Brain Injury in Maine
A Needs Assessment

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PREPARED BY
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FOR
The Office of Aging and Disability Services (OADS)
Maine Department of Health and Human Services

AND
The Maine Acquired Brain Injury Advisory Council

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Executive Summary

Introduction

The Brain Injury Association of America – Maine Chapter (BIAA-ME) contracted with Koné Consulting to complete this needs assessment of brain injury survivors and their family members, caregivers, and providers in Maine, building off three previous needs assessments. To complete this needs assessment, Koné Consulting conducted a mixed methods assessment that included interviews of 18 people, a survey of 274 survivors, caregivers, and family members, a survey of 177 providers, and 2 focus groups with 14 survivors, caregivers, and family members. The assessment explores brain injury services and unmet needs, training and resource needs of providers, needs of caregivers, and the intersection of brain injury and behavioral health. For brevity, survivors, family members, and caregivers who completed the survey are referred to as "consumers."

Key Findings and Opportunities for Improvement

Awareness

Consumers and providers both ranked increasing awareness of brain injury first among five options when asked what would most positively impact Mainers with brain injury. Limited awareness impacts prevention of brain injury and reinforces stigma at the community level. It also limits identification of brain injury–especially of mild injuries that may go overlooked– and delays intervention. Consumers also indicated the lack of awareness of the services available as a significant barrier to receiving care and therefore slowing the recovery process.

> "What can we do to tell stories and **raise awareness**? How might awareness lead to **better treatment options and better prevention**?"
> *- Survivor*

Injury Screening and Diagnosis

There is a need to increase and improve screening for brain injury and improve diagnosis of brain injury

About 80% of consumers who completed the survey reported that the nature of their injury was a blow to the head or a stroke. The cause of respondents' injuries were more varied, with auto accident and a fall cited the most often. Diagnosing a brain injury soon after it happens is a critical step in providing care for the survivor. About 73% of consumers were diagnosed between 0 to 3 months of their injury. Awareness of brain injury within the community and among providers is also an important piece of survivors' healing process. Screening for brain injury is a critical piece of a person's recovery, but Maine does not have a

standardized tool. About 26% of providers indicated they do not screen for brain injury. Over half of consumers indicated they use MaineCare to pay for their services.

Health-related services

Primary barriers to services are lack of awareness of services, not having services near where survivors live, and not understanding the process to get services

Consumers in general have good experiences with rehabilitation services. Three-quarters of the consumers said they were satisfied or very satisfied. The main rehabilitation service used by consumers is outpatient neuro-rehabilitation, indicating aspects of this service could be incorporated in other parts of the system to improve consumer service experience. Consumers and providers identified unmet needs for three services: brain injury diagnosis and assessment, specialized medical services (neurologist, neuropsychologist), and residential in-home support.

Consumers and providers differ on when services are more difficult to access after an injury

Consumers identified the time immediately after the brain injury as the point when services are most difficult to access. In contrast, providers identified two or more years after the injury as the time period when services are most difficult to access.

Over 40% of consumer respondents stated that they are currently receiving mental health services. Consumers indicated that the mental health service they wish they could use more was a peer group (21%). When consumers were turned away by providers, one of the main reasons given was that a brain injury specialist was not available (19%). This survey attempted to capture individuals who were receiving both mental health and substance use services, however in targeted questions about substance use services, only 4% of consumers indicated that they were currently receiving substance use services. The limited number of survey responses is believed to be an underrepresentation of those experiencing brain injury and substance use and therefore prevented an in-depth analysis of substance use services.

Additionally, survey results reveal an opportunity to increase awareness of brain injury among police and medics; only 14% of the consumers who had interactions with emergency responders were asked if they had a brain injury. Fortunately, these interactions with emergency responders largely have not resulted in negative impacts on access to services for consumers.

Daily Living

Affordable housing and residential services remain as needs, leading to waiting lists and sending survivors out of state for care

Survivors require support services to meet their daily needs and progress towards full recovery. Three support services of interest are education, housing, and employment services. Consumers have education consultation and wrap-around family support or home visiting services at the top of their wish list for education services.

Consumers were the least satisfied with employment services. Among the primary limitations for gaining and keeping employment were consumers' changing needs over time (59%) and having a hard time finding a job that will accommodate their brain injury (40%).

Close to 60% of the consumers reported living independently in their own homes with modifications, assistive technology or with a personal care provider. When asked to identify [describe?] their challenges with housing, consumers indicated that the cost of housing and having the skills to live safely on their own prevented them from getting or keeping a place to live. Providers indicated the highest needs were for in-home personal care provider services (67%), low-income/subsidized housing (65%), and permanent supportive housing (64%). Just over half (54%) of the providers identified **long-term residential services as an unmet need**, yet this was the highest identified need during stakeholder interviews [because it?] leads to waiting lists.

Satisfaction with Services

Consumers and providers have different perspectives on service barriers

The proportion of consumers who were satisfied to very satisfied with support services (health-related or for daily living) ranged from 69% to 76%. These estimates summarized in Table 1 show that there is room for improvement in delivery and quality of services. Particular attention could be paid to the demands of consumers regarding employment services, the support service with the lowest satisfaction ratings. Providers were asked to identify the top three barriers they believe prevent people with brain injuries from accessing services. Over half responded that **waiting lists** are an issue, with **limited training for providers** and **location** as the second and third most-selected responses.

Table 1: Percent of Consumers satisfied or very satisfied with support services

Level of Injury Severity	Rehabilitation (N=214)	Education (N=161)	Employment (N=92)	Housing (N=130)	Provider Communication/ Coordination (N=173)
Mild	68%	77%	69%	69%	72%
Moderate	80%	68%	65%	78%	58%
Severe	71%	64%	56%	70%	84%

System Coordination and Support for Providers and Caregivers

Consumers and providers have different priorities regarding service coordination needs

Seventy percent (70%) of consumers are satisfied or very satisfied with how their providers communicate and collaborate with one another. Consumers who responded they were dissatisfied or very dissatisfied with communication and collaboration between their providers identified that **having someone to help them navigate services** and **having one case manager who could work across supports** would be most helpful in improving service coordination, while providers overwhelmingly believe that having **more options for services and supports** would be most helpful.

Provider training could be improved–especially cross-training across fields

Providers and caregivers need ongoing support and training to be able to care for survivors. Providers responded they need additional funding for staff to attend trainings and high-quality online training options. There also remains a need to train providers who work outside of healthcare and rehabilitation, including those in the behavioral health, domestic violence, and education fields. Unfortunately, stakeholders report there are **workforce shortages** in Maine, specifically of specialists, such as Neuropsychologists and Physiatrists, as well as in-home care providers, which worsened during the COVID-19 pandemic. Workforce shortages were also reported as impacting the length and quality of training, especially in settings where staffing shortages are due to high turnover and the need for coverage is prioritized over training procedures.

Caregivers need more support–especially in navigating service systems

Family members and caregivers indicated that support and information are the most important services they need.

Systems Level

There has been progress to improve services for people with brain injury in Maine

Support from the Legislature and Executive leadership have allowed for changes that have increased services to a broader range of people based on the impact of their injury rather than the cause. The Legislature recently funded Neuroresource Facilitation services, brain injury support groups, and a new Brain Injury & Stroke Resource Directory. Maine is also unique due to the community rehabilitation clinics which are based on a trans-disciplinary team model and are known for better outcomes for survivors, reducing the impact on the healthcare system, and increases the state's ability to serve its very rural communities.

Data on the incidence and prevalence of brain injury is not available statewide or collected within state systems

There is need to improve statewide data collection on brain injury incidence and prevalence. This need has been identified in previous assessments and emerged again as a theme during this needs assessment.

Best practices also confirm the importance of data collection not only to identify brain injuries but also to improve connecting people to services and funding support services. Current publicly available data from the Maine Center for Disease Control and Prevention (CDC) is outdated and limited to a narrow scope of information. Data on brain injury is also not available for people receiving services through the Department of Education Special Education Services, the Department of Corrections, or the Office of Behavioral Health.

State silos continue to be a challenge and lead to gaps in services

Stakeholders report that the siloed nature of state services limits the ability to provide whole-person, client-centered care, focusing instead on what the person is eligible to receive funding for. Despite increased efforts to collaborate between state agencies around brain injury, there remain opportunities to advance towards person-centered care determined by needs rather than funding, especially for those with co-occurring brain injury and behavioral health needs.

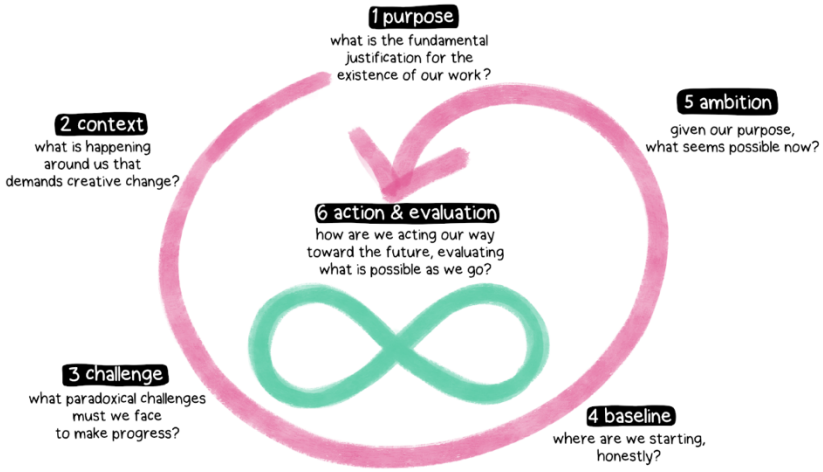
Next Steps

Given the existing initiatives and opportunities for improvement determined through this needs assessment, the recommended next step is to engage in a strategic planning process with key stakeholders, including representatives from DHHS, ABIAC, and BIAA-ME. One strategic planning approach that has been successful with other organizations is called the Knotworking approach, which also uses Ecocycle planning; both from the Liberating Structures method of facilitation.[1]

If making a strategic plan were simple, a team would develop a list of tasks, decide who is doing what, what resources are needed, and forge ahead. This assumes resources are predictable, conditions are static, and the future is stable and knowable. That is not reality. Traditional strategic planning approaches start with an analysis of strengths, weaknesses, opportunities, and threats (SWOT analysis), followed by an environmental scan of the political, economic, social, and technological factors (PEST analysis) impacting an organization. These approaches often assume a linear future will unfold, and concentrate design, ownership and implementation in a top-down model and pin hopes on wonderful-but-vague mission statements. Traditional planning frameworks fail to unleash and engage those who must execute and build on data without a sense-making step that would help the group ground factors in the context of how things actually get implemented in their organization.

[1] https://www.liberatingstructures.com/31-ecocycle-planning/

Strategy Knotworking could be used instead to create a living state plan for brain injury services and supports that delivers valuable, actionable next steps and an ability to flex and evolve in changing contexts. The process includes a data gathering and analysis step when answering the second question, "What is happening around us that demands creative change?" In this case, the planning committee could use the results of this Brain Injury Needs Assessment as the background data for that step.



Knotworking is an inclusive process involving a series of workshops that would be conducted with a broad group of stakeholders, such as members of the Maine ABIAC. The plan is built by all stakeholders through answering six key questions. The set of interrelated answers to the questions become a compelling narrative–much more than the individual elements reveal. Shaping these answers together builds ownership, trust, and momentum.

Performance measurement is also a way to organize staff, stakeholders, and the broader community around a shared understanding of a system's performance today—and where it is heading in the future. As a part of the planning process, ME-BIAA, DHHS, and ABIAC members have an opportunity to work together to create a set of performance measures to make strategic goals and the program's performance relative to that strategy visible over time. One method that governments and non-profits have used successfully is a method called the PuMP Blueprint. Developed by Stacey Barr, the PuMP Blueprint lays out an eight-step process for creating and using performance measures that is particularly well-suited to measuring seemingly intangible goals and creating shared understanding and buy-in for those measures. For example, a small group at the PuMP workshops might work on a plan for measuring how much the independence and overall health and well-being of all people with brain injury in Maine has improved as a result of these efforts. The group would answer a series of questions like: What results could you see, hear, smell, taste or touch that would provide evidence of achieving this goal? How can that be quantified over time objectively? What could be an unintended consequence of achieving this result? The outcome of the workshops would be clear definitions of the measures for each goal and a plan and assignments for gathering the data and reporting results, including the thresholds that would trigger program management decisions.

Introduction

Background

This needs assessment of Maine's brain injury community is a continuation of prior work and builds off of three needs assessments conducted in 2016, 2010, and 2005 about where to focus brain injury efforts and resources in Maine. Most recently, in 2016, the Muskie School of Public Service completed a needs assessment of brain injury survivors, family members, and caregivers by conducting a paper survey and focus groups.[2] This needs assessment differs from that one in a few substantial ways. First, we included people outside of MaineCare, which allowed us to hear from people with brain injuries who pay privately for healthcare services or through other payment types. We also emphasized efforts to reach people receiving or in need of behavioral health services. And, in addition to hearing from people with brain injury, their families, and caregivers (also referred to as consumers throughout this report), we included providers of services to people with brain injuries.

The Brain Injury Association of America – Maine Chapter (BIAA-ME) contracted Koné Consulting to complete this needs assessment with assistance from a project team from BIAA-ME and a project Steering Committee. The project team from BIAA included people from BIAA's national office and state chapter. The Steering Committee met monthly for the duration of the project and was recruited from the Maine Acquired Brain Injury Advisory Council (ABIAC) and from Maine's Office of Behavioral Health. ABIAC provides oversight and advice to DHHS and the Legislature and is a group of survivors, family members, caregivers, providers, advocates, and state agency representatives who have served as the mandated Advisory Board for four Federal TBI Partnership grants to improve Maine's system of care for people with brain injury.

Study Objectives

The purpose of this study is to assess four areas:

1. Overall brain injury community and unmet needs
2. Providers training and resource needs
3. Caregivers needs
4. Intersection of brain injury and behavioral health

[2] Living with a Brain Injury in Maine. 2016. https://digitalcommons.usm.maine.edu/cgi/viewcontent.cgi?article=1050&context=aging

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Approach/Methodology

We used a **mixed methods approach** to complete this study, including a review of extant materials, interviews, a survey of survivors, caregivers, and family members, a survey of providers, and focus groups. We reviewed **existing materials** to understand the **current landscape** of services and **recent assessments** evaluating needs of survivors, including "Living with a Brain Injury in Maine" [3] and "Brain Injury in Maine: A Needs Assessment"[4], which were conducted in 2016 and 2010 respectively by the Muskie School of Public Service. We found information about current services provided through MaineCare at the Department of Health and Human Service (DHHS) website[5] and the BIAA-ME Brain Injury & Stroke Resource Directory.[6] Additional background materials include, but are not limited to, ABIAC annual reports,[7] Maine Center for Disease Control and Prevention: Concussion and Traumatic Brain Injury (2012), Department of Labor Brain Injury Support, TBI in the US: Epidemiology and Rehabilitation CDC report to Congress, and Maine Highway Safety Plan (FY 2020).

We conducted 12 **interviews** with 18 people from a variety of organizations and backgrounds. We interviewed several individuals from state government, including from the Office of Aging and Disability, Department of Education, Office of Behavioral Health, and the team working on the state's opioid response. We spoke to healthcare providers, including rehabilitation providers for people with brain injuries and a mental health and substance use counseling provider. Finally, we learned from other individuals in advocacy spaces, including Disability Rights Maine and Brain Injury Voices. Our interview protocol, included in Appendix A, includes many questions about healthcare provision, special populations, provider and caregiver training, and data that could be tailored depending on the interviewee.

We conducted two **surveys**; one for survivors, their caregivers, and their family members, and one for service providers. We refer to the first as the "consumer survey" and the second as the "provider survey." At the beginning of the consumer survey, people assisting or responding on behalf of someone with a brain injury were instructed to respond to survey questions from the survivor's perspective. Caregivers and family members were instructed to respond from their own perspective with the knowledge they have of their loved one's experience. When describing survey results, we will use the term "consumer respondent" or "consumer" to describe all respondents of the consumer survey. Many of the questions on

[3] Ibid.
[4] Brain Injury in Maine: A Needs Assessment. 2010. https://digitalcommons.usm.maine.edu/cgi/viewcontent.cgi?article=1028&context=aging
[5] Adults with Brain Injury. State of Maine Department of Health and Human Services. https://www.maine.gov/dhhs/oads/get-support/adults-with-brain-injury
[6] Brain Injury & Stroke Resource Directory. Maine. Third Edition. https://www.biausa.org/downloads/find-bia/Maine/Maine%20Directory%20Third%20Edition%202019.pdf
[7] Acquired Brain Injury Advisory Council of Maine Annual Report. January 15, 2021. http://legislature.maine.gov/doc/4876

the consumer and provider surveys were aligned so that we could compare answers from the two groups, such as questions about services for people with brain injuries, barriers to services, provider and caregiver training needs, and ideas to facilitate service coordination. Appendix B shows the flyer used for recruitment of survey participants. The Steering Committee helped distribute surveys by circulating them among organizations in their networks. Communities targeted for participation by the Steering Committee included the BIAA-ME network, ABIAC network, behavioral health providers, domestic violence agencies, Tribal communities, the veteran community, and aging/older adults who were underrepresented in previous needs assessments. While the 2016 needs assessment only used paper surveys mailed to people receiving MaineCare benefits, surveys completed by consumers for this needs assessment were mostly web-based, except for 23 consumers who completed paper surveys. All providers completed web-based surveys. Unlike the 2016 assessment, this needs assessment also included people outside of those receiving MaineCare, which allowed us to hear from people with brain injuries who pay privately for healthcare services or through other payment types. An example of the consumer survey is provided in Appendix C and an example of the provider survey is in

Appendix D. Finally, when reporting survey results for a question, we only include responses of respondents who did not skip the question. Throughout the report, the number of respondents for each question is included as "N" either in a footnote or chart caption.

We surveyed 274 people who have a brain injury or are a caregiver or family member of a survivor. More than half (52%) of the respondents identified as an **adult with a brain injury**, 13% were a **family member and caregiver**, and 13% were **parents of children** with brain injuries. See Table 2 for the complete breakdown. Thirty-four percent (34%) of consumer respondents represent **urban** counties, 41% represent **rural** counties, and 25% did not respond. Consumers represented all counties in Maine, with the majority of responses from Cumberland (14%), Kennebec (13%), Knox (13%), and Penobscot (12%) (Table 4).

Table 2: Consumer Respondents

Adult with a brain injury	52%
Family member or significant other of a person with a brain injury, and their caregiver	13%
Parent of a child with a brain injury	13%
Another person assisting the person with a brain injury	11%
Family member or significant other of a person with a brain injury, but not their caregiver	8%
Guardian of a person with a brain injury	3%

Consumer Survey Question #1: What best describes your connection to brain injury issues? N=272.

We surveyed 177 providers working in a range of fields. More than half of these providers (52%) have worked in their field for 11 years or more.[8] The largest categories of provider respondents were **case managers/care coordinators** (22%), **mental health providers** (16%), and **rehabilitation providers** (16%). See Table 3 for a breakdown of provider types.

Table 3: Types of Providers

Case Manager/ Care Coordinator	22%
Mental Health Provider	16%
Rehabilitation Provider (Speech/ language therapy, occupational therapy, physical therapy)	16%
Healthcare Professional (Doctor, Nurse, etc.)	6%
Domestic Violence Advocate	5%
Waiver Service Provider	5%
Advocate	4%

[8] Provider Survey Question #3: How long have you been working in your field? N=177.

Vocational/ Employment support	3%
Homeless Services Provider	3%
School staff/ Teacher/ Nurse/ Counselor	3%
Veterans Services	2%
Policymaker	2%
Specialized Healthcare Professional (Neuropsychologist, Psychometrist)	1%
Substance Use Disorder Service Provider	1%
Police, Probation, or Corrections Officer	1%
Funder	0%

Provider Survey Question #1: What is your profession or how are you connected to brain injury? N=176.
Note: "Other" write-in responses with more than one entry: Peer Support (2), Co-occurring MH/SUD (2)

Sixty percent (60%) of providers work in urban counties, 33% in rural counties, and 7% provided services in multiple counties or statewide. Providers represented every county except Franklin, with the majority of responses from Cumberland (24%), Penobscot (15%), York (12%), and Kennebec (11%) (Table 4).

Table 4: Percentage of Consumers and Providers from Each County

County	Percentage of Consumer Respondents	Percentage of Provider Respondents
Androscoggin	8%	7%
Aroostook	2%	3%
Cumberland	14%	24%
Franklin	1%	0%
Hancock	5%	3%
Kennebec	13%	11%
Knox	13%	5%
Lincoln	3%	1%
Oxford	6%	2%
Penobscot	12%	15%
Piscataquis	1%	3%
Sagadahoc	3%	1%
Somerset	4%	3%
Waldo	5%	1%
Washington	0.5%	1%
York	9%	12%
Other (multiple counties or statewide)	--	7%

Consumer Survey Question #51: What county do you live in? N=206.
Provider Survey Question #2: What county or counties do you work or provide services in? N=177.

We designated consumers and providers as **urban or rural** based on their county of residence or practice. We used the Office of Management and Budget (OMB) definition of urban and rural counties, which identifies rural counties as ones that are not part of any Metropolitan Area.[9] These designations are listed in Table 5. We identified providers as "multicounty" if they work in multiple counties or statewide. We acknowledge that using OMB's definition of a rural county is imperfect, especially considering that Maine is the most rural state in the US.[10]

[9] See a map of rural and urban counties based on OMB standards on page 3: https://www.ers.usda.gov/webdocs/DataFiles/53180/25574_ME.pdf?v=0.
[10] World Population Review. https://worldpopulationreview.com/state-rankings/most-rural-states.

Table 5: Office of Management and Budget (OMB) Definition of Rural and Urban Counties in Maine

Urban	Rural
Androscoggin	Aroostook
Cumberland	Franklin
Penobscot	Hancock
Sagadahoc	Kennebec
York	Knox
	Lincoln
	Oxford
	Piscataquis
	Somerset
	Waldo
	Washington

We also conducted two **focus groups** with a total of 14 survivors, family members, and caregivers. These participants were recruited with the help of the project Steering Committee and compensated for their time. An example of the flyer used for recruitment is shown in

20. Next to each employment support service option, please select yes if you provide this service or no if you do not.

	Yes	No
Physical and mental restoration services	○	○
Assessment services to determine eligibility and vocational rehabilitation needs	○	○
Counseling and guidance	○	○
Job placement services	○	○
Individualized Plan for Employment (IEP)	○	○
Employment training and other training services	○	○
Self-employment services, including technical assistance and consultation for the establishment of small business operations	○	○
Occupational licenses, tools, equipment, and initial stocks and supplies	○	○
Rehabilitation Technology/ Assistive Technology	○	○
Job coaching and supported employment services	○	○
Individualized transition services to support movement from school to work	○	○
Pre-Employment transition services to support movement from school to work	○	○
Pre-Employment transition services for students with disabilities	○	○

Other (please specify)

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21. Is there an unmet need for these services for individuals with brain injury?

	Yes	No	I don't know
Physical and mental restoration services	○	○	○
Assessment services to determine eligibility and vocational rehabilitation needs	○	○	○
Counseling and guidance	○	○	○
Job placement services	○	○	○
Individualized Plan for Employment (IEP)	○	○	○
Employment training and other training services	○	○	○
Self-employment services, including technical assistance and consultation for the establishment of small business operations	○	○	○
Occupational licenses, tools, equipment, and initial stocks and supplies	○	○	○
Rehabilitation Technology/ Assistive Technology	○	○	○
Job coaching and supported employment services	○	○	○
Individualized transition services to support movement from school to work	○	○	○
Pre-Employment transition services to support movement from school to work	○	○	○
Pre-Employment transition services for students with disabilities	○	○	○

Other (please specify)

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22. What types of services and supports are most successful in helping individuals with brain injury gain employment? (select all that apply)

- [ ] Physical and mental restoration services
- [ ] Assessment services to determine eligibility and vocational rehabilitation needs
- [ ] Counseling and guidance
- [ ] Job placement services
- [ ] Individualized Plan for Employment (IPE)
- [ ] Employment training and other training services
- [ ] Self-employment services, including technical assistance and consultation for the establishment of small business operations
- [ ] Occupational licenses, tools, equipment, and initial stocks and supplies
- [ ] Rehabilitation Technology/ Assistive Technology
- [ ] Job coaching and supported employment services
- [ ] Individualized transition services to support movement from school to work
- [ ] Pre-Employment transition services to support movement from school to work
- [ ] Pre-Employment transition services for students with disabilities
- [ ] Other (please specify)

* 23. What do you think is the biggest barrier to employment for individuals with brain injury? (select top THREE)

- [ ] Employer need for ongoing training or support
- [ ] Employer limitations to providing accommodation
- [ ] The individual's ability to maintain a schedule
- [ ] The individual's ability to remain focused over a long period of time
- [ ] The individual's changing needs
- [ ] Not applicable
- [ ] Other (please specify)

Maine Brain Injury Needs Assessment: Provider Survey

Housing, residential services, and homelessness

24. The following is a list of housing related services. For each option, please select yes if you provide this service or no if you do not.

	Yes	No
Modifications for independent living (ex: grab bars, wheelchair ramp)	○	○
Assistive technology for independent living	○	○
In-home personal care provider services	○	○
Assisted living	○	○
Group home	○	○
Nursing home	○	○
Long-term residential facility	○	○
Low-income/ subsidized housing	○	○
Homeless shelter	○	○
Domestic violence shelter	○	○
Permanent supportive housing	○	○

Other (please specify)

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25. Is there an unmet need for these services for individuals with brain injury?

	Yes	No	I don't know
Modifications for independent living (ex: grab bars, wheelchair ramp)	○	○	○
Assistive technology for independent living	○	○	○
In-home personal care provider services	○	○	○
Assisted living	○	○	○
Group home	○	○	○
Nursing home	○	○	○
Long-term residential facility	○	○	○
Low-income/ subsidized housing	○	○	○
Homeless shelter	○	○	○
Domestic violence shelter	○	○	○
Permanent supportive housing	○	○	○

Other (please specify)

26. What are the biggest barriers to gaining and/ or maintaining safe, stable housing for individuals with brain injury? (select all that apply)

- [ ] The cost of housing
- [ ] Limited housing vouchers or other financial supports to help pay for a home or apartment
- [ ] Not enough housing available
- [ ] Not enough residential supportive housing
- [ ] Individuals don't have the skills to live safely on their own
- [ ] Individuals don't have the skills to live safely with others
- [ ] Other (please specify)
- [ ] Challenging behaviors or medication management issues
- [ ] Need for crisis or respite support services
- [ ] Criminal record
- [ ] Poor rental history
- [ ] Not applicable

Maine Brain Injury Needs Assessment: Provider Survey

Emergency responders and legal system

27. What types of services are most successful in preventing individuals with brain injury from getting arrested or remaining incarcerated? (select all that apply)

- [ ] Crisis services
- [ ] Crisis intervention training
- [ ] Therapeutic/ diversion courts
- [ ] Other (please specify)

28. Is there training on brain injury required for the following positions?

	Yes	No	I don't know
Police Officers	○	○	○
State Patrol	○	○	○
Corrections Officers	○	○	○
Public Defense Council	○	○	○

Maine Brain Injury Needs Assessment: Provider Survey

Mental health and substance use

29. Does your organization provide behavioral health services?

- ◯ Yes
- ◯ No
- ◯ Not applicable
- ◯ Other (please specify)

30. The following is a list of behavioral health services. Next to each option, please select yes if your organization provides this service or no if you do not.

	Yes	No
Community mental health case manager	◯	◯
Crisis line	◯	◯
Walk in crisis center	◯	◯
Behavioral intervention plan	◯	◯
Mental health counseling	◯	◯
Substance use outpatient treatment	◯	◯
AA (Alcoholics Anonymous) or NA (Narcotics Anonymous)	◯	◯
Medical detox	◯	◯
Peer support	◯	◯
Inpatient psychiatric hospital	◯	◯
Inpatient substance use treatment	◯	◯

Other (please specify)

31. Is there an unmet need for these services for individuals with brain injury?

	Yes	No	I don't know
Community mental health case manager	○	○	○
Crisis line	○	○	○
Walk in crisis center	○	○	○
Behavioral intervention plan	○	○	○
Mental health counseling	○	○	○
Substance use outpatient treatment	○	○	○
AA (Alcoholics Anonymous) or NA (Narcotics Anonymous)	○	○	○
Medical detox	○	○	○
Peer support	○	○	○
Inpatient psychiatric hospital	○	○	○
Inpatient substance use treatment	○	○	○

Other (please specify)

32. Have you ever denied behavioral health services to an individual with brain injury? (select all that apply)

- ☐ Yes, because we had a waitlist
- ☐ Yes, because the individual could not pay for care and/or did not have insurance that we accept
- ☐ Yes, because the person did not live in our service region
- ☐ Yes, because we could not communicate with the individual
- ☐ Yes, because the individual is not eligible for services at our office because of past behavior
- ☐ Yes, because we are not trained to serve people with brain injury
- ☐ No
- ☐ Not applicable
- ☐ Other (please specify)

33. Where would you refer someone for behavioral health services that you cannot provide? (select all that apply)

- [ ] Behavioral Health Agency
- [ ] Office of Behavioral Health (formerly SAMHS)
- [ ] To a local emergency department
- [ ] I don't know - there aren't any options
- [ ] Not applicable
- [ ] Other (please specify)

34. What do you think the biggest barrier to services is for individuals experiencing brain injury and behavioral health issues? (select top THREE)

- [ ] Unable to navigate service systems
- [ ] Siloed nature of the service systems that discourage coordination (ex: funding, training, etc.)
- [ ] Challenging behaviors that limit service options
- [ ] Not enough treatment options (alternatives to hospitals) for crisis stabilization
- [ ] Not enough transition support options for when returning to the community
- [ ] I don't know
- [ ] Other (please specify)

35. What is the one thing that would increase care collaboration between brain injury services and behavioral health services?

Maine Brain Injury Needs Assessment: Provider Survey

Service Coordination

36. How do you coordinate brain injury services and supports? (select all that apply)

- [ ] We provide care coordination within our organization
- [ ] Clients coordinate their own care with our active support
- [ ] Caregivers/ family members help clients coordinate their care, with our active support
- [ ] Peers help clients coordinate their care
- [ ] We work with vocational rehabilitation case managers
- [ ] Other (please specify)
- [ ] We work with mental health case managers
- [ ] We work with waiver case managers
- [ ] We work with school care managers
- [ ] Not applicable

37. How well coordinated are brain injury services and supports?

- ○ Extremely well
- ○ Very well
- ○ Moderately well
- ○ Other (please specify)
- ○ Slightly well
- ○ Not well at all
- ○ Not applicable

38. What could improve service coordination? (select all that apply)

- [ ] Having one case manager or care coordinator who could work across the programs, services, and supports
- [ ] Making it easier for providers and case managers to share information
- [ ] Having funding or coverage integrated so client care is less dependent on who pays for which services
- [ ] Other (please specify)
- [ ] Having more options for case management
- [ ] Having more options for brain injury services and supports

39. Is there anything else you would like to share about how services are coordinated and what would make it easier for providers to collaborate?

40. Where does your organization get information about brain injury resources, services and supports? (select all that apply)

- [ ] The Brain Injury Association of America – Maine Chapter (BIAA-Maine)
- [ ] Brain injury advocacy/ educational organizations
- [ ] Disability advocacy organizations
- [ ] On-site/ In-person trainings
- [ ] Webinars and other online trainings
- [ ] Conferences
- [ ] Stand alone presentations
- [ ] We don't currently have a source for information on brain injury
- [ ] Other (please specify)

41. Have you attended a BIAA-ME conference or event?

- ○ Yes
- ○ No

42. What did you find to be most valuable about attending a BIAA-ME conference or event?

43. What additional education, training, technical assistance, or other professional development do you wish existed to help you better serve people with brain injury? (select all that apply)

- [ ] Additional training/ education for direct care workers in college or technical school
- [ ] High quality online training options
- [ ] Coordinated education, training, and professional development requirements/ career ladder incorporating brain injury across services and supports (cross-disability)
- [ ] Additional funding to allow staff to attend conferences, trainings, and workshops
- [ ] Regional or more geographically dispersed conferences, trainings, or workshops
- [ ] Ability to use brain injury specialists for additional, case-specific technical assistance
- [ ] Other (please specify)

44. Are current reimbursement rates adequate for you to maintain a stable, qualified direct care workforce?

Extremely inadequate	Somewhat inadequate	Somewhat adequate	Extremely adequate	N/A
○	○	○	○	○

45. What is the most important action needed to address workforce shortages in brain injury services in Maine?

Maine Brain Injury Needs Assessment: Provider Survey

Recommendations and Close

This next set of questions is about what you think would contribute the most to improving services for Mainers with brain injury.

46. Which of the following would most positively impact Mainers with brain injury? Click and drag into the order of importance, with the most important at the top.

- Increase awareness of brain injury
- Improve screening/ identification of brain injury
- Improve service coordination across services and supports
- Improve service coordination across phases of recovery/ over a lifetime following a brain injury
- Improve provider training so they can better support the unique needs of people with brain injury

47. Thank you for taking the time to respond to this survey. Your answers will help direct efforts to better serve Mainers with brain injury and their caregivers and families.

Please use the space below if you have any other comments you would like to share regarding brain injury services or your experiences.

Appendix E. The focus group interview protocol, Appendix F, has the questions we asked focus groups about increasing awareness about brain injuries, services, barriers to accessing services, service coordination, and provider and caregiver training. During the focus groups, we discussed some information gathered from surveys to validate the findings and dig deeper into the "why." In the report we included several quotes from the focus groups to enhance understanding of survey data.

Finally, we convened a group of project team and Steering Committee members to facilitate a workshop to review findings. Which is referred to as a technical group in this report.

Limitations and Considerations

All methods of data collection face limitations. This needs assessment faced limitations on the limited available extant quantitative data for analysis and limitations on the primary data collection methods. Maine does not currently have a registry to collect information on brain injury incidence and prevalence at the state level, making it difficult to understand the full picture of brain injury in Maine. Data reported from the Maine CDC is outdated, with reports of reduced resources and capacity even before more organizational resources were diverted for the COVID-19 response.

Brain injury services and support challenges encompass a large scope with a high degree of complexity. This analysis could be much longer and more comprehensive, but possibly at the expense of readability and utility. Despite efforts to reach a broad group, the survey data is not inclusive of all survivors or providers in Maine, nor was it a random sample that is representative of the state population. Those who received the survey likely had some connection to services as well as having access to resources and the skillset [capability?] to complete the survey, but likely did not reach those with unmet needs who are experiencing difficulty connecting to services and supports. Self-selection bias also exists in surveys and those who choose to complete them. Also, because caregivers or family members could respond on behalf of a person with brain injury, there were unknown or not applicable responses based on their knowledge.

This needs assessment was conducted during the COVID-19 pandemic. Therefore, all interviews and focus groups were conducted online. During this time, groups such as BIAA-ME's support groups also shifted to meeting in virtual spaces. Because these brain injury community members were already familiar with remote meeting technology, our virtual focus groups had a higher chance of success in attendance and participation. Additionally, we recognize the significant impact of COVID-19 on the brain injury community-the additional isolation and challenges to accessing services; the outstanding efforts of providers, healthcare workers, advocates, and State agencies who had to adapt to continue to provide services and support while observing changing health and safety guidelines. We also acknowledge the additional impact of COVID-19 causing brain injury–both as a primary cause and as a secondary cause due to the increased rates of domestic violence, child abuse, and opioid use during the pandemic.

Overview

Brain Injury in the United States

Brain injury is a significant public health concern that affects the lives of millions of Americans each year and can have long-term and unpredictable impacts. Brain injury is unique in that it can happen to anyone at any time in their life through a broad range of causes and with varying degrees of severity. An acquired brain injury (ABI) is an injury to the brain that has occurred after birth and is not hereditary, or related to congenital, or degenerative disease. There are two types of ABI: traumatic and non-traumatic. A traumatic brain injury (TBI) is defined as an alteration in brain function caused by an external force.

Several federal agencies support estimates and research of the incidence of brain injuries and the prevalence of brain injury survivors. The U.S. Centers for Disease Control and Prevention (CDC) focuses on TBI and indicates TBI is a major cause of death and disability in the United States and "can lead to lifelong problems that not only affect the lives of individuals and their families, but also have a significant impact on society and the economy." [11]

TBI care needs and the cost of life are significant in terms of emergency department visits (2.2 million), hospitalizations (280,000), and an average of 50,000 deaths every year (61,000 in 2019). The extent of brain injuries is likely to be underestimated due to under-screening, under-reporting, and misdiagnosing in the healthcare system. The need for improved screening and identification tools of brain injury remains, and there are still significant gaps at certain settings due to limitations on identification of TBI as a function of injury severity.

These estimates also do not take into account the impact on the quality of life for people living with TBI and of their family members. TBI also has an impact on services outside health care settings, such as housing, education, employment and similar services for providing [supporting? sustaining?] independence and quality of life.

Maine Brain Injury Services Landscape

Overall estimates

The 2008 report from the Maine Center for Disease Control and Prevention (CDC) indicated that there were 263 TBI-related deaths and 998 TBI-related hospital discharges among Maine residents. The information is outdated and attempts to get updated data on emergency department visits,

[11] TBI in the US: Epidemiology and Rehabilitation. CDC Report to Congress. 2015
https://www.cdc.gov/traumaticbraininjury/pubs/congress_epi_rehab.html

hospitalizations, hospital discharges and deaths related to brain injury from the Maine CDC were unsuccessful. Brain injury in Maine has likely increased in line with national incidence and as awareness of brain injury has increased among providers, and a rural/urban divide is also likely to have grown in one of the most rural states in the US.[12]

Estimates of individuals being served by DHHS

As of today, the Brain Injury Waiver (see description under Maine Strengths section below) is actively serving **212** people.

Estimates of individuals on the waitlist

There are **38** people with funded offers who are waiting for services to start and **142** people on the waitlist.

Estimates of individuals being served out-of-state

There are **30** people currently being served out of state. It is important to note that these individuals may have neurocognitive disorders related to a brain injury that do not meet Maine's statutory definition to receive brain injury services.

Maine Strengths

Brain Injury Waiver in 2016

Home and Community Based Services (HCBS) provide opportunities for Medicaid beneficiaries to receive service in their own home or community rather than institutions or other settings. Centers for Medicare & Medicaid Services (CMS) added Appendix K to the HCBS 1915(c) waiver temporarily[13], as a response to the COVID-19 declaration of nationwide emergency allowing participants to choose to self-direct at any time while receiving HCBS waiver services, which helps survivors living in their own homes receive in-home support services.

Recent Legislation

Some states run brain injury services through a trust fund program, some use TBI/ ABI Medicaid HCBS Waiver programs, and some use a combination of both. Maine runs a Medicaid HCBS Waiver Program that includes Acquired Brain Injury (TBI is under that umbrella). In doing so, they include severe epilepsy, strokes, and substance use/opioid overdose. This puts the state in a better position to respond to needs regardless of how the injury occurred – focusing more on the impacts of the injury. Legislative Document 297 allowed for NeuroResource facilitation services for Maine brain injury survivors, families, and

[12] Concussion and Traumatic Brain Injury. Maine Center for Disease Control and Prevention. 2012. https://www.maine.gov/dhhs/mecdc/population-health/inj/documents/TBIConcussion.pdf

[13] Appendix K: Emergency Preparedness and Response. Centers for Medicare and Medicaid. https://www.medicaid.gov/state-resource-center/downloads/me-combined-appendix-k-appvl.pdf

providers, brain injury support groups received support and education, and a new Brain Injury & Stroke Resource Directory was developed.[14]

One issue that the Disability Rights Brain Injury Advocacy Program has taken up through legislative advocacy is a bill intended to create a task force for identifying gaps and defining a statement of rights for brain injury clients, which effectively opens the doors to the existing grievance system for people with brain injury.[15]

Community-based rehabilitation clinics

Maine has 8 free-standing neurorehabilitation clinics in the community that serve an average of 800-1000 people a year. The clinics are based on a trans-disciplinary team model where physical therapy (PT), occupational therapy (OT), and speech-language pathology (SLP) are integrated rather than siloed, allowing practitioners with different types of expertise to come together and reducing rehabilitation costs. People getting rehabilitation services early on after injury have better outcomes and also reduces the impact on the health system. These clinics are rare nationally because of Medicaid limitations on funding brain injury services and therefore an example of how Maine is forward thinking and has created a large scope/support for practitioners (PT, OT, SLP, recreational therapy) and also increased the state's ability to serve rural communities.

Supportive Leadership

The brain injury community in Maine[?] has been able to successfully advocate to the Legislative and Executive branches, which have been receptive and supportive. Maine received a federal grant from the Administration for Community Living (ACL) and the ABIAC was written into statute in 2007 to provide oversight and recommendations. Last year, ACL recommendations to the Legislature were enacted that expand the ABIAC and include more individuals who experienced brain injury, their family members and advocates.

[14] BIAA Maine Brain Injury and Stroke Resource Directory

[15] Disability Rights Maine. 2020 Annual Report. https://drme.org/assets/annual_reports/2020-Annual-Report.pdf

Findings

The findings below seek to provide a dual perspective on the current services, needs, and challenges of survivors of brain injury by gathering information from survivors, their family members, and caregivers as one group and providers as another. As described in Approach/Methodology, we will refer to survivors, their family members, and caregivers as "consumer respondents" or simply "consumers" when reporting findings. Although the terms ABI and TBI are often used interchangeably, TBI is a type of ABI. The findings below pertain in general to ABI and specify TBI where appropriate.

Injuries

The effects of a brain injury are complex and depend on factors such as cause, location, and severity. Non-traumatic brain injury (often referred to as an ABI) causes damage to the brain by internal factors, such as lack of oxygen, exposure to toxins, or pressure from a tumor, including the following examples: stroke, near-drowning, aneurysm, tumor, and infectious diseases. TBIs are an alteration in brain function or other evidence of brain pathology, caused by an external force and can be defined as closed (or non-penetrating) or open (penetrating) [wounds? injuries?] and include the following examples: falls, assaults, motor vehicle accidents, sports injuries.

The 2016 and 2010 needs assessments asked survey respondents about the type of brain injury. We chose to not to ask the same question because longitudinal data already existed and, to align with current epidemiological approaches,[16] shifted to asking respondents about the source and nature of the injury to further understand the cause of injury. However, there are still challenges in disentangling source and nature of the injury and this way of differentiating in the survey seems to have caused confusion because 44% of respondents chose "other" as the injury response and provided a write-in response. In many instances, consumer respondents wrote in the nature of the injury when asked for the source.

Table 6 and Table 7 display the top responses from consumers about the source and nature of their or their loved ones' injuries. The top two sources of brain injury correspond with most common injuries nationally, which are auto accidents and unintentional falls according to the most recent TBI surveillance report.[17] Maine Department of Transportation does not publicly provide data on traffic-related brain injuries as part of their reporting, but did indicate the annual count of serious traffic injuries has been decreasing over time.[18]

[16] State Injury Indicators Report: Instructions for Preparing 2019 Data. Center for Disease Control and Prevention. February 2021. https://www.cdc.gov/injury/pdfs/2019_state_injury_indicator_instructions-508.pdf

[17] TBI Surveillance Report. United States. 2016 and 2017. https://www.cdc.gov/traumaticbraininjury/pdf/TBI-surveillance-report-2016-2017-508.pdf

[18] Highway Safety Plan. FFY 2021. Maine. https://www.nhtsa.gov/sites/nhtsa.gov/files/documents/me_fy21_hsp_.pdf

Table 6: Source of Injuries

Auto Accident	22%
Injury from a fall	15%
Hit in the head or face	8%
Brain surgery	8%
Other vehicle accident	7%
Other*	44%

Consumer Survey Question #2: Please tell us how you were injured. Select all that apply for multiple injuries. N=261.
Note: *43 out of 114 "other" responses were stroke, 7 were aneurysm, and 6 were injury at birth.

Table 7: Nature of Injuries

Blow to Head	49%
Stroke	32%
Loss of oxygen	14%
Penetrating injury*	8%
Aneurysm	5%

Consumer Survey Question #3: Please tell us the nature of your injury. (Select all that apply for multiple injuries.) N=269.
*Note: Penetrating injury includes surgery.

Diagnosing a brain injury soon after it happens is a critical step in providing care for the survivor. A survivor may experience challenges if there is a delay in diagnosis or if their injury is misdiagnosed. When behaviors related to brain injury are misdiagnosed and treatment doesn't consider the brain injury, the treatment is less likely to be helpful and could potentially cause harm to the client. This is especially true when a survivor has co-occurring or related diagnoses, such as mental health diagnoses.

> "We often work with folks who have **never had** a brain injury diagnosis, but who experienced **repeated** TBI and anoxic/ hypoxic brain injury."
> *- Provider*

Of the consumer respondents, most (73%) were diagnosed between 0-3 months of their injury. Table 8 includes a breakdown of other responses.

Table 8: Timing to Diagnosis

0 to 3 months	73%
3 to 6 months	5%
6 months to 1 year	3%
1 to 3 years	5%
3 to 5 years	2%
Over 5 years	8%

Consumer Survey Question #6: How long after your brain injury were you diagnosed? N=260.

Brain injury severity can be defined differently depending on the assessment [type? tool? approach?] or scale. For the purposes of this needs assessment, we used a generally accepted definition of severity based on whether there is loss of consciousness and how long that lasts.[19] Table 9 illustrates a summary of the severity of survey respondents' injuries. It is important to note that "mild" is a misnomer as these injuries, which include concussions, can have long-term consequences for the survivor.

Table 9: Injury Severity

Mild	0-30 minutes loss of consciousness (or concussion)	17%
Moderate	30 minutes to less than 24 hours loss of consciousness	14%
Severe	more than 24 hours loss of consciousness	28%
Non-traumatic	brain injury was non-traumatic (stroke, aneurysm, tumor, etc.)	20%
Don't Know		12%

Consumer Survey Question #4: How severe was your traumatic brain injury? N= 266.

Most consumer respondents with severe brain injuries were diagnosed between 0-3 months (86%). Of consumers with moderate brain injuries, about half were diagnosed in the same timeframe (54%). Consumers with mild brain injuries were less likely to be diagnosed between 0-3 months than consumers with severe brain injuries but more likely to be diagnosed in this timeframe than consumers with moderate brain injuries (68%).

[19] About Brain Injury. Injury Severity. https://www.biausa.org/brain-injury/about-brain-injury/basics/injury-severity Brain Injury Association of America.

Awareness

When asked "What would most positively impact Mainers with brain injury?", consumers and providers both ranked increasing awareness of brain injury first among five options.[20] Additionally, participants of a technical group noted that awareness of brain injuries has increased over the years but isn't at the level it needs to be. Awareness of brain injury is critical at many different stages of survivors' healing process. Survivors and their families and caregivers need to be made aware of services for brain injury survivors to benefit from them. This is especially important when survivors are returning from the hospital to the community. Additionally, providers of all different types, including behavioral health providers, need to be aware of brain injuries to best serve their clients. There is also a need for brain injury to be understood as a disability within the disability community and by the general public.

> "I didn't know about vocational rehab until **2 years** after I left the hospital."
>
> *– Survivor*

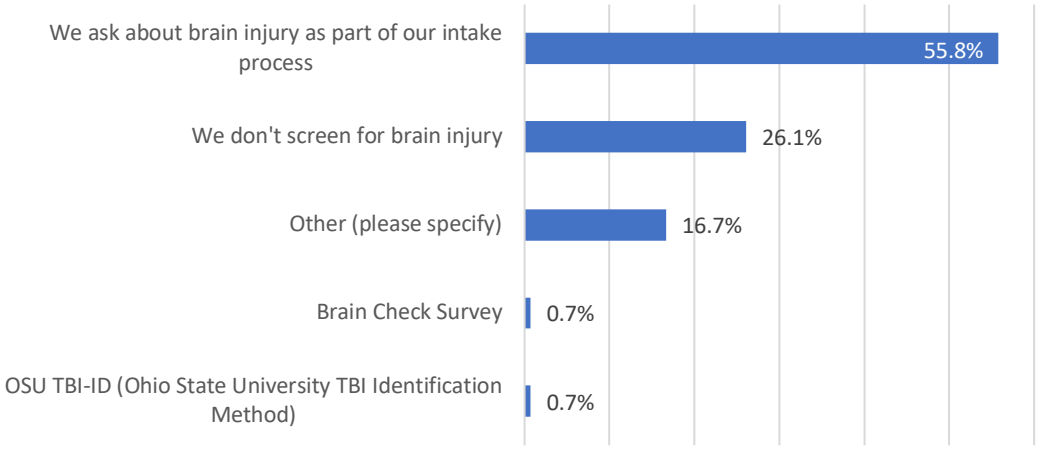
Screening, Eligibility, and Payment

Screening and early identification are important factors in a person's recovery. However, there is no standardized screening tool for identifying brain injury in Maine. Figure 1 illustrates provider responses for the type of screening tool they use to identify if someone has a brain injury. Over 50% of providers ask about brain injury as part of their intake process.

> "There is a need for **public education** about the dangers of brain injuries and the long-term impacts. Too often people (family members, friends, employers) hear 'concussion' and think they know what this means, **assuming** the injury is not a big deal and the recovery will be quick and easy."
>
> *- Caregiver*

[20] Consumer Survey Question #55 Which of the following would most positively impact Mainers with brain injury? N=176. Provider Survey Question #46: Which of the following would most positively impact Mainers with brain injury? N=91.

Figure 1: Type of screening tool used by providers



Provider Survey Question #5: What type of screening tool does your organization use to identify when someone has a brain injury? N=138. Note: other write-ins included: Review of Medical Records (9), Brain Injury Assessment Tool (BIAT) (3), MAXIMUM assessment (1), MPAI (1). Domestic Violence advocates ask about strangulation.

Of the providers who indicated they don't screen for brain injuries, the top three types were case manager/care coordinator, domestic violence advocate, and mental health provider.

When providers were asked their policy for documenting that someone has a brain injury, about half (51%) indicated they enter a diagnosis code for a brain injury if it is a primary driver for why the person needs services.[21] Sixty percent (60%) of providers who document brain injury diagnoses using a case note or referral do not enter a diagnosis code. Diagnoses documented by case notes or referrals alone are harder to track.

Providers in urban areas are more likely that providers in rural areas to document a brain injury with a diagnosis code (54% vs 48%), enter the injury as a case note (45% vs 41%), and make a referral for the brain injury (23% vs 16%). More rural providers provided write-in responses for other screening methods than urban providers (16% vs 11% respectively).

[21] Provider Survey Question #6: What is your organization's policy for documenting when an individual has been identified as having a brain injury? N=140.

The majority of providers use medical diagnosis or functional need to determine eligibility for services.[22] Specifically, about 51% of providers use a medical diagnosis and 54% use functional need. Functional need is usually determined with an assessment that evaluates what supports a person needs to perform tasks to take care of themself, such as getting dressed or going grocery shopping.

> "Just because **I look fine**, doesn't mean I'm not having struggles every day, every minute."
> *- Survivor*

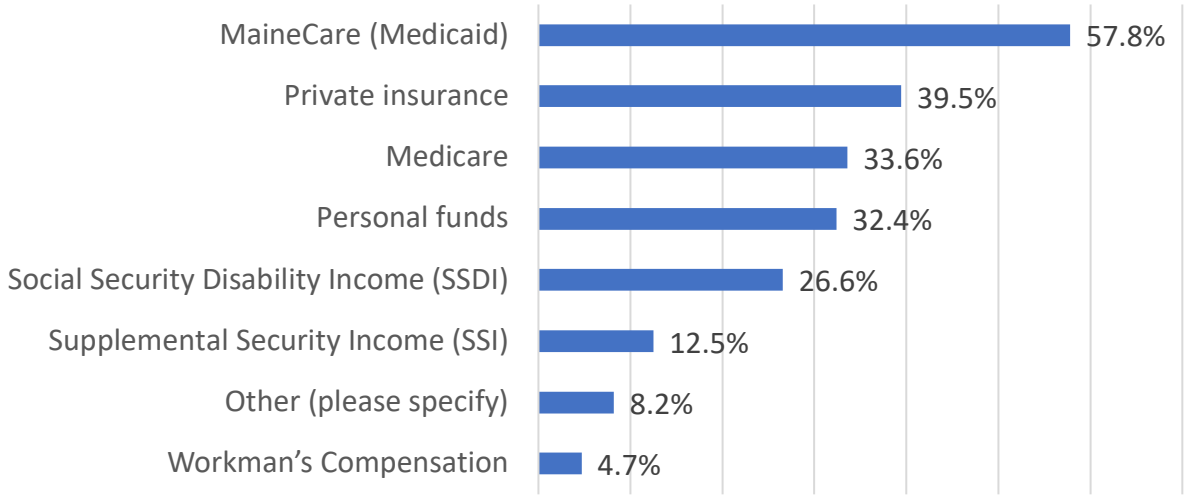
Case managers, mental health providers, and rehabilitation providers are the primary users of functional need or medical diagnosis as a tool for determination of eligibility. About half of each of these groups use medical diagnosis to determine eligibility for services (48%, 39%, and 64% respectively). Waiver Service providers are required to use medical diagnosis for determination of eligibility.

There are differences in use of these tools by geographic area. Urban providers use functional need as an eligibility tool substantially more than providers in rural and multicounty areas (57%, 50%, and 33%, respectively).

More than half of survey respondents have used MaineCare to pay for services. After MaineCare, the most-used methods of payment are private insurance, Medicare, and personal funds. A summary of these and other payment types are illustrated in Figure 2.

[22] Provider Survey Question #7: How do you determine eligibility for your services? (Select all that apply.) N=140.

Figure 2: Consumers' Payment for Services



Consumer Survey Question #8: How have you covered the cost of services you've received? (Select all that apply) N=256.

Survey respondents were asked to indicate what rehabilitation services they wished they could use.[23] There were some differences in answers depending on the type of payment the consumer uses to cover services. The largest differences between the groups of people using the two most-used payment types were:

- Consumers paying with **private insurance** wish they could use **occupational therapy** (14%) and **physical therapy** (8%) more so than those paying with MaineCare (8% and 3% respectively). Currently, consumers paying with private insurance use occupational therapy (25%) and physical therapy (33%) less than those paying with MaineCare (48% and 49% respectively).
- Consumers paying with **MaineCare** wish they could use **rehabilitation (inpatient)** (5%) more so than those paying with private insurance (3%), although people with paying with MaineCare are already using in-patient care at higher rates than those paying with private insurance (14% compared to 4%).

Rehabilitation and Health-Related Services

Rehabilitation services are a critical component of the recovery of individuals with a brain injury. These services are essential for the support and improvement of the survivors' functioning. In addition to rehabilitation, the needs assessment sought to address services related to behavioral health (mental health and substance use disorder), and the interaction of survivors with emergency services. For each of these services, we discuss the consumers' satisfaction with the services received, past or current use of

[23] Consumer Survey Question #10: For each rehabilitation service, please select whether you are currently using, have previously received, wish you could use, or don't need.

specific services, when it became difficult to access these services, and what challenges they faced in accessing these services. The perspective from the consumers will be complemented with the findings from the provider survey on the rehabilitation and the other health-related services.

Of the rehabilitation services that are used the most,[24] outpatient neuro-rehabilitation (Goodwill, Maine Center for Integrated Rehabilitation (MCIR), Center for Integrated Neuro-Rehab) is [was rated?] the most popular with consumers (50%). There are five other services with similar levels of utilization:

1. Specialty Hospital Brain Injury Services (25%)
2. Vocational Rehabilitation (24%)
3. Mental Health/Substance Use Treatment (23%)
4. Care Coordination (23%)
5. Assistive Technology (20%)

Overall, consumers are satisfied or very satisfied (77%) with the rehabilitation services they have received.[25] Consumers with a nontraumatic injury or "other" level of injury[26] showed high levels of satisfaction (above 80% of each injury level group) relative to consumers with a mild (the least satisfied) or with a severe injury.

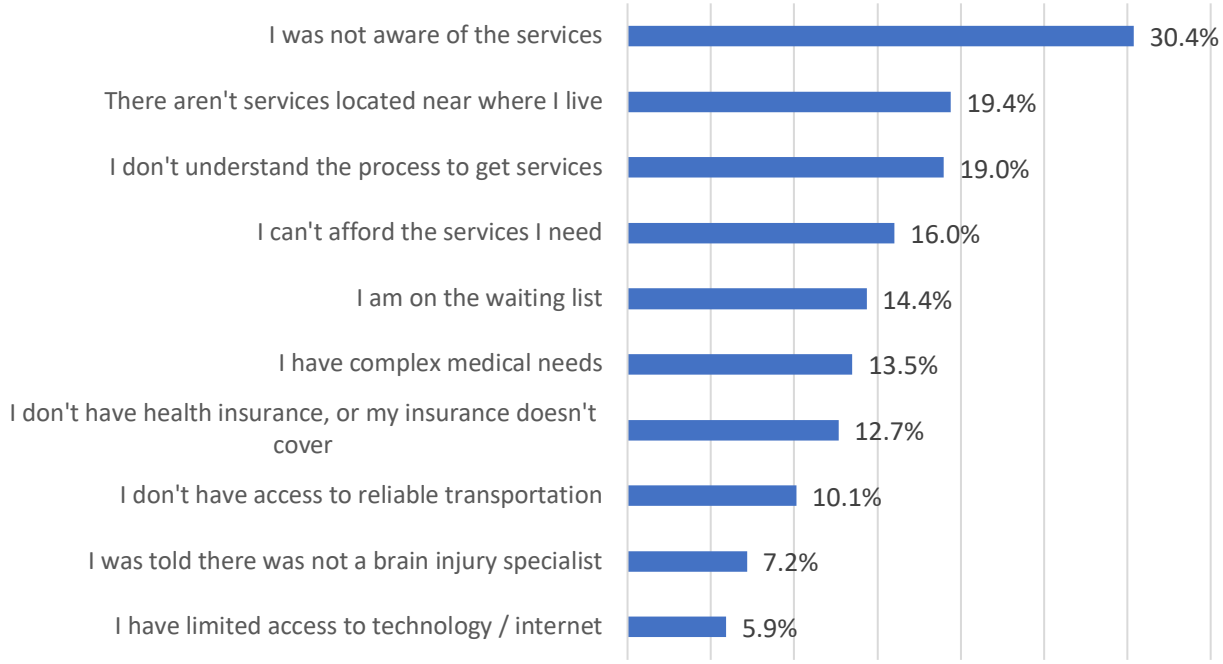
Service providers identified three services as unmet rehabilitation needs: brain injury diagnosis and assessment, specialized medical services (neurologist, neuropsychologist), and residential in-home support.[27] Providers rated these programs at a similar level of unmet need (54-61%).

Consumers were asked what has prevented them from accessing rehabilitation services while providers were asked why they have denied rehabilitation services to survivors. The reasons selected most often by providers are that the survivor could not pay for care or did not have insurance (14%) and there was a waiting list (17%).[28] Both issues correspond to two core topics: capacity and service financing. A third, less-frequent reason for denying services identified by providers is that the person had complex medical needs (9%). Consumers gave very different responses for what prevented them from accessing rehabilitation services, with the primary reason being that they were not aware of available services (See

[24] Consumer Survey Question #9: What other types of services have you received or are currently receiving? (select all that apply). N=233.
[25] Consumer Survey Question #14: How satisfied are you with the rehabilitation services you have received? N=214, excluding N/A responses.
[26] Consumers noted a wide range of references from "Levels apply to different people", "Long-term, low-level exposures to neurotoxins", or "20+ weeks in utero", for example.
[27] Provider Survey Question #13: Is there an unmet need for these services for individuals with brain injury? N=120.
[28] Provider Survey Question #14: Have you ever denied rehabilitation services to an individual with brain injury? (Select all that apply) N=125.

Figure 3). Waiting list and payment capacity, which were identified as primary barriers by providers, were ranked fourth and fifth by consumers.

Figure 3: Barriers to Access Rehabilitation Services (Consumers)

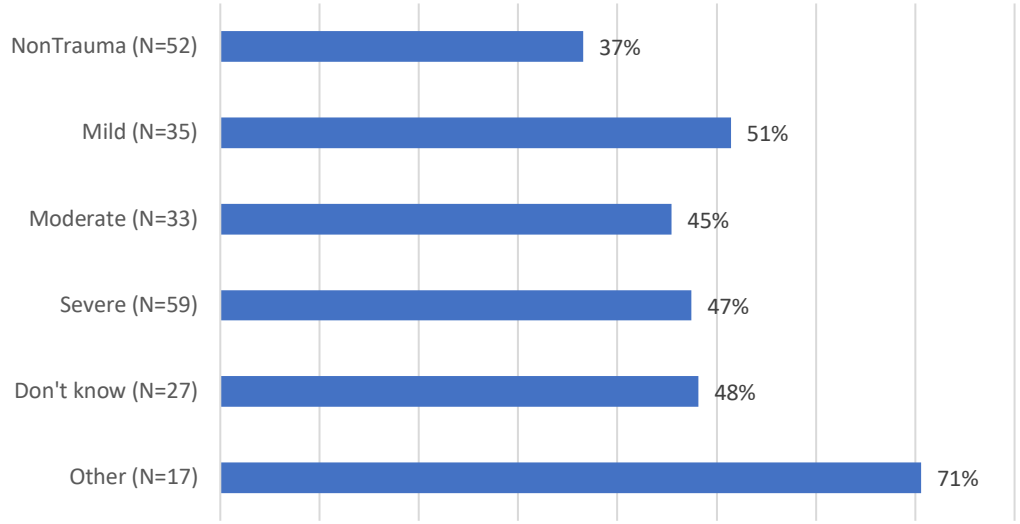


Consumer Survey Question #12: What has prevented you from using rehabilitation services you wish to use? (select all that apply) N=237.

When we disaggregated consumers' perspective by urban and rural residence, we found that fewer people in rural areas report waiting lists (7%) and not being able to afford services (11%) as barriers than those in urban areas (23% and 19%, respectively).

When asked about their experience with **emergency responders** (police, medics) since sustaining their brain injury, 47% of consumers said they have had an encounter with emergency responders. The distribution by level of injury severity shows that people with non-traumatic injuries have less encounters with emergency responders compared to people with mild, moderate, or severe injuries (Figure 4).

Figure 4: Percentage of survivors who have engaged with emergency responders by type of injury



Consumer Survey Question #28: Have you ever called 911 or engaged with emergency responders, such as police or medics, since sustaining your brain injury?
Note: Captions for each group include number of people in group who responded to the question.

There is room to increase awareness of brain injury in these incidents, as only 14% of consumers in an interaction with emergency responders were asked if they have had a brain injury.[29]

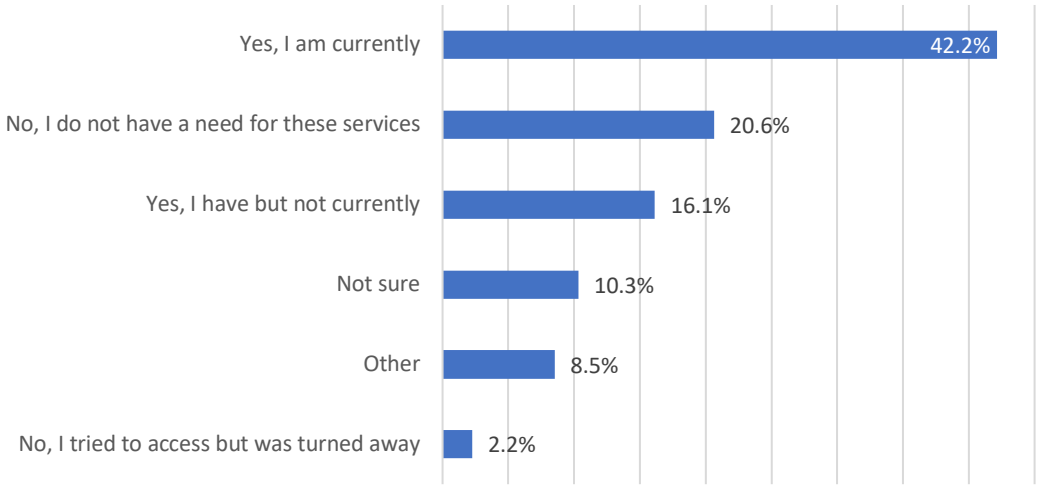
In terms of the interaction with the police, 18% of consumers have been stopped or detained by the police since their injury.[30] Three percent (3%) of those stopped or detained by police reported going to jail when the consumer believes they should have gone to the hospital[31] and 2% had negative outcomes from their interactions with the police or legal system ("It is harder for me to access services" or "It is harder for me to find a place to live").[32] The opposite outcome was observed for 2% of the consumers who felt they were connected to more services, sometimes as a result of diversion or therapeutic court systems. We were not able to access data on the prevalence of brain injury among those who are currently incarcerated or supervised by community corrections in Maine. There were previous efforts and a federal grant focused on screening in corrections that did not come to fruition in Maine. Nationally, we know many people in jails and prisons have experienced a TBI, which can cause challenges both while incarcerated and on return to

[29] Consumer Survey Question #31: In your encounter(s) with emergency responders, were you ever asked if you had a brain injury? N=209.
[30] Consumer Survey Question #29: Have you been stopped or detained by police since sustaining your brain injury? N=227.
[31] Consumer Survey Question #30: In any of these encounters, did you go to jail when you thought you should go to the hospital? N=212.
[32] Consumer Survey Question #32: How, if at all, has your interaction with police or legal system changed your access to programs or support services? N=204.

the community.[33] This is an area for further exploration in Maine and should include the juvenile corrections system.

Mental health services are important services for the survivor population. As noted by a steering committee member, "We are only just beginning to understand what the issues are. It's going to require a significant investment in integration of these services into the brain injury community." Forty-two percent (42%) of the survey respondents stated that they are currently receiving mental health services, 16% had received these services in the past, and 21% did not have a need for mental health services (Figure 5). This survey attempted to capture individuals who were receiving both mental health and substance use services. However, none of the respondents identified themselves as receiving both services. This could have been an issue with the survey sample or an aversion to self-identification.

Figure 5: Receipt of Mental Health Services (Consumers)



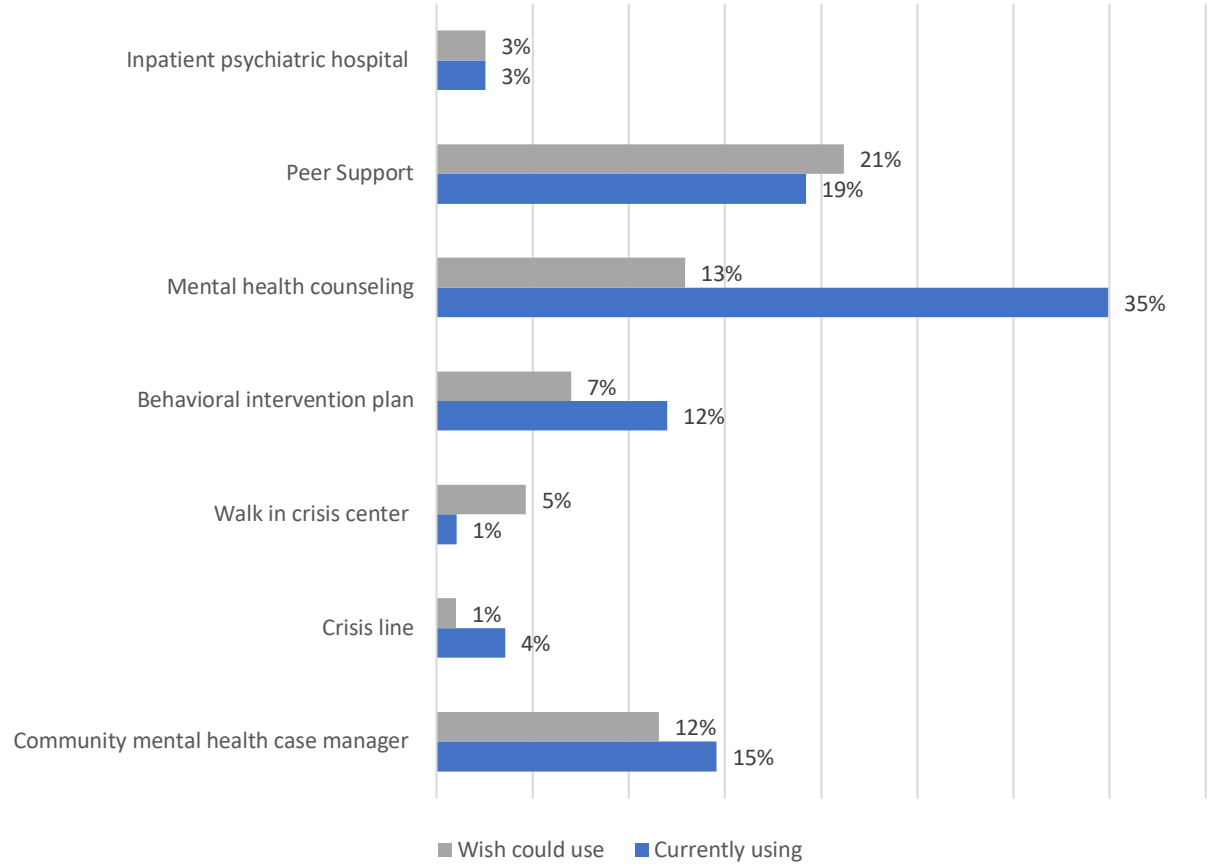
Consumer Survey Question #33: Have you or are you currently receiving mental health services? N=223.

Out of several mental health services, consumers indicated that the service they wish they could use more was a peer support group (21%) followed by mental health counseling (13%) (Figure 6).[34]

[33] Traumatic Brain Injury in Prisons and Jails: An Unrecognized Problem. https://www.cdc.gov/traumaticbraininjury/pdf/Prisoner_TBI_Prof-a.pdf

[34] Consumer Survey Question #34: Next to each mental health service option, please select if you are currently using, previously received, or wish you could use these services. N=215.

Figure 6: Types of Mental Health Services



Consumer Survey Question #34: Next to each mental health service option, please select if you are currently using, previously received, or wish you could use these services. N=215.

It is worth noting that 14% of consumers have been turned away from mental health services. The reasons consumers believe they were turned away[35] include:

- I was told a brain injury specialist was not available (19%)
- I was told an assessment for brain injury was not available (16%)
- I was told that they do not treat people with brain injury (15%)

Data on the number of children in behavioral health services with a brain injury is not available. The Office of Child and Family Services acknowledged the need to increase screening and provider training on brain injury, especially due to higher rates of abusive head trauma in infants in Maine. Stakeholders report there aren't services specific for children with brain injury in Maine and that those in need of residential services (especially with co-occurring brain injury and behavioral health) are often sent out of state. Services that

[35] Consumer Survey Question #36: Why do you think you were turned away from mental health services? (select all that apply) N=159.

children are eligible for also change when they turn 18 and age out of services and stakeholders report transitioning to adult services is not smooth.

In targeted questions about **substance use disorder (SUD) services**, 4% of consumers indicated that they were currently receiving substance use services and 8% indicated they had in the past but not currently.[36] Eighty-one percent (81%) of consumer respondents indicated they did not have a need for these services. Due to the very small number of respondents who identified as receiving substance use services, the remaining questions from the consumer survey on this topic and associated data remains inconclusive and therefore it requires further exploration.

The intersection between brain injury and the opioid crisis in Maine is concerning given the bi-directional risk of increased overdoses of opioids for people with a brain injury and the increased risk of substance use disorder among those with a brain injury. Brain injuries can also be caused during an overdose due to loss of oxygen to the brain. The Opioid Response program is acting on the opioid epidemic in Maine and the brain injury[37] system response includes hosting webinars on brain injury and SUD, creating a forum connecting the behavioral health and brain injury communities, dedicating conference sessions to the intersection of brain injury and SUD at BIAA-ME's annual brain injury conference, and conducting outreach to and education to Maine SUD providers.[38]

Supports for Daily Life

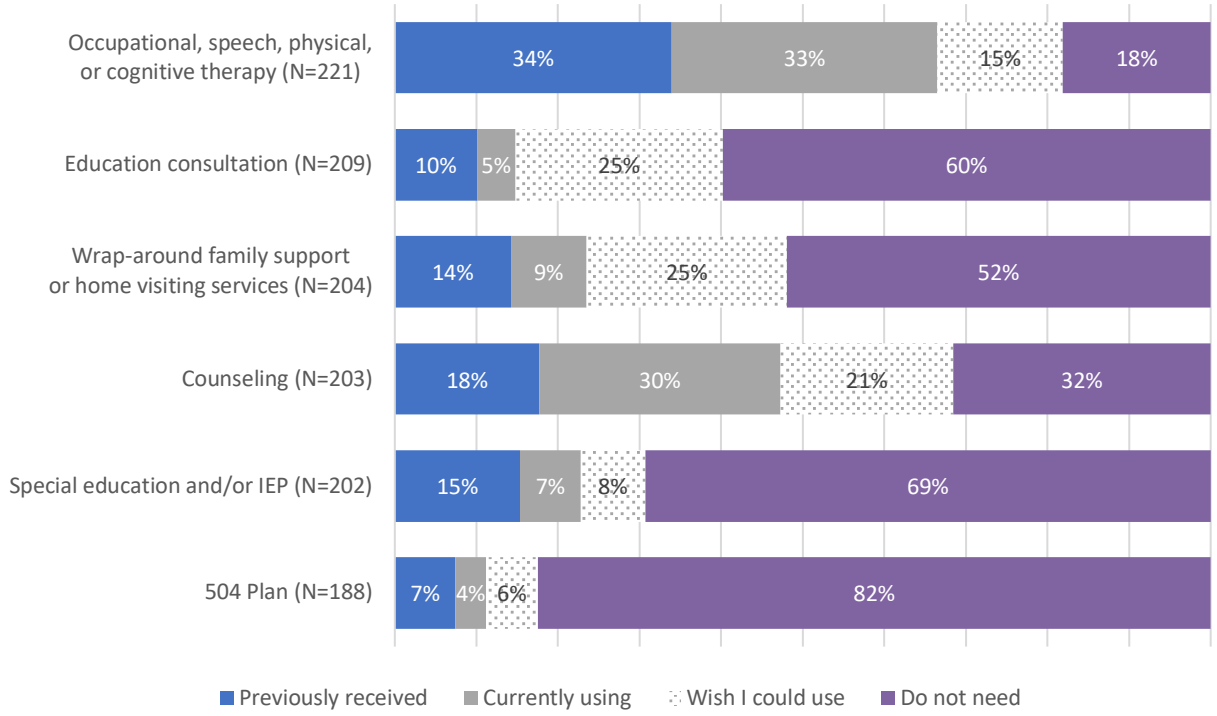
Survivors require support services to meet their daily functions and move towards full recovery. This needs assessment covers three types of services: **education, housing, and employment services**. As we did above, we discuss the consumers' satisfaction with the services received, past or current use of specific services, when it became difficult to access these services, and what challenges they faced in accessing these services.

In terms of **education**, consumers indicated the services they wish they could use are education consultation and wrap-around family support or home visiting services, followed by counseling. These preferences are illustrated in Figure 7. The percentages of "wish I could use" were calculated relative to the number of respondents for each type of education service (not to exceed the total number of respondents for this question)." Over 80% of consumers indicated they do not need a 504 Plan, which is a plan to ensure that a child with a disability receives accommodations at school. It is possible this high number is due to those respondents not knowing what a 504 Plan is. The Department of Education does

[36] Consumer Survey Question #38: Have you or are you currently receiving substance use services? N=200.
[37] Maine Opioid Response Strategic Action Plan. https://www.maine.gov/future/sites/maine.gov.future/files/inline-files/MaineOpioidResponse.StrategicActionPlan.FINAL_.12.11.19.pdf
[38] ABIAC Annual Report. 2020.

not compile information on students with brain injury through their Special Education services, so we are not able to provide prevalence of brain injury among students in Maine.

Figure 7: Use of Education services, support, or accommodations (current, past, wish, do not need)



Consumer Survey Question #17: "Next to each option in the list of education services, support, or accommodation, please select if you are currently using, have previously used, wish you could use, or don't need the services." Caption for each option includes the number of respondents.

Consumers have a positive view of education services, support, or accommodations; 70% are satisfied or very satisfied.[39] Of the different levels of injury, 77% of consumers with a mild injury showed the highest levels of satisfaction and consumers with a severe injury were the least satisfied. Providers have a skeptical perspective on how well schools are serving youth with brain injury; 92% of providers indicated that schools serve youth not very well or not well at all.[40] Depending on their geographical residence, consumers had distinct perspectives on barriers to access education-related services and supports.[41]

[39] Consumer Survey Question #19: How satisfied are you with the education services, support, or accommodations you have received? N=161, excluding N/A responses.
[40] Provider Survey Question #16: How well do schools serve youth with brain injury? N=60, excluding N/A responses.
[41] Consumer Survey Question #18: What has prevented you from being able to use education services, support, or accommodations you wish to use? (Select all that apply) N=227.

When sorted in terms of difference in percentage points:

- Fewer people in rural areas (30%) reported not being able to **afford the services** relative to their counterparts in urban areas (69%)
- Fewer people in rural areas (20%) were on a **waiting list** than those in urban areas (80%)
- Fewer people in rural areas (49%) report **not being aware of services** as a barrier than those in urban areas (51%)

Employment supports are another important type of service, yet consumers are the least satisfied (63%) with these services of all the support services assessed in the study.[42] However, consumers who did not know how to categorize their injury level showed very high levels of satisfaction (above 80% of consumers in this category). Consumers with a non-traumatic injury had the least satisfaction of all groups (less than 50%), which is one of the lowest levels of satisfaction across all services discussed with consumers.

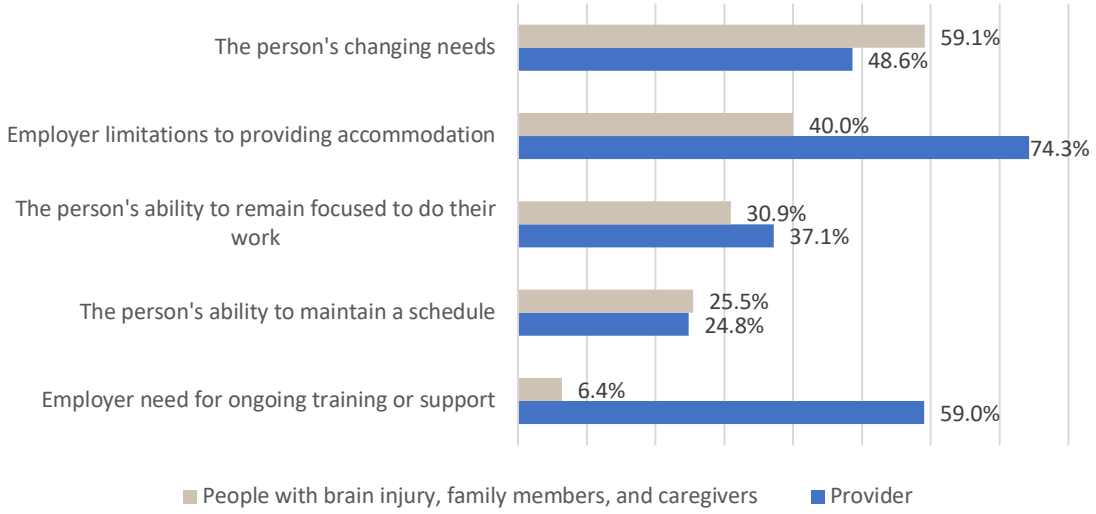
Consumers' primary limitations for gaining and keeping employment[43] are changing needs over time (59%) and having a hard time finding jobs that will accommodate their brain injury (40%) (

[42] Consumer Survey Question #22: How satisfied are you with employment support services you have received? N=92, excluding N/A responses.

[43] Consumer Survey Question #23: What are the challenges, if any, you experience gaining and keeping a job? (Select all that apply) N=110, excluding N/A responses.

Figure 8). Consumers who found it challenging to maintain a work schedule (12%) are more likely to work part-time (29%), and those consumers who are no longer working are more likely to face barriers finding jobs that will accommodate for their brain injury (24%) or have needs that change over time (20%). Regarding the consumer population that has more employment barriers, those who experienced their first brain injury earlier in their lifetime report more employment barriers.

Figure 8: Barriers to Employment



Consumer Survey Question #23: What are the challenges, if any, you experience gaining and keeping a job? (Select all that apply) N=110, excluding N/A responses.
Provider Survey Question #23: What do you think is the biggest barrier to employment for individuals with brain injury? (select top THREE) N=105, excluding N/A responses.

Maine is part of a national movement called Employment First, a framework for systems change that is centered on the premise that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life. However, there remain barriers to survivors in progressing through Vocational Rehabilitation programs. Some stakeholders report there is a need for more workforce readiness training that focuses on building soft skills.

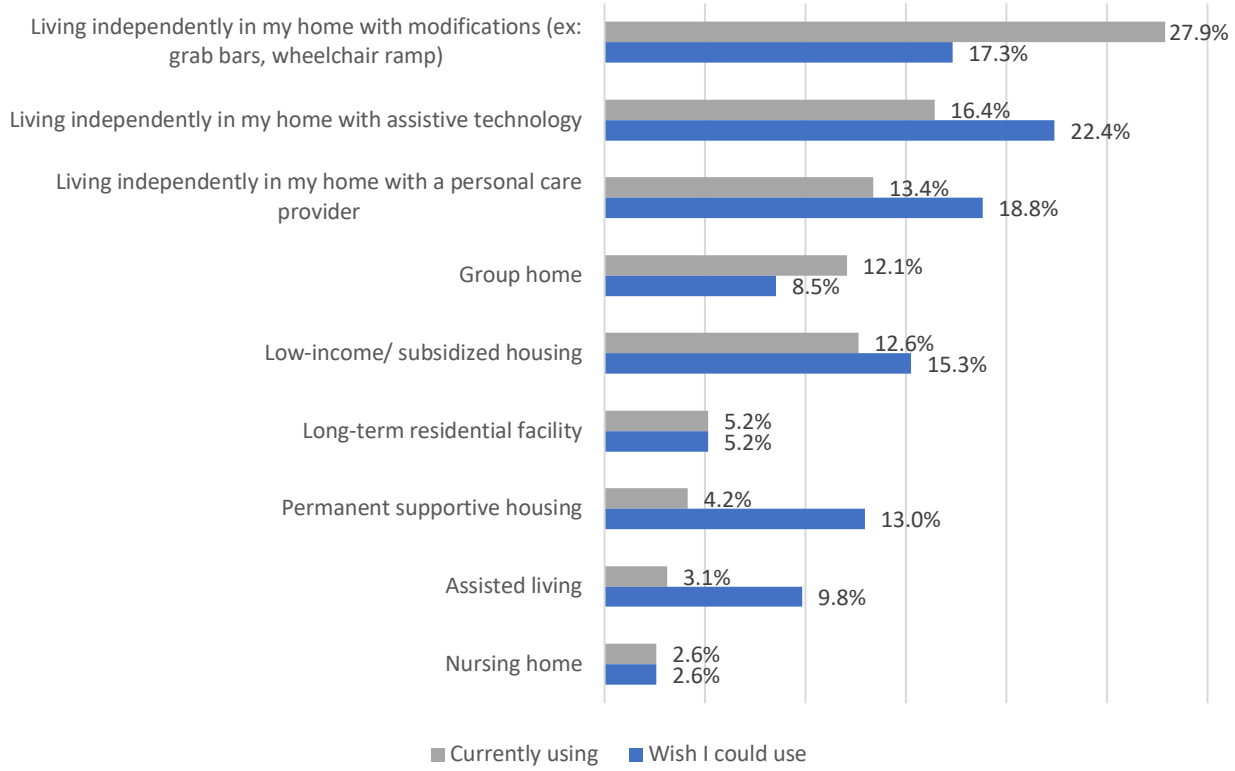
Another important service for survivors is **housing**. Close to 60% of consumers live independently in their own homes with modifications, assistive technology or with a personal care provider (Figure 9).[44] Although over half of consumers receive these services, they were also the primary items that consumers wish they had.

Providers were asked what housing related services they offered and 35% said modifications for independent living, 29% provided group home settings, and 23% provided assistive technology for independent living.[45] A group home is a housing service available to consumers, but it is not ranked high in the current or future[?] wish list of housing services for consumers. When looking at geographic differences in services offered, there are more providers of assisted living and in-home personal care in rural settings than in urban settings; a 20 percentage point difference.

[44] Consumer Survey Question #25: "For each housing related service, please select if you are currently using, previously received, wish you could use or don't need." N=220.
[45] Provider Survey Question #24: The following is a list of housing related services. For each option, please select yes if you provide this service or no if you do not. N=101.

Overall, consumers are generally satisfied (73%) with housing support services.[46] Consumers who indicated "other" level of injury level showed the highest levels of satisfaction (above 90% satisfied or more). The remaining consumer groups had lower levels of satisfaction (around 70%) with the exception of consumers with a moderate injury (78% were satisfied to very satisfied with housing support services). The 27% of consumers dissatisfied or very dissatisfied with their housing situation are those with severe injuries (37%) and those with nontraumatic injuries (20%).

Figure 9: Use and Wish List of Housing-related services



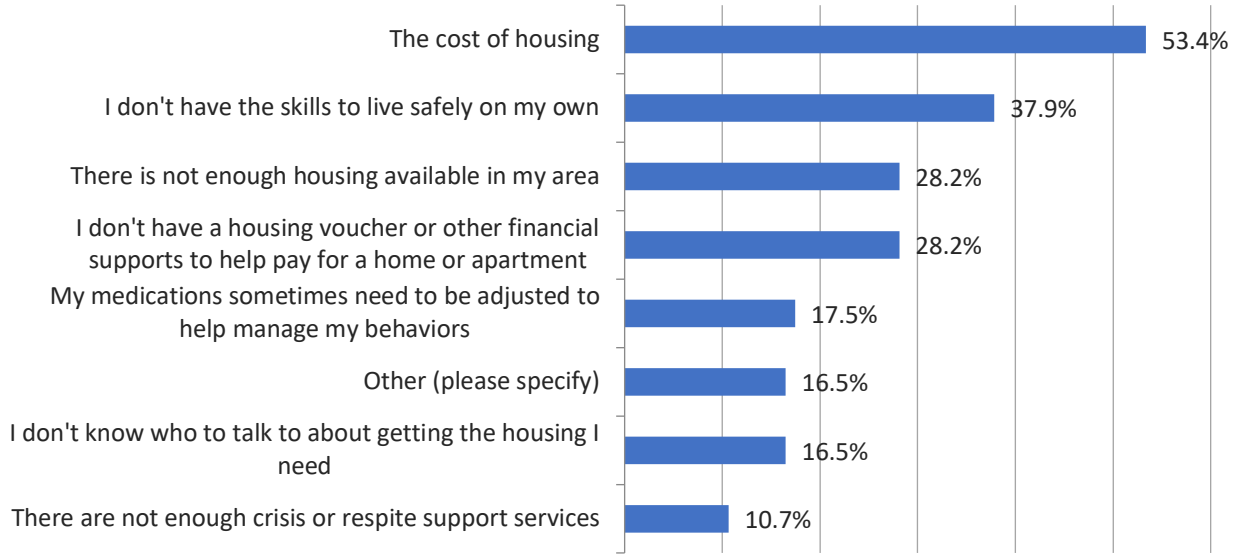
Consumer Survey Question #25: "For each housing related service, please select if you are currently using, previously received, wish you could use or don't need." N=220.

When asked about challenges with housing, consumers indicated that the cost of housing and having the skills to live safely on their own prevented them from getting and/or keeping a place to live (Figure 10).[47]

[46] Consumer Survey Question #26: How satisfied are you with housing related services you have received? N=130, excluding N/A responses.

[47] Consumer Survey Question #27: What are the challenges for you, if any, to getting and/or keeping a place to live? (select all that apply) N=103, excluding N/A responses.

Figure 10: Barriers to Housing



Consumer Survey Question #27: "What are the challenges for you, if any, to getting and/or keeping a place to live? (select all that apply)" N=103.

When providers were asked if there is an unmet need for housing services for people with brain injury, the highest responses were for in-home personal care provider services (67%), low-income/subsidized housing (65%), and permanent supportive housing (64%).[48] Fifty-four percent (54%) of provider respondents identified **long-term residential services as an unmet need**, yet this was the highest need identified during stakeholder interviews. Hospital Social Workers report great difficulty establishing discharge plans for survivors who are unhoused-especially those with co-occurring behavioral health issues-and find this often results in the person returning to the emergency department. Stakeholders also identified survivors with complex needs, such as chronic health issues, behavioral issues, and those who are on the sex offender registry, as difficult to find [place in?] an appropriate setting when discharging from the hospital. Survivors in situations like these are sometimes sent to services out-of-state for care.

System Coordination & Barriers to Services

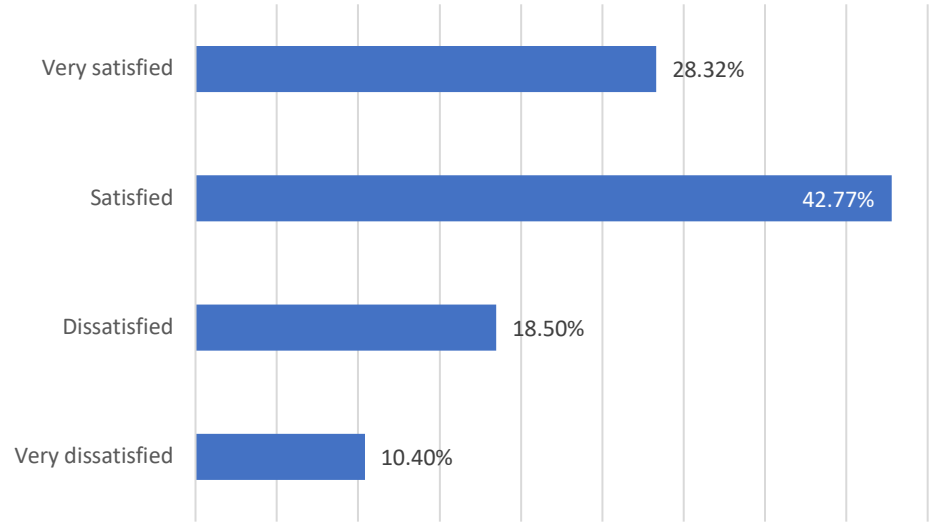
Brain injury is a chronic condition, impacting all aspects of life, and can occur at any age - therefore requiring a lens used across service systems, so people with brain injury can be integrated into broader services and support structures in their communities.

While over 70% of consumers are satisfied or very satisfied with how their providers **communicate and collaborate** with one another, almost 30% are dissatisfied, with about 10% of those consumers very

[48] Provider Survey Question #25: Is there an unmet need for these services for individuals with brain injury? N=102.

dissatisfied. A summary of responses are provided in Figure 11. It is worth noting that consumers with a severe injury showed the highest level of satisfaction relative to consumers with other injuries. Consumers with a moderate injury had the lowest level satisfaction; 58% being satisfied to very satisfied with their provider's communication.

Figure 11: Consumer Satisfaction with Provider Communication and Collaboration



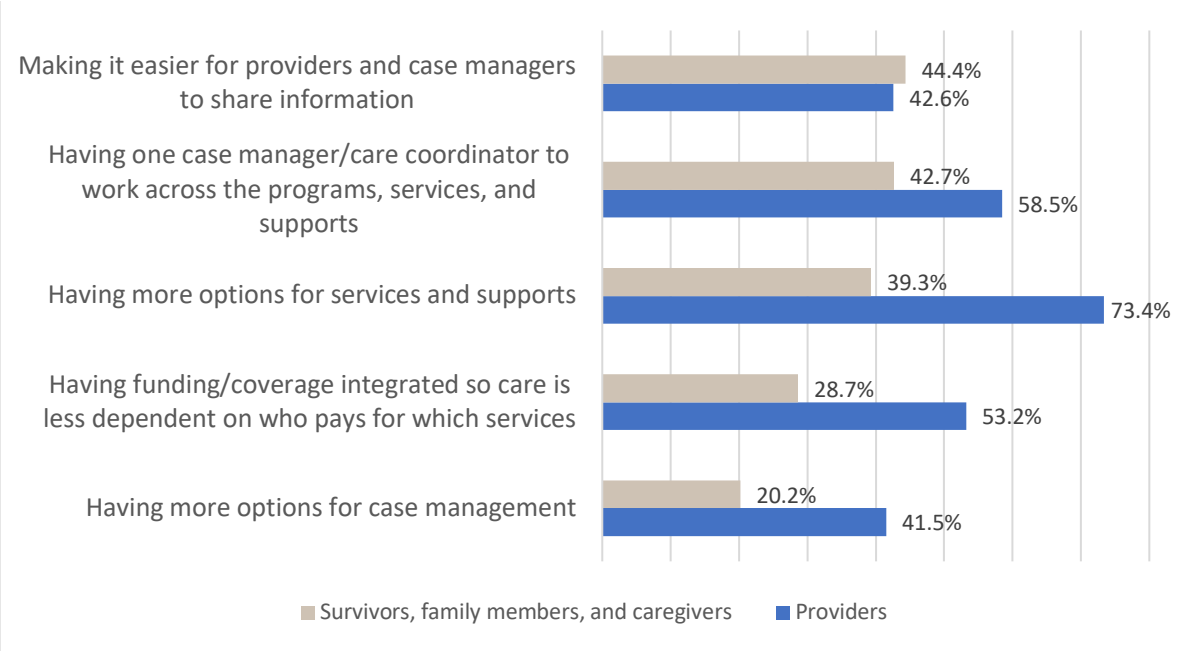
Consumer Survey Question #44: How satisfied are you with how your service providers communicate with each other and collaborate your care? N=173, excluding N/A responses.

Consumers and providers were both asked what would improve coordination of services for survivors. Providers tended to select more choices than consumers. Additionally, consumers and providers have different opinions on what would improve service coordination. For example, providers overwhelmingly believe (73%) that having more options for services and supports would be helpful. In contrast, only 39% of consumers indicated this would be helpful. A summary of provider and consumer responses is illustrated in

> "There are too many **'moving parts'** in the system. It's hard to keep track who to contact about what."
>
> *- Medical Power of Attorney*

Figure 12, in order of the top responses from consumers.

Figure 12: Ideas to Improve Service Coordination



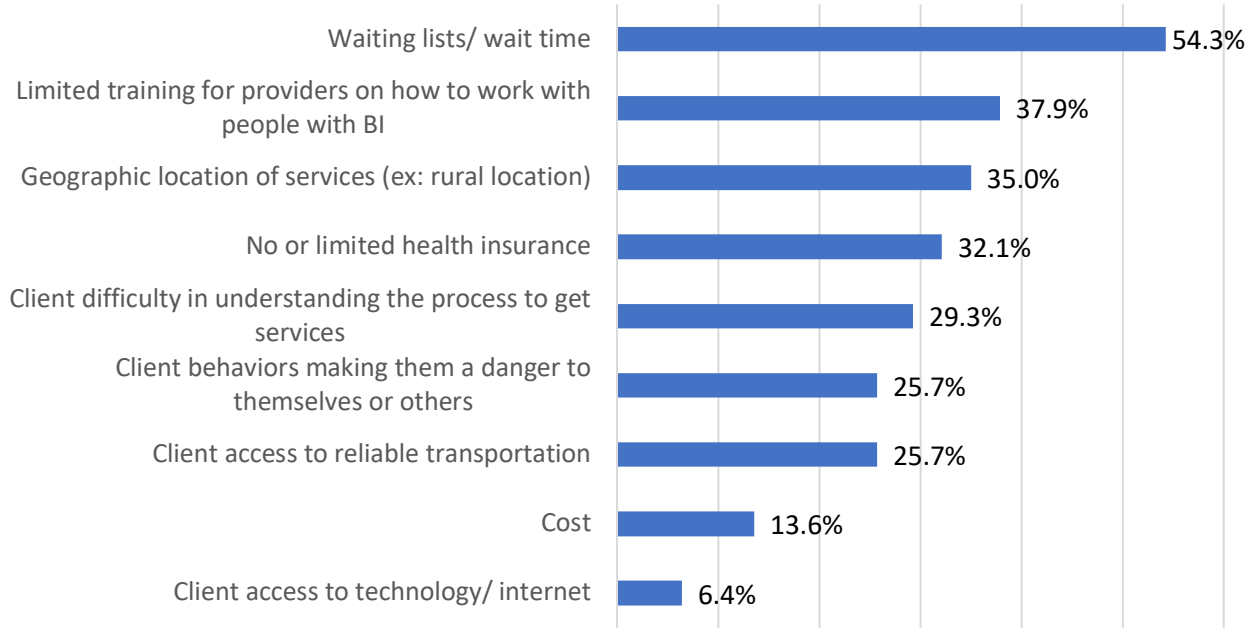
Consumer Survey Question #45: What could improve your service coordination? (Select all that apply.) N=178.
Provider Survey Question #38: What could improve service coordination? (Select all that apply.) N=83.

Answers to the question about service coordination differed based on whether people were already satisfied with coordination among their providers. Consumers who responded they were dissatisfied or very dissatisfied with communication and collaboration between their providers identified **having someone to help them navigate services** (53% and 38% respectively) and **having one case manager who could work across supports** (59% and 50% respectively) as what would be most helpful in improving service coordination.

Providers were asked to identify the top three barriers they believe prevent people with brain injuries from accessing services. Over half (54%) responded that **waiting lists** are an issue. **Limited training for providers** and **location** were the second and third most-selected responses. These and other responses are shown in

Figure 13. While both urban and rural providers saw waiting lists as the biggest barriers for survivors in accessing services (58% and 48% respectively), rural providers considered geographic location to be almost as big of a barrier as waiting lists (45%).

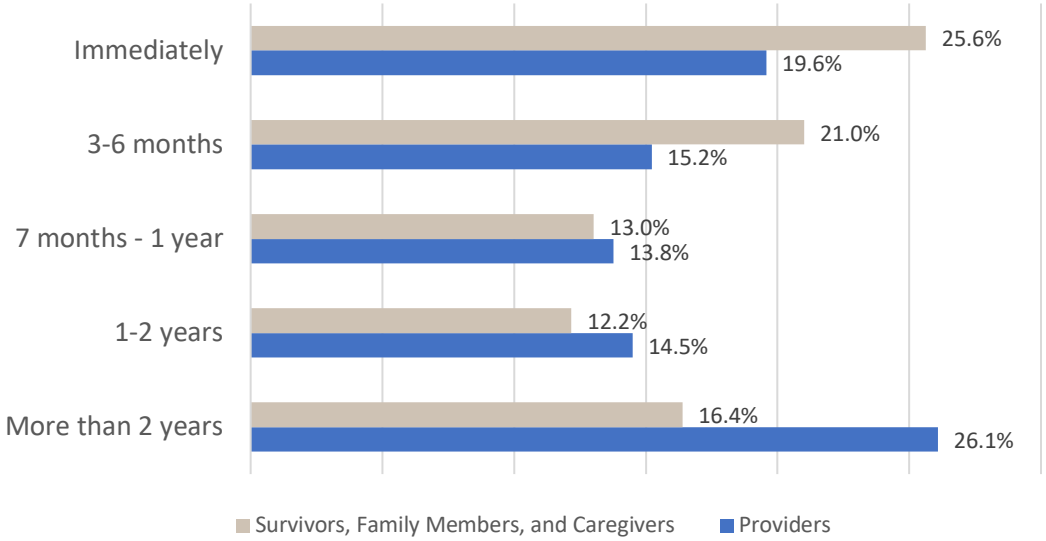
Figure 13: Barriers to Services (Providers)



Provider Survey Question #9: What are the biggest challenges for individuals with brain injuries in obtaining services? N=140.
Note: Respondents were given a choice to select their top three candidates.

Consumers were asked at what points during their recovery were rehabilitation services most difficult to access, and providers were asked more generally at what points services are most difficult to access. Consumers identified the time immediately after the brain injury as the point when services are most difficult to access. In contrast, providers saw two or more years after the injury as the time period when services are most difficult to access. These responses are illustrated in Figure 14.

Figure 14: Points in time where it becomes difficult to access services



Consumer Survey Question #13: At what points in time after your brain injury diagnosis were rehabilitation services more difficult to access? (Select all that apply.) N=238, including N/A responses.
Provider Survey Question #8: At what points in time after an individual's brain injury are services most challenging to access? N=138, including N/A responses.

There are differences in perception between rural and urban providers, particularly on how challenging it is access to services one year after the brain injury (7% vs 18% respectively).

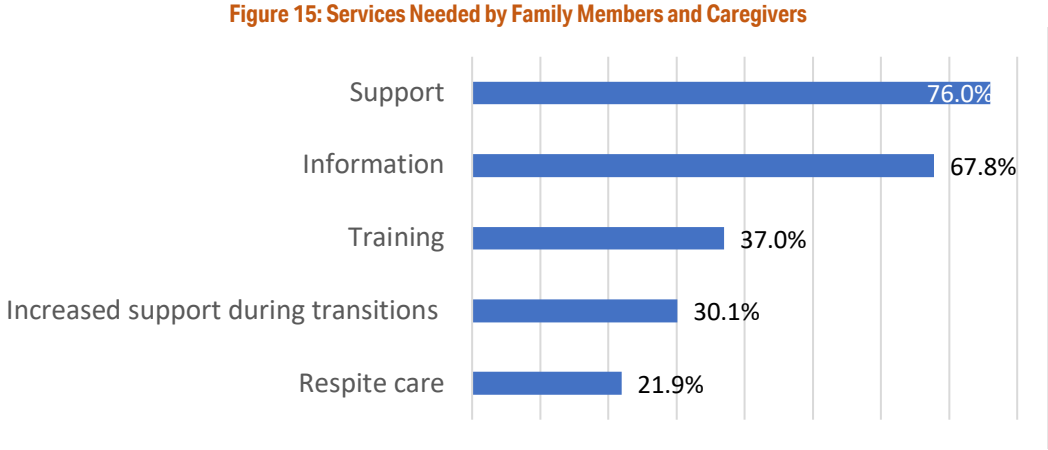
Consumers with mild brain injuries reported having a harder time accessing services immediately after their injury (30%) than consumers with moderate, severe, and non-traumatic injuries (24%, 27%, and 22% respectively). Consumers with severe brain injuries had a harder time accessing services more than two years after their injury (26%) than consumers with mild, moderate, and non-traumatic injuries (9%, 13%, and 13% respectively).

> "If we had more support and information in the first **6 months**, I believe we would have had a better outcome."
>
> *- Family Member*

Caregiver Support and Provider Training

When asked about the three most important services that family members and caregivers need to support their loved ones with brain injuries, **support** and **information** were their highest priorities. Figure 15 shows these and other answers.

Figure 15: Services Needed by Family Members and Caregivers



Consumer Survey Question #47: As a family member or caregiver, what are the three most important services that you need? (Select top three.) N=146.

Family members and caregivers were asked what important changes to services and supports could be made so that people with brain injury and their families could have a better quality of life. Some of their answers were:

> "To have **consistent support** from a case worker, who is creative, in their approach to all manner of rehab services."
>
> *– Caregiver*

> "A **guide for families** that addresses what to do when your family member sustains a brain injury. I had no idea who to contact or where to begin to seek help."
>
> *– Family Member*

A Brain Injury Family Training for family members of adults who have recently experienced brain injuries and reside in Maine was prepared by the Muskie School of Public Service and is available on DHHS website.[49]

[49] Brain Injury Family Training for family members of adults who have recently experienced brain injuries and reside in Maine was prepared by the Muskie School of Public Service https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Brain-Injury-Service-Family-Training-2018.pdf

Provider training and education is essential in having an educated workforce that can serve brain injury survivors. Unfortunately, stakeholders report there are **workforce shortages** in Maine, specifically of specialists, such as Neuropsychologists and Physiatrists, and in-home care providers, which worsened during the COVID-19 pandemic. Workforce shortages were also reported to impact the length and quality of training, especially in settings where there are staffing shortages and the need for coverage is prioritized over training procedures.

Additionally, when asked about the adequacy of MaineCare reimbursement rates to maintain a stable, qualified direct care workforce, 44% of providers responded they are somewhat adequate, while over half responded that they are extremely inadequate or somewhat inadequate (31% and 24% respectively).[50] The mixed response could be a result of pay variance between agencies because residential providers are paid per diem and determine the amount they pay direct support professionals.

It is important for providers to have training to understand brain injury and how best to support survivors and the unique challenges they face. For example, stakeholders report staff in some settings are more inclined to physically assist survivors rather than supporting survivors in gaining independence through the use of verbal cues and tools. When asked to identify the education and training they wish existed to help them better serve people with brain injury, providers most often identified **additional funding**, **online training options**, and **coordinated education across services** most often. These and other answers are summarized in

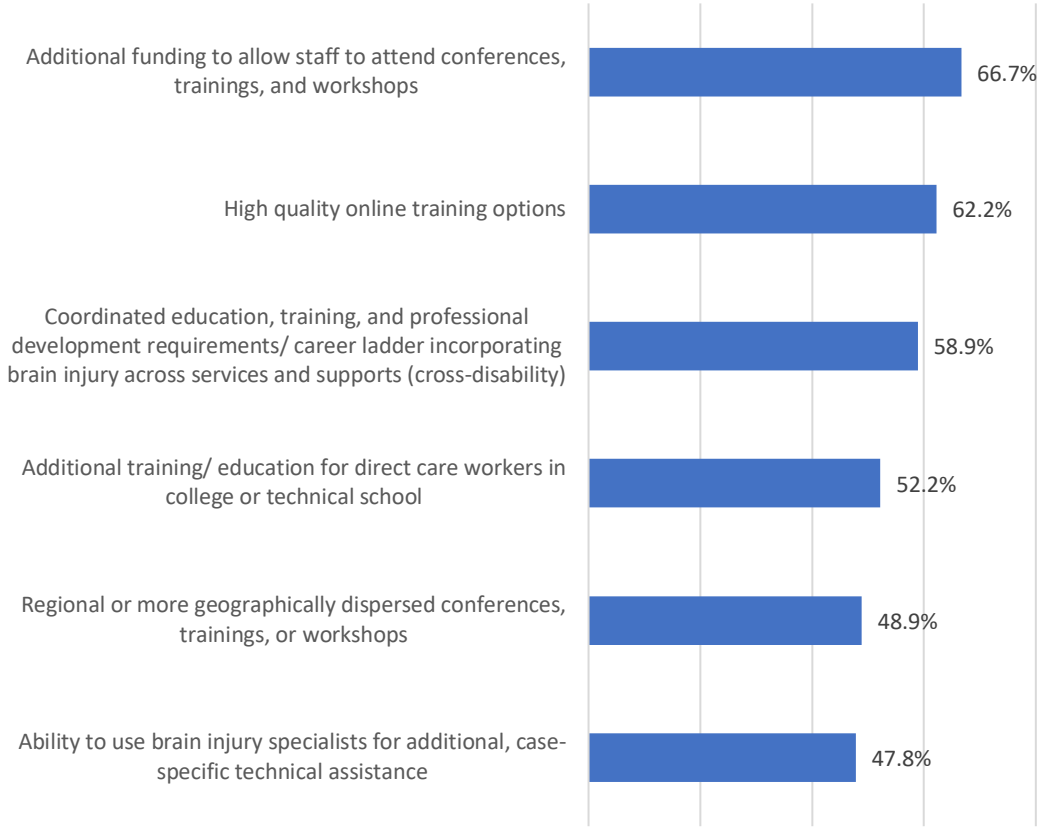
[50] Provider Survey Question #44: Are current reimbursement rates adequate for you to maintain a stable, qualified direct care workforce? N=54, excluding N/A responses.

Figure 16.

"In a rural state there isn't much **opportunity** in state for top notch training. There are **travel costs** to access that training. In a Medicaid program, it gets harder to make training dollars stretch."

– Steering Committee Member

Figure 16: Education and Training Needed by Providers



Provider Survey Question #43: What additional education, training, technical assistance, or other professional development do you wish existed to help you better serve people with brain injury? (Select all that apply) N=90.

Systems Level

Data

The need to improve collection of information and estimates of how many Mainers experience brain injury has been identified in numerous reports, including the 2005, 2010 and 2016 needs assessments, which indicated tracking brain injury incidence as remaining on the "to-do" list in Maine. This gap in available data was also a theme throughout stakeholder interviews and identified during attempts to collect and analyze data for the purposes of this needs assessment. For this assessment, we faced limitations when requesting data on brain injury prevalence from the Maine CDC, as well as when seeking available data at the Department of Education, Office of Behavioral Health, Department of Transportation, Department of Corrections, and Office of Child and Family Services.

A recent report on best practices in data also confirms the importance of data collection not only to identify brain injuries but also to improve connecting people to services and funding support services.[51] Stakeholders in Maine report data collection remains a challenge for several reasons, one being the limited capacity of the Maine CDC because funding cuts in the Injury Prevention Program prevent effective systematic collection, analysis, and interpretation of health data. This existing limited capacity was exacerbated by the COVID-19 pandemic when public health resources were diverted to prioritize pandemic response. There are some gains being made in Maine with data collection related to the drug epidemic as a result of a collaboration between several state departments, the Governor's Office, and the University of Maine; its public health metrics and data visualizations could be expanded to include injury prevention (and therefore brain injury) pending the awarding of a federal grant. [52]

Another identified barrier to implementing a mechanism to identify how many residents sustain a brain injury each year and the overall number of people living with a brain injury is the expense to develop and the lack of the necessary financial support across the key players for reporting. The requirement that hospitals and healthcare providers transition from the International Classification of Diseases, Ninth Edition, Clinical Modification, to the Tenth Edition (ICD-9-CM to ICD-10-CM) as their means of reporting medical diagnoses effects public health surveillance because the ICD-10-CM contains almost five times the number of codes found in the ICD-9-CM. This potentially will provide more detailed information, however, there remain effects of the transition including a new surveillance definition for TBI morbidity by the US CDC.

That said, it is vital to capture an accurate picture of the nature and prevalence of this chronic condition so Maine can better determine the support services needed and help contribute to the national understanding of brain injuries, which continue to be underestimated since the National Concussion Surveillance System has been enacted but remains to be funded.

Silos

Stakeholders report that the siloed nature of state services limits the ability to provide whole-person, client-centered care, focusing instead on what the person is eligible to receive funding for. This is true both between types of services as well as between services for children and adults. One of the most influential gaps in service delivery and payer structures exists between primary medical care and behavioral health care. In this study, consumers denied mental health services believed this was due to the agencies' inability to or unwillingness to serve someone with a brain injury.

[51] Best Practices for Using TBI Registries to Connect People to Services: A National Guide. Prepared by the National Association of State Head Injury Administrators for the Administration for Community Living TBI State Partnership Grant Workgroup. April 2021. https://www.nashia.org/acl-using-data

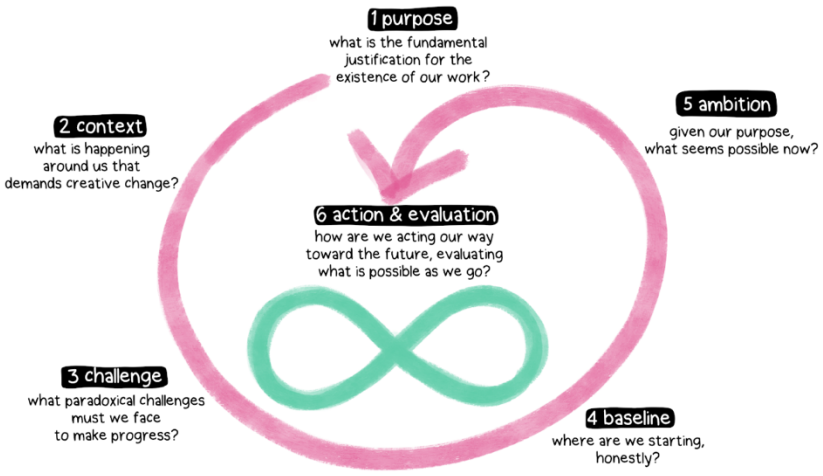
[52] Maine Drug Data Hub https://mainedrugdata.org

Collaboration of services between state agencies around brain injury has improved, particularly related to mental health services, as a result of the Augusta Mental Health Institute (AMHI) Consent Decree increasing cross-team attendance at discharge meetings with mental health centers and education of mental health and children's services [workers?] regarding brain injury services and supports.[53] Yet confusion persists on whether and how to delineate brain injury and behavioral health conditions.

Conclusion and Next Steps

Given the existing initiatives and opportunities for improvement determined through this needs assessment, the recommended next step is to engage in a strategic planning process with key stakeholders, including representatives from DHHS, ABIAC, and BIAA-ME. One strategic planning approach that has been successful with other organizations is called the Knotworking approach, which also uses Ecocycle planning- both from the Liberating Structures method of facilitation.[54]

If making a strategic plan were simple, a team would develop a list of tasks, decide who is doing what, what resources are needed, and forge ahead. This assumes resources are predictable, conditions are static, and the future is stable and knowable. That is not reality. Traditional strategic planning approaches start with an analysis of strengths, weaknesses, opportunities, and threats (SWOT analysis), followed by an environmental scan of the political, economic, social, and technological factors (PEST analysis) impacting an organization. These approaches often assume a linear future will unfold, and concentrate design, ownership and implementation in a top-down model and pin hopes on wonderful-but-vague mission statements. Traditional planning frameworks fail to unleash and engage those who must execute and build on data without a sense-making step that would help the group ground factors in the context of how things get implemented in their organization.



Strategy Knotworking could be used instead to create a living state plan for brain injury services and supports that delivers valuable, actionable

[53] The AMHI Consent Decree. Disability Rights Maine. https://drme.org/assets/brochures/CD-Presentation.pdf
[54] https://www.liberatingstructures.com/31-ecocycle-planning/

next steps and an ability to flex and evolve in changing contexts.

The process includes a data gathering and analysis step when answering the second question, "What is happening around us that demands creative change?" In this case, the planning committee could use the results of this Brain Injury Needs Assessment as the background data. The workshops would help to group and prioritize the recommended actions gathered for this report, including the following ideas developed as themes:

Brain Injury Screening and Assessment

Develop a best practice protocol for screening, identification, and assessment of brain injury statewide, and screen for brain injury history among people who receive state-funded health and social services. Consider funding a second opinion clinical review team through MaineCare to provide comprehensive review of complex cases (pulling in an array of specialists as needed).

Support for Providers

Support providers by increasing the availability of brain injury specialists to train and consult across systems and levels of service providers, emphasizing cross training of behavioral health providers who screen, diagnosis, or prescribe psychotropic medications. In addition, train health and social service providers to recognize behaviors related to brain injury and how best to serve people with brain injury based on growing understanding and current medical knowledge. Provide ongoing support and training incentives for brain injury service providers–especially for positions experiencing workforce shortages and high turnover.

Brain Injury Services

Identify the critical elements where service delivery is going well and consider incorporating them into other areas of the system where there are identified needs. Investigate opportunities to improve workforce readiness services for survivors and engage employers around reasonable accommodations for people with disabilities to support survivors in gaining employment. Also prioritize brain health through physical fitness and brain nutrition as much as [equal to? in parity with?] employment for individuals with brain injury. Maine could also staff crisis teams & respite services with brain injury trained clinicians and provide equal access to these resources.

Awareness of Brain Injury Services

Continue efforts to increase awareness about brain injury with: 1) the public, emphasizing prevention and reducing stigma, 2) consumers of services, emphasizing service options, and 3) providers across all fields. Could develop a service "road map" for survivors, family members, and caregivers to follow the services and increase awareness of services available at different stages

of recovery and lifetime. Consider partnering with an organization like the Frameworks Institute[55] to assist in communication strategies.

Barriers to Accessing Services

Systemic barriers to accessing services especially affect adults and children with co-occurring brain injury and behavioral health. Reduce barriers by continuing efforts to collaborate with behavioral health agencies and recruit a representative from the Office of Behavioral Health and the Office of Children and Families Services to serve on ABIAC. Increase availability of and access to affordable housing and residential facilities to allow for people with brain injury to receive care close to their community and support system and not have to seek services out of state. Look toward other states efforts to use Medicaid funding to pay for supportive services in permanent supportive housing programs.

Coordination of Care

Coordinate care over time and across an individual's continuum of needs so it is person-centered, patient-driven care. Could integrate peer support into the brain injury system to help survivors and caregivers navigate services, increase self-advocacy skills, and more effectively lead the person-centered planning process. Increase collaboration with the Community Housing of Maine and the Maine State Housing Authority to allow for survivors to continue living as independently as possible. Maine could also link the brain injury system to resources, research, and training on dementia in older adults because of the prevalence of early onset dementia in persons with brain injury.

Systemized reporting and data collection

Continuing efforts towards funding and coordinating a brain injury data collection system are vital to address the needs of Mainers with brain injury. The system could map geographic data on injuries and service needs to determine locations of residential and other services, and explore geographic gaps, including addressing wait lists in rural areas and inability to pay for services in urban areas. Data reporting could also be improved through strengthened partnerships between MaineCare, DHHS, Maine CDC and other sources such as private insurance.

Knotworking is an inclusive planning process involving a series of workshops that would be conducted with a broad group of stakeholders. The plan is built by all stakeholders by answering six compelling questions. The set of interrelated answers to the questions become a compelling narrative – much more than the individual elements reveal. Shaping these answers together builds ownership, trust, and momentum.

[55] https://www.frameworksinstitute.org/

Performance measurement is also a way to organize staff, stakeholders, and the broader community around a shared understanding of a system's performance today—and where it is heading in the future. As a part of the planning process, ME-BIAA, DHHS, and ABIAC have an opportunity to work together to create a set of performance measures to make strategic goals and the program's performance relative to that strategy visible over time. The PuMP Blueprint developed by Stacey Barr Is one method that governments and non-profits have used successfully. The PuMP Blueprint (or simply PuMP) lays out an eight-step process for creating and using performance measures. PuMP is particularly well-suited to measuring seemingly intangible goals and creating shared understanding and buy-in for those measures. For example, a small group at the PuMP workshops might work on a plan for measuring how much the independence and overall health and well-being of all people with TBI in Maine has improved as a result of these efforts. The group would answer a series of questions, like: What results could you see, hear, smell, taste or touch that would provide evidence of achieving this goal? How can that be quantified over time objectively? What could be an unintended consequence of achieving this result? The outcome of the workshops would be clear definitions of the measures for each goal and a plan and assignments for gathering the data and reporting results, including the thresholds that would trigger program management decisions.

Appendices

Appendix A: Interview Protocol

#	Question (All)	Response
	Please tell us a little more about yourself, your position/role and your organization.	
	Which brain injury initiatives in the state of Maine are you familiar with? [*ex: CDC recommendations improved tracking of brain injury incidence and prevalence, increased analyses of brain injury causes, treatment, prevention, and service needs*]	
	How do you think awareness of brain injury has changed over the past 10 years? In what ways has it changed? What factors lead to an increase in awareness?	
	Service Providers	
	What type of services or supports do you provide? Are these services targeted at specific populations? About how many people do you serve? Do you have a waiting list? What funding sources support your work?	
	How do people access your services? How do referrals work? How do you work with other providers?	
	What works well in terms of your service delivery?	
	What doesn't work as well in terms of your service delivery?	
	Do you have a wait list? Do agencies you refer to have a wait list? What factors affecting waiting lists? [ex: *funding constraints, workforce shortages, etc.]*	
	What services/supports are more broadly available for people with brain injury? What are the most commonly used services? And why? Do you refer people to these other services? Are there characteristics of individuals with brain injury who are most likely to be served successfully in a community setting? What services beyond case management are available for those not on Medicaid?	
	What do you see as the unmet needs or gaps in services?	
	What population is the most impacted by gaps in services? OR What population groups are being underserved?	

	[*prompt ex: co-occurring TBI/SUD/MH, prison/corrections, homeless, DV, children/youth, older adults - people transitioning from nursing facilities back into the community, veterans, etc.*]	
	Special Populations	
	What service access challenges does this special population experience?	
	How are people with brain injuries served in institutional settings? [prompt ex: *State Hospitals, Correctional facilities, Nursing homes, etc.*] What are the waiting lists/average wait time?	
	What services are available to transition people out of institutional settings?	
	What factors are important in your cross-agency collaboration? [*prompt ex: other providers, other state agencies, external groups like advocates or schools, etc.*]	
	Workforce (Provider and Caregiver Training and Resource needs)	
	What are the training and resource needs of providers specific to brain injury? What unmet training needs are the highest priority? [*prompt: professional and para-professional*]	
	What are the training and resource needs of providers specific to co-occurring brain injury and substance use? What unmet training needs are the highest priority? [*prompt: professional and para-professional*]	
	What are the unmet needs of caregivers?	
	What is the first thing you would do to better support providers serving people with co-occurring TBI/SUD?	
	Data	
	How do you gather data? Do you have data on prevalence of TBI in your service system? Do you have data on TBI and co-occurring diagnoses?	
	Have you been involved in establishing the Maine TBI state registry?	
	What are the biggest challenges in working with your available data?	
	Conclusion (all)	Response
	Are there any resources you think are important for us to be aware of in this process?	
	Anything else you think is important for us to know or something we should be sure to ask others? Anything we didn't ask but should have?	
	Anyone you think we should be sure to interview?	

Appendix B: Survey Recruitment Flyer

We Need Your Help

MAINE BRAIN INJURY NEEDS ASSESSMENT

BIAA-ME and the Maine Department of Health and Human Services ("the Department") is looking for input from Mainers with a brain injury, their families, caregivers, and providers. This survey includes questions about your injury and your experience accessing or trying to access different services. The information you share will provide needed insight for the Department's direction of efforts to strengthen Maine's system of brain injury services and supports.

Survivor/Family Member Survey

Provider Survey

Feel free to share the survey with people you know who also have an experience with brain injury services.

For questions related to the survey or needs assessment, please contact Sarah Jordan by email.

Survivors, Caregivers & Family

Providers

Appendix C: Consumer Survey (Survivor, Caregiver, and Family)

Maine Brain Injury Needs Assessment: Survivor, Caregiver, and Family Survey

Introduction

Thank you for taking the time to complete this survey. The Brain Injury Association of America's Maine Chapter is conducting this survey in collaboration with the Office of Aging and Disability Services and the Acquired Brain Injury Advisory Council.

We are **looking for input** from people with a brain injury, their families and caregivers. The information you provide will **help guide the direction of efforts to strengthen Maine's system of brain injury services and supports**. Your open and honest answers will help us know what is working and where there are unmet needs. Any personal information you share will be kept **confidential**.

Survey instructions:

- Please complete the survey by **Wednesday, April 28th**.
- Please allow approximately 30 minutes to complete the survey.
- You may skip section(s) that don't apply to your situation.
- If you need to take a break:
    - Click on the "Save and Continue" button.
    - When you return to the same device and the same browser (e.g. Chrome, Firefox, Safari, Internet Explorer) you can continue where you left off until you click the "Done" button.

By completing this survey, you will have a chance to enter a **drawing to receive a $100** Visa gift card. Thanks in advance for sharing your feedback!

Questions about this survey? Please contact the BIAA-ME via email at sjordan@biausa.org or Koné Consulting via email at karin.ellis@koneconsulting.com.

1. What best describes your **connection to brain injury** issues?

- ◯ I am an adult with a brain injury
- ◯ I am a parent of a child with a brain injury
- ◯ I am a family member or significant other of a person with a brain injury, but not their caregiver
- ◯ I am a family member or significant other of a person with a brain injury, and their caregiver
- ◯ I am a guardian of a person with a brain injury
- ◯ I am another person assisting the person with a brain injury (please describe)

The following pages ask about your brain injury. If you've experienced **more than one**, please answer based on your **worst** injury.

If you are **assisting or responding on behalf** of someone with a brain injury, please respond to survey questions from their perspective.

Caregivers or family members - please respond from your perspective with the knowledge you have of the person's experience.

2. Please tell us **how** you were injured. (select all that apply for multiple injuries)

- ☐ Auto accident
- ☐ Other vehicle accident (ex: motorcycle, ATV)
- ☐ Bicycle accident
- ☐ Pedestrian accident
- ☐ Sports injury
- ☐ Injury from a fall
- ☐ Other (please specify)

- ☐ Domestic violence
- ☐ Gunshot
- ☐ Hit in the head or face
- ☐ Choked
- ☐ Blast injury
- ☐ Overdose

- ☐ Near drowning
- ☐ Industrial/job related injury
- ☐ Brain surgery
- ☐ Military service related injury
- ☐ Self-inflicted injury

3. Please tell us the **nature** of your injury. (select all that apply for multiple injuries)

- ☐ **Blow** to the head/ brain (ex: concussion, blast injury, closed head injury)
- ☐ **Penetrating injury** to the head/ brain (including surgery)
- ☐ **Loss of oxygen** (anoxic or hypoxic injury)
- ☐ **Infection** of brain (ex: spinal meningitis, COVID-19)
- ☐ Other (please specify)

- ☐ **Aneurism**
- ☐ **Stroke**
- ☐ **Brain Tumor**
- ☐ **Exposure to chemical toxins**

4. How **severe** was your **traumatic** brain injury? (based on loss of consciousness)

- ○ **Mild** = 0-30 minutes loss of consciousness (or concussion)
- ○ **Moderate** = 30 minutes to less than 24 hours loss of consciousness
- ○ **Severe** = more than 24 hours loss of consciousness
- ○ **I don't know**
- ○ **My brain injury was non-traumatic** (stroke, aneurism, tumor, etc)
- ○ Other (please specify)

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5. **How old** were you when your brain injury occurred?

	First injury	Second injury, if applicable	Third injury, if applicable
Under 18	○	○	○
18-24	○	○	○
25-34	○	○	○
35-44	○	○	○
45-54	○	○	○
55-64	○	○	○
65+	○	○	○

6. **How long after** your brain injury were you **diagnosed**? (please select one)

- ○ 0 to 3 months
- ○ 3 to 6 months
- ○ 6 months to 1 year
- ○ Other (please specify)
- ○ 1 to 3 years
- ○ 3 to 5 years
- ○ Over 5 years

7. **Who** helped you **recognize** you may have a brain injury? (please select all that apply for multiple injuries)

- ☐ Hospital or emergency room provider
- ☐ Family Doctor or Pediatrician
- ☐ Medical specialist (ex: Neuropsychologist, Neurologist)
- ☐ Occupational, Physical, or Speech Therapist
- ☐ Other (please specify)
- ☐ Family member
- ☐ Social worker, counselor, or case manager
- ☐ School teacher, coach, or school Nurse

Programs/Benefits

8. How have you **covered the cost of services** you've received? (please select 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
- ☐ Other (please specify)

9. What other types of services **have you received** or are **currently receiving**? (please select ALL that apply)

- ☐ **Legal Aid Services**
- ☐ **Vocational Rehabilitation** (VR)
- ☐ **Veteran's Administration** (VA)
- ☐ **Division for the Blind and Visually Impaired**
- ☐ **Residential Services** (ex: Goodwill, Charlotte White Center, Neuro-restorative, Creative Works Systems, Northern Maine General)
- ☐ **Outpatient Neuro-rehabilitation Services** (ex: Goodwill, MCIR, CINR)
- ☐ **Nursing Facility Brain Injury Services** (ex: RiverRidge, Brewer Rehabilitation)
- ☐ **Specialty Hospital Brain Injury Services** (ex: New England Rehabilitation Hospital, Northeast Rehab, Spaulding Rehab)
- ☐ Other (please specify)
- ☐ **Mental Health/Substance Abuse Treatment** (ex: Tri-County, Crisis and Counseling, AMHC, Community Health and Counseling, Broadreach)
- ☐ **Home Health Coordination** (ex: Alpha One or EIM)
- ☐ **Medicaid WAIVERS** 18, 19, 20, 21, or 29
- ☐ **Visiting Nurse Services**
- ☐ **Care Coordination**
- ☐ **Assistive Technology**
- ☐ **Independent Living Agency**

Rehabilitation Services

10. For each **rehabilitation service**, please select whether you are currently using, have previously received, wish you could use, or don't need.

	I'm currently using	I previously received	I wish I could use	I don't need
Acute Care	○	○	○	○
Assistive technology	○	○	○	○
Brain Injury Diagnosis and Assessment	○	○	○	○
Care Coordination	○	○	○	○
Cognitive Training	○	○	○	○
General Medical (Primary Care Physician)	○	○	○	○
Neuro-rehabilitation	○	○	○	○
Occupational Therapy	○	○	○	○
Physical Therapy	○	○	○	○
Recreational Therapy	○	○	○	○
Rehabilitation (Inpatient)	○	○	○	○
Residential in-home support	○	○	○	○
Specialized Medical (Neurologist, Neuropsychologist)	○	○	○	○
Speech Therapy	○	○	○	○

11. For each rehabilitation service **setting**, please select whether you are currently using, have previously received, wish you could use or don't need.

	I'm currently using	I previously received	I wish I could use	I don't need
Brain injury clubhouse	○	○	○	○
Nursing home	○	○	○	○
Residential Treatment (24 hours/day x 7 days/week)	○	○	○	○
Outpatient Neurorehabilitation	○	○	○	○
Vocational Rehabilitation (for assessment of vocational needs, preparation for work, help finding a job)	○	○	○	○
Employment (for providing work support, helping securing and keeping a job)	○	○	○	○
Education (ex: school or training center)	○	○	○	○
In-home rehabilitation support	○	○	○	○

Other (please specify)

12. What has **prevented you from using rehabilitation services** you wish to use? (Select all that apply)

- ☐ I am on the waitlist
- ☐ I was not aware of the services
- ☐ There aren't services located near where I live
- ☐ I am a non-native English speaker
- ☐ The provider does not support the method of communication that I use
- ☐ I don't understand the process to get services
- ☐ I don't have health insurance, or my health insurance doesn't cover the services I need
- ☐ I can't afford the services I need
- ☐ I have complex medical needs
- ☐ I have been turned away from providers due to my actions
- ☐ I was told there was not a brain injury specialist that could serve me
- ☐ I have limited access to technology / internet
- ☐ I don't have access to reliable transportation
- ☐ Not applicable
- ☐ Other (please specify)

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13. At what points in time **after your brain injury diagnosis** were rehabilitation services **more difficult to access**? (Select all that apply)

- [ ] Immediately
- [ ] 1-2 years
- [ ] 3-6 months
- [ ] More than 2 years
- [ ] 7 months - 1 year
- [ ] N/A
- [ ] Other (please specify)

14. How **satisfied** are you with the rehabilitation services you have received?

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied	N/A
○	○	○	○	○

15. Is there anything else you would like to share about your experience **attempting to access rehabilitation services** for brain injury?

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Maine Brain Injury Needs Assessment: Survivor, Caregiver, and Family Survey

Education

This next set of questions are about your education services, support, or accommodation. For example, these services would include Special Education or a 504 plan.

16. What is the highest level of **education you have completed**? (please select one)

- ○ Kindergarten - 5th grade
- ○ 6th - 8th grade
- ○ 9th - 12th grade
- ○ High school or GED
- ○ Other (please specify)
- ○ Some college/ Vocational Technical/ Trade School
- ○ Bachelor's degree
- ○ Master's degree
- ○ Doctoral degree

17. Next to each option in the list of **education services, support, or accomodation**, please select if you are currently using, have previously used, wish you could use, or don't need the services.

	Currently using	Previously received	Wish I could use	I don't need
Education consultation	○	○	○	○
Special education and/ or Individualized Education Plan (IEP)	○	○	○	○
504 Plan	○	○	○	○
Counseling	○	○	○	○
Occupational, speech, physical, or cognitive therapy	○	○	○	○
Wrap-around family support or home visiting services	○	○	○	○

Other (please specify)

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18. What has prevented you from being able to use education services, support, or accommodations you wish to use? (Select all that apply)

- [ ] I am on the waitlist
- [ ] I was not aware of the services
- [ ] There aren't services located near where I live
- [ ] I am a non-native English speaker
- [ ] The provider does not support the method of communication that I use
- [ ] I don't understand the process to get services
- [ ] I don't have health insurance, or my health insurance doesn't cover the services I need
- [ ] Other (please specify)
- [ ] I can't afford the services I need
- [ ] I have complex medical needs
- [ ] I have been turned away from providers due to my actions
- [ ] I was told there was not a brain injury specialist that could serve me
- [ ] I have limited access to technology / internet
- [ ] I don't have access to reliable transportation
- [ ] Not applicable

19. How **satisfied** are you with the **education services, support, or accomodations** you have received?

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied	N/A
○	○	○	○	○

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Employment

This next set of questions is about employment support services. These are services you may have received through the Division of Vocational Rehabilitation.

20. What kind of **work** are you **currently** doing?

- ◯ Full-time work outside the home
- ◯ Part-time work outside the home
- ◯ Underemployed and looking for more work
- ◯ Working inside the home (ex: caregiver, parent)
- ◯ Unemployed and looking for work
- ◯ Other (please specify)
- ◯ Full-time student
- ◯ Part-time student
- ◯ Military service
- ◯ I am not looking for work
- ◯ I am no longer able to work

21. Next to each **employment support service** option, please select if you currently use, previously used or wish you could use or don't need these services.

	Currently using	Previously received	I wish I could use these	I don't need
Physical and mental restoration services	◯	◯	◯	◯
Assessment services to determine eligibility and vocational rehabilitation needs	◯	◯	◯	◯
Counseling and guidance	◯	◯	◯	◯
Job placement services	◯	◯	◯	◯
Individualized Plan for Employment (IPE)	◯	◯	◯	◯
Employment training and other training services	◯	◯	◯	◯
Self-employment services, including technical assistance and consultation for the establishment of small business operations	◯	◯	◯	◯
Occupational licenses, tools, equipment, and initial stocks and supplies	◯	◯	◯	◯

	Currently using	Previously received	I wish I could use these	I don't need
Rehabilitation Technology/ Assistive Technology	○	○	○	○
Job coaching and supported employment services	○	○	○	○
Individualized transition services to support movement from school to work	○	○	○	○
Pre-Employment transition services to support movement from school to work	○	○	○	○
Pre-Employment transition services for students with disabilities	○	○	○	○

Other (please specify)

22. How **satisfied** are you with **employment support services** you have received?

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied	N/A
○	○	○	○	○

23. What are the **challenges**, if any, you experience gaining and keeping a **job**? (Select all that apply)

- ☐ My employer/ supervisor needs ongoing training or support
- ☐ I find it challenging to manage my work schedule or get to work on time
- ☐ I'm not able to stay focused enough to do my work
- ☐ I have a hard time finding jobs that will accommodate for my brain injury
- ☐ My needs change over time - I have good days and bad days
- ☐ Not applicable
- ☐ Other (please specify)

Maine Brain Injury Needs Assessment: Survivor, Caregiver, and Family Survey

Living Situation

24. Where are you **currently living**?

- ◯ At home with my parents, grandparents, and/ or siblings
- ◯ At home with my spouse or partner
- ◯ In my own home or apartment
- ◯ In a group home
- ◯ In a foster home
- ◯ In a residential treatment facility
- ◯ In a hospital
- ◯ Other (please specify)
- ◯ In a rehabilitation facility
- ◯ In a nursing home
- ◯ In a shelter
- ◯ In a vehicle
- ◯ With friends in their home
- ◯ On the streets

25. For each **housing related service**, please select if you are currently using, previously received, wish you could use or don't need.

	Currently using	Previously received	Wish I could use	I don't need
Living independently in my home with modifications (ex: grab bars, wheelchair ramp)	○	○	○	○
Living independently in my home with assistive technology	○	○	○	○
Living independently in my home with a personal care provider	○	○	○	○
Assisted living	○	○	○	○
Group home	○	○	○	○
Nursing home	○	○	○	○
Long-term residential facility	○	○	○	○
Low-income/ subsidized housing	○	○	○	○
Homeless shelter	○	○	○	○
Domestic violence shelter	○	○	○	○
Permanent supportive housing	○	○	○	○

Other (please specify)

26. How **satisfied** are you with **housing related services** you have received?

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied	N/A
○	○	○	○	○

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27. What are the **challenges** for you, if any, to getting and/or keeping a **place to live**? (select all that apply)

- [ ] The cost of housing
- [ ] I don't have a housing voucher or other financial supports to help pay for a home or apartment
- [ ] There is not enough housing available in my area
- [ ] I don't have the skills to live safely on my own
- [ ] I don't have the skills to live safely with others
- [ ] My medications sometimes need to be adjusted to help manage my behaviors
- [ ] Other (please specify)

- [ ] There are not enough crisis or respite support services
- [ ] My criminal record makes it hard for me to find hosing
- [ ] I have a poor rental history
- [ ] I don't know who to talk to about getting the housing I need
- [ ] Not applicable

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Emergency services

This next set of questions is about your experience with emergency responders such as police, medics and/or the criminal justice system (if you've been arrested).

28. Have you ever **called 911** or **engaged with emergency responders**, such as police or medics, since sustaining your brain injury?

- ◯ Yes
- ◯ No

29. Have you **been stopped or detained by the police** since sustaining your brain injury?

- ◯ Yes
- ◯ No

30. In any of these encounters, did you **go to jail** when you thought you should go to the **hospital**?

- ◯ Yes
- ◯ No

31. In your encounter(s) with emergency responders, **were you ever asked if you had a brain injury**?

- ◯ Yes
- ◯ No

32. How, if at all, **has your interaction** with police or legal system **changed your access to programs or support services**?

- ◯ No change
- ◯ It is harder for me to access services
- ◯ It is harder for me to find a place to live
- ◯ I am connected to more services through therapeutic courts
- ◯ Other (please specify)

Mental health

33. Have you or are you currently receiving **mental health services**?

- ◯ Yes, I am currently
- ◯ Yes, I have but not currently
- ◯ No, I tried to access but was turned away
- ◯ Other (please specify)
- ◯ No, I do not have a need for these services
- ◯ Not sure

34. Next to each **mental health service** option, please select if you are currently using, previously received, or wish you could use these services.

	Currently using	Previously received	Wish I could use	I don't need
Community mental health case manager	◯	◯	◯	◯
Crisis line	◯	◯	◯	◯
Walk in crisis center	◯	◯	◯	◯
Behavioral intervention plan	◯	◯	◯	◯
Mental health counseling	◯	◯	◯	◯
Peer support	◯	◯	◯	◯
Inpatient psychiatric hospital	◯	◯	◯	◯

Other (please specify)

35. Have you ever been **turned away** from **mental health services**?

- ◯ Yes
- ◯ No

36. **Why** do you think you were turned away from **mental health services?** (select all that apply)

- ☐ I wasn't able to pay for the care
- ☐ I was told that they do not treat people with brain injury
- ☐ I have been barred from this provider, so they will no longer serve me
- ☐ The provider does not support the method of communication that I use
- ☐ I was told an assessment for brain injury was not available
- ☐ I was told a brain injury specialist was not available
- ☐ Other (please specify)

37. Is there anything else you would like to share about your experience with **mental health services** you have received or wish you could access?

Substance Use

38. Have you or are you currently receiving **substance use** services?

- ◯ Yes, I am currently
- ◯ Yes, I have but not currently
- ◯ No, I tried to access, but was turned away
- ◯ Other (please specify)
- ◯ No, I do not have a need for these services
- ◯ Not sure

39. Next to each **substance use service** option, please select if you are currently using, previously received, or wish you could use these services.

	Currently using	Previously received	Wish I could use	I don't need
Crisis line	◯	◯	◯	◯
Walk in crisis center	◯	◯	◯	◯
Behavioral intervention plan	◯	◯	◯	◯
Substance use outpatient treatment	◯	◯	◯	◯
AA (Alcoholics Anonymous) or NA (Narcotics Anonymous)	◯	◯	◯	◯
Medical detox	◯	◯	◯	◯
Peer support	◯	◯	◯	◯
Inpatient treatment	◯	◯	◯	◯

Other (please specify)

40. Have you ever been **turned away** from **substance use services**?

- ◯ Yes
- ◯ No

41. **Why** do you think you were turned away from substance use services? (select all that apply)

- ☐ I wasn't able to pay for the care
- ☐ I was told that they do not treat people with brain injury
- ☐ I have been barred from this provider, so they will no longer serve me
- ☐ The provider does not support the method of communication that I use
- ☐ I was told an assessment for brain injury was not available
- ☐ I was told a brain injury specialist was not available
- ☐ Other (please specify)

42. Is there **anything else** you would like to share about your experience with **substance use services** you have received or wish you could access?

Service Coordination

This next set of questions are about your experience working with multiple service providers (ex: Doctors, Therapists, Case Managers, etc.).

43. How **involved are you in determining the services and supports** you need and connecting yourself to them as needed/wanted?

- ◯ No involvement
- ◯ Little involvement
- ◯ Moderate involvement
- ◯ Very involved
- ◯ I do everything
- ◯ N/A

44. How **satisfied** are you with how your service providers communicate with each other and collaborate your care?

Very dissatisfied	Dissatisfied	Satisfied	Very satisfied	N/A
◯	◯	◯	◯	◯

45. What could **improve your service coordination**? (select all that apply)

- ☐ Having one case manager or care coordinator who could work across the programs, services, and supports I receive
- ☐ Having someone who understands the service systems available to answer questions so I can navigate them easier
- ☐ Making it easier for providers and case managers to share information, so I don't have to repeat the same information all the time
- ☐ Having funding or coverage integrated so my care is less dependent on who pays for which services
- ☐ Having more options for case management
- ☐ Having more options for services and supports
- ☐ Other (please specify)

46. Is there **anything else** you would like to share about **how your services are coordinated** and what would make it easier for your providers to collaborate?

Caregivers and families

This next set of questions is for caregivers and family members supporting a person with brain injury.

47. As a family member or caregiver, what are the three most important services that you need? (select top THREE)

- ☐ Information
- ☐ Support
- ☐ Respite care
- ☐ Other (please specify)
- ☐ Training
- ☐ Increased support during transitions (ex: returning to home, community, school, work)

48. As a family member or caregiver supporting a person with a brain injury, **what is the most important change to Maine's brain injury services and supports** that you would make so that people with brain injury and their families could have a better quality of life?

Support Groups

You can find information about Maine brain injury support groups on BIAA-Maine's website.

49. Have you participated in a **support group** for people with brain injury?

- ◯ Yes
- ◯ No

50. How **helpful** are the support group(s) you attend?

Extremely helpful	Very helpful	Not very helpful	Not at all helpful	N/A
◯	◯	◯	◯	◯

Maine Brain Injury Needs Assessment: Survivor, Caregiver, and Family Survey

Information About You

Please tell us a little about yourself. This information will not be associated with your name, and will help better serve all Mainers in need of program services.

* 51. What county do you live in?

52. How old are you?

- 0-17
- 18-22
- 23-34
- 35-44
- 45-54
- 55-64
- 65+
- Prefer not to say

53. What is your gender?

- Female
- Male
- Transgender
- Not listed (please specify)
- Gender non-binary
- Prefer not to say

54. What race/ethnicity best describes you? (select all that apply)

- [ ] American Indian or Alaska Native
- [ ] Asian or Asian American
- [ ] Black or African American
- [ ] Hispanic or Latino/a/x
- [ ] Native Hawaiian or other Pacific Islander
- [ ] White
- [ ] Prefer not to say
- [ ] Not listed (please specify)

Recommendations and Close

55. Which of the following would **most positively impact Mainers with brain injury**? Click and drag or select the number to rank - with 1 being most impactful.

- Increase awareness of brain injury
- Improve screening/ identification of brain injury
- Improve service coordination across services and supports
- Improve service coordination across phases of recovery/ over a lifetime following a brain injury
- Improve provider training so they can better support the unique needs of people with brain injury

56. Thank you for taking the time to respond to this survey. Your answers will help direct efforts to better serve Mainers with brain injury and their caregivers and families.

Please use the space below if you have **any other comments** you would like to share regarding brain injury services or your experiences.

57. By completing this survey, you are eligible to enter a drawing to receive a **$100 Visa gift card**. A random drawing will be conducted on Friday, April 30th. Please enter your name and contact information below if you would like to be included in the drawing. Your personal information will be kept confidential and will not be associated with your survey response.

Name	
Email Address	
Phone Number	

Appendix D: Provider Survey

Maine Brain Injury Needs Assessment: Provider Survey

Introduction

This survey for providers who serve people who have a brain injury.

Thank you for taking the time to complete this survey. The Brain Injury Association of America's Maine Chapter is conducting this survey in collaboration with the Office of Aging and Disability Services and the Acquired Brain Injury Advisory Council.

We are **looking for input** from providers from a range of services, and other interested parties across Maine. We have created a separate survey for people with a brain injury, their families and caregivers. The information you provide will **help guide the direction of efforts to strengthen Maine's system of brain injury services and supports.** Your open and honest answers will help us know what is working and where there is room for improvement.

Please complete the survey by **Wednesday, April 28th**.

We estimate that it will take approximately 20 minutes to complete the survey. The survey is organized into multiple sections by topic or service type. You can skip the topics that don't apply to your experience.

If you have any questions about this survey, please contact the BIAA-ME via email at sjordan@biausa.org or Koné Consulting via email at karin.ellis@koneconsulting.com.

1. What is your profession or how are you connected to brain injury?

- ◯ Advocate
- ◯ Case Manager/ Care Coordinator
- ◯ Domestic Violence Advocate
- ◯ Funder
- ◯ Healthcare Professional (Doctor, Nurse, etc)
- ◯ Homeless Services Provider
- ◯ Mental Health Provider
- ◯ Policymaker
- ◯ Other (please specify)
- ◯ Police, Probation, or Corrections Officer
- ◯ Rehabilitation Provider (Speech/ language therapy, occupational therapy, physical therapy)
- ◯ School staff/ Teacher/ Nurse/ Counselor
- ◯ Substance Use Disorder Service Provider
- ◯ Veterans Services
- ◯ Vocational/ Employment support
- ◯ Waiver Service Provider

* 2. What county or counties do you work or provide services in? (If more than one, hold down command key while selecting)

1

3. How long have you been working in your field?

- ◯ Less than 12 months
- ◯ 1-3 years
- ◯ 4-5 years
- ◯ 6-10 years
- ◯ 11 years or more

Maine Brain Injury Needs Assessment: Provider Survey

Programs/Benefits

4. Which of the following forms of payment do you accept for services? (please select ALL that apply)

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

5. What type of screening tool does your organization use to identify when someone has a brain injury?

- ◯ We ask about brain injury as part of our intake process
- ◯ OSU TBI-ID (Ohio State University TBI Identification Method)
- ◯ Brain Check Survey
- ◯ We don't screen for brain injury
- ◯ Other (please specify)

6. What is your organization's policy for documenting when an individual has been identified as having a brain injury? (select all that apply)

- ☐ We enter it as a diagnosis code if it is one of our primary drivers for why the person needed services
- ☐ We enter it as a case note
- ☐ We send a referral
- ☐ Other (please specify)
- ☐ We do not document brain injury diagnosis
- ☐ Not applicable

7. How do you determine eligibility for your services? (select all that apply)

- [ ] Functional need
- [ ] Medical diagnosis
- [ ] Not applicable
- [ ] Other (please specify)

8. At what points in time after an individuals brain injury are services are needed but are most challenging to access? (ex: system barriers based on eligibility criteria, individual barriers based on changing needs)

- [ ] Immediately
- [ ] 3-6 months
- [ ] 7 months - 1 year
- [ ] 1-2 years
- [ ] More than 2 years
- [ ] Not applicable
- [ ] Other (please specify)

* 9. What are the biggest challenges for individuals with brain injuries in obtaining services? (select top THREE)

- [ ] Waiting lists/ wait time
- [ ] No or limited health insurance
- [ ] Cost
- [ ] Client difficulty in understanding the process to get services
- [ ] Limited training for providers on how to work with people with brain injury
- [ ] Geographic location of services (ex: rural location)
- [ ] Client access to technology/ internet
- [ ] Language barrier
- [ ] Client access to reliable transportation
- [ ] Client behaviors making them a danger to themselves or others
- [ ] Clients generally do not experience barriers

10. What constrains your ability to serve people with brain injury? (click and drag or select number with 1 being most signifiant constraint.)

Reimbursement rates negatively impacting your ability to hire additional staff or retain staff long-term

High staff turnover

Inability to meet needs of clients with more complex

Limited service options and chronic nature of brain injury means limited turnover in clients as they need services and supports over the long term

Brain injury is not a covered diagnosis

Licensing or regulatory restrictions on capacity

Maine Brain Injury Needs Assessment: Provider Survey

Rehabilitation Services

11. Does your organization provide rehabilitation services?

- Yes
- No
- Not applicable
- Other (please specify)

12. For each rehabilitation service, please select yes if you provide this service or no if you do not.

	Yes	No
Brain Injury Diagnosis and Assessment		
Acute Care		
General Medical (Primary Care Physician)		
Specialized Medical (Neurologist, Neuro-psychologist)		
Inpatient Rehabilitation		
Neuro-rehabilitation		
Physical Therapy (outpatient)		
Occupational Therapy (outpatient)		
Speech Therapy (outpatient)		
Cognitive Training		
Recreational therapy		
Assistive technology		
Care Coordination		
Rehabilitation (Inpatient)		
Residential in-home support		

5

13. Is there an unmet need for these services for individuals with brain injury?

	Yes	No	I don't know
Brain Injury Diagnosis and Assessment	○	○	○
Acute Care	○	○	○
General Medical (Primary Care Physician)	○	○	○
Specialized Medical (Neurologist, Neuro-psychologist)	○	○	○
Inpatient Rehabilitation	○	○	○
Neuro-rehabilitation	○	○	○
Physical Therapy (outpatient)	○	○	○
Occupational Therapy (outpatient)	○	○	○
Speech Therapy (outpatient)	○	○	○
Cognitive Training	○	○	○
Recreational therapy	○	○	○
Assistive technology	○	○	○
Care Coordination	○	○	○
Rehabilitation (Inpatient)	○	○	○
Residential in-home support	○	○	○

14. Have you ever denied rehabilitation services to an individual with brain injury? (select all that apply)

- ☐ Yes, because we had a waitlist
- ☐ Yes, because the individual could not pay for care and/or did not have insurance that we accept
- ☐ Yes, because the person did not live in our service region
- ☐ Yes, because we could not communicate with the individual
- ☐ Yes, because the individual had complex medical needs
- ☐ Other (please specify)
- ☐ Yes, because the individual is not eligible for services at our office because of past behavior
- ☐ Yes, because we are not trained to treat people with brain injury
- ☐ No
- ☐ Not applicable

15. Where would you refer someone for rehabilitation services that you cannot provide? (select all that apply)

- [ ] Brain Injury Nursing Facility
- [ ] Specialty Hospital Brain Injury Services
- [ ] Outpatient Neurorehabilitation Services
- [ ] Emergency department
- [ ] Inpatient Rehabilitation
- [ ] In-home support services
- [ ] Nursing facility
- [ ] Residential Treatment Services
- [ ] Out of state options
- [ ] I don't know - there aren't any options
- [ ] Not applicable
- [ ] Other (please specify)

Maine Brain Injury Needs Assessment: Provider Survey

Education

16. How well do schools serve youth with brain injury?

- ○ Extremely well
- ○ Very well
- ○ Moderately well
- ○ Other (please specify)
- ○ Slightly well
- ○ Not well at all
- ○ Not applicable

17. What could be improved to support students with brain injury? (select all that apply)

- [ ] Faster identification of brain injury
- [ ] Improved communication across service providers
- [ ] Increased follow up as youth progress with their recovery or transition to higher education, training or employment
- [ ] Other (please specify)
- [ ] Improved access to services or supports for youth
- [ ] Improved access to services or supports for families or caregivers

18. What types of education services, support, or accomodations are most successful in helping students with brain injury? (select all that apply)

- [ ] Education consultation
- [ ] Special education and/ or Individualized Education Plan (IEP)
- [ ] 504 Plan
- [ ] Other (please specify)
- [ ] Counseling
- [ ] Occupational, speech, physical, or cognitive therapy
- [ ] Wrap-around family support or home visiting services

Maine Brain Injury Needs Assessment: Provider Survey

Employment

19. Does your organization provide employment or vocational rehabilitation services?

- ( ) Yes
- ( ) No
- ( ) Not applicable
- ( ) Other (please specify)

20. Next to each employment support service option, please select yes if you provide this service or no if you do not.

	Yes	No
Physical and mental restoration services	○	○
Assessment services to determine eligibility and vocational rehabilitation needs	○	○
Counseling and guidance	○	○
Job placement services	○	○
Individualized Plan for Employment (IEP)	○	○
Employment training and other training services	○	○
Self-employment services, including technical assistance and consultation for the establishment of small business operations	○	○
Occupational licenses, tools, equipment, and initial stocks and supplies	○	○
Rehabilitation Technology/ Assistive Technology	○	○
Job coaching and supported employment services	○	○
Individualized transition services to support movement from school to work	○	○
Pre-Employment transition services to support movement from school to work	○	○
Pre-Employment transition services for students with disabilities	○	○

Other (please specify)

9

21. Is there an unmet need for these services for individuals with brain injury?

	Yes	No	I don't know
Physical and mental restoration services	○	○	○
Assessment services to determine eligibility and vocational rehabilitation needs	○	○	○
Counseling and guidance	○	○	○
Job placement services	○	○	○
Individualized Plan for Employment (IEP)	○	○	○
Employment training and other training services	○	○	○
Self-employment services, including technical assistance and consultation for the establishment of small business operations	○	○	○
Occupational licenses, tools, equipment, and initial stocks and supplies	○	○	○
Rehabilitation Technology/ Assistive Technology	○	○	○
Job coaching and supported employment services	○	○	○
Individualized transition services to support movement from school to work	○	○	○
Pre-Employment transition services to support movement from school to work	○	○	○
Pre-Employment transition services for students with disabilities	○	○	○

Other (please specify)

10

22. What types of services and supports are most successful in helping individuals with brain injury gain employment? (select all that apply)

- [ ] Physical and mental restoration services
- [ ] Assessment services to determine eligibility and vocational rehabilitation needs
- [ ] Counseling and guidance
- [ ] Job placement services
- [ ] Individualized Plan for Employment (IPE)
- [ ] Employment training and other training services
- [ ] Self-employment services, including technical assistance and consultation for the establishment of small business operations
- [ ] Occupational licenses, tools, equipment, and initial stocks and supplies
- [ ] Rehabilitation Technology/ Assistive Technology
- [ ] Job coaching and supported employment services
- [ ] Individualized transition services to support movement from school to work
- [ ] Pre-Employment transition services to support movement from school to work
- [ ] Pre-Employment transition services for students with disabilities
- [ ] Other (please specify)

* 23. What do you think is the biggest barrier to employment for individuals with brain injury? (select top THREE)

- [ ] Employer need for ongoing training or support
- [ ] Employer limitations to providing accommodation
- [ ] The individual's ability to maintain a schedule
- [ ] The individual's ability to remain focused over a long period of time
- [ ] The individual's changing needs
- [ ] Not applicable
- [ ] Other (please specify)

Maine Brain Injury Needs Assessment: Provider Survey

Housing, residential services, and homelessness

24. The following is a list of housing related services. For each option, please select yes if you provide this service or no if you do not.

	Yes	No
Modifications for independent living (ex: grab bars, wheelchair ramp)	○	○
Assistive technology for independent living	○	○
In-home personal care provider services	○	○
Assisted living	○	○
Group home	○	○
Nursing home	○	○
Long-term residential facility	○	○
Low-income/ subsidized housing	○	○
Homeless shelter	○	○
Domestic violence shelter	○	○
Permanent supportive housing	○	○

Other (please specify)

25. Is there an unmet need for these services for individuals with brain injury?

	Yes	No	I don't know
Modifications for independent living (ex: grab bars, wheelchair ramp)	○	○	○
Assistive technology for independent living	○	○	○
In-home personal care provider services	○	○	○
Assisted living	○	○	○
Group home	○	○	○
Nursing home	○	○	○
Long-term residential facility	○	○	○
Low-income/ subsidized housing	○	○	○
Homeless shelter	○	○	○
Domestic violence shelter	○	○	○
Permanent supportive housing	○	○	○

Other (please specify)

26. What are the biggest barriers to gaining and/ or maintaining safe, stable housing for individuals with brain injury? (select all that apply)

- [ ] The cost of housing
- [ ] Limited housing vouchers or other financial supports to help pay for a home or apartment
- [ ] Not enough housing available
- [ ] Not enough residential supportive housing
- [ ] Individuals don't have the skills to live safely on their own
- [ ] Individuals don't have the skills to live safely with others
- [ ] Other (please specify)
- [ ] Challenging behaviors or medication management issues
- [ ] Need for crisis or respite support services
- [ ] Criminal record
- [ ] Poor rental history
- [ ] Not applicable

Maine Brain Injury Needs Assessment: Provider Survey

Emergency responders and legal system

27. What types of services are most successful in preventing individuals with brain injury from getting arrested or remaining incarcerated? (select all that apply)

- [ ] Crisis services
- [ ] Crisis intervention training
- [ ] Therapeutic/ diversion courts
- [ ] Other (please specify)

28. Is there training on brain injury required for the following positions?

	Yes	No	I don't know
Police Officers	○	○	○
State Patrol	○	○	○
Corrections Officers	○	○	○
Public Defense Council	○	○	○

Maine Brain Injury Needs Assessment: Provider Survey

Mental health and substance use

29. Does your organization provide behavioral health services?

- ◯ Yes
- ◯ No
- ◯ Not applicable
- ◯ Other (please specify)

30. The following is a list of behavioral health services. Next to each option, please select yes if your organization provides this service or no if you do not.

	Yes	No
Community mental health case manager	◯	◯
Crisis line	◯	◯
Walk in crisis center	◯	◯
Behavioral intervention plan	◯	◯
Mental health counseling	◯	◯
Substance use outpatient treatment	◯	◯
AA (Alcoholics Anonymous) or NA (Narcotics Anonymous)	◯	◯
Medical detox	◯	◯
Peer support	◯	◯
Inpatient psychiatric hospital	◯	◯
Inpatient substance use treatment	◯	◯

Other (please specify)

31. Is there an unmet need for these services for individuals with brain injury?

	Yes	No	I don't know
Community mental health case manager	○	○	○
Crisis line	○	○	○
Walk in crisis center	○	○	○
Behavioral intervention plan	○	○	○
Mental health counseling	○	○	○
Substance use outpatient treatment	○	○	○
AA (Alcoholics Anonymous) or NA (Narcotics Anonymous)	○	○	○
Medical detox	○	○	○
Peer support	○	○	○
Inpatient psychiatric hospital	○	○	○
Inpatient substance use treatment	○	○	○

Other (please specify)

32. Have you ever denied behavioral health services to an individual with brain injury? (select all that apply)

- ☐ Yes, because we had a waitlist
- ☐ Yes, because the individual could not pay for care and/or did not have insurance that we accept
- ☐ Yes, because the person did not live in our service region
- ☐ Yes, because we could not communicate with the individual
- ☐ Yes, because the individual is not eligible for services at our office because of past behavior
- ☐ Yes, because we are not trained to serve people with brain injury
- ☐ No
- ☐ Not applicable
- ☐ Other (please specify)

33. Where would you refer someone for behavioral health services that you cannot provide? (select all that apply)

- [ ] Behavioral Health Agency
- [ ] Office of Behavioral Health (formerly SAMHS)
- [ ] To a local emergency department
- [ ] I don't know - there aren't any options
- [ ] Not applicable
- [ ] Other (please specify)

34. What do you think the biggest barrier to services is for individuals experiencing brain injury and behavioral health issues? (select top THREE)

- [ ] Unable to navigate service systems
- [ ] Siloed nature of the service systems that discourage coordination (ex: funding, training, etc.)
- [ ] Challenging behaviors that limit service options
- [ ] Not enough treatment options (alternatives to hospitals) for crisis stabilization
- [ ] Not enough transition support options for when returning to the community
- [ ] I don't know
- [ ] Other (please specify)

35. What is the one thing that would increase care collaboration between brain injury services and behavioral health services?

Maine Brain Injury Needs Assessment: Provider Survey

Service Coordination

36. How do you coordinate brain injury services and supports? (select all that apply)

- [ ] We provide care coordination within our organization
- [ ] Clients coordinate their own care with our active support
- [ ] Caregivers/ family members help clients coordinate their care, with our active support
- [ ] Peers help clients coordinate their care
- [ ] We work with vocational rehabilitation case managers
- [ ] We work with mental health case managers
- [ ] We work with waiver case managers
- [ ] We work with school care managers
- [ ] Not applicable
- [ ] Other (please specify)

37. How well coordinated are brain injury services and supports?

- ○ Extremely well
- ○ Very well
- ○ Moderately well
- ○ Other (please specify)
- ○ Slightly well
- ○ Not well at all
- ○ Not applicable

38. What could improve service coordination? (select all that apply)

- [ ] Having one case manager or care coordinator who could work across the programs, services, and supports
- [ ] Making it easier for providers and case managers to share information
- [ ] Having funding or coverage integrated so client care is less dependent on who pays for which services
- [ ] Other (please specify)
- [ ] Having more options for case management
- [ ] Having more options for brain injury services and supports

39. Is there anything else you would like to share about how services are coordinated and what would make it easier for providers to collaborate?

40. Where does your organization get information about brain injury resources, services and supports? (select all that apply)

- [ ] The Brain Injury Association of America – Maine Chapter (BIAA-Maine)
- [ ] Brain injury advocacy/ educational organizations
- [ ] Disability advocacy organizations
- [ ] On-site/ In-person trainings
- [ ] Webinars and other online trainings
- [ ] Conferences
- [ ] Stand alone presentations
- [ ] We don't currently have a source for information on brain injury
- [ ] Other (please specify)

41. Have you attended a BIAA-ME conference or event?

- ◯ Yes
- ◯ No

42. What did you find to be most valuable about attending a BIAA-ME conference or event?

43. What additional education, training, technical assistance, or other professional development do you wish existed to help you better serve people with brain injury? (select all that apply)

- [ ] Additional training/ education for direct care workers in college or technical school
- [ ] High quality online training options
- [ ] Coordinated education, training, and professional development requirements/ career ladder incorporating brain injury across services and supports (cross-disability)
- [ ] Additional funding to allow staff to attend conferences, trainings, and workshops
- [ ] Regional or more geographically dispersed conferences, trainings, or workshops
- [ ] Ability to use brain injury specialists for additional, case-specific technical assistance
- [ ] Other (please specify)

44. Are current reimbursement rates adequate for you to maintain a stable, qualified direct care workforce?

Extremely inadequate	Somewhat inadequate	Somewhat adequate	Extremely adequate	N/A
◯	◯	◯	◯	◯

45. What is the most important action needed to address workforce shortages in brain injury services in Maine?

Maine Brain Injury Needs Assessment: Provider Survey

Recommendations and Close

This next set of questions is about what you think would contribute the most to improving services for Mainers with brain injury.

46. Which of the following would most positively impact Mainers with brain injury? Click and drag into the order of importance, with the most important at the top.

- Increase awareness of brain injury
- Improve screening/ identification of brain injury
- Improve service coordination across services and supports
- Improve service coordination across phases of recovery/ over a lifetime following a brain injury
- Improve provider training so they can better support the unique needs of people with brain injury

47. Thank you for taking the time to respond to this survey. Your answers will help direct efforts to better serve Mainers with brain injury and their caregivers and families.

Please use the space below if you have any other comments you would like to share regarding brain injury services or your experiences.

Appendix E: Focus Group Recruitment Flyer

BRAIN INJURY ASSOCIATION OF AMERICA — MAINE

BRAIN INJURY NEEDS ASSESSMENT GROUP INTERVIEW RECRUITMENT

The Brain Injury Association of America's Maine Chapter, under contract with the Maine Department of Health and Human Services, has engaged Koné Consulting, LLC to conduct a **Needs Assessment** of MaineCare-funded **brain injury services and supports** (to include all other public and privately sourced funding opportunities).

You may have already completed an online survey. We now invite **those with brain injury**, **their families**, **caregivers**, and **service providers** to participate in an online group interview to **share experiences with brain injury services and supports**, and **thoughts on where improvements can be made.**

WE'RE OFFERING TWO OPPORTUNITIES TO PARTICIPATE:

Tuesday, May 11th
12-1:30pm
Zoom link

or

Thursday, May 13th
5:30-7pm
Zoom link

We appreciate the time and participation of attendees and will provide **brain injury survivors, their family members, and caregivers a $25 Visa gift card.**

To participate, please email Erika at erika.larimer@koneconsulting.com. Space is limited, so **please RSVP** as soon as possible.

Appendix F: Focus Group Interview Protocol

#	Introduction Questions	Response
	Please introduce yourself (name, pronouns so we know how to refer to you) how you are connected to brain injury, and what county you live in.	
	Please take a minute to consider the services that are – or should be – available to you, your family or people with brain injury you care for or provide services to, and answer the following: In one or two words, what comes to mind when you think about your experience with brain injury services and supports in Maine?	
	Key Questions	
	[Preliminary data from survey] Increasing awareness is ranked first by people with brain injury, family members, caregivers and providers when asked what would most positively impact Mainers with brain injury. Where would you focus efforts to increase awareness that would be the most helpful for strengthening services and supports for people with brain injury in Maine?	
	What services are the most helpful to you, your family member, people you work with in daily life? [*Prompt: and why are they most helpful?]*	
	When (at what critical points) during your recovery were services the most helpful? (ex: at diagnosis, during transitions between hospital and community, school or work) [*Prompt: and how were they helpful?]*	
	*When asked **what has prevented being able to use services**, the most common responses are:* • *Not being aware of services,* • *Not understanding the process to get services, and* • *Not having services located nearby* What would help make more people aware of brain injury services and how to access them?	
	Who do you think is most affected by these barriers to services? [*prompt: what about people who have co-occurring substance use disorders?, mental health? homeless, DV, children/youth, older adults, veterans, prison/corrections, etc.*]	
	If you had a magic wand and could instantly change one thing about brain injury services and supports in Maine, what would that be?	
	Service Coordination	
	*When asked **what could improve service coordination** between multiple providers, there was agreement on top four choices:* • *Making it easier for providers to share information (44%)*	

	• *Having one case manager or care coordinator who could work across programs, services, and supports I receive (43%)* • *Having more options for services and supports (39%)* • *Having someone who understands the service systems available to answer questions so I can navigate them easier (38%)* What would be the first thing you would do to improve service coordination?	
	Provider and Caregiver Training and Resource needs	
	*When asked what **training** or other professional development wish existed, providers selected these top three:* • *Additional funding for conferences, trainings, and workshops (67%)* • *High quality online training options (62%)* • *Coordinated professional development/career ladder incorporating brain injury across services and supports (59%)* What are the most important topics for trainings that would help providers serving people with brain injury? What type of provider would most benefit from these trainings?	
	*When asked what the most important **services family or caregivers need**, the top three selected:* • *Support (76%)* • *Information (68%)* • *Training (37%)* What are some examples or types of support that help caregivers? Why do you think that type of support is important?	
	Concluding Questions	Response
	What would you like to see happen in five years as a result of our work?	
	What other thoughts or suggestions would you like to share about what would help people with brain injury?	