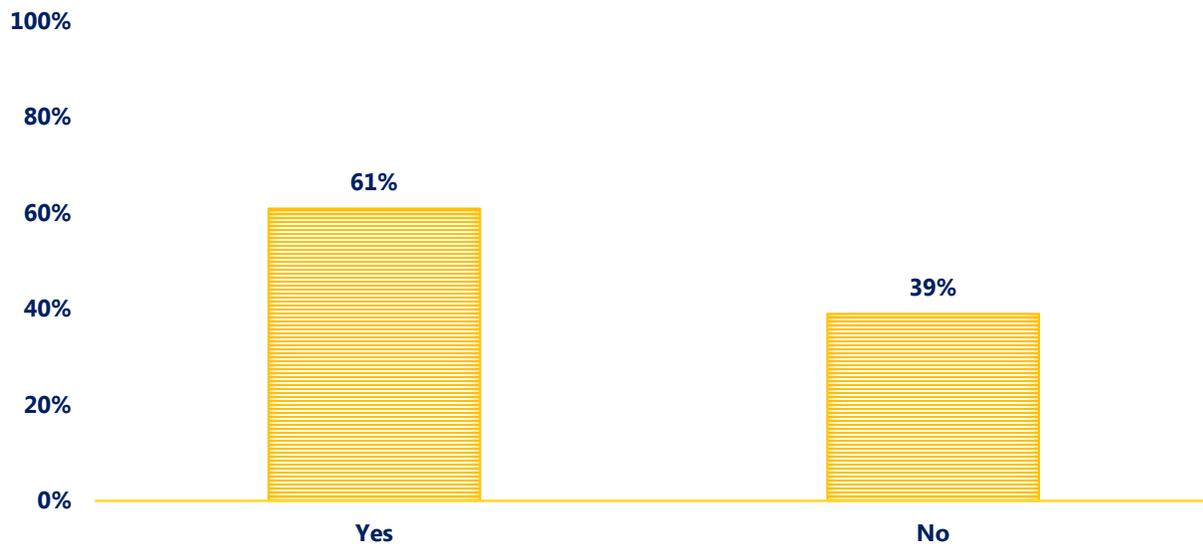


Figure 6 – Survey Question #5

- ◆ Over 60% of respondents have had more than one brain injury. This reflects the significant ongoing risks for those persons who suffer a brain injury.
- ◆ Multiple brain injuries also reflects the health complexity for persons and families struggling to manage in the wake of the initial injury.

Individual Experiences & Perceptions

- ◆ "I had a brain tumor and then I also had a stroke, which left me paralyzed."
- ◆ "Before my injury, I had four concussions."
- ◆ "I had ridden [horses] all my life and had several concussions."

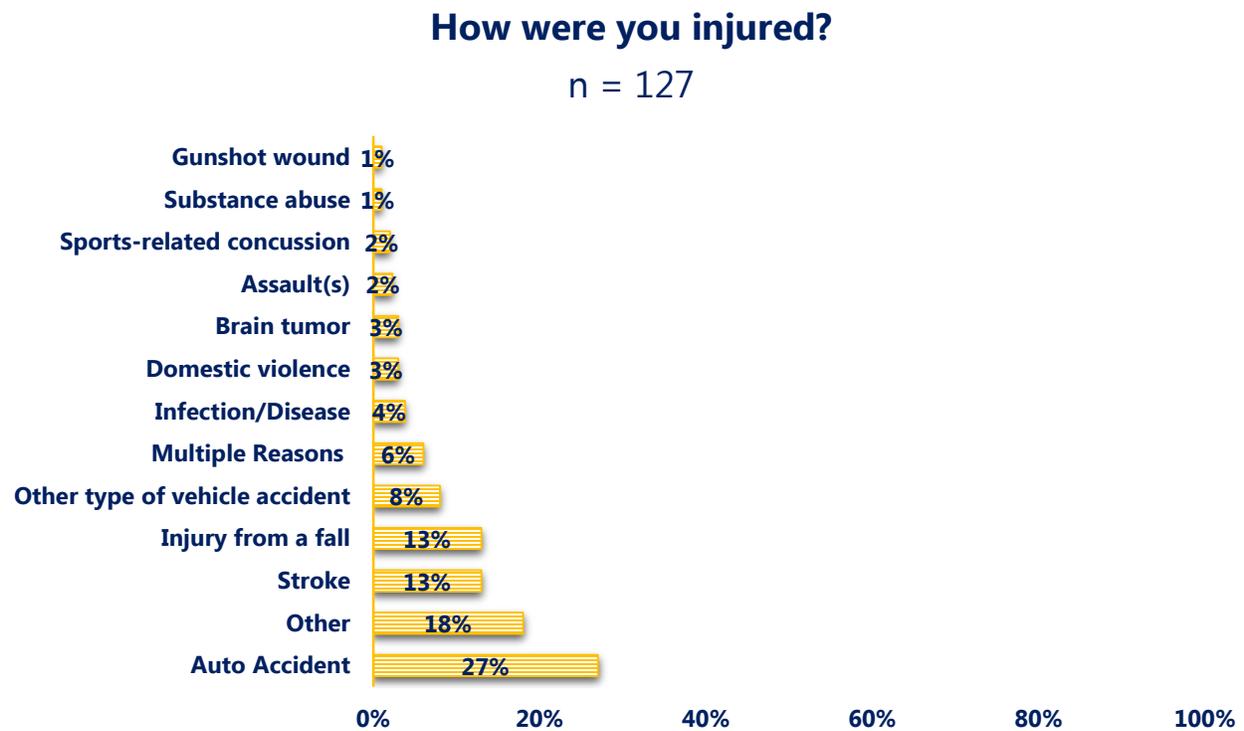


Figure 7 – Survey Question #7

- ◆ Over a quarter of the brain injuries of survey respondents were the result of auto accidents and of those, 68% identified as being male. This is consistent with national statistics.³⁰
- ◆ When all motor vehicle-related brain injuries are added together, this results in over one-third of all brain injuries reported in this survey. Five persons responded in the “Other” section, that their brain injuries were the result of a motor vehicle accident plus an additional cause(s).
- ◆ “Other” causes of brain injury identified by respondents were, for instance, episodes of self-inflicted or other-inflicted violence, various other medical causes, e.g., aneurysm, and non-vehicular accidents, e.g., near-drowning, work-related concussion.

³⁰ Traumatic Brain Injury (n.d.), What are the causes of traumatic brain injury? *Traumaticbraininjury.com* Accessed 11 Jan. 2016.

How old were you when your brain injury occurred?

n = 120

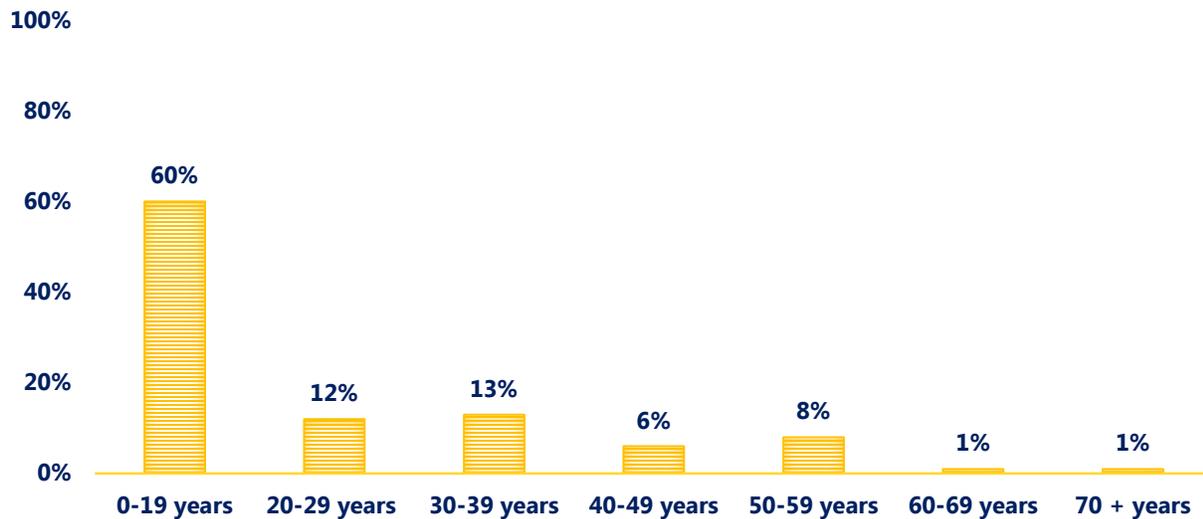


Figure 8 – Survey Question #8

- ◆ 60% of respondents identified being under the age of 19 when the brain injury occurred.
- ◆ Of these:
 - 33% were injured in an auto accident or other type of vehicle accident
 - 24% were injured by other means, e.g., non-vehicle accidents, abuse, near drowning, lack of oxygen at birth.
 - 14% were injured from a fall
- ◆ These survey results do not reflect the risk of brain injury to older adults.

How severe were your injuries?

n = 124

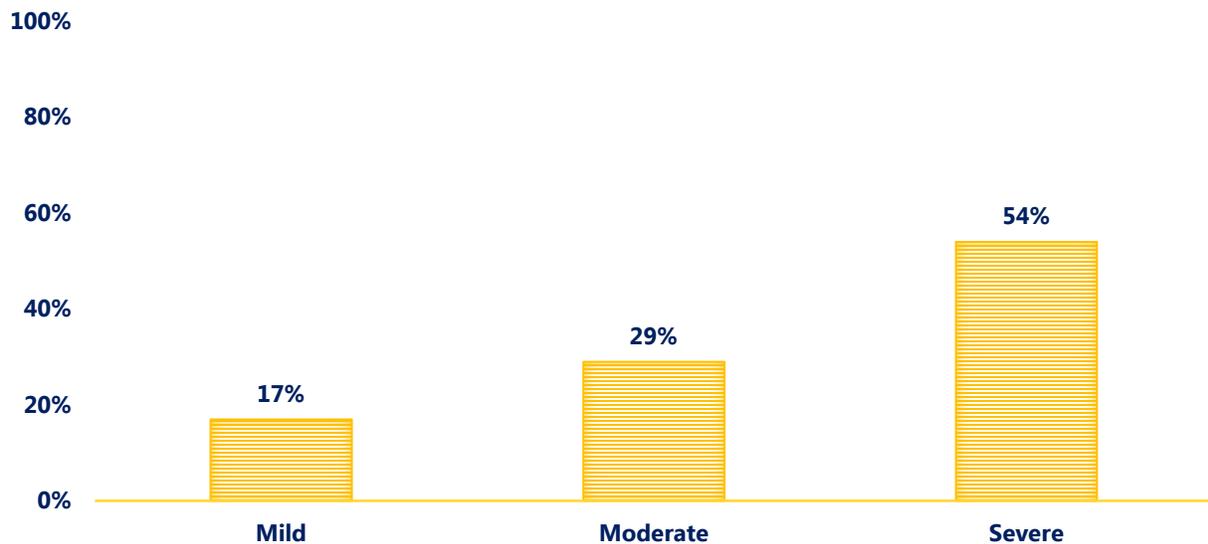


Figure 9 – Survey Question #10

-
- ◆ Over half of the respondents have suffered a severe brain injury and nearly one-third have a moderate injury.
 - ◆ It is noteworthy that even mild and moderate brain injuries can result in limitations that impact daily function, relationships, and quality of life.
 - ◆ The percentage of survey respondents reporting a severe brain injury has increased to 54% from 40% of respondents in the 2005 survey.

How long after your most severe brain injury were you diagnosed?

n = 116

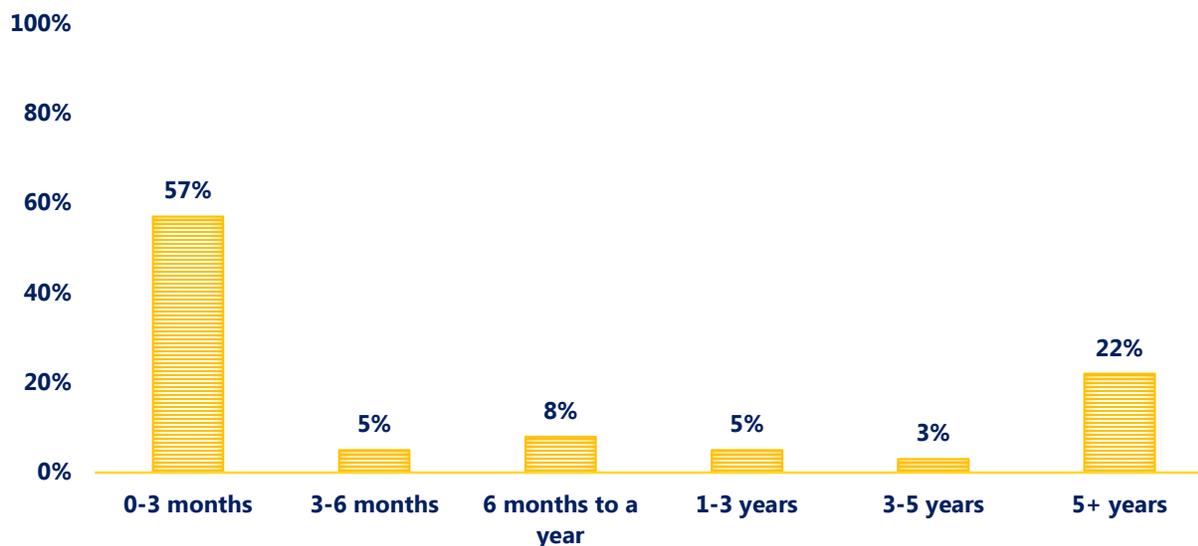


Figure 10 – Survey Question #9

- ◆ While just over half of the brain injuries were diagnosed soon after the injury, it is notable that 25% were not diagnosed until three or more years after the injury.
- ◆ Delays in diagnosis are particularly problematic for children and adolescents, for whom early intervention is essential to successful outcomes.³¹

Individual Experiences & Perceptions

- ◆ “There are many who haven’t been diagnosed and they are struggling to function, especially in rural areas. They are wondering what is wrong and ‘Why can’t I do this?’”
- ◆ “In my case, they did not even have brain injury listed as a problem. Instead, they gave me a mental health diagnosis. That didn’t work out too well.”
- ◆ “They said ‘go home, you’ll be fine.’ They are reluctant to diagnose you; [they said] ‘it’s a mental illness.’”
- ◆ “I went back to work within 48 hours... I would never have done that if someone had said ‘You have injured your brain.’”

³¹ Ponsford, J., Willmott, C., Rothwell, A., Cameron, P., Ayton, G., Nelms, R., ...& Ng, K. (2001). Impact of early intervention on outcome after mild traumatic brain injury in children. *Pediatrics*, 108(6), 1297-1303.

For your most severe brain injury, how did you find out that you had it? (please check ALL that apply)

n = 132

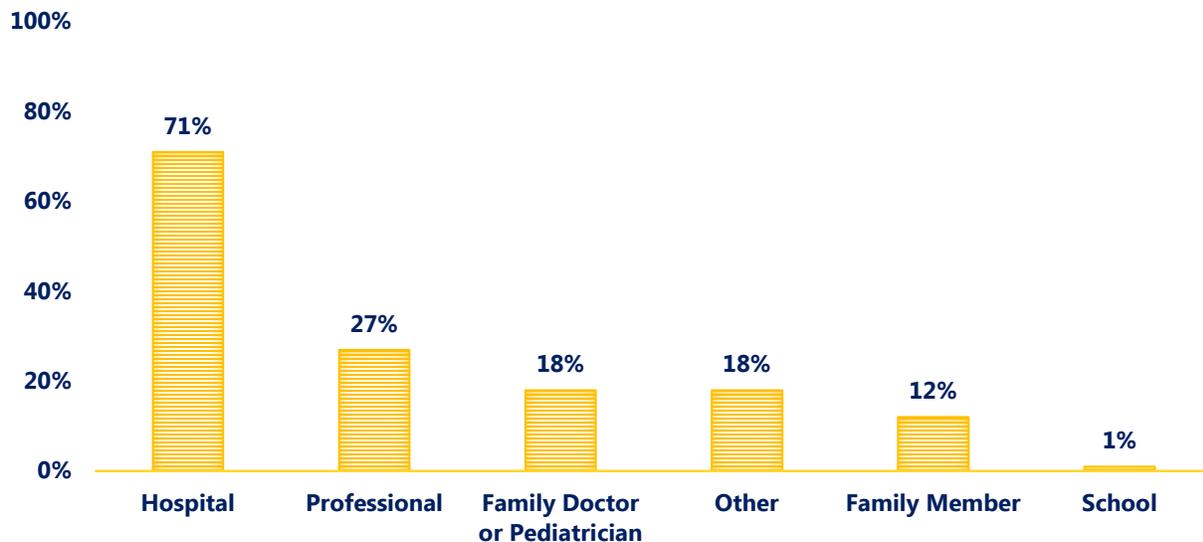


Figure 11 – Survey Question #11

- ◆ This survey question asked for “all that apply”; 39 respondents selected more than one option.
- ◆ These results reveal that a variety of health professionals are often involved in the diagnosis of brain injuries.
- ◆ The “Other” responses include primarily healthcare persons and settings, e.g., “Psychiatric hospital,” “Center for Integrated Rehabilitation,” “Neuropsych doctor”.

Individual Experiences & Perceptions

- ◆ “There are many people out there...who don’t even know they have a brain injury, especially in rural areas.”
- ◆ “I didn’t realize for years that I had a brain injury.”

Do you have another diagnosis in addition to the brain injury?

n = 129

If yes, (please describe)?

n = 98

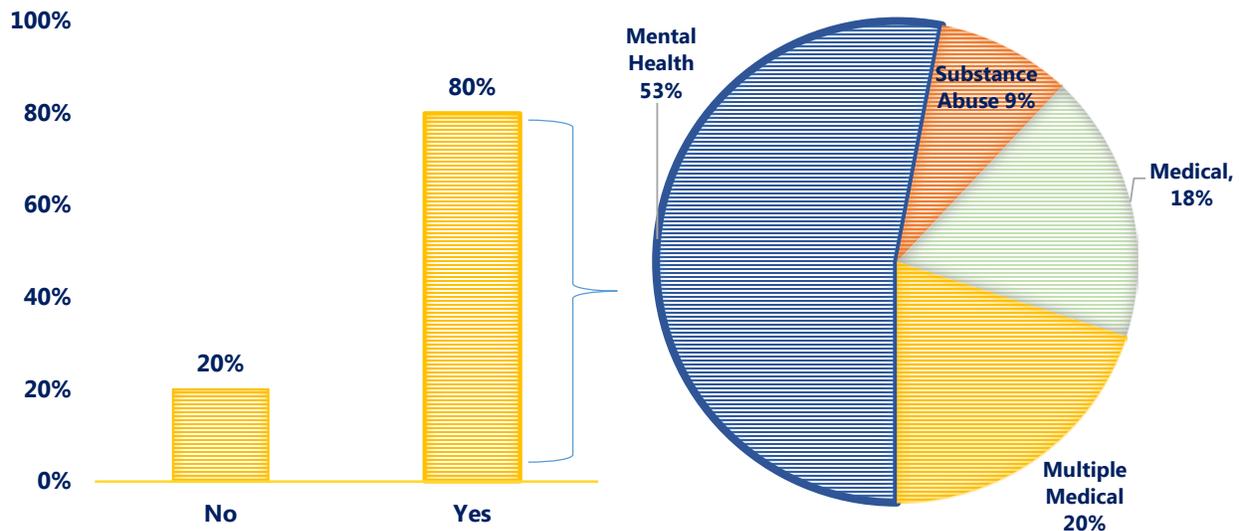


Figure 12 – Survey Question #12

- ◆ Nearly all survey respondents are dealing with physical and mental health conditions in addition to the original brain injury.
- ◆ 53% of those with additional diagnoses, have mental health diagnoses. 25% of those with additional diagnoses have multiple mental health diagnoses.
- ◆ 18% of respondents have one additional medical diagnosis and 20% have multiple additional medical diagnoses. 9% have an additional substance abuse diagnosis.
- ◆ Multiple mental health diagnoses included diagnoses of, for example, PTSD, Schizophrenia, Bipolar, Personality Disorder, Paranoia, Panic Disorder, and Obsessive Compulsive Disorder.

Did you have this diagnosis before your brain injury?

n = 118

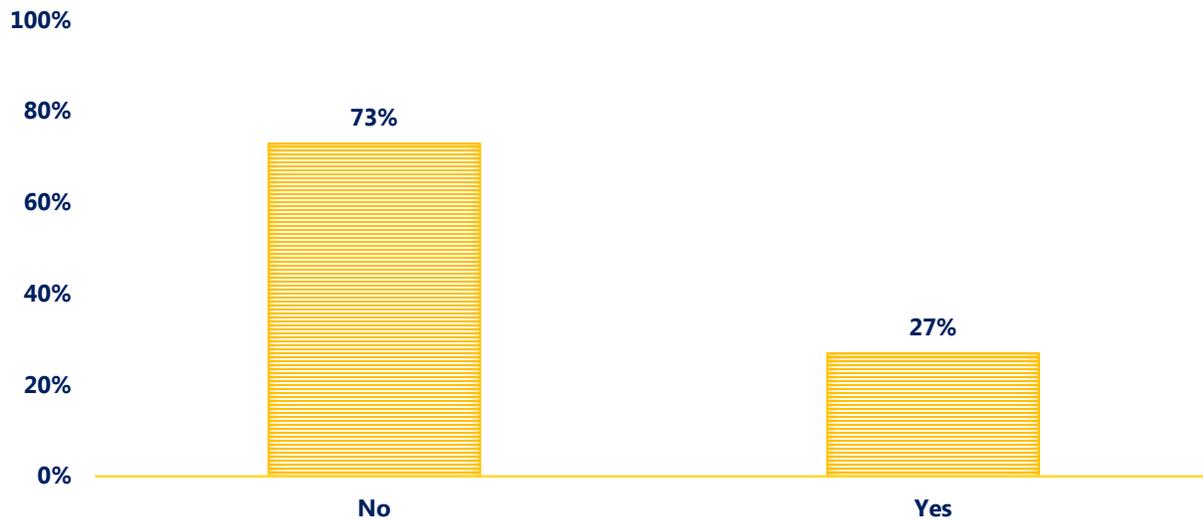


Figure 13 – Survey Question #13

- ◆ Nearly three-quarters of the respondents with additional diagnoses, did not have these diagnoses before the brain injury.
- ◆ These responses highlight the strong correlation between brain injury and ongoing, complex health conditions.

Individual Experiences & Perceptions

- ◆ "Brain injury is not an acute condition, but it is treated like one. It is a chronic condition."
- ◆ "Progress for us is figuring out strategies to cope with the limitations."
- ◆ "We have a cognitive disability and we are being asked to do cognitive things to manage our injury."
- ◆ "So we are supposed to not get depressed? We still live with this ongoing, chronic illness."
- ◆ "I am also legally blind. To decipher a bus schedule is hard for a person who has had a brain injury."

Do you have an alcohol, substance abuse or self-medicating problem?

n = 126

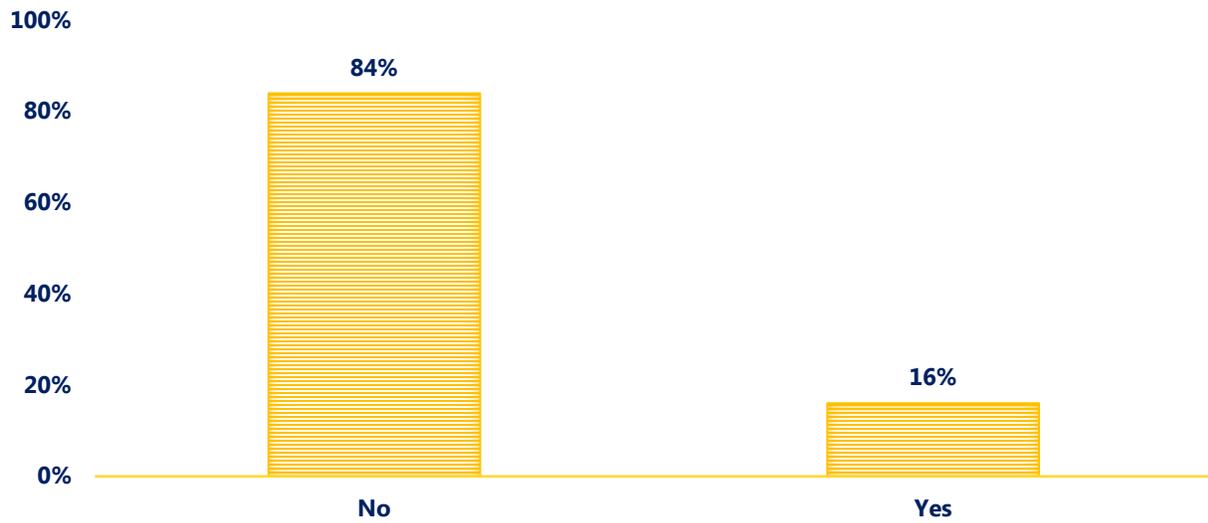


Figure 14 – Survey Question #14

- ◆ Very few respondents reported alcohol or other substance abuse issues. This response is somewhat consistent with the responses to Survey Question #12 (Figure 12) indicating that of those persons with other diagnoses, 11 responded that the diagnoses were related to substance abuse.

BRAIN INJURY EFFECTS

Survey responses indicate that nearly all persons with a brain injury feel differently about themselves as a result of the injury. Many feel misunderstood by others and are very aware that others treat them differently. The brain injuries have a profound effect on relationships, activities, education, and work.

Brain Injury Effects

The past several years has seen increased research focus on the “perceptions and lived experiences of people with TBI to inform strategies for the evaluation of services”.³² The community of persons with brain injury has become more visible and outspoken about the challenging consequences of brain injuries. As Maine and the nation continue in efforts to provide appropriate medical care to persons with brain injury, it is important that simultaneous effort is made in addressing the mental health and emotional challenges that often accompany brain injuries.

The open-ended responses to the survey questions that ask about “how your brain injury has affected your life” and the focus group discussions overall, describe significant obstacles to navigating family and work relationships in the wake of injury. Many respondents feel very different from their “pre-injury” selves and they are often misunderstood by others, including close family members. Many have “lost friends” and spouses and are sometimes “made fun of, picked on, [and] labeled”.

The scientific literature in this area describes feelings of loss that include disconnection from one’s pre-injury self, a mind-body disconnect, and social disconnect. (Levack, 2010, p. 994). This theme runs throughout the personal stories highlighted in the 2005 Maine needs assessment report on persons with brain injuries as well as in this current study. As one focus group participant described it: “It’s challenging when you don’t want to be treated differently, but things *are* different”. Another stated that even “counselors...have a hard time understanding a person with a brain injury”. Studies have identified that reconstructing one’s self-concept after severe brain injury is significantly assisted by social engagement and social support which then leads to improved “psychological functioning, community integration, family functioning, life satisfaction, and quality of life”.³³ (Douglas, 2013, p. 70).

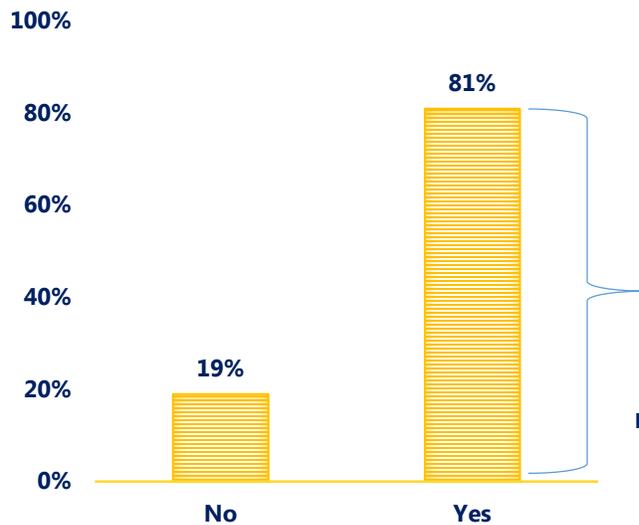
Of the many and varied responses to survey question number 46 asking “What are the three most important services that are missing or need to be developed to help you”, the highest number were in the social or activities category. The comments that accompanied the answers to this question hint at the magnitude of loss associated with brain injuries and include: “someone to spend time – friend, girlfriend, wife,” “contact with my peers,” “I want a relationship,” “get me a cat as company,” “get me a new roommate for company.” We have made advances keeping persons with brain injury alive, and now it is time to better understand and respond to their need for meaningful social engagement in our efforts to enhance quality of life.

³² Levack, W. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability and rehabilitation*, 32(12), 986-999.

³³ Douglas, J. M. (2013). Conceptualizing self and maintaining social connection following severe traumatic brain injury. *Brain injury*, 27(1), 60-74.

Has your brain injury changed how you feel about yourself?

n = 124



If yes, (please describe)?

n = 93

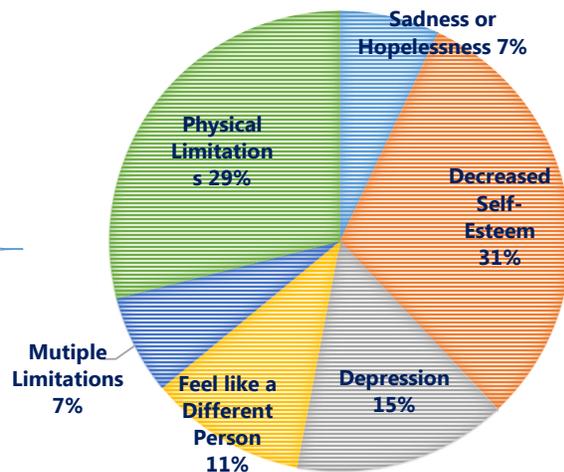


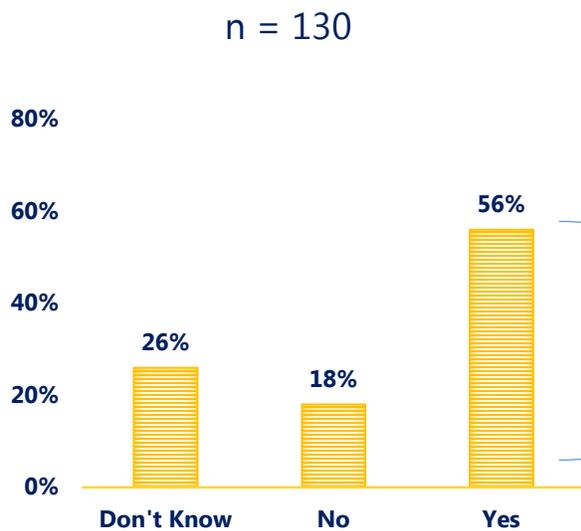
Figure 15 – Survey Question #16

- ◆ 81% of respondents indicate changes in the way they perceive themselves as a result of the brain injury.
- ◆ This response underscores the immense loss of identity associated with a brain injury and the unique nature of treatment and service interventions that should be available for this population.
- ◆ Of those who provided an answer to “Yes (please describe)”, the responses could be categorized as follows:
 - Decreased Self-Esteem - 31%
 - Feel like a Different Person - 11%
 - Physical Limitations - 29%
 - Sadness or Hopelessness - 7%
 - Depression - 15%
 - Multiple Limitations - 7%
- ◆ The open-ended responses to this question were especially poignant and several are referenced on the next page. These comments provide a strong sense of how a brain injury profoundly influences how respondents feel about themselves.

Individual Experiences & Perceptions

- ◆ "I was a teenager at time of injury. I never completed the teen to adulthood phase. It completely changed my life forever."
- ◆ "I am not the same person."
- ◆ "I feel insecure and different."
- ◆ "It is hard to find people who understand."
- ◆ "My injury has made feel like I'm not good enough as a... person. I also struggle with the fact that I feel less capable and confident."
- ◆ "Most days I feel overwhelmingly depressed." "I feel inadequate, unneeded, and unproductive."
- ◆ "It is a really strange thing remembering to do things, but you don't know how to do them anymore."
- ◆ "I am never going to get back to who I was before, but that doesn't mean I can't still make progress."
- ◆ "I have to process one thing at a time."
- ◆ "The fatigue is just incredible."
- ◆ "My struggle shows that the face of brain injury is not pretty."

Has your brain injury changed how people respond to you?



If yes, (please describe)?

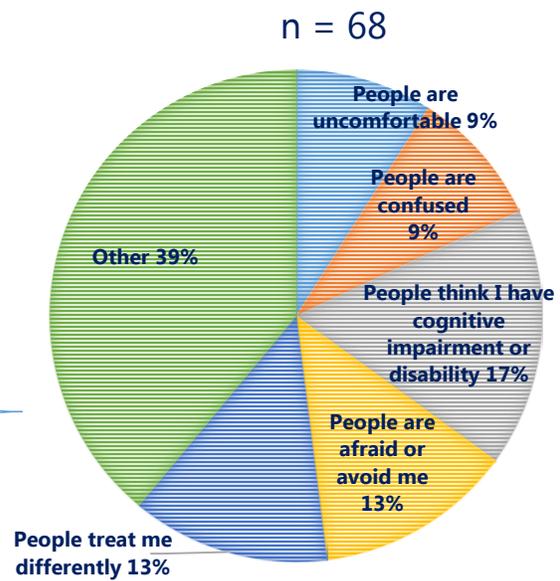


Figure 16 – Survey Question #17

- ◆ Of those who provided an answer to “Yes (please describe)” n=68, the responses could be categorized as follows:
 - Other - 39%
 - People think I have cognitive impairment or disability - 17%
 - People treat me differently - 13%
 - People are afraid or avoid me - 13%
 - People are uncomfortable - 9%
 - People are confused - 9%

- ◆ Of the 39% (“Other”) that could not be easily categorized, all had a negative association, e.g., “treat me like a child,” “family no longer visits,” “very difficult to have regular conversations.”

If yes, are you concerned about other people's perceptions of you?

n = 100

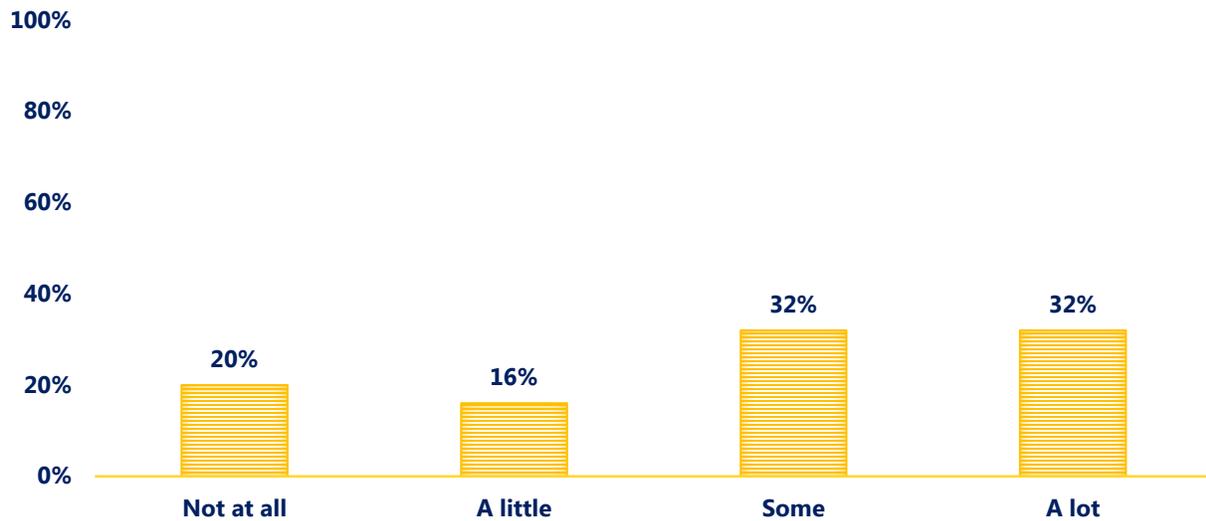


Figure 17 – Survey Question #18

- ◆ Over three-quarters of respondents have concern about others' perceptions of them and nearly one-third of those have "a lot" of concern.
- ◆ Some of the respondents who answered "Don't Know" or "No" to the question "Has your brain injury changed how people respond to you?" (Fig. 16), still provided a response to the question above other than "Not at all". This indicates that while some respondents may feel that others do not respond to them differently, they are still concerned about others' perceptions of them.

Individual Experiences & Perceptions

- ◆ "No one wants to take a chance to get to know me for me."
- ◆ "A lot of my friends and family members are now afraid/worried/concerned."
- ◆ "There is a lot of misunderstanding."

Has your brain injury had an impact on any of these areas of your life (please check ALL that apply)?

n = 132

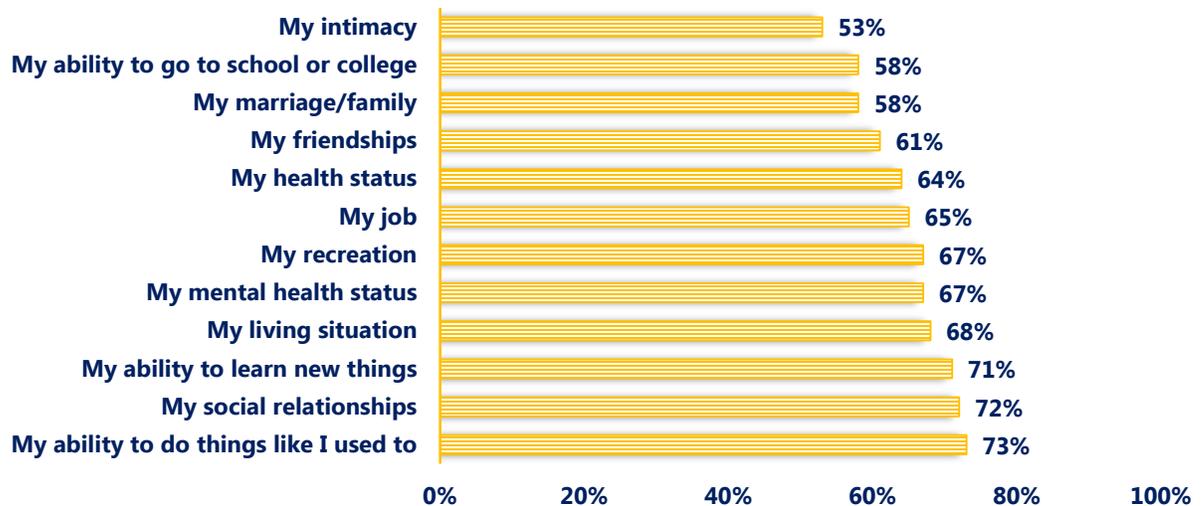


Figure 18 – Survey Question #20

- ◆ Most respondents indicated that their brain injury had an impact in several areas of life.
- ◆ This graph highlights the extent to which a brain injury affects quality of life across the spectrum of human relationships and activities.
- ◆ The high percentage of responses in the categories of relationships and activities is consistent with the open-ended survey responses to the questions about “most important services” graphed at Figures 27, 28, and 29.

Individual Experiences & Perceptions

- ◆ “Pet therapy - my dog - got me through a period when I just wanted to isolate myself. There were no services for me; I did not qualify.”
- ◆ “I worry about isolation. I went to an outpatient counselor who didn’t know anything. It took a long time to find the right counselor who could help with brain injury.”

BRAIN INJURY SERVICES & SUPPORTS

A consistent percentage of person with brain injury are not receiving needed or desired services and supports. Survey and focus group participants request more services, greater awareness, and improved access to existing services. Survey responses highlight a need for social and behavioral health services, and focus group discussions highlight a need for case management services.

Brain Injury Services and Supports

“Next to non-existent” was how one focus group participant answered the question: “In one or two words, what comes to mind when you think of brain-injury services in Maine?” This response highlights that for some persons, there is a feeling that no one is out there to assist them; that they are alone in facing and managing a new reality in the wake of injury. While brain injury services and supports are increasing in Maine and there are greater levels of outreach and awareness just in the past few years, there are still challenges in widening access to services and linking specialized services to the persons and families who need them.

The survey instrument asked a variety of service-related questions in order to better understand service utilization and unfilled service needs. The first two charts ask about sub-categories of acute care and rehabilitative care services. Figures 21, 22, and 23 ask the survey respondents to identify where they would place themselves along a spectrum of need for any one or more of a long list of specified services and supports. The graphs for the open-ended questions about service needs that were at the end of the survey instrument are included in this section as a continuation of the overall picture of service use and service gaps. There are also several assessment-type questions about education and employment and follow up questions about education and employment service needs.

Survey responses confirm that persons with brain injury use a wide variety of services and supports, ranging from acute healthcare services, to medical and vocational rehabilitation services, to social and activity supports, and home care and transportation services. When asked about services that are missing and still needed, the most frequent responses also span that wide spectrum, with the most frequently cited needs as social needs and behavioral therapy services (see Figure 28). Similar patterns are seen when family members are asked this same question (see Figure 29). These answers support the survey responses in the previous section on the effects of brain injury and the toll it takes on relationships, attitudes, behavior, and quality of life.

The focus group discussions on this topic often centered on the lack of awareness on the part of many healthcare workers of the available service array unless individuals were in a rehabilitative setting. Once released from, or insurance no longer paid for, rehabilitation services, several participants felt that they became disconnected from persons who could help them locate continuing support. One participant stated, “There were no services for me; I did not qualify. I just had to take care of it”. Another stated, “There are no services once you are beyond a critical point”. Many focus group participants echoed the sentiment that they consider a brain injury to be a chronic condition that needs ongoing, long term support, though it is not treated that way in the healthcare or insurance communities -- much to their frustration.

Nearly all – 90% - of survey respondents were not participating in a regular support group (Figure 30), but nearly half indicated that they would be interested in doing so (Figure 31). Most responded that they would prefer to be in a support group with people who had injuries similar to their own and this, once

again, confirms the desire of most persons with brain injury to make connection with others who have a shared experience. Many of the focus group respondents – all of whom were currently participating in ongoing support group sessions - indicated that the fellowship shared with group members was very important to them. Expanding brain injury support groups across Maine and making them accessible for remote participants may be one avenue for supporting the social needs of this population and for disseminating awareness of other brain injury services in Maine communities.

Just over one-third of survey respondents received formal education after their brain injury, and an additional one-fifth obtained a GED or engaged in technical or skills training. Just over half received educational support services. The majority of respondents (87%) are not currently working and, while many indicate that they are not working because of limitations from their injuries, 50% of them are interested in finding out more about opportunities that might be available to them. This likely indicates that many of those surveyed have not been linked with information about educational and employment support that is appropriate for them. MaineCare's new Brain Injury Waiver program does provide support career planning and for linking members to Maine's Employment First services.³⁴

³⁴ <http://www.maine.gov/dhhs/oads/community-support/employment-volunteering/developmental-services.html>

Acute Rehabilitation Services

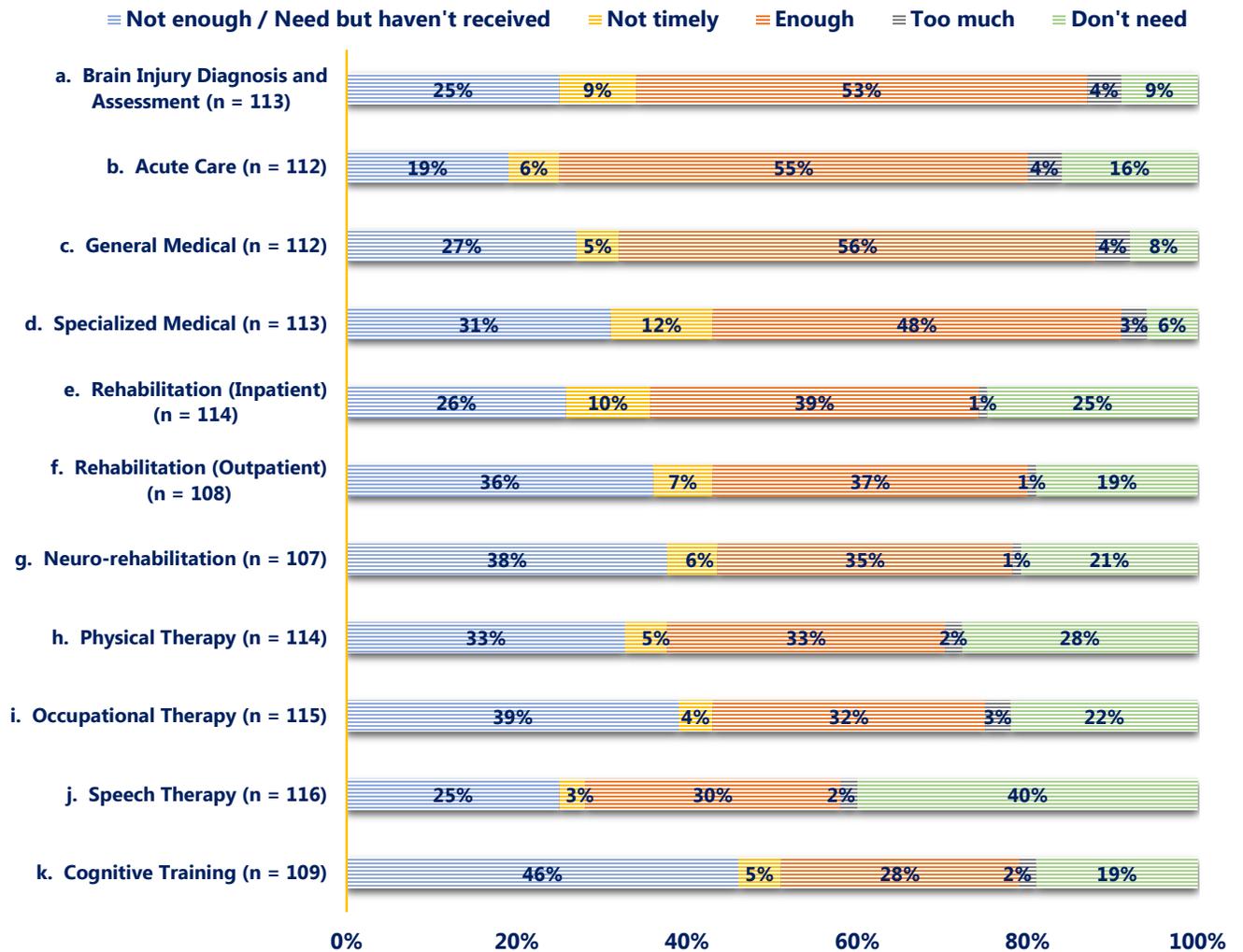


Figure 19 – Survey Question #21

- ◆ There is a persistent and significant percentage of respondents, between 19% and 46%, that need one or more brain injury-related acute rehabilitation services.
- ◆ The high percentages of need for therapeutic services, particularly cognitive training, is consistent with the CDC Report which notes that “[t]he most frequently reported unmet health care need by parents is for cognitive services”. (CDC Report, pg. 38).
- ◆ The continuing need for a variety of services is also consistent with the high percentage of persons with multiple diagnoses and with many of the focus group participants expressing frustration with the

lack of services, with difficulty accessing services, or with limits on the reimbursement for services, particularly the caps on therapy services.

- ◆ While half, or just over half, of respondents are getting enough of the services they need across the spectrum of acute care, general medical, and specialized medical services, this still leaves a considerable percentage of individuals without enough of these essential services.

Individual Experiences & Perceptions

- ◆ "Neurorehab helped me improve my reading, cooking, and live a healthier lifestyle."
- ◆ "Referral to rehab services was very helpful with turning things around within that first year. This is what helped me...but it was nearly a year before that came into play."
- ◆ "My autistic son got a lot of services, but there is nothing like that for brain injury."
- ◆ "Services are limited, and those that are out there are hard to find."
- ◆ "I don't think there is a lot out there for those of us who are beyond the critical point."

Rehabilitation Services

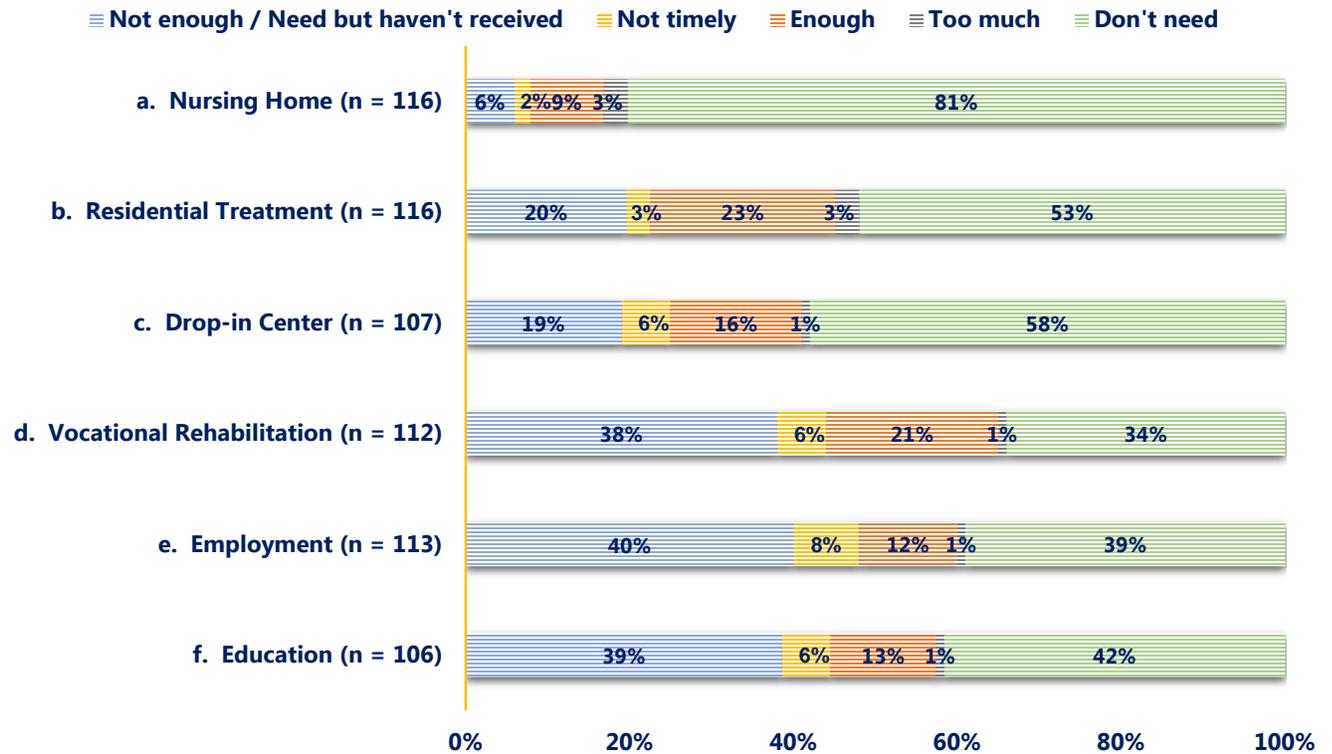


Figure 20 – Survey Question #22

- ◆ While most survey respondents do not need nursing home or residential care, nearly 40% still need or have not yet received sufficient vocational rehabilitation, employment, and education services. This is consistent with the high number of respondents reporting interest in available education and employment services (Fig. 34).
- ◆ One-fifth (20%) of respondents are still in need of residential treatment services.

Need for Services and Supports

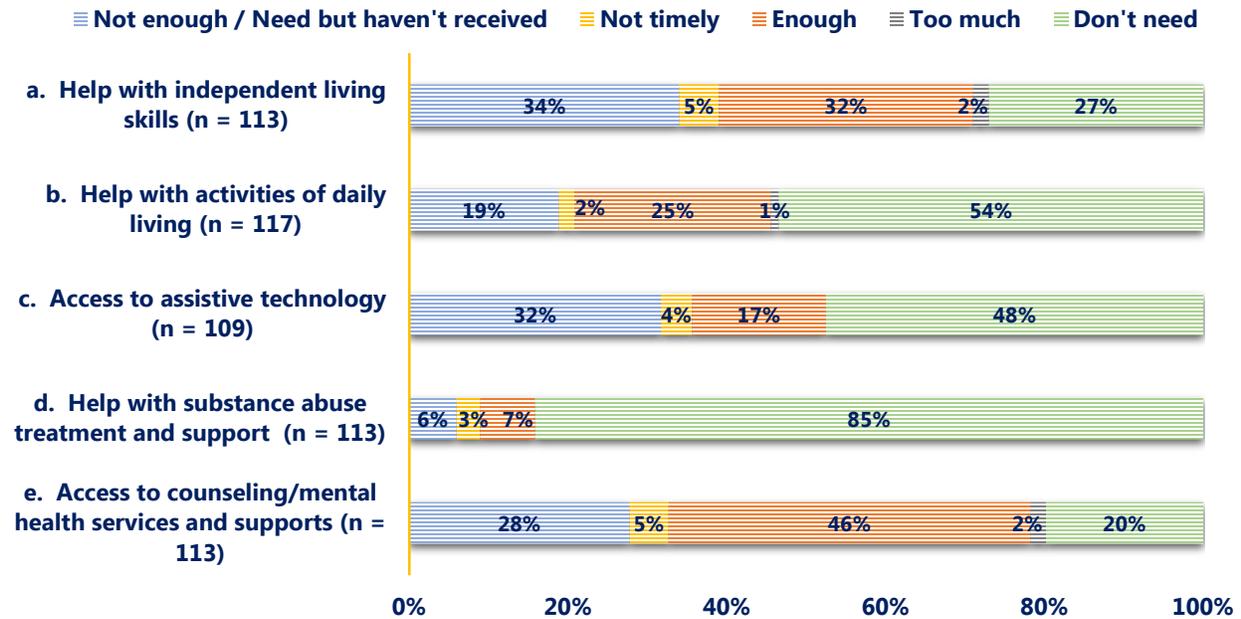


Figure 21 – Survey Question #23 (continues on Figure 22)

- ◆ Over a third of respondents still have need for assistance with living more independently and assistive technology also remains a need.
- ◆ Nearly one-third of respondents have need for mental health services. This is consistent with Fig. 12 and the number of survey respondents reporting mental health, or multiple mental health diagnoses.
- ◆ The survey results reflect that a very small percentage (6%) of person with brain injury have need for substance abuse services. This is consistent with Fig. 14 indicating that only 16% of respondents report a substance abuse problem.

Individual Experiences & Perceptions

- ◆ “We need the availability of a hotline of some sort that could be utilized by the individual with the problem; it would be a go-to person who could help them get what they need.”
- ◆ “My brain injury happened in Maine and I did not have any support at all. It may have been somewhere, but I didn’t know where.”

Need for Services and Supports cont'd

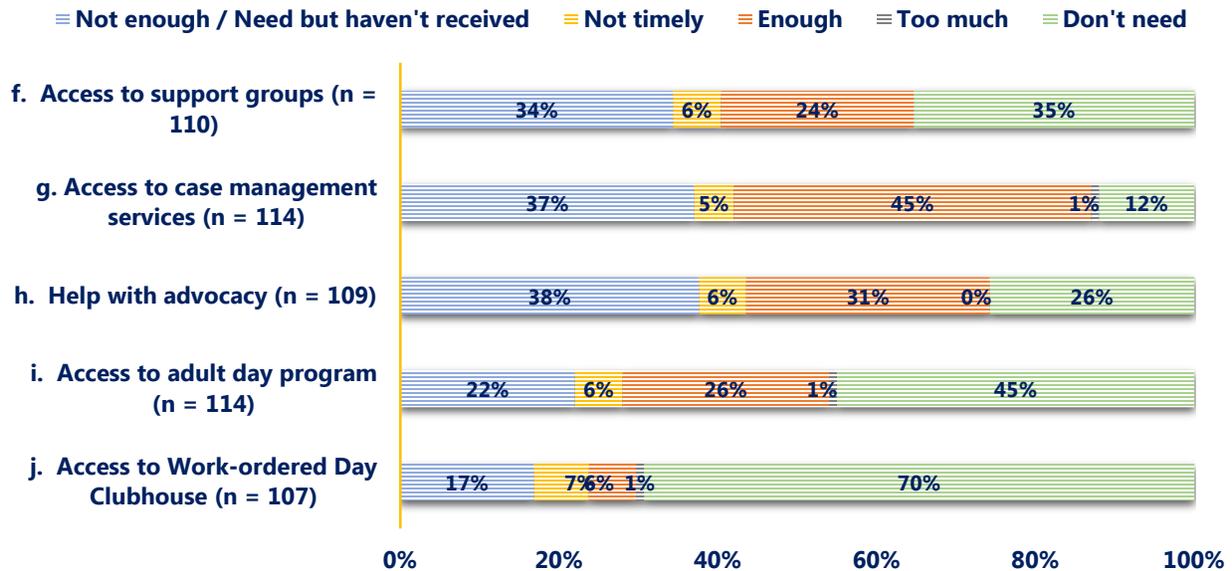


Figure 22 – Survey Question #23 (continues on Figure 23)

- ◆ Survey results reflect the continuing significant need for case management, advocacy, and support group access.
- ◆ These survey responses are also supported by many of the comments in the focus groups, the majority of whom had been living with their brain injury for several years.

Individual Experiences & Perceptions

- ◆ "There was a big gap for me in case management services."
- ◆ "I want to have someone to help me like a life coach; someone to help me with where I can go from here."
- ◆ "There is no case management; there is no one person to call and ask 'How do I manage all of this?'"
- ◆ "Case management is so crucial – if you can get it – if it even exists."
- ◆ "For every one of us, there are probably another dozen people who have a brain injury and have not received services and do not know that services are available."

Need for Services and Supports cont'd

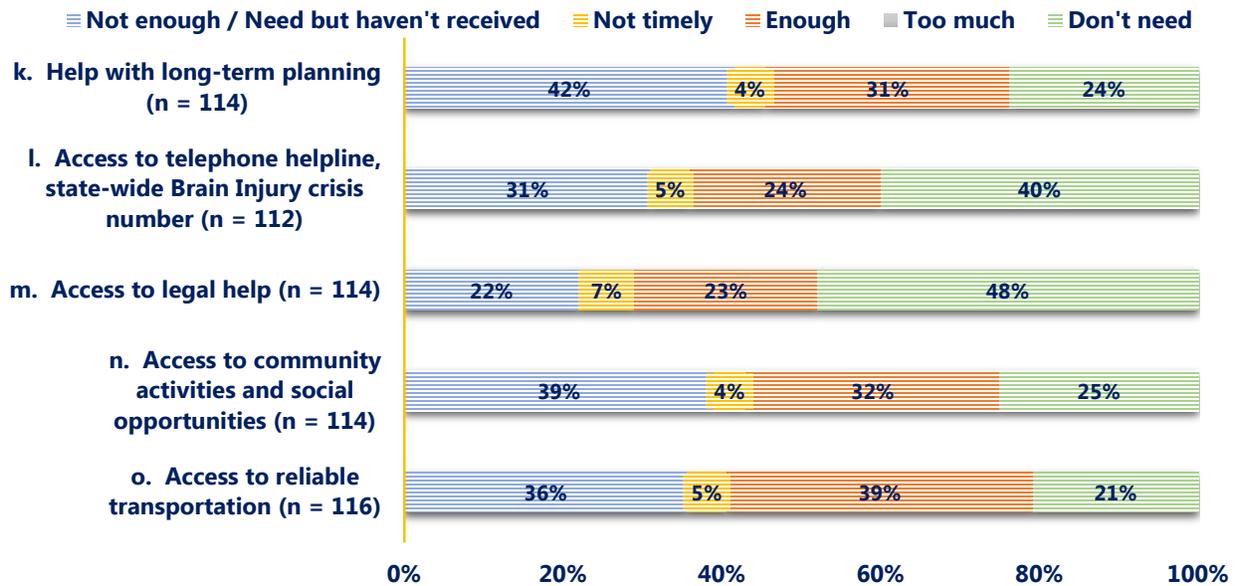


Figure 23 – Survey Question #23

- ◆ More than one-third of respondents need or want help with long-term planning, telephone HELP line, access to activities, and access to transportation. These were also frequent topics in the focus group conversations.
- ◆ Even though most survey respondents have been living with their brain injuries for many years – some for decades – many need and want the ongoing support of the social service community.

Individual Experiences & Perceptions

- ◆ “It would be great if there was a [central clearinghouse] for brain injury.”
- ◆ “We need maintenance programs for those who have finished their acute care and outpatient rehab and who still need help and assistance at different times in their lives while working on their strategies.”
- ◆ “Another thing we need is interim transportation so you don’t have to wait two years to become...approved in order to drive and get to your doctors.”

Have any of the following stopped you from finding or using needed services (please check ALL that apply)?

n = 132

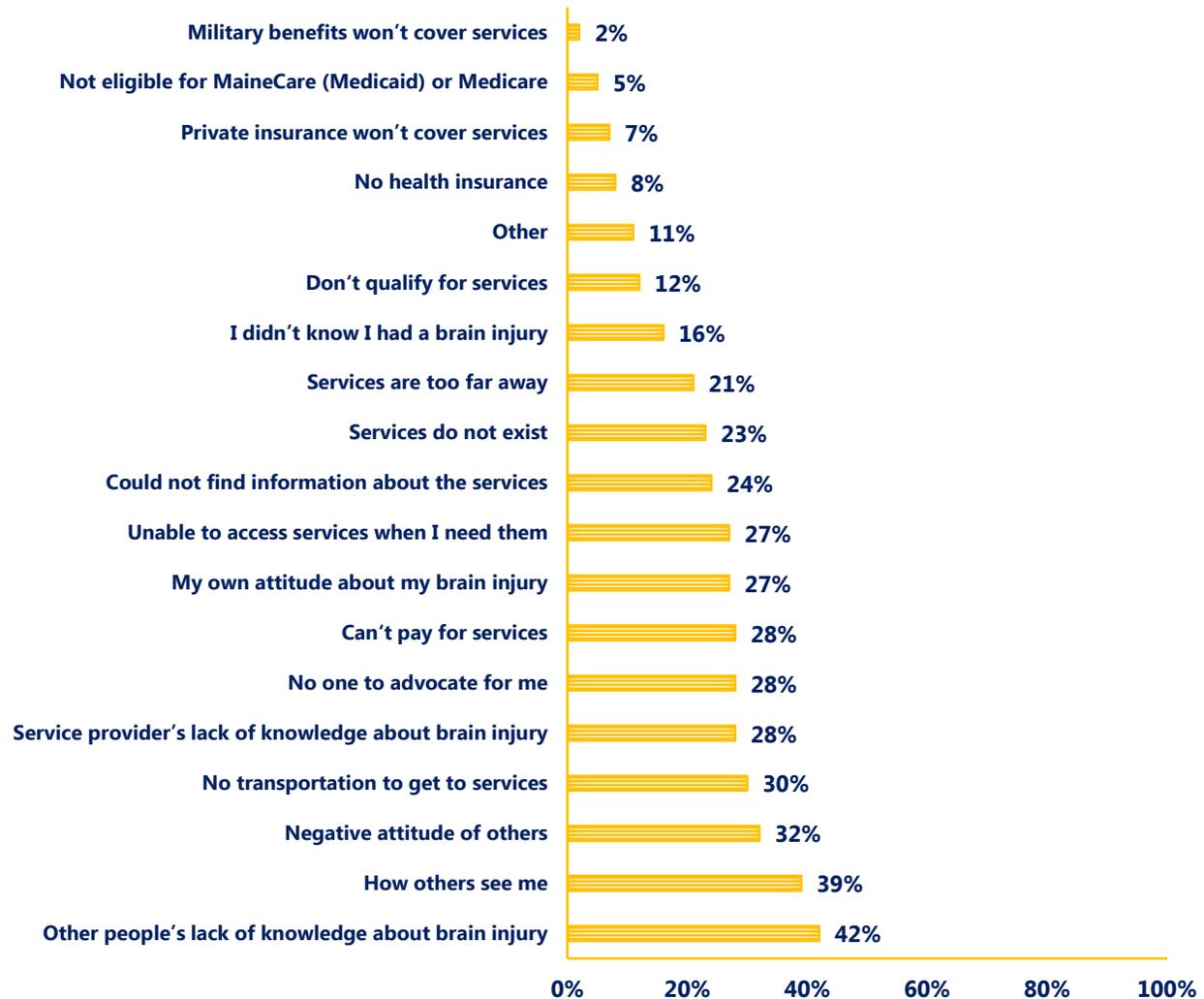


Figure 24 – Survey Question #24

- ◆ This graph illustrates that for between 27% and 42% of survey respondents, the primary barriers to finding or using services fall into the categories of attitudes (self or others), awareness, cost, and transportation.
- ◆ Several of the “other” responses included variations on these themes: “Afraid to ask,” “Didn’t know I qualified,” “Case manager could never help,” “No one I can call.”
- ◆ For nearly one-quarter of respondents, the needed services “do not exist”.

How have you paid for the services you've received? (please check ALL that apply)?

n = 132

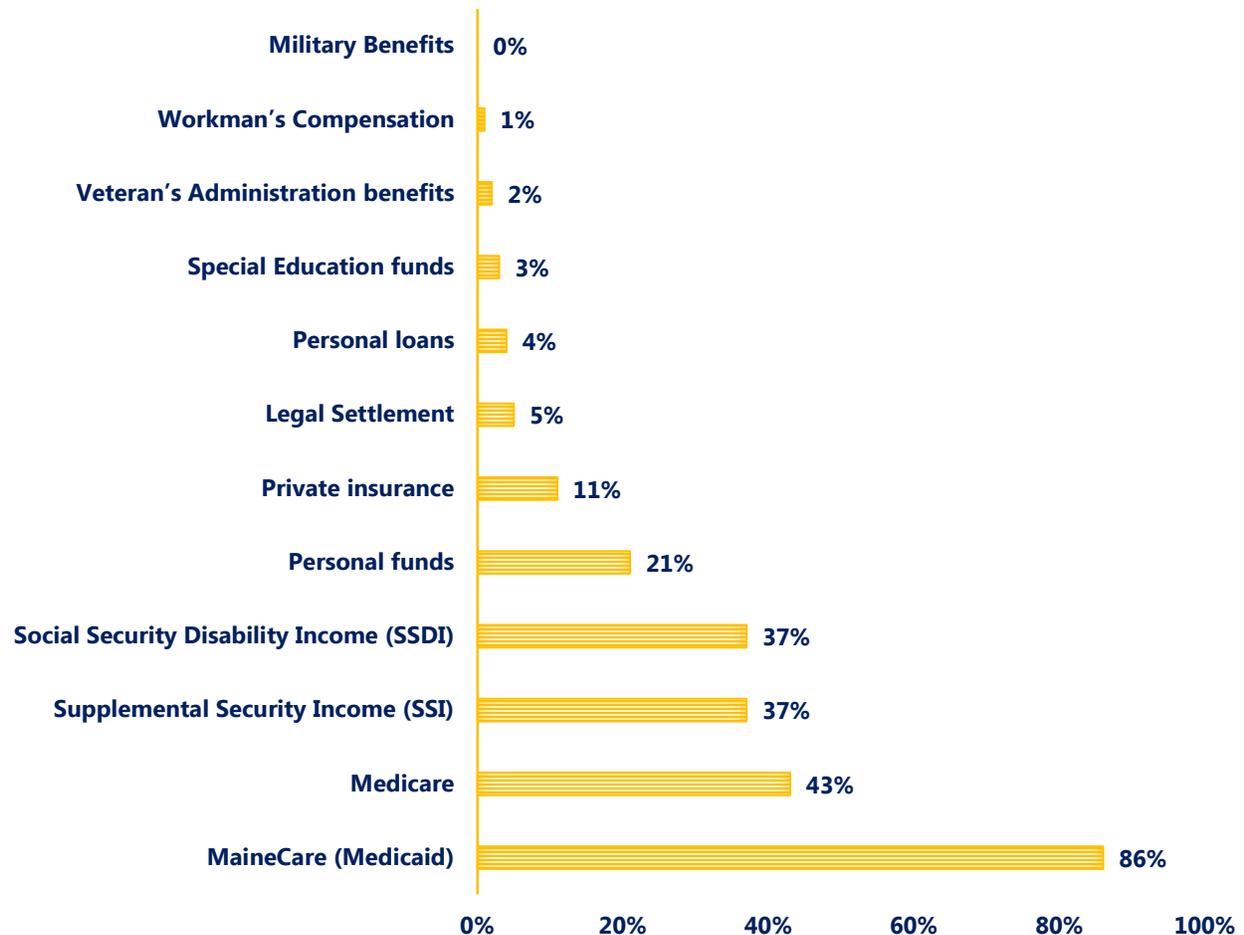


Figure 25 – Survey Question #25

- ◆ The high use of MaineCare reflects that the survey was sent to recipients of MaineCare services.
- ◆ Many focus group participants expressed frustration with private insurance limits on services.

Individual Experiences & Perceptions

- ◆ "I was [in rehabilitation] for two months and my insurance company said that was enough and they would not pay for more."

What other types of assistance do you receive? (please check ALL that apply)?

n = 132

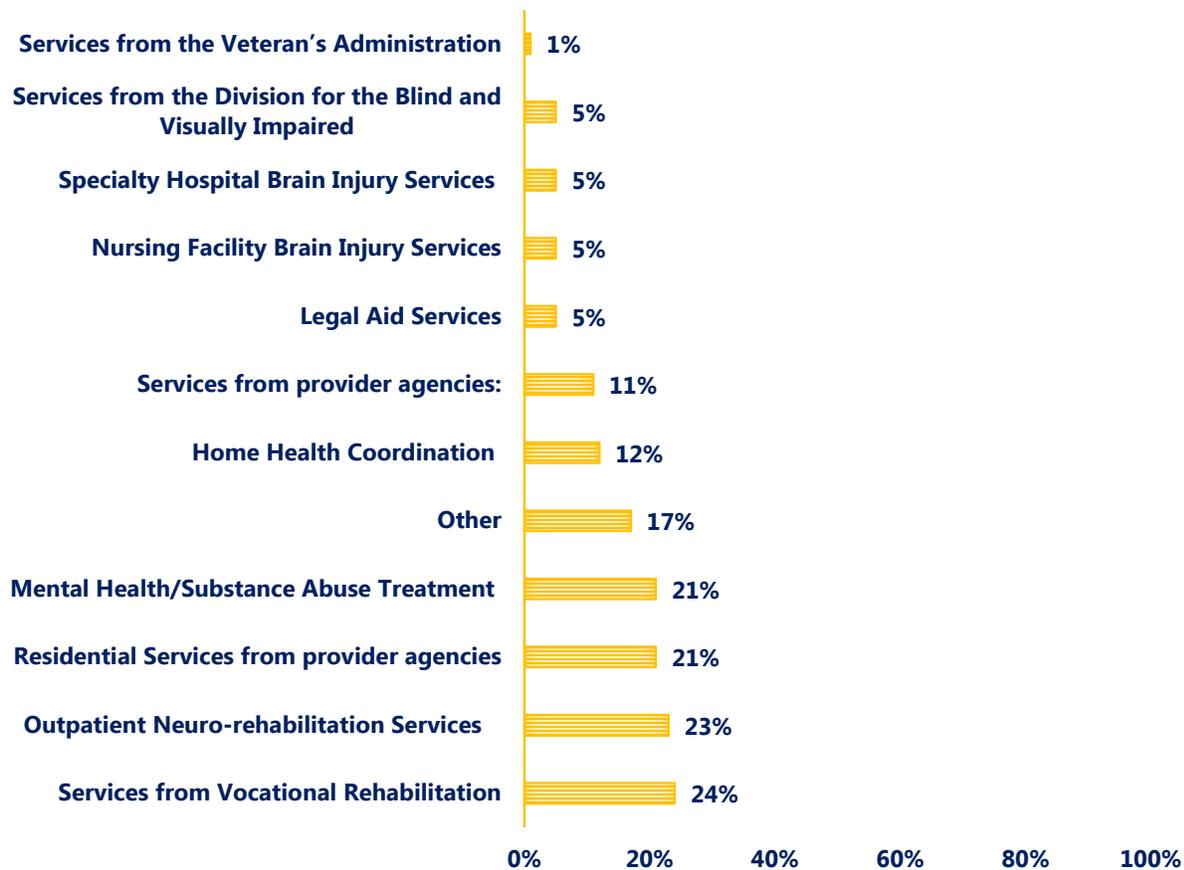


Figure 26 – Survey Question #26

- ◆ These responses reflect the current services used, but not the current need. The relatively small numbers may reflect that many respondents have been living with their injuries for many years and are using fewer services even though they may still have a need.

What are the three most important services that you get or that you received in the past?

n = 132

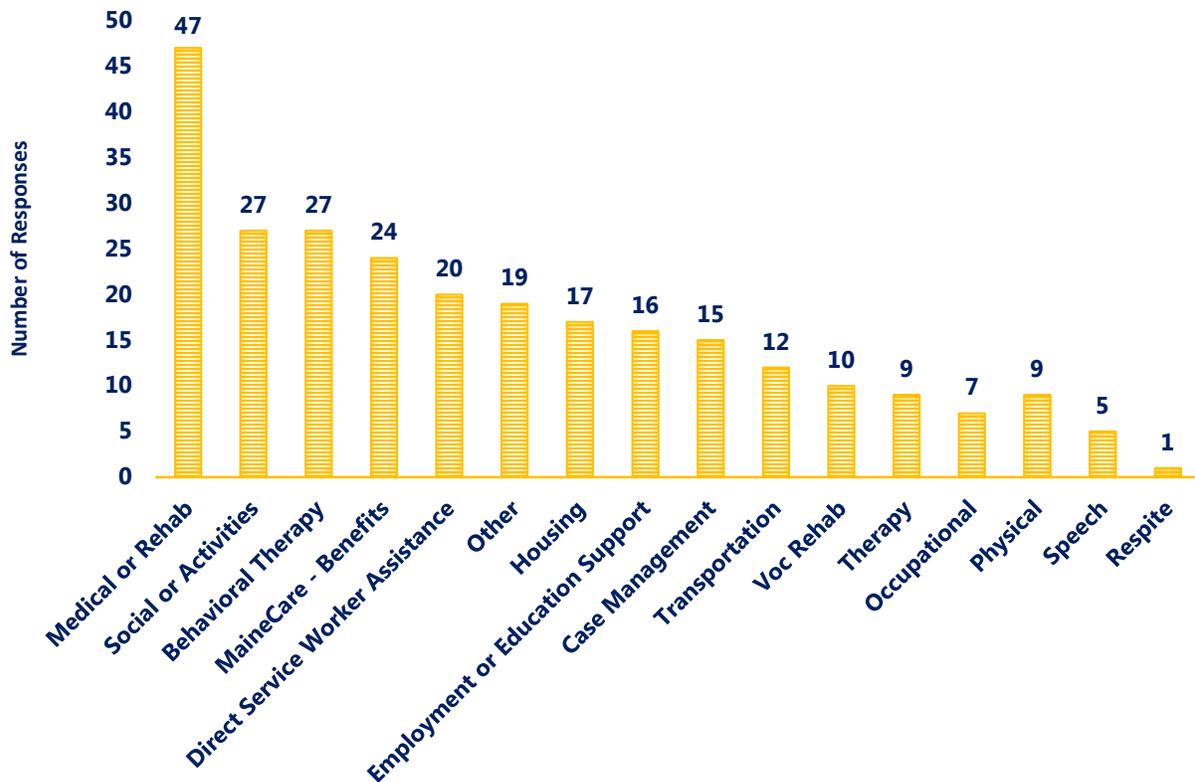


Figure 27 – Survey Questions #45

- ◆ This question asked for open-ended responses that have been grouped into the categories represented in the chart above and in the charts at Figures 28 and 29.
- ◆ The Social/Activities category was the second most commonly selected category, along with Behavioral Therapy. This is consistent with the next chart (Fig. 28) indicating that these services are currently missing or needed.
- ◆ The relatively high number of responses in the “Direct Service Worker Assistance” category reflects the importance of direct care assistance at some point post-injury.
- ◆ The 19 “Other” responses were varied. Examples are: “Advocacy,” “Learning how to focus,” “Understanding of people,” “Better living situation,” and “Financial.”

What are the three most important services that are missing or need to be developed to help you?

n = 132

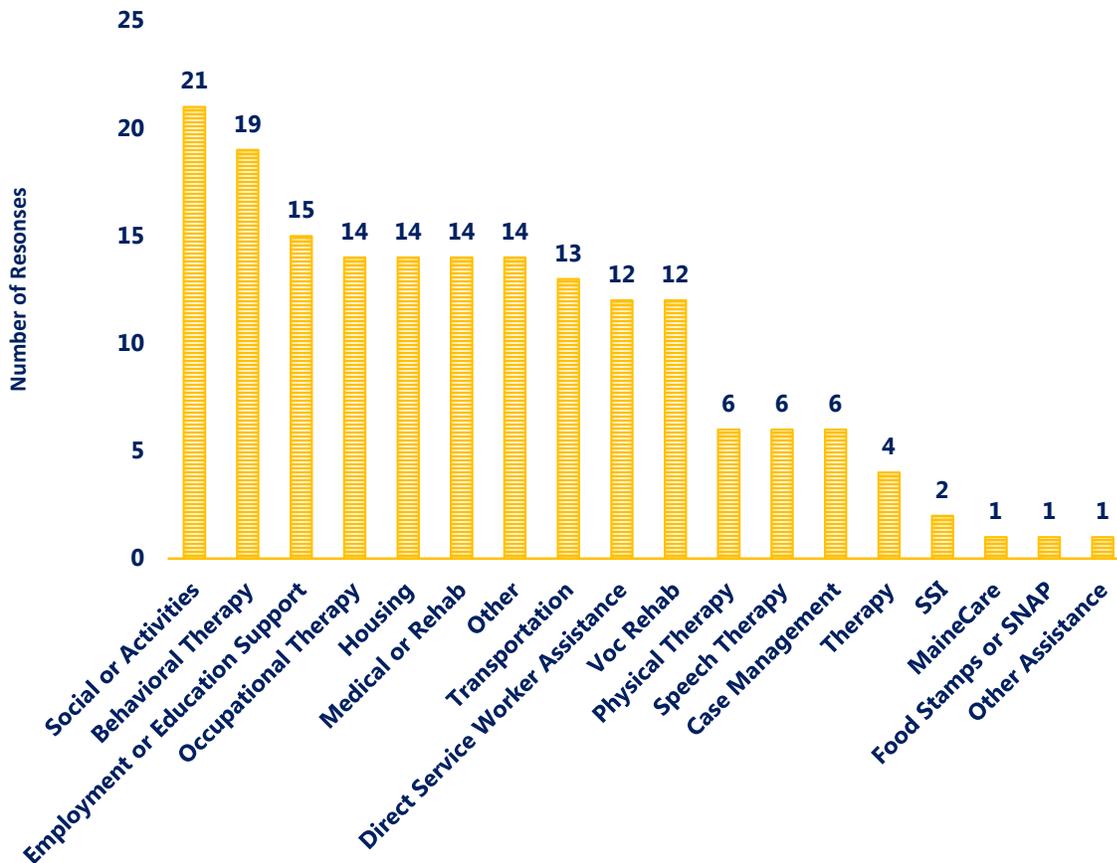


Figure 28 – Survey Question #46

- ◆ The many individuals trying to cope with mental health diagnoses (Fig. 12) is reflected in the high number of respondents indicating a continued need for Behavioral Therapy.
- ◆ Behavioral health need was a topic of focus group conversation as well. For instance, one individual stated, “[Dialectical Behavior Therapy] was the difference between me being employed for the last 10 years and not having a job. It provided me the ability to maintain a job because it helped calm me down and deal with the stresses of dealing with employment and dealing with the public.”
- ◆ The 14 “Other” responses were varied. Examples are: “Understanding mood changes associated with brain injury,” “Training for police in dealing with brain injury,” “Assistance with medical appointments,” “Help finding resources that I need.”

As a family member or person supporting a person with an acquired brain injury, what are the three most important services that you need?

n = 132

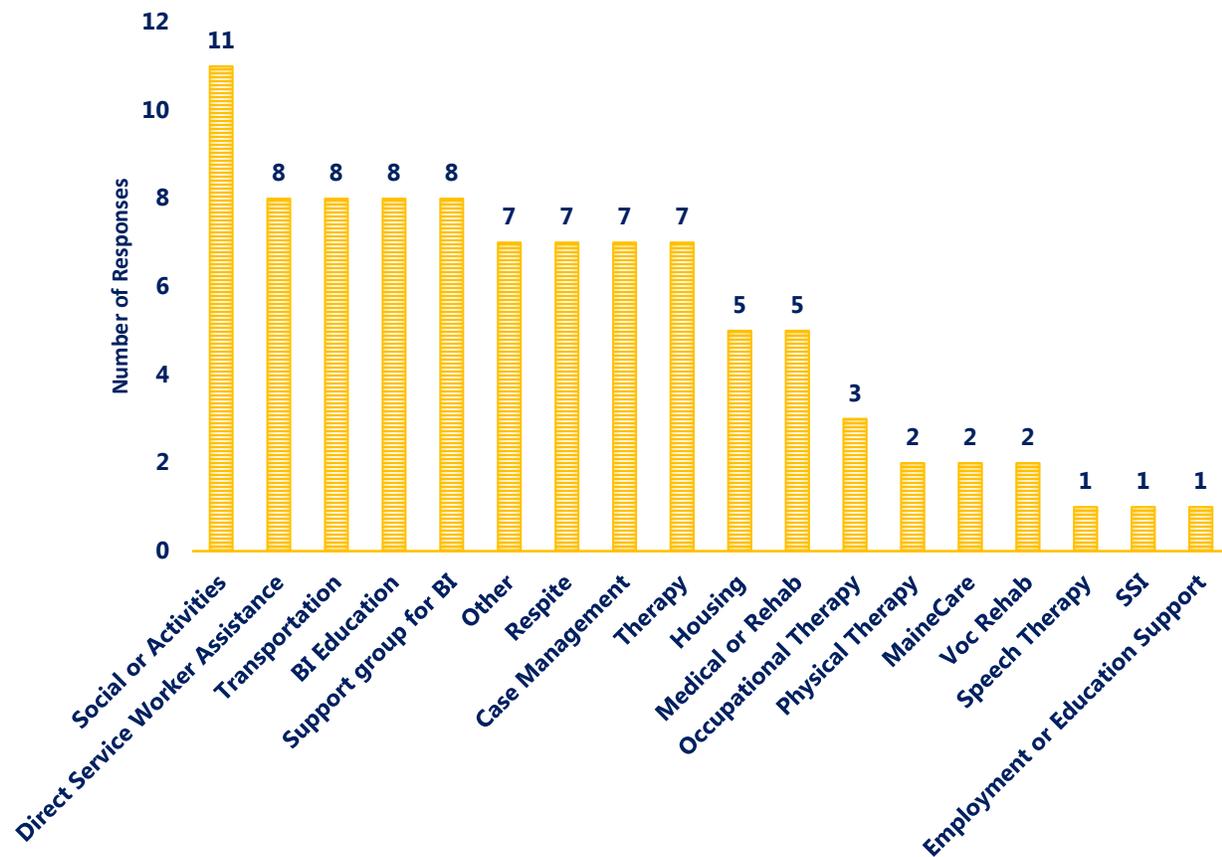


Figure 29 – Survey Question #47

- ◆ Unsurprisingly, the needs of family members reflect the burden on them. They need greater assistance from direct care workers and they have a greater need for transportation and respite services.
- ◆ The higher number of responses for brain injury education for family members was also reflected in the focus group discussions. For instance, one member noted, “I really suffered as a family member when my wife was injured. No one was there to let me know what to do to help her.”
- ◆ The seven “Other” responses reflect familiar themes, for instance, “More TBI services in rural areas,” “Lifetime follow up from agencies,” “Life skills,” and “Legal Aid.”

Do you attend a support group for individuals with a brain injury?

n = 124

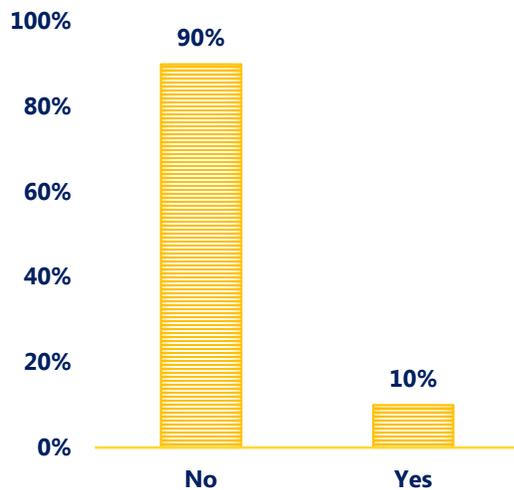


Figure 30 – Survey Question #27

If you do not attend, would you like to join a support group?

n = 106

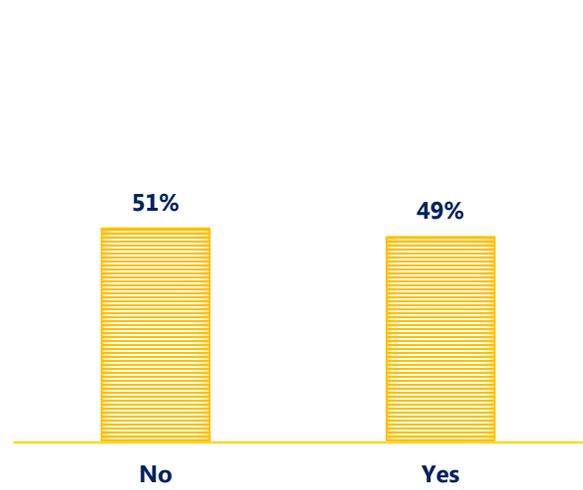


Figure 31 – Survey Question #28

- ◆ The overwhelming majority of respondents currently do not attend a brain injury support group, but just over half of those would like to join one.
- ◆ This response is consistent with the open-ended survey responses indicating a need for socialization and increased activity levels. It is also consistent with the focus group comments expressing gratitude for the opportunity for friendship, learning, and support that is provided in the support group setting.

Individual Experiences & Perceptions

- ◆ "I would like to see support groups throughout the State of Maine, especially in rural areas."
- ◆ "There are only ten support groups in Maine, and none in [Aroostook County]."
- ◆ "We used to have the Maine Brain Injury resource phone line, and you could call and ask 'Where can I find a support group?'"

If you want to attend a support group for individuals with a brain injury, which type of group would you prefer?

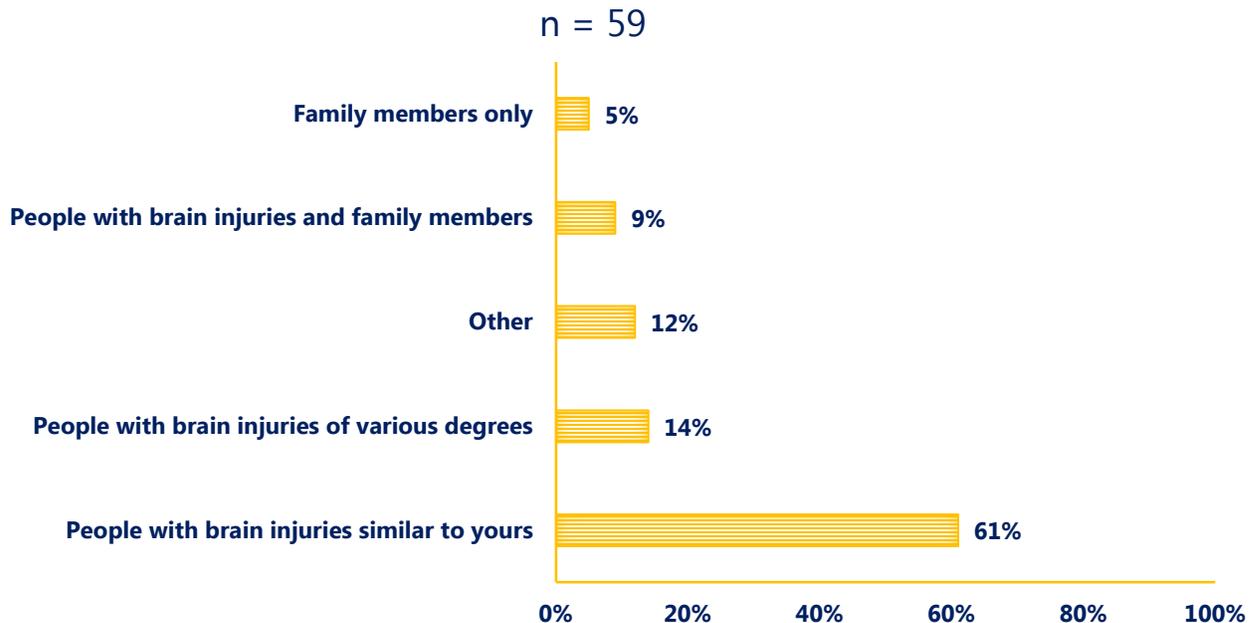


Figure 32 – Survey Question #30

- ◆ Over 60% of respondents wishing to participate in a support group want to be with individuals who have injuries similar to their own. “Other” responses include, for example, “Small groups,” “Individual sessions,” and “Specific activity or topic.”
- ◆ The focus group comments reveal that, despite the reality that brain injuries can be very different from one another, the camaraderie experienced among members of the group is highly valued.
- ◆ Focus group comments also reveal that members of the support group tend to share service information and are, therefore, referral resources for one another.

Individual Experiences & Perceptions

- ◆ “I found the support group in a list of support services and made a lot of phone calls before we found it.”
- ◆ “The support group here is really all I have for support at this point... and I appreciate everyone in it.”
- ◆ “Not that we all have similar symptoms, but we have the same challenges.”

How far did you go in school before you had your Brain Injury?

n = 117

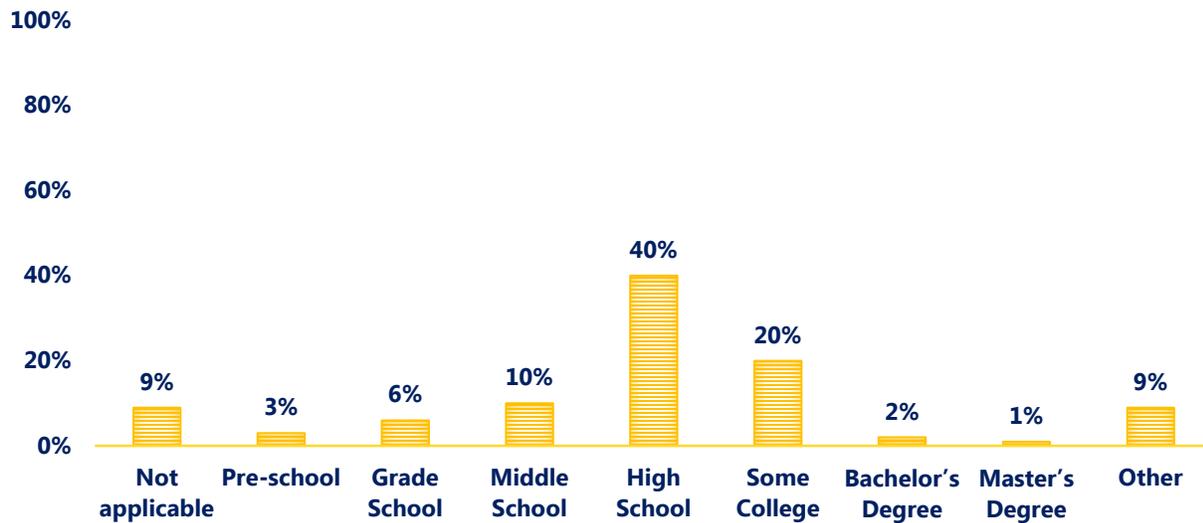


Figure 33 – Survey Question #31

- ◆ This spread of education before injury reflects that most survey respondents were injured when they were age 19 or younger (Fig. 8).
- ◆ Some of the “Other” responses were, for example, GED obtainment, some high school, adult education classes, and Job Corps skills training.
- ◆ The quote below highlights that meeting the specific needs of a person with a brain injury can sometimes be determinative of success at school or on the job.

Individual Experiences & Perceptions

- ◆ “The Office of Disability Services at my college was run by the Dean and he was an advocate for me, for instance, when I needed a single room. Having someone to call makes a difference.”

Are you interested in finding out more about your educational needs and opportunities?

n = 118

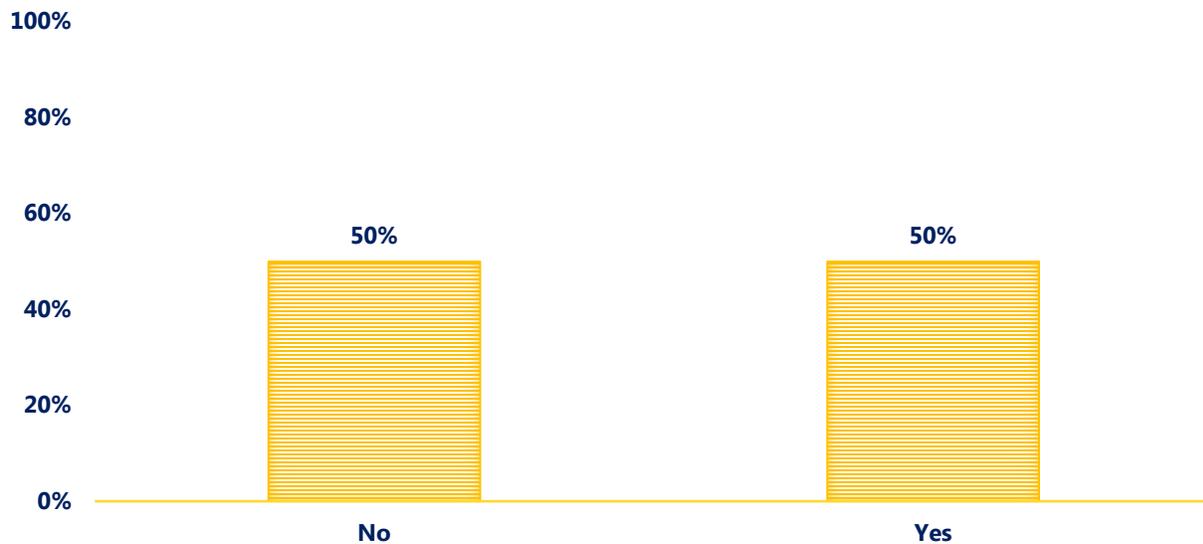


Figure 34 – Survey Question #32

- ◆ Half of all survey respondents want more information about educational services. This indicates a desire for more meaningful engagement and a desire for self-improvement, but perhaps the existence of barriers to access the desired information.

Individual Experiences & Perceptions

- ◆ “Figuring out what we need and then going to talk to someone about it is exhausting.”

What education have you had since you've had your Brain Injury?

n = 110

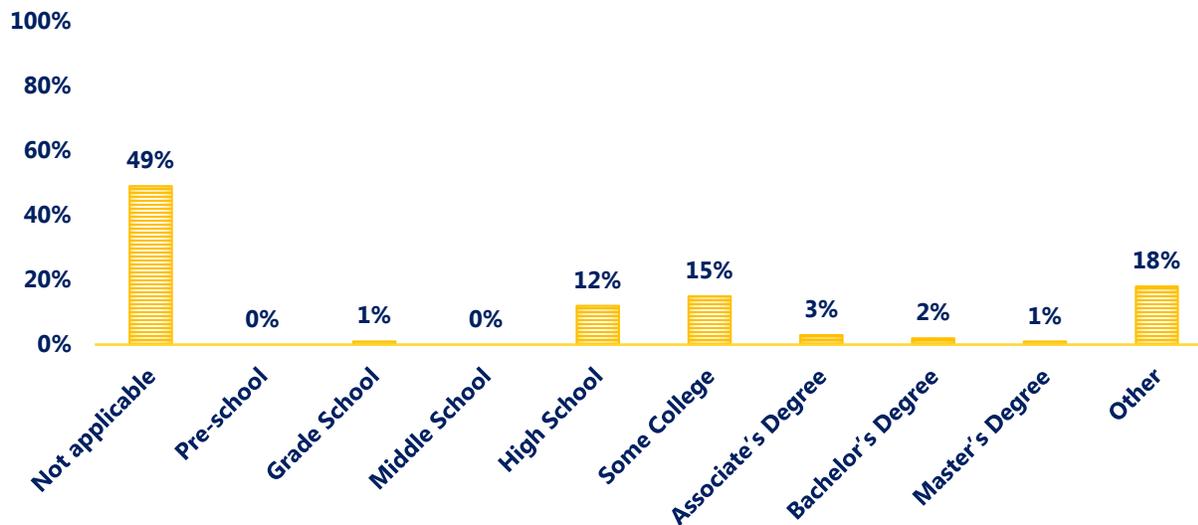


Figure 35 – Survey Question #33

- ◆ This survey question did not have “None” as a response option; consequently, respondents who had no education after their brain injury likely chose “Not applicable” as their response.
- ◆ The low percentages of individuals receiving education post-injury may be an indication of the unique cognitive challenges associated with brain injuries.
- ◆ The “Other” responses were primarily trade and technical schools and certifications.

Did you need special education services, support or accommodations in a school or college program?

n = 120

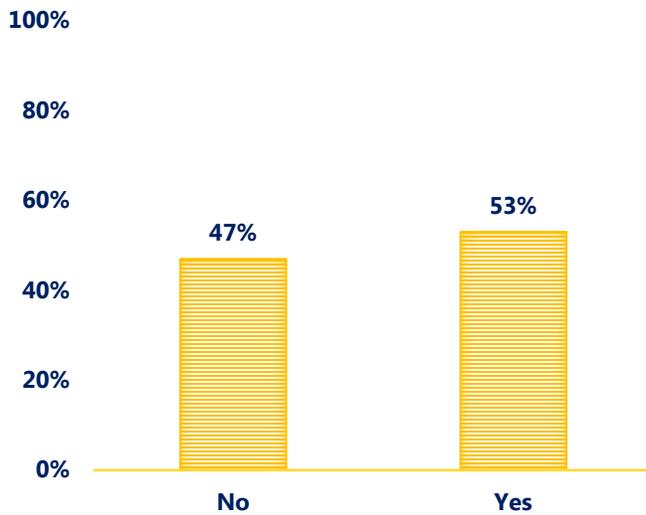


Figure 36 – Survey Question #34

If yes, did they meet your needs?

n = 67

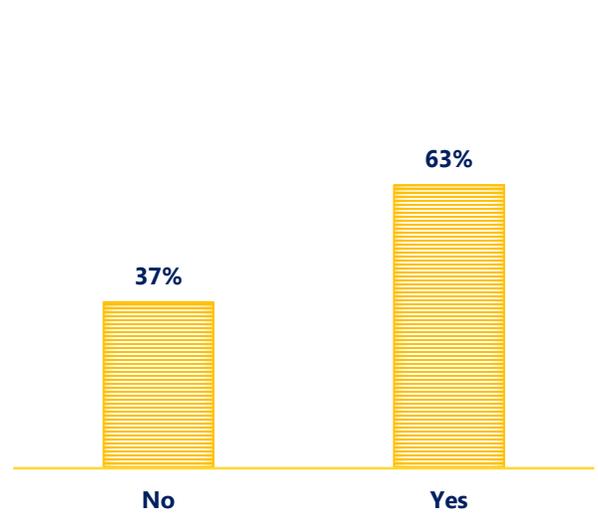


Figure 37 – Survey Question #35

- ◆ Just over half of respondents needed supportive services in school and for 63% of those who received them, the services were helpful.

Are you currently working?

n = 127

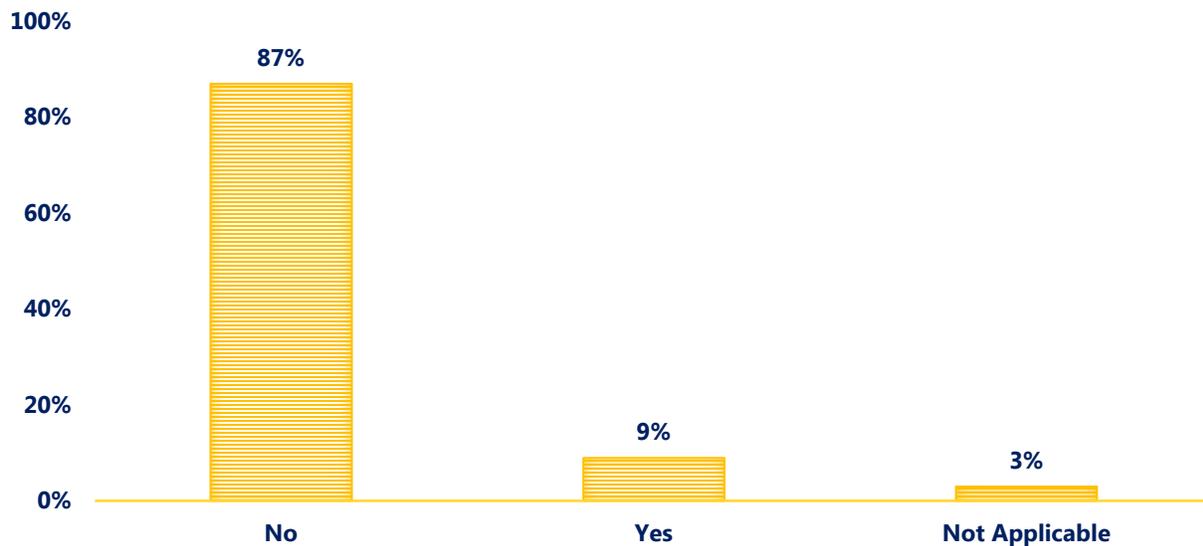


Figure 38 – Survey Question #36

- ◆ Nearly all respondents are not currently working. This high percentage may be due to several reasons: all survey respondents are MaineCare recipients; over half of respondents have a brain injury that is classified as “severe”; many respondents received their brain injury when they were younger and may have exhausted many of the options for vocational rehabilitation.
- ◆ Figure 44 reveals that most respondents are not currently working as a result of the effects of their brain injury.

Individual Experiences & Perceptions

- ◆ “Most of us in this room cannot work anymore.”
- ◆ “When you can’t work, what do you do?”

Have you worked since the time you were injured?

n = 123

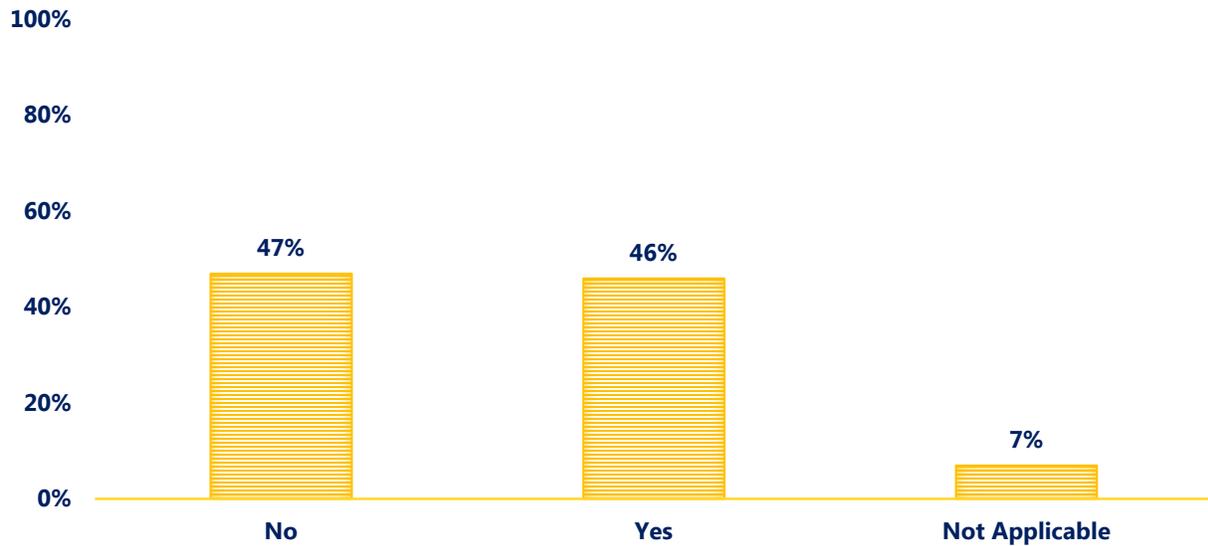


Figure 39 – Survey Question #37

- ◆ Almost half of those surveyed have worked since their injury.

Individual Experiences & Perceptions

- ◆ “Imagine you’re a high school graduate and you get injured and then you’re laid off because you can’t do your job.”
- ◆ “It is very, very hard to get the support while you are working.”
- ◆ “I worked with my therapist and plotted out a gradual return to work with some accommodations.”

Have you been enrolled in Vocational Rehabilitation Services?

n = 124

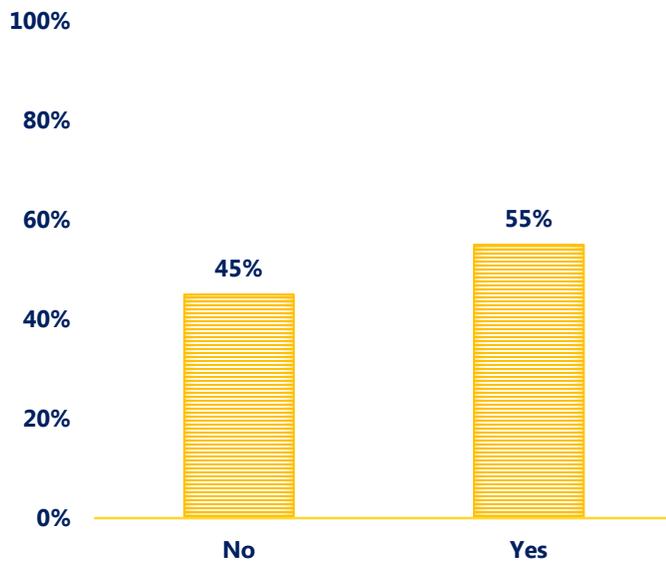


Figure 40 – Survey Question #38

If yes, did you get help finding a job?

n = 81

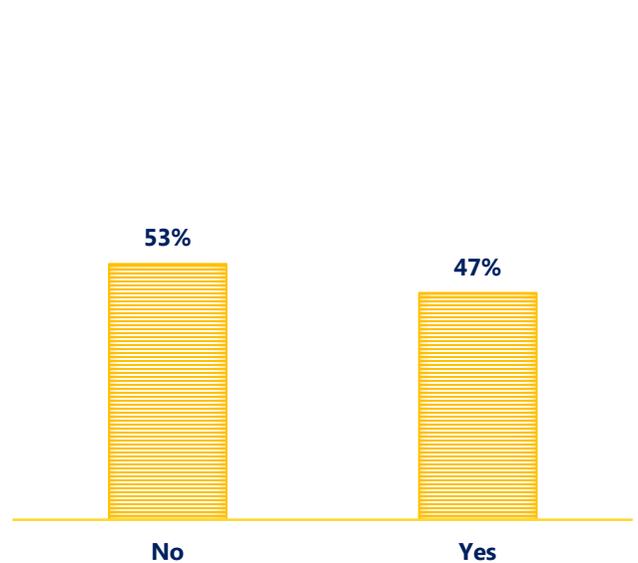


Figure 41 – Survey Question #39

-
- ◆ Nearly half of those enrolled in vocational rehabilitation services did obtain help finding a job. It is unclear why the remaining half did not get help.
 - ◆ Figures 38 through 44 demonstrate the likelihood that persons with a brain injury may not be able to keep a job as a result of the effects of their injury, despite prior use of vocational rehabilitation.

Did you get a job?

n = 93

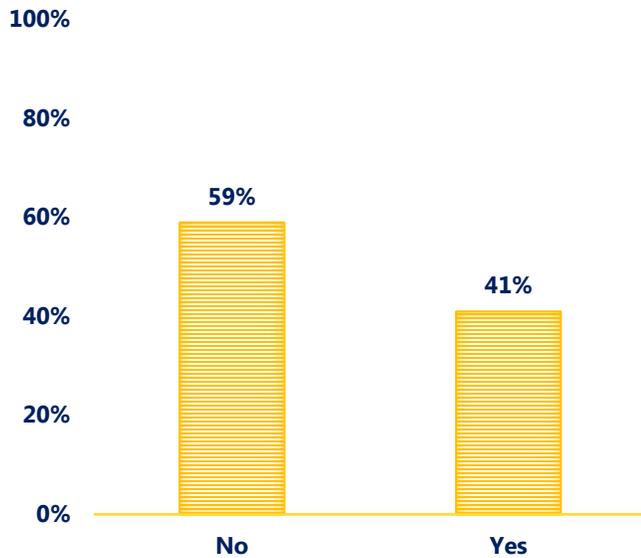


Figure 42 – Survey Question #40

Has your brain injury impacted the kind of work you do?

n = 109

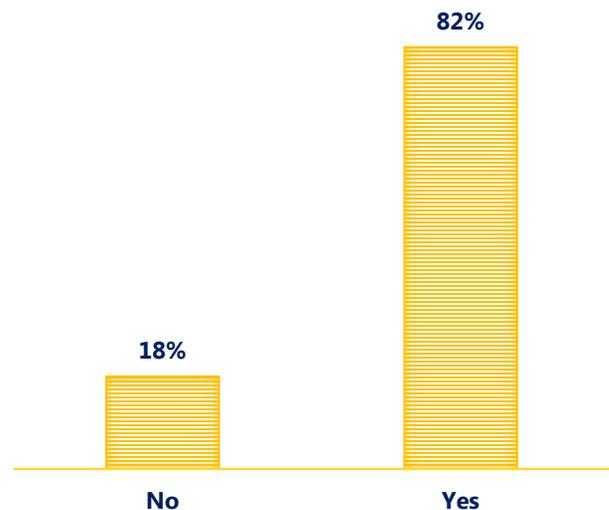


Figure 43 – Survey Question #41

- ◆ Over 80% of respondents report that their brain injury has impacted the work they do, or in the case of most, the work they can no longer do (Fig. 44).

Individual Experiences & Perceptions

- ◆ “All I need is an employer who will put up with me showing up when I can, and going home when I have to.”
- ◆ “My manager asked what he could do to help me and what he could do to help me improve.”
- ◆ “My employer simply decided they were not going to accommodate [me] anymore.”

If you are not working now, why not? (please check all that apply)

n = 132

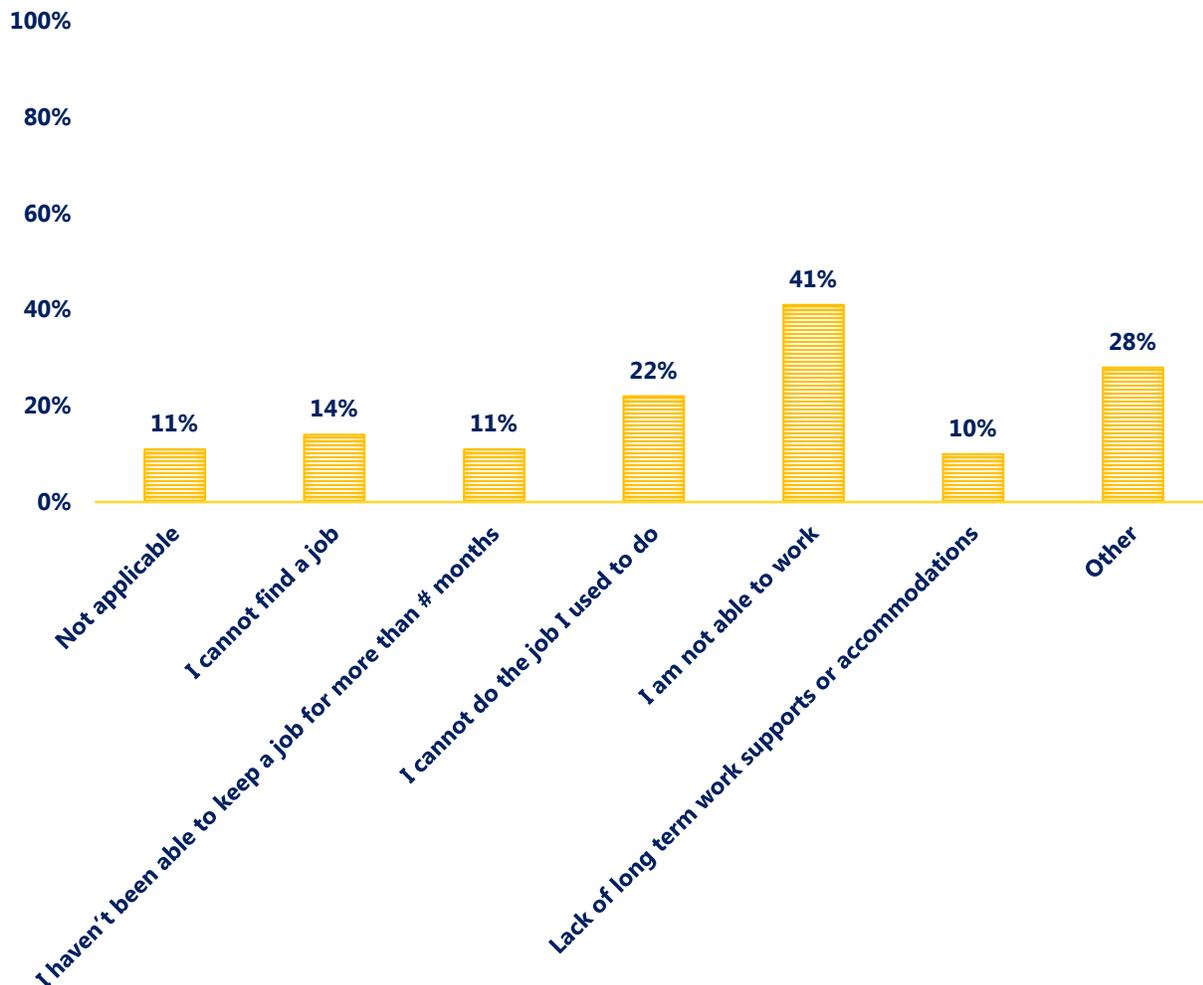


Figure 44 – Survey Question #42

- ◆ Some respondents who checked one of the stated responses also provided a response under “Other”.
- ◆ Of the 28% (n=51) of “Other” responses, only two indicated pending employment; the remaining entries explained the reasons for unemployment, which were primarily related to the physical or mental health effects of the brain injuries, e.g., “My body functioning,” “I cannot remember things,” “Depression and physical health,” “Can’t remember certain tasks.”

How do you travel from place to place on a daily basis?

n = 132

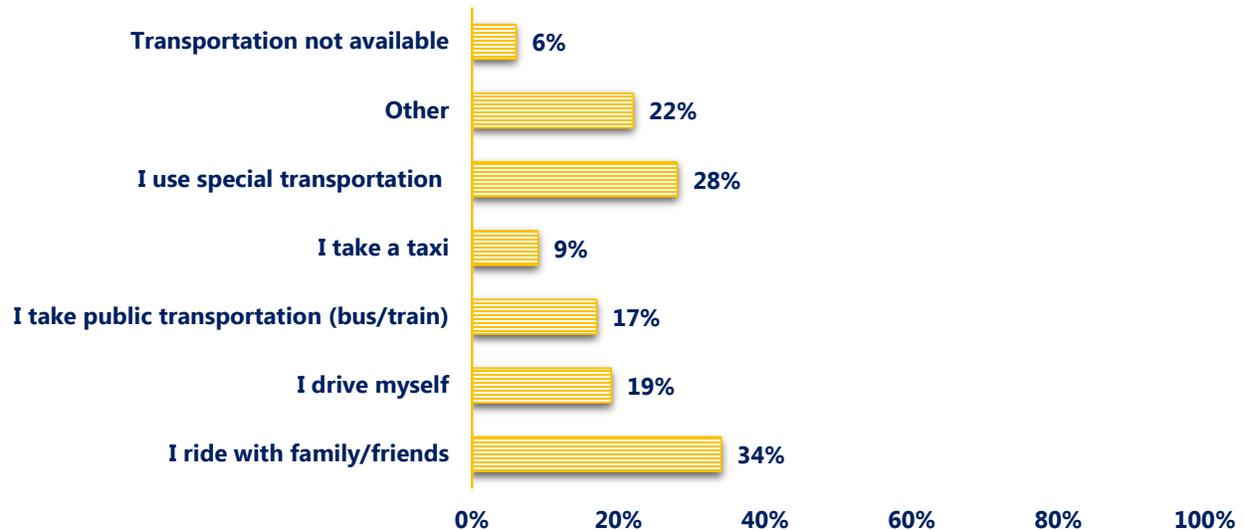


Figure 45 – Survey Question #44

- ◆ Fewer than 20% of survey respondents are able to drive themselves to where they need or want to go.
- ◆ Over one-third of respondents must rely on family and friends for transportation needs.
- ◆ “Other” responses include transportation provided by facility staff, home care workers, specific transportation agencies, and local public transportation options.

Individual Experiences & Perceptions

- ◆ “I could not drive up here, so there was a two-day plan just for me to be here for two hours.”
- ◆ “Many of us can’t drive or can drive only limited distances. I actually was told that I could not drive.”
- ◆ “A lot of places in Maine do not even have a bus schedule.”
- ◆ “I am only allowed to drive seven miles from my house... on a good day.”

Noteworthy Conclusions

The paper survey instrument covered a broad range of topics. While the number of survey respondents was relatively small, a general profile and several striking messages emerged from the responses. These messages were confirmed by the discussion among the focus group members and they provide additional support for recommendations made in previous brain injury reports as well as the annual recommendations of the Acquired Brain Injury Advisory Council.

The dominant overall message from the survey and the focus groups is that **persons with brain injury must manage largely invisible, chronic, but enormously complex physical and mental health circumstances. Most individuals require ongoing, long term services and supports across a wide spectrum and their need for services varies over time**, moving from immediate and critical acute diagnostic and treatment needs to much longer term emotional, social, education, and employment support. Supportive services are expanding in Maine as a result of the efforts of the State of Maine Department of Health and Human Services, the Acquired Brain Injury Advisory Council, and the brain injury advocacy and health care provider communities. However, services exist in pockets around the state and brain injury awareness, while growing, is still inadequate. This is evidenced by the commonly expressed frustrations of survey respondents and focus group participants that they feel misunderstood and invisible and that information about, and access to, services is lacking. Further, increased data collection that will inform future service and policy decisions is necessary at the national and state levels.

Brain Injury Diagnoses

This survey reveals the large number of brain injuries that occur to persons under the age of 19 as a result of vehicular accidents. One-third of the reported brain injuries were diagnosed more than a year after the injury and nearly a quarter more than five years after the injury. This delay in diagnosis can result in a lack of medical and rehabilitative services that could improve both short and long term outcomes. **Many persons with brain injury have had more than one brain injury and most are managing multiple medical and mental health diagnoses that are the result of the brain injury.** These individuals need medical, therapeutic, and social service assistance in order to locate, access, and coordinate appropriate care both immediately after an injury and on an ongoing basis. Persons with brain injuries have complex health circumstances that are not always immediately recognized by healthcare and social service providers.

Brain Injury Effects

Persons with brain injuries have ongoing, chronic needs. **The effects of a brain injury are often lifelong and have a substantial impact on all of the domains of human existence: relationships, education, employment, social activities, and perhaps most critically, one's own feelings of self-worth.** Most individuals feel worse about themselves after their injury and feel that others treated them differently, often shunning them out of fear or discomfort. Many feel isolated and long for a more normal life with social engagements and activities. A significant number are managing physical and cognitive limitations that impact their ability to find meaningful employment or continue their education. Many sense that

others lack awareness and sensitivity to the unique circumstances of a person with a brain injury and, perhaps as a result, they perceive that others are unwilling to accommodate those circumstances in health care, employment, and other settings. Despite this, half of the respondents are interested in finding out more about their educational opportunities and many are looking for case management services to assist them in navigating a way to greater functionality and productivity. Despite challenges, this population is willing and motivated to improve their situation. They need accurate, timely, relevant information and assistance to link to existing, accessible services and supports. The existing brain injury support group network should be expanded and made more inclusive so that there are a variety of ways to meaningfully participate.

Brain Injury Services and Supports

The prevailing view is that the necessary services do not exist, and if they do exist, they are not easily accessible. While work is currently underway to disseminate information necessary to link individuals with services and supports, there may be ongoing challenges to understanding and resolving the service needs of Maine's most rural and isolated populations. Transportation remains a barrier for many, since much of the service need is for hands-on, in-person rehabilitative and therapeutic care, including mental health services. Most respondents are not currently involved in a brain injury support group, but half would like to be. This is likely a reflection of the separateness that many individuals experience and the need to connect with persons who have a shared reality. **Roughly one-third of surveyed individuals currently need one or more of several services across the service array, ranging from in-home assistance to mental health counseling, case management, transportation, access to community activities, or help with long term planning.** Many of the desired services exist in some locations and the immediate task at hand is to enlarge the network of service information so that it reaches appropriate audiences of patients, family members, and providers.

Next Steps

As important as it is to make note of what we have learned from the individuals participating in this report, it is also important to note what might be missing and identify some possible next steps:

- ◆ We have not yet heard from our youngest and oldest persons with brain injuries – the children and the older adults – and these ends of the age spectrum are at increased risk. Similarly, more information about persons with brain injury residing in rural areas of the state would provide much needed data about their unique challenges.
- ◆ A survey of individuals with newly acquired brain injuries would provide feedback on recent efforts aimed at greater awareness, more timely assessment and diagnosis, and more available treatments for brain injury.
- ◆ Continued inquiry into the lived experience of persons with brain injury will insure that policy makers, service providers, researchers, and advocates are staying connected to what really matters for these individuals and their family members.
- ◆ An inventory of services and supports that are available to persons with brain injuries, mapped geographically, would improve resource allocation among services and strengthen routes to services.
- ◆ A survey of individuals with brain injury who have private insurance or who pay privately for services would round out the profile of service needs and utilization in Maine.
- ◆ An expanded array of metrics and measures related to, for example, types of injuries, at-risk populations, treatment interventions, and service utilization would improve resource and policy decision-making.
- ◆ The creation of a comprehensive strategic plan that incorporates efforts by the wide variety of brain injury stakeholders and is routinely reviewed and updated would reinforce and create synergies among the already existing collaborative stakeholder network.

It is noteworthy that many of the recommendations made by the National CDC in its report to Congress mirror information gaps at the state level. As nationally collected data expand our knowledge of incidence and prevalence rates and research emerges around brain injury acute and rehabilitative interventions, Maine will be able to use this information to further refine services and allocate resources within the state. The National CDC has recommended that state-specific TBI estimates be generated. This information should be collected at the state level and regularly tracked and used for refining brain injury-related efforts by all stakeholders.

Appendices

- A. Survey Instrument
- B. Survey Instrument with Percentage and Number of Responses
- C. Focus Group Protocol
- D. Summaries: State of Maine Brain Injury Waiver Program and Traumatic Brain Injury State Implementation partnership Grant
- E. Glasgow Coma Scale

Maine Needs Assessment Survey of Individuals with an Acquired Brain Injury (ABI), their Families, or Significant Others

This survey is to be completed by adults with an acquired brain injury or by individuals/family members who assist an individual to complete the survey. By acquired brain injury, we mean an injury to the brain that occurred after birth, either from physical trauma (e.g., auto accident, assault, gunshot wound, falling and striking the head) or from causes not related to trauma (e.g., stroke, brain tumor, encephalitis, substance abuse, anoxia, infection/disease).

I. BASIC INFORMATION ABOUT YOU. Throughout this survey, “YOU” refers to the individual with a brain injury.

1. I am a/an (please check ONE):

- Adult with an acquired brain injury
- Guardian
- Family member
- Other person assisting the individual (please describe):

2. I live in:

City/Town: _____ State: _____ Zip: _____

3. My gender is:

- Male
- Female

4. My birth date is:

Month/Day/Year): _____ / _____ / _____

II. IN THIS SECTION WE ASK QUESTIONS ABOUT YOUR BRAIN INJURY(S).

5. Have you had more than one brain injury?

- No
- Yes

6. If yes, how many? _____

| 7. For each brain injury, tell us how you were injured (please check ONE): | | |
|---|---------------------------|---|
| How were you injured? | First Brain Injury | Second Brain Injury, if applicable |
| a. Auto accident | <input type="radio"/> | <input type="radio"/> |
| b. Other type of vehicle accident (e.g., motorcycle, ATV, etc.) | <input type="radio"/> | <input type="radio"/> |
| c. Sports-related concussion | <input type="radio"/> | <input type="radio"/> |
| d. Injury from a fall | <input type="radio"/> | <input type="radio"/> |
| e. Domestic violence | <input type="radio"/> | <input type="radio"/> |
| f. Gunshot wound | <input type="radio"/> | <input type="radio"/> |
| g. Assault(s) | <input type="radio"/> | <input type="radio"/> |
| h. Stroke | <input type="radio"/> | <input type="radio"/> |
| i. Brain tumor | <input type="radio"/> | <input type="radio"/> |
| j. Infection /disease | <input type="radio"/> | <input type="radio"/> |
| k. Military service-related injury | <input type="radio"/> | <input type="radio"/> |
| l. Substance abuse | <input type="radio"/> | <input type="radio"/> |
| m. Other (please specify): | | |

8. How old were you when your brain injury occurred?

First Brain Injury _____ years old

Second Brain Injury, if applicable _____ years old

9. How long after your most severe brain injury were you diagnosed (please check ONE)?

- 0 to 3 months
- 3 to 6 months
- 6 months to 1 year
- 1 to 3 years
- 3 to 5 years
- Over 5 years

| 10. How severe were your injuries? | | | |
|---|-----------------------|-----------------------|-----------------------|
| | Mild | Moderate | Severe |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

11. For your **most severe brain injury**, how did you find out that you had it (please check ALL that apply)?

- Hospital
- Family doctor or pediatrician
- School (for example, a school nurse)
- Family member
- Professional (e.g., a counselor, an occupational or speech therapist, a neuropsychologist)
- Other (please describe): _____

12. Do you have another diagnosis in addition to the brain injury (e.g., mental health condition, substance abuse condition, physical condition)?

- No
- Yes (please describe): _____

13. Did you have this diagnosis before your brain injury?

- No
- Yes

14. Do you have an alcohol, substance abuse or self-medicating problem?

- No
- Yes (please describe): _____

III. IN THIS SECTION WE ASK YOU HOW YOUR BRAIN INJURY HAS AFFECTED YOUR LIFE.

| 15. How has your first and second (if applicable) brain injury affected your life (please check ONE for each column that applies)? | | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|---------------------------|-----------------------|
| | Enough | Not enough | Too much | Not timely | Need but haven't received | Don't need |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |

16. Has your brain injury changed how you feel about yourself?

- No
- Yes (please describe): _____

17. Has your brain injury changed how people respond to you?

- Don't Know
- No
- Yes (please describe):

18. If yes, are you concerned about other people's perceptions of you?

- Not at all
- A little
- Some
- A lot

19. Do people mistake your brain injury for a mental health problem or intellectual disability?

- Don't Know
- No
- Yes (please describe):

20. Has your brain injury had an impact on any of these areas of your life (please check ALL that apply)?

- My marriage/family
- My job
- My ability to learn new things
- My ability to go to school or college
- My ability to do things like I used to
- My living situation
- My health status
- My intimacy
- My mental health status
- My friendships
- My social relationships
- My recreation

IV. IN THIS SECTION WE ASK YOU TO RATE YOUR REHABILITATION SERVICES.

21. Acute Rehabilitation Services.

Under the following services, please check the categories that apply:

- If you have received or are receiving services, check whether it was **Enough, Not enough or Too much.**
- If the services were not received in a timely fashion, check **Not timely.**
- If you need help but have not received help, check **Need but haven't received.**
- If you don't need the services, check **Don't need.**

| | Enough | Not enough | Too much | Not timely | Need but haven't received | Don't need |
|---|-----------------------|-----------------------|-----------------------|-----------------------|---------------------------|-----------------------|
| a. Brain Injury Diagnosis and Assessment | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| b. Acute Care | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| c. General Medical (Primary Care Physician) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| d. Specialized Medical (Neurologist, Neuro-psychologist) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| e. Rehabilitation (Inpatient) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| f. Rehabilitation (Outpatient) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| g. Neuro-rehabilitation | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |

| | Enough | Not enough | Too much | Not timely | Need but haven't received | Don't need |
|------------------------------------|--------|------------|----------|------------|---------------------------|------------|
| h. Physical Therapy | | | | | | |
| First Brain Injury | 0 | 0 | 0 | 0 | 0 | 0 |
| Second Brain Injury, if applicable | 0 | 0 | 0 | 0 | 0 | 0 |
| i. Occupational Therapy | | | | | | |
| First Brain Injury | 0 | 0 | 0 | 0 | 0 | 0 |
| Second Brain Injury, if applicable | 0 | 0 | 0 | 0 | 0 | 0 |
| j. Speech Therapy | | | | | | |
| First Brain Injury | 0 | 0 | 0 | 0 | 0 | 0 |
| Second Brain Injury, if applicable | 0 | 0 | 0 | 0 | 0 | 0 |
| k. Cognitive Training | | | | | | |
| First Brain Injury | 0 | 0 | 0 | 0 | 0 | 0 |
| Second Brain Injury, if applicable | 0 | 0 | 0 | 0 | 0 | 0 |

22. Rehabilitation Services by Type of Setting.

Under the following service settings, please check the categories that apply:

- If you have received or are receiving services in the setting, check whether it was **Enough, Not enough** or **Too much**.
- If the services were not received in the setting in a timely fashion, check **Not timely**.
- If you need help but have not received help in the setting, check **Need but haven't received**.
- If you don't need the services in the setting, check **Don't need**.

| | Enough | Not enough | Too much | Not timely | Need but haven't received | Don't need |
|--|-----------------------|-----------------------|-----------------------|-----------------------|---------------------------|-----------------------|
| a. Nursing Home | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| b. Residential Treatment (24 hours/day x 7 days/week) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| c. Drop-in Center | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| d. Vocational Rehabilitation (for assessment of vocational needs, preparation for work, help finding a job) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| e. Employment (for providing work support, helping securing and keeping a job) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |
| f. Education (e.g., school or training center) | | | | | | |
| First Brain Injury | <input type="radio"/> | <input type="radio"/> |
| Second Brain Injury, if applicable | <input type="radio"/> | <input type="radio"/> |

V. IN THIS SECTION WE ASK YOU TO RATE YOUR NEED FOR SERVICES AND SUPPORTS.

Under the following list of services and supports, please check ALL that apply:

- If you have received or are receiving services, check whether it was **Enough, Not enough or Too much.**
- If the services were not received in a timely fashion, check **Not timely.**
- If you need help with services but have not received help with services, check **Need but haven't received.**
- If you don't need the services, check **Don't Need.**

| 23. Need for Services and Supports | | Enough | Not enough | Too much | Not timely | Need but haven't received | Don't need |
|---|--|-----------------------|-----------------------|-----------------------|-----------------------|----------------------------------|-----------------------|
| a. | Help with independent living skills (shopping, laundry, housecleaning, cooking, money management) | <input type="radio"/> | <input type="radio"/> |
| b. | Help with activities of daily living (dressing, eating, toileting, other personal care assistance) | <input type="radio"/> | <input type="radio"/> |
| c. | Access to assistive technology | <input type="radio"/> | <input type="radio"/> |
| d. | Help with substance abuse treatment and support | <input type="radio"/> | <input type="radio"/> |
| e. | Access to counseling/mental health services and supports | <input type="radio"/> | <input type="radio"/> |
| f. | Access to support groups | <input type="radio"/> | <input type="radio"/> |
| g. | Access to case management services (information and referral, help completing paperwork, help with developing a personal plan, help with long term planning) | <input type="radio"/> | <input type="radio"/> |
| h. | Help with advocacy | <input type="radio"/> | <input type="radio"/> |
| i. | Access to adult day program | <input type="radio"/> | <input type="radio"/> |
| j. | Access to Work-ordered Day Clubhouse | <input type="radio"/> | <input type="radio"/> |
| k. | Help with long-term planning | <input type="radio"/> | <input type="radio"/> |
| l. | Access to telephone helpline, statewide Brain Injury crisis number | <input type="radio"/> | <input type="radio"/> |
| m. | Access to legal help | <input type="radio"/> | <input type="radio"/> |
| n. | Access to community activities and social opportunities (recreational, spiritual, social) | <input type="radio"/> | <input type="radio"/> |
| o. | Access to reliable transportation | <input type="radio"/> | <input type="radio"/> |
| p. | Other (please describe): | | | | | | |

VI. IN THIS SECTION WE ASK YOU ABOUT THINGS THAT GET IN THE WAY OF GETTING HELP.

24. Have any of the following stopped you from finding or using needed services (please check ALL that apply)?

- I didn't know I had a brain injury
- My own attitude about my brain injury
- Service provider's lack of knowledge about brain injury
- Other people's lack of knowledge about brain injury
- Negative attitude of others
- How others see me
- Could not find information about the services
- No one to advocate for me
- Unable to access services when I need them
- Services are too far away
- No transportation to get to services
- Services do not exist
- Don't qualify for services
- Can't pay for services
- No health insurance
- Not eligible for MaineCare (Medicaid) or Medicare
- Private insurance won't cover services
- Military benefits won't cover services
- Other (please describe): _____

VII. IN THIS SECTION WE ASK YOU ABOUT YOUR SOURCES OF HELP.

25. How have you paid for the services you've received (please check ALL that apply)?

- MaineCare (Medicaid)
- Medicare
- Supplemental Security Income (SSI)
- Social Security Disability Income (SSDI)
- Private insurance
- Workman's Compensation
- Personal funds
- Personal loans
- Veteran's Administration benefits
- Special Education funds
- Legal Settlement
- Military Benefits

26. What other types of assistance do you receive (please check ALL that apply)?

- Legal Aid Services
- Services from provider agencies:
 - Residential Services from provider agencies (e.g., Goodwill, Charlotte White Center, Neuro-restorative, Lakeview, Creative Works Systems, Northern Maine General)
 - Outpatient Neuro-rehabilitation Services (e.g., Goodwill, MCIR, CINR)
 - Nursing Facility Brain Injury Services (e.g., RiverRidge, Brewer Rehabilitation)
 - Specialty Hospital Brain Injury Services (e.g., New England Rehabilitation Hospital)
 - Mental Health/Substance Abuse Treatment (Tri-County, Crisis and Counseling, AMHC, Community Health and Counseling, Broadreach)
 - Home Health Coordination (e.g., Alpha One or EIM)
- Services from Vocational Rehabilitation (VR)
- Services from the Veteran's Administration (VA)
- Services from the Division for the Blind and Visually Impaired
- Other (please describe): _____

VIII. IN THIS SECTION WE ASK YOU ABOUT SUPPORT GROUPS.

27. Do you attend a support group for individuals with a brain injury?

- No
- Yes

28. If you do not attend, would you like to join a support group?

- No
- Yes

29. If you do not attend, what prevents you from attending (e.g., transportation) (please describe)?

30. If you want to attend a support group for individuals with a brain injury, which type of group would you prefer (please check ONE)?

- People with brain injuries similar to yours
- People with brain injuries of various degrees
- People with brain injuries and family members
- Family members only
- Other (please describe): _____

IX. IN THIS SECTION WE ASK YOU ABOUT YOUR EDUCATION.

31. How far did you go in school before you had your Brain Injury (please check ONE)?

- Not applicable
- Pre-school
- Grade School
- Middle School
- High School
- Some College/Vocational Technical/Trade School
- Bachelor's Degree
- Master's Degree
- Other (please describe): _____

32. Are you interested in finding out more about your educational needs and opportunities?

- No
- Yes

33. What education have you had since you've had your Brain Injury (please check ONE)?

- Not applicable
- Pre-school
- Grade School
- Middle School
- High School
- Some College
- Associate's Degree
- Bachelor's Degree
- Master's Degree
- Other (please describe): _____

34. Did you need special education services, support or accommodations in a school or college program?

- No
- Yes (please describe): _____

35. If yes, did they meet your needs?

- No
- Yes (please describe): _____

X. IN THIS SECTION WE ASK YOU ABOUT EMPLOYMENT.

36. Are you currently working?

- No
- Yes
- Not Applicable (i.e., not age appropriate)

37. Have you worked since the time you were injured?

- No
- Not Applicable
- Yes (please describe): _____

38. Have you been enrolled in Vocational Rehabilitation services?

- No
- Yes

39. If yes, did you get help finding a job?

- No
- Yes

40. Did you get a job?

- No
- Yes

41. Has your brain injury impacted the kind of work you do?

- No
- Yes

42. If you are not working now, why not (please check ALL that apply)?

- Not applicable
- I cannot find a job
- I haven't been able to keep a job for more than _____ number of months
- I cannot do the job I used to do
- I am not able to work
- Lack of long term work supports or accommodations
- Other (please describe): _____

XI. IN THIS SECTION WE ASK YOU ABOUT YOUR HOME LIFE.

43. Where are you currently living (please check ONE)?

- In a house or apartment:
 - Alone
 - With parents
 - With spouse/partner
 - With roommate
- Group home
- Foster home
- Residential treatment facility
- Hospital
- Rehabilitation facility
- Nursing home
- Other (please describe): _____

44. How do you travel from place to place on a daily basis?

- I drive myself
- I ride with family/friends
- I take public transportation (bus/train)
- I take a taxi
- I use special transportation (please describe): _____
- Other (please describe): _____
- I use special transportation (please describe): _____
- Other (please describe): _____
- Transportation is not available (please explain): _____

XII. IN THIS SECTION WE ASK ABOUT SERVICES THAT ARE IMPORTANT TO YOU AND THOSE SERVICES THAT ARE MISSING.

45. What are the three most important services that you get or that you received in the past?

- 1. _____
- 2. _____
- 3. _____

46. What are the three most important services that are missing or need to be developed to help you?

1. _____

2. _____

3. _____

XIII. QUESTIONS IN THIS SECTION ARE FOR GUARDIANS, FAMILY MEMBERS OR OTHERS.

47. As a family member or person supporting a person with an acquired brain injury, what are the three most important services that you need?

XIV. THIS LAST QUESTION IS FOR YOU TO CONSIDER.

48. Would you be interested in being part of a focus group?

No

Yes

If yes, please give us your information so we can contact you.

Name: _____

Address: _____

Phone Number: _____

Email Address: _____

Maine Needs Assessment Survey of Individuals with an Acquired Brain Injury (ABI), their Families, or Significant Others

This survey is to be completed by adults with an acquired brain injury or by individuals/family members who assist an individual to complete the survey. By acquired brain injury, we mean an injury to the brain that occurred after birth, either from physical trauma (e.g., auto accident, assault, gunshot wound, falling and striking the head) or from causes not related to trauma (e.g., stroke, brain tumor, encephalitis, substance abuse, anoxia, infection/disease).

I. BASIC INFORMATION ABOUT YOU. Throughout this survey, "YOU" refers to the individual with a brain injury.

1. I am a/an (please check ONE):

| % | n | |
|-----|-----|--|
| 80% | 101 | Adult with an acquired brain injury |
| 7% | 9 | Guardian |
| 7% | 9 | Family member |
| 6% | 7 | Other person assisting the individual (please describe): |

2. I live in:

City/Town: _____ State: _____ Zip: _____

3. My gender is:

| % | n | |
|-----|----|--------|
| 56% | 73 | Male |
| 44% | 58 | Female |

4. My birth date is:

Month/Day/Year): _____ / _____ / _____

II. IN THIS SECTION WE ASK QUESTIONS ABOUT YOUR BRAIN INJURY(S).

5. Have you had more than one brain injury?

| % | n | |
|-----|----|-----|
| 61% | 79 | No |
| 39% | 51 | Yes |

6. If yes, how many? _____

| 7. For each brain injury, tell us how you were injured (please check ONE): | | | | |
|--|--------------------|----|------------------------------------|---|
| How were you injured? | First Brain Injury | | Second Brain Injury, if applicable | |
| | % | n | % | n |
| a. Auto accident | 27% | 34 | 14% | 6 |
| b. Other type of vehicle accident (e.g., motorcycle, ATV, etc.) | 8% | 10 | 5% | 2 |
| c. Sports-related concussion | 2% | 2 | 7% | 3 |
| d. Injury from a fall | 13% | 16 | 18% | 8 |
| e. Domestic violence | 3% | 4 | 5% | 2 |
| f. Gunshot wound | 1% | 1 | 0% | 0 |
| g. Assault(s) | 2% | 3 | 9% | 4 |
| h. Stroke | 13% | 17 | 16% | 7 |
| i. Brain tumor | 3% | 4 | 9% | 4 |
| j. Infection /disease | 4% | 5 | 2% | 1 |
| k. Military service-related injury | 0% | 0 | 0% | 0 |
| l. Substance abuse | 1% | 1 | 2% | 1 |
| m. Other (please specify): | 18% | 23 | 14% | 6 |
| Multiple Causes | 6% | 7 | 0% | 0 |

8. How old were you when your brain injury occurred?

First Brain Injury _____ years old

Second Brain Injury, if applicable _____ years old

9. How long after your most severe brain injury were you diagnosed (please check ONE)?

| % | n | |
|-----|----|--------------------|
| 57% | 66 | 0 to 3 months |
| 5% | 6 | 3 to 6 months |
| 8% | 9 | 6 months to 1 year |
| 5% | 6 | 1 to 3 years |
| 3% | 3 | 3 to 5 years |
| 22% | 26 | Over 5 years |

| 10. How severe were your injuries? | Mild | | Moderate | | Severe | |
|------------------------------------|------|----|----------|----|--------|----|
| | % | n | % | n | % | n |
| First Brain Injury | 17% | 21 | 29% | 36 | 54% | 67 |
| Second Brain Injury, if applicable | 22% | 11 | 35% | 18 | 43% | 22 |

11. For your most severe brain injury, how did you find out that you had it (please check ALL that apply)?

- | % | n | |
|-----|----|--|
| 71% | 93 | Hospital |
| 18% | 24 | Family doctor or pediatrician |
| 1% | 1 | School (for example, a school nurse) |
| 12% | 16 | Family member |
| 27% | 36 | Professional (e.g., a counselor, an occupational or speech therapist, a neuropsychologist) |
| 18% | 24 | Other (please describe): _____ |

12. Do you have another diagnosis in addition to the brain injury (e.g., mental health condition, substance abuse condition, physical condition)?

- | % | n | |
|-----|-----|------------------------------|
| 20% | 26 | No |
| 80% | 103 | Yes (please describe): _____ |

13. Did you have this diagnosis before your brain injury?

- | % | n | |
|-----|----|-----|
| 73% | 86 | No |
| 27% | 32 | Yes |

14. Do you have an alcohol, substance abuse or self-medicating problem?

- | % | n | |
|-----|-----|------------------------------|
| 84% | 106 | No |
| 16% | 20 | Yes (please describe): _____ |

III. IN THIS SECTION WE ASK YOU HOW YOUR BRAIN INJURY HAS AFFECTED YOUR LIFE.

| 15. How has your first and second (if applicable) brain injury affected your life (please check ONE for each column that applies)? | | | | | | | | | | | | |
|--|--------|----|------------|---|----------|----|------------|---|---------------------------|---|------------|---|
| | Enough | | Not enough | | Too much | | Not timely | | Need but haven't received | | Don't need | |
| | % | n | % | n | % | n | % | n | % | n | % | n |
| First Brain Injury | 33% | 33 | 7% | 7 | 49% | 49 | 3% | 3 | 3% | 3 | 5% | 5 |
| Second Brain Injury, if applicable | 40% | 14 | 11% | 4 | 39% | 14 | 3% | 1 | 3% | 1 | 6% | 2 |

16. Has your brain injury changed how you feel about yourself?

| % | n | |
|-----|-----|---------------------------------------|
| 19% | 24 | No |
| 81% | 100 | Yes (please describe): _____ _____ |

17. Has your brain injury changed how people respond to you?

| % | n | |
|-----|----|---------------------------------------|
| 26% | 34 | Don't Know |
| 18% | 23 | No |
| 56% | 73 | Yes (please describe): _____ _____ |

18. If yes, are you concerned about other people's perceptions of you?

| % | n | |
|-----|----|------------|
| 20% | 20 | Not at all |
| 16% | 16 | A little |
| 32% | 32 | Some |
| 32% | 32 | A lot |

19. Do people mistake your brain injury for a mental health problem or intellectual disability?

| % | n | |
|-----|----|---------------------------------------|
| 40% | 51 | Don't Know |
| 16% | 21 | No |
| 44% | 56 | Yes (please describe): _____ _____ |

20. Has your brain injury had an impact on any of these areas of your life (please check ALL that apply)?

| % | n | |
|----------|----------|--|
| 58% | 77 | My marriage/family |
| 65% | 86 | My job |
| 71% | 94 | My ability to learn new things |
| 58% | 77 | My ability to go to school or college |
| 73% | 96 | My ability to do things like I used to |
| 68% | 90 | My living situation |
| 64% | 84 | My health status |
| 53% | 70 | My intimacy |
| 67% | 89 | My mental health status |
| 61% | 81 | My friendships |
| 72% | 95 | My social relationships |
| 67% | 88 | My recreation |

IV. IN THIS SECTION WE ASK YOU TO RATE YOUR REHABILITATION SERVICES.

21. Acute Rehabilitation Services.

Under the following services, please check the categories that apply:

- If you have received or are receiving services, check whether it was **Enough, Not enough or Too much.**
- If the services were not received in a timely fashion, check **Not timely.**
- If you need help but have not received help, check **Need but haven't received.**
- If you don't need the services, check **Don't need.**

| | Enough | | Not enough | | Too much | | Not timely | | Need but haven't received | | Don't need | |
|---|--------|----|------------|----|----------|---|------------|----|---------------------------|---|------------|----|
| | % | n | % | n | % | n | % | n | % | n | % | n |
| a. Brain Injury Diagnosis and Assessment | | | | | | | | | | | | |
| First Brain Injury | 53% | 60 | 19% | 21 | 4% | 5 | 9% | 10 | 6% | 7 | 9% | 10 |
| Second Brain Injury, if applicable | 40% | 18 | 24% | 11 | 4% | 2 | 4% | 2 | 11% | 5 | 16% | 7 |
| b. Acute Care | | | | | | | | | | | | |
| First Brain Injury | 55% | 62 | 12% | 13 | 4% | 4 | 6% | 7 | 7% | 8 | 16% | 18 |
| Second Brain Injury, if applicable | 44% | 19 | 21% | 9 | 2% | 1 | 5% | 2 | 5% | 2 | 23% | 10 |
| c. General Medical (Primary Care Physician) | | | | | | | | | | | | |
| First Brain Injury | 56% | 63 | 21% | 23 | 4% | 4 | 5% | 6 | 6% | 7 | 8% | 9 |
| Second Brain Injury, if applicable | 49% | 20 | 15% | 6 | 2% | 1 | 7% | 3 | 10% | 4 | 17% | 7 |
| d. Specialized Medical (Neurologist, Neuro-psychologist) | | | | | | | | | | | | |
| First Brain Injury | 48% | 54 | 23% | 26 | 3% | 3 | 12% | 14 | 8% | 9 | 6% | 7 |
| Second Brain Injury, if applicable | 48% | 19 | 20% | 8 | 3% | 1 | 13% | 5 | 8% | 3 | 10% | 4 |
| e. Rehabilitation (Inpatient) | | | | | | | | | | | | |
| First Brain Injury | 39% | 44 | 21% | 24 | 1% | 1 | 10% | 11 | 5% | 6 | 25% | 28 |
| Second Brain Injury, if applicable | 35% | 14 | 23% | 9 | 3% | 1 | 5% | 2 | 5% | 2 | 30% | 12 |

| | Enough | | Not enough | | Too much | | Not timely | | Need but haven't received | | Don't need | |
|---------------------------------------|--------|----|------------|----|----------|---|------------|---|---------------------------|----|------------|----|
| | % | n | % | n | % | n | % | n | % | n | % | n |
| f. Rehabilitation (Outpatient) | | | | | | | | | | | | |
| First Brain Injury | 37% | 40 | 29% | 31 | 1% | 1 | 7% | 7 | 7% | 8 | 19% | 21 |
| Second Brain Injury, if applicable | 27% | 11 | 29% | 12 | 2% | 1 | 5% | 2 | 15% | 6 | 22% | 9 |
| g. Neuro-rehabilitation | | | | | | | | | | | | |
| First Brain Injury | 35% | 37 | 26% | 28 | 1% | 1 | 6% | 6 | 12% | 13 | 21% | 22 |
| Second Brain Injury, if applicable | 26% | 10 | 32% | 12 | 3% | 1 | 5% | 2 | 11% | 4 | 24% | 9 |
| h. Physical Therapy | | | | | | | | | | | | |
| First Brain Injury | 33% | 37 | 24% | 27 | 2% | 2 | 5% | 6 | 9% | 10 | 28% | 32 |
| Second Brain Injury, if applicable | 28% | 11 | 23% | 9 | 3% | 1 | 5% | 2 | 8% | 3 | 33% | 13 |
| i. Occupational Therapy | | | | | | | | | | | | |
| First Brain Injury | 32% | 37 | 29% | 33 | 3% | 3 | 4% | 5 | 10% | 12 | 22% | 25 |
| Second Brain Injury, if applicable | 31% | 13 | 24% | 10 | 2% | 1 | 2% | 1 | 14% | 6 | 26% | 11 |
| j. Speech Therapy | | | | | | | | | | | | |
| First Brain Injury | 30% | 35 | 19% | 22 | 2% | 2 | 3% | 4 | 6% | 7 | 40% | 46 |
| Second Brain Injury, if applicable | 27% | 11 | 24% | 10 | 2% | 1 | 2% | 1 | 5% | 2 | 39% | 16 |
| k. Cognitive Training | | | | | | | | | | | | |
| First Brain Injury | 28% | 31 | 29% | 32 | 2% | 2 | 5% | 5 | 17% | 18 | 19% | 21 |
| Second Brain Injury, if applicable | 24% | 10 | 31% | 13 | 2% | 1 | 0% | 0 | 24% | 10 | 19% | 8 |

22. Rehabilitation Services by Type of Setting.

Under the following service settings, please check the categories that apply:

- If you have received or are receiving services in the setting, check whether it was **Enough, Not enough** or **Too much**.
- If the services were not received in the setting in a timely fashion, check **Not timely**.
- If you need help but have not received help in the setting, check **Need but haven't received**.
- If you don't need the services in the setting, check **Don't need**.

| | Enough | | Not enough | | Too much | | Not timely | | Need but haven't received | | Don't need | |
|--|--------|----|------------|----|----------|---|------------|---|---------------------------|----|------------|----|
| | % | n | % | n | % | n | % | n | % | n | % | n |
| a. Nursing Home | | | | | | | | | | | | |
| First Brain Injury | 9% | 10 | 3% | 4 | 3% | 3 | 2% | 2 | 3% | 3 | 81% | 94 |
| Second Brain Injury, if applicable | 9% | 4 | 9% | 4 | 0% | 0 | 0% | 0 | 0% | 0 | 83% | 38 |
| b. Residential Treatment (24 hours/day x 7 days/week) | | | | | | | | | | | | |
| First Brain Injury | 23% | 27 | 10% | 11 | 3% | 3 | 3% | 3 | 10% | 11 | 53% | 61 |
| Second Brain Injury, if applicable | 18% | 7 | 8% | 3 | 0% | 0 | 3% | 1 | 8% | 3 | 63% | 24 |
| c. Drop-in Center | | | | | | | | | | | | |
| First Brain Injury | 16% | 17 | 11% | 12 | 1% | 1 | 6% | 6 | 8% | 9 | 58% | 62 |
| Second Brain Injury, if applicable | 3% | 1 | 24% | 9 | 8% | 3 | 0% | 0 | 11% | 4 | 55% | 21 |
| d. Vocational Rehabilitation (for assessment of vocational needs, preparation for work, help finding a job) | | | | | | | | | | | | |
| First Brain Injury | 21% | 24 | 27% | 30 | 1% | 1 | 6% | 7 | 11% | 12 | 34% | 38 |
| Second Brain Injury, if applicable | 5% | 2 | 41% | 17 | 2% | 1 | 0% | 0 | 24% | 10 | 29% | 12 |
| e. Employment (for providing work support, helping securing and keeping a job) | | | | | | | | | | | | |
| First Brain Injury | 12% | 14 | 22% | 25 | 1% | 1 | 8% | 9 | 18% | 20 | 39% | 44 |
| Second Brain Injury, if applicable | 7% | 3 | 24% | 11 | 0% | 0 | 0% | 0 | 33% | 15 | 36% | 16 |

| | Enough | | Not enough | | Too much | | Not timely | | Need but haven't received | | Don't need | |
|---|--------|----|------------|----|----------|---|------------|---|---------------------------|----|------------|----|
| | % | n | % | n | % | n | % | n | % | n | % | n |
| f. Education (e.g., school or training center) | | | | | | | | | | | | |
| First Brain Injury | 13% | 14 | 20% | 21 | 1% | 1 | 6% | 6 | 19% | 20 | 42% | 44 |
| Second Brain Injury, if applicable | 5% | 2 | 21% | 9 | 0% | 0 | 2% | 0 | 29% | 12 | 43% | 18 |

V. IN THIS SECTION WE ASK YOU TO RATE YOUR NEED FOR SERVICES AND SUPPORTS.

Under the following list of services and supports, please check ALL that apply:

- If you have received or are receiving services, check whether it was **Enough, Not enough** or **Too much**.
- If the services were not received in a timely fashion, check **Not timely**.
- If you need help with services but have not received help with services, check **Need but haven't received**.
- If you don't need the services, check **Don't Need**.

| 23. Need for Services and Supports | | | | | | | | | | | | | |
|---|--|--------|----|------------|----|----------|---|------------|---|---------------------------|----|------------|----|
| | | Enough | | Not enough | | Too much | | Not timely | | Need but haven't received | | Don't need | |
| | | % | n | % | n | % | n | % | n | % | n | % | n |
| a. | Help with independent living skills (shopping, laundry, housecleaning, cooking, money management) | 32% | 36 | 25% | 28 | 2% | 2 | 5% | 6 | 9% | 10 | 27% | 31 |
| b. | Help with activities of daily living (dressing, eating, toileting, other personal care assistance) | 25% | 29 | 14% | 16 | 1% | 1 | 2% | 2 | 5% | 6 | 54% | 63 |
| c. | Access to assistive technology | 17% | 18 | 17% | 19 | 0% | 0 | 4% | 4 | 15% | 16 | 48% | 52 |
| d. | Help with substance abuse treatment and support | 7% | 8 | 3% | 3 | 0% | 0 | 3% | 3 | 3% | 3 | 85% | 96 |
| e. | Access to counseling/mental health services and supports | 46% | 52 | 18% | 20 | 2% | 2 | 5% | 5 | 10% | 11 | 20% | 22 |
| f. | Access to support groups | 24% | 26 | 17% | 19 | 0% | 0 | 6% | 7 | 17% | 19 | 36% | 39 |
| g. | Access to case management services (information and referral, help completing paperwork, help with developing a personal plan, help with long term planning) | 45% | 51 | 21% | 24 | 1% | 1 | 5% | 6 | 16% | 18 | 12% | 14 |
| h. | Help with advocacy | 31% | 34 | 22% | 24 | 0% | 0 | 6% | 6 | 16% | 17 | 26% | 28 |
| i. | Access to adult day program | 26% | 30 | 12% | 14 | 1% | 1 | 6% | 7 | 10% | 11 | 45% | 51 |
| j. | Access to Work-ordered Day Clubhouse | 6% | 6 | 9% | 10 | 1% | 1 | 7% | 7 | 8% | 8 | 70% | 75 |
| k. | Help with long-term planning | 31% | 35 | 20% | 23 | 0% | 0 | 4% | 4 | 22% | 25 | 24% | 27 |
| l. | Access to telephone helpline, statewide Brain Injury crisis number | 24% | 27 | 11% | 12 | 0% | 0 | 5% | 6 | 20% | 22 | 40% | 45 |
| m. | Access to legal help | 23% | 26 | 11% | 12 | 0% | 0 | 7% | 8 | 11% | 13 | 48% | 55 |

| 23. Need for Services and Supports | | | | | | | | | | | | | |
|---|---|--------|----|------------|----|----------|---|------------|---|---------------------------|----|------------|----|
| | | Enough | | Not enough | | Too much | | Not timely | | Need but haven't received | | Don't need | |
| | | % | n | % | n | % | n | % | n | % | n | % | n |
| n. | Access to community activities and social opportunities (recreational, spiritual, social) | 32% | 36 | 26% | 30 | 0% | 0 | 4% | 5 | 13% | 15 | 25% | 28 |
| o. | Access to reliable transportation | 39% | 45 | 28% | 32 | 0% | 0 | 5% | 6 | 8% | 9 | 21% | 24 |
| p. | Other (please describe): | | | | | | | | | | | | |

VI. IN THIS SECTION WE ASK YOU ABOUT THINGS THAT GET IN THE WAY OF GETTING HELP.

24. Have any of the following stopped you from finding or using needed services (please check ALL that apply)?

| % | n | |
|-----|----|---|
| 16% | 21 | I didn't know I had a brain injury |
| 27% | 36 | My own attitude about my brain injury |
| 28% | 37 | Service provider's lack of knowledge about brain injury |
| 42% | 55 | Other people's lack of knowledge about brain injury |
| 32% | 42 | Negative attitude of others |
| 39% | 52 | How others see me |
| 24% | 31 | Could not find information about the services |
| 28% | 37 | No one to advocate for me |
| 27% | 35 | Unable to access services when I need them |
| 21% | 27 | Services are too far away |
| 30% | 40 | No transportation to get to services |
| 23% | 30 | Services do not exist |
| 12% | 16 | Don't qualify for services |
| 28% | 37 | Can't pay for services |
| 8% | 10 | No health insurance |
| 5% | 7 | Not eligible for MaineCare (Medicaid) or Medicare |
| 7% | 9 | Private insurance won't cover services |
| 2% | 2 | Military benefits won't cover services |
| 11% | 15 | Other (please describe): _____ |

VII. IN THIS SECTION WE ASK YOU ABOUT YOUR SOURCES OF HELP.

25. How have you paid for the services you've received (please check ALL that apply)?

| % | n | |
|-----|-----|--|
| 86% | 113 | MaineCare (Medicaid) |
| 43% | 57 | Medicare |
| 37% | 49 | Supplemental Security Income (SSI) |
| 37% | 49 | Social Security Disability Income (SSDI) |
| 11% | 14 | Private insurance |
| 1% | 1 | Workman's Compensation |
| 21% | 28 | Personal funds |
| 4% | 5 | Personal loans |
| 2% | 2 | Veteran's Administration benefits |
| 3% | 4 | Special Education funds |
| 5% | 7 | Legal Settlement |
| 0% | 0 | Military Benefits |

26. What other types of assistance do you receive (please check ALL that apply)?

| % | n | |
|-----|----|---|
| 5% | 7 | Legal Aid Services |
| 11% | 15 | Services from provider agencies: |
| | | Residential Services from provider agencies (e.g., Goodwill, Charlotte White Center, Neuro-restorative, Lakeview, Creative Works Systems, Northern Maine General) |
| 21% | 27 | |
| 23% | 30 | Outpatient Neuro-rehabilitation Services (e.g., Goodwill, MCIR, CINR) |
| 5% | 6 | Nursing Facility Brain Injury Services (e.g., RiverRidge, Brewer Rehabilitation) |
| 5% | 6 | Specialty Hospital Brain Injury Services (e.g., New England Rehabilitation Hospital) |
| 21% | 27 | Mental Health/Substance Abuse Treatment (Tri-County, Crisis and Counseling, AMHC, Community Health and Counseling, Broadreach) |
| 12% | 16 | Home Health Coordination (e.g., Alpha One or EIM) |
| 24% | 32 | Services from Vocational Rehabilitation (VR) |
| 1% | 1 | Services from the Veteran's Administration (VA) |
| 5% | 6 | Services from the Division for the Blind and Visually Impaired |
| 17% | 23 | Other (please describe): _____ |

VIII. IN THIS SECTION WE ASK YOU ABOUT SUPPORT GROUPS.

27. Do you attend a support group for individuals with a brain injury?

| % | n | |
|-----|-----|-----|
| 90% | 112 | No |
| 10% | 12 | Yes |

28. If you do not attend, would you like to join a support group?

| % | n | |
|-----|----|-----|
| 51% | 54 | No |
| 49% | 52 | Yes |

29. If you do not attend, what prevents you from attending (e.g., transportation) (please describe)?

30. If you want to attend a support group for individuals with a brain injury, which type of group would you prefer (please check ONE)?

| % | n | |
|-----|----|---|
| 61% | 36 | People with brain injuries similar to yours |
| 14% | 8 | People with brain injuries of various degrees |
| 9% | 5 | People with brain injuries and family members |
| 5% | 3 | Family members only |
| 12% | 7 | Other (please describe): _____ |

IX. IN THIS SECTION WE ASK YOU ABOUT YOUR EDUCATION.

31. How far did you go in school before you had your Brain Injury (please check ONE)?

| % | n | |
|-----|----|--|
| 9% | 10 | Not applicable |
| 3% | 4 | Pre-school |
| 6% | 7 | Grade School |
| 10% | 12 | Middle School |
| 40% | 47 | High School |
| 20% | 23 | Some College/Vocational Technical/Trade School |
| 2% | 2 | Bachelor's Degree |
| 1% | 1 | Master's Degree |
| 9% | 11 | Other (please describe): _____ |

32. Are you interested in finding out more about your educational needs and opportunities?

| % | n | |
|-----|----|-----|
| 50% | 59 | No |
| 50% | 59 | Yes |

33. What education have you had since you've had your Brain Injury (please check ONE)?

| % | n | |
|-----|----|--------------------------------|
| 49% | 54 | Not applicable |
| 0% | 0 | Pre-school |
| 1% | 1 | Grade School |
| 0% | 0 | Middle School |
| 12% | 13 | High School |
| 15% | 16 | Some College |
| 3% | 3 | Associate's Degree |
| 2% | 2 | Bachelor's Degree |
| 1% | 1 | Master's Degree |
| 18% | 20 | Other (please describe): _____ |

34. Did you need special education services, support or accommodations in a school or college program?

| % | n | |
|-----|----|------------------------------|
| 47% | 56 | No |
| 53% | 64 | Yes (please describe): _____ |

35. If yes, did they meet your needs?

| % | n | |
|-----|----|------------------------------|
| 37% | 25 | No |
| 63% | 42 | Yes (please describe): _____ |

X. IN THIS SECTION WE ASK YOU ABOUT EMPLOYMENT.

36. Are you currently working?

| % | n | |
|-----|-----|--|
| 87% | 111 | No |
| 9% | 12 | Yes |
| 3% | 4 | Not Applicable (i.e., not age appropriate) |

37. Have you worked since the time you were injured?

| % | n | |
|-----|----|------------------------------|
| 47% | 58 | No |
| 7% | 8 | Not Applicable |
| 46% | 57 | Yes (please describe): _____ |

38. Have you been enrolled in Vocational Rehabilitation services?

| % | n | |
|-----|----|-----|
| 45% | 56 | No |
| 55% | 68 | Yes |

39. If yes, did you get help finding a job?

| % | n | |
|-----|----|-----|
| 53% | 43 | No |
| 47% | 38 | Yes |

40. Did you get a job?

| % | n | |
|-----|----|-----|
| 59% | 55 | No |
| 41% | 38 | Yes |

41. Has your brain injury impacted the kind of work you do?

| % | n | |
|-----|----|-----|
| 18% | 20 | No |
| 82% | 89 | Yes |

42. If you are not working now, why not (please check ALL that apply)?

| % | n | |
|-----|----|--|
| 11% | 15 | Not applicable |
| 14% | 19 | I cannot find a job |
| 11% | 15 | I haven't been able to keep a job for more than _____ number of months |
| 22% | 29 | I cannot do the job I used to do |
| 41% | 54 | I am not able to work |
| 10% | 13 | Lack of long term work supports or accommodations |
| 28% | 37 | Other (please describe): _____ _____ |

XI. IN THIS SECTION WE ASK YOU ABOUT YOUR HOME LIFE.

43. Where are you currently living (please check ONE)?

| % | n | |
|-----|----|---|
| 65% | 82 | In a house or apartment: |
| 44% | 36 | Alone |
| 23% | 19 | With parents |
| 20% | 16 | With spouse/partner |
| 13% | 11 | With roommate |
| 14% | 17 | Group home |
| 0% | 0 | Foster home |
| 6% | 7 | Residential treatment facility |
| 2% | 2 | Hospital |
| 1% | 1 | Rehabilitation facility |
| 3% | 4 | Nursing home |
| 10% | 13 | Other (please describe): _____ _____ |

44. How do you travel from place to place on a daily basis?

| % | n | |
|-----|----|---|
| 19% | 25 | I drive myself |
| 34% | 45 | I ride with family/friends |
| 17% | 23 | I take public transportation (bus/train) |
| 9% | 12 | I take a taxi |
| 23% | 30 | I use special transportation (please describe): _____ |
| 14% | 18 | Other (please describe): _____ |
| 5% | 7 | I use special transportation (please describe): _____ |
| 8% | 11 | Other (please describe): _____ |
| 6% | 8 | Transportation is not available (please explain): _____ |

XII. IN THIS SECTION WE ASK ABOUT SERVICES THAT ARE IMPORTANT TO YOU AND THOSE SERVICES THAT ARE MISSING.

45. What are the three most important services that you get or that you received in the past?

1. _____
2. _____
3. _____

46. What are the three most important services that are missing or need to be developed to help you?

1.

2.

3.

XIII. QUESTIONS IN THIS SECTION ARE FOR GUARDIANS, FAMILY MEMBERS OR OTHERS.

47. As a family member or person supporting a person with an acquired brain injury, what are the three most important services that you need?

XIV. THIS LAST QUESTION IS FOR YOU TO CONSIDER.

48. Would you be interested in being part of a focus group?

| % | n | |
|-----|----|-----|
| 50% | 57 | No |
| 50% | 57 | Yes |

If yes, please give us your information so we can contact you.

Name:

Address:

Phone Number:

Email Address:

APPENDIX C

**Brain Injury
Focus Group Protocol**

Part One - Introduction**Facilitator Script (F): (verbatim or slight paraphrasing every bullet) and consent form retrieval. (15 minutes)**

F: Welcome everyone, my name is (introduce self) and this is (name) our note taker and timer. We've asked you to participate in this focus group to help us better understand the service needs of persons with brain injury and/or their family members. This information, along with the information from a paper survey earlier this year, will be compiled in a report that we at the Muskie School will be drafting and presenting to the Maine Department of Health and Human Services, Office of Aging and Disability. While we are not certain how the State will use the report, we expect that they will use it to make requests of the Maine Legislature to increase funding for services for persons with brain injury in Maine.

We also expect that the State will make copies available to brain injury advocacy groups in Maine and so, ultimately, you may be able to review the report yourselves, although we cannot guarantee that.

- Our discussion is scheduled to take about an hour and 3/4. So, if you need to take a break, please feel free to come and go as you wish.
- We want you to feel comfortable sharing thoughts and ideas, and to feel comfortable remaining silent if you prefer not to discuss any of the questions.
- We also want to remind you that your participation is completely voluntary, and anything said, written down or recorded during this discussion will remain confidential. No individual names will be used in any reports about what is shared here.
- We ask that you not share any names or information you hear in this session to help us protect everyone's privacy.
- There are some ground rules for our discussion:
 - Just a reminder to turn off any cellphones or put them on vibrate so that we are not interrupted in our conversations.
 - We want to encourage everyone to participate and to remind you all that everyone has something to contribute.
 - Please respect each other's contributions. We all have different experiences, and there are no right or wrong answers here.
 - If you speak first on a question, please give someone else a chance to speak first on the other questions.
 - The questions are open-ended and we are hoping to hear from everyone, so please understand if we need to limit you on the length of time for your answer.

- Please let us know if you need us to repeat any of the questions – just raise your hand.
- Please share any ideas or thoughts as they occur. Please **do** add ideas and thoughts triggered by what others say. And, at the same time, please do not interrupt one another.
- In addition to recording, (name of note taker) and I will be taking notes during our conversation to be sure we clearly capture what you are telling us.
- Does anyone have any questions about the plan for our discussion or the consent forms you have signed?
- If not, before we begin we need to just check and insure that we have a signed consent form for everyone participating today.

Note taker - gathers forms, checking for signatures, compares with count of heads in room and waves facilitator on or notes missing form needed.

Part Two - Questions

Introductory Question (15 minutes)

1. F: Please introduce yourself and tell us where you live.

Transition Question (10 minutes)

F: As we begin our discussion, please take a minute to consider the services that are – or should be - available to you as an individual with brain injury and answer the following:

2. In one or two words, what comes to mind when you think of brain-injury services in Maine?

F: From this point on, please do not feel you need to raise your hands or go in order around the room. It will be most helpful if this to be more of a conversation where you build on each other's thoughts. This is particularly important because we want cover several short time. Our note taker will let us know if we are out of time on a question.

Key Questions

3. F: (1 hour 15 minutes)
 - a. What services are the most helpful to you now in your daily life and why?
 - b. What services were the most helpful to you at a critical moment in your life with a brain injury and how were they helpful? [Might need to explain "critical moment"]
 - c. What are your frustrations with brain injury services in Maine?
 - d. What gets in the way of your receiving the services you need or want?

- e. If you could change one thing about brain injury services in Maine, what would that be?
- f. Are there brain injury services that you need or want that are not available?

Note taker: wave @ 1 hour

4. Ending Questions (15 minutes)

- a. What other thoughts or suggestions would you like to share about things that would help you as a person with a brain injury?
- b. Is there anything else you would like us to know that we did not cover in our conversation today?

Note taker: Wave @ 1 hour 55 minutes

Part Three - Wrap Up & Debrief

Focus Group Wrap:

F: (1 minutes) *Sounds like our time is up. This has been interesting and informative. Thank you all. We appreciate your sharing your experience. (Note taker – if you could please turn off the recorder, I think we need to let these kind folks head home.)*

Facilitator & Note taker (F&N) Debrief

When: Immediately following each focus group session.

Points of discussion:

- Notable difference from other session, if applicable
- Non-verbal responses and other contextual considerations that may help inform the notes and future analysis of the session.
- Key points to be certain to capture
- Other noteworthy points

F & N: Agree upon note exchange deliverable date.

HRSA Traumatic Brain Injury State Partnership Grant

The State of Maine Department of Health and Human Services (DHHS) is committed to Maine people living safe, healthy, and productive lives. The Office of Aging and Disability Services falls within DHHS. At the foundation of the Office of Aging and Disability Services is the belief that all individuals, through self-determination, can achieve a quality of life consistent with the community in which they live. This mission aligns well with the purpose of this grant which is to increase access to rehabilitation and other services for individuals with traumatic brain injury. The Office of Aging and Disability Services established partnerships with eight community entities to carry out the goals of the grant. In particular, the grant activities focus on increasing access to rehabilitation and other services by (1) screening to identify individuals with TBI, (2) building a trained TBI workforce by providing professional training, (3) providing information about TBI to families and referrals to appropriate service providers, and (4) facilitating access to needed services through resource facilitation.

Information provided by: State of Maine, Department of Health and Human Services, Office of Aging and Disability Services, Program Manager for Brain Injury Services.

Brain Injury Waiver

18.01 INTRODUCTION

This benefit is a Home and Community-Based Waiver for Adults with Brain Injury who are 18 or older, meet criteria for care in an intermediate care facility or nursing facility and choose to live in the community with the support of this waiver. This Home and Community-Based Waiver is designed to maximize the opportunity for members to achieve the greatest degree of self-sufficiency and independence chosen by the member. Member choice in all services and components of services is a primary goal of this waiver. Additionally, the principles of conflict-free care coordination, services provided in the least restrictive modality and effective use of assistive technology for communication, environmental control and safety are inherent to this waiver.

This benefit has been designed and will be implemented in such a manner so as to ensure that every waiver service setting:

- ◆ Is integrated in and supports full access to the greater community;
- ◆ Is selected by the member from among setting options;
- ◆ Ensures members rights of privacy, dignity and respect, and freedom from coercion and restraint;
- ◆ Optimizes autonomy and independence in making life choices; and
- ◆ Facilitates choice regarding services and who provides them.

From: Section 18 Home and Community Based Services for Adults with Effective Brain Injury. MaineCare Benefits Manual Chapter II, §§101-10-144 (2014).

| Glasgow Coma Scale | | |
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| Response | Scale | Score |
| Eye Opening Response | Eyes open spontaneously | 4 Points |
| | Eyes open to verbal command, speech, or shout | 3 Points |
| | Eyes open to pain (not applied to face) | 2 Points |
| | No eye opening | 1 Point |
| Verbal Response | Oriented | 5 Points |
| | Confused conversation, but able to answer questions | 4 Points |
| | Inappropriate responses, words discernible | 3 Points |
| | Incomprehensible sounds or speech | 2 Points |
| | No verbal response | 1 Point |
| Motor Response | Obeys commands for movement | 6 Points |
| | Purposeful movement to painful stimulus | 5 Points |
| | Withdraws from pain | 4 Points |
| | Abnormal (spastic) flexion, decorticate posture | 3 Points |
| | Extensor (rigid) response, decerebrate posture | 2 Points |
| | No motor response | 1 Point |
| Minor Brain Injury = 13-15 points; Moderate Brain Injury = 9-12 points; Severe Brain Injury = 3-8 points | | |

Source: Teasdale G, Jennett B. Assessment of coma and impaired consciousness. A practical scale. *Lancet*. 1974;2:81-4.

From: Liou, I. (2013). *Core concepts. Diagnosis and management of hepatic encephalopathy*. Hepatitis C Online. Accessed 10 Feb. 2016. <http://www.hepatitisc.uw.edu/go/management-cirrhosis-related-complications/hepatic-encephalopathy-diagnosis-management/core-concept/all>