Brain Injury Needs Assessment - 2019





Brain Injury Needs Assessment Survey

- Open for 1 month
- Snowball Sample
- 74 Individuals with brain injury
- 72 Family members/Caregivers
- 165 Medical/Service providers

Information on data

- Participants were gathered using a snowball sample
 - A survey link was emailed to potential participants using relevant listservs
 - Individuals were encouraged to share the survey invitation with others
- Participants had to be aged 18 years or older and either be:
 - An individual with a brain injury
 - A family member/caregiver/guardian of an individual with a brain injury
 - A Medical or Service Provider
- Participants were able to complete multiple tracks
 - E.g. Because they were an individual with a brain injury and a Service Provider
- Participants were allowed to skip questions

Limitations of data

- A small sample size of responses were received in relation to Alaska's overall population of:
 - Individuals with a brain injury
 - Family members/caregivers/guardians of individuals with a brain injury
 - Medical or Service Providers
- Data may have been reduced because:
 - Snowball distributions can efficiently reach large audiences, however, cannot guarantee to reach the entire desired population
 - Potential respondents may have been undiagnosed/unaware they experienced a brain injury
 - Participants were allowed to skip questions reducing the overall number of responses

Brain Injury Survivor and Family Member Tracks

Online, mail, and telephone surveys completed

Respondents:

- 74 Individuals with brain injury
- 72 Family members/Caregivers

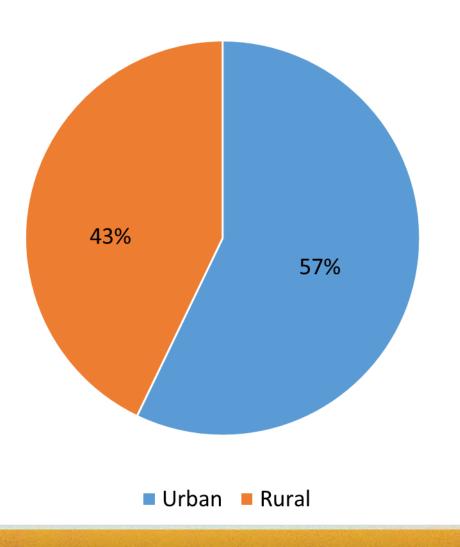
When looking at the results from this section please note:

- Results are based on answers from both the 'individual with a brain injury' and
 'family member/caregiver' survey responses combined, unless otherwise stated.
- Participants in the 'family member/caregiver' survey answered questions about their family member/client with a brain injury.
- Data shown is from survey responses only and may not be representative of all individuals with a brain injury in Alaska.

BRAIN INJURY PARTICIPANT DEMOGRAPHICS

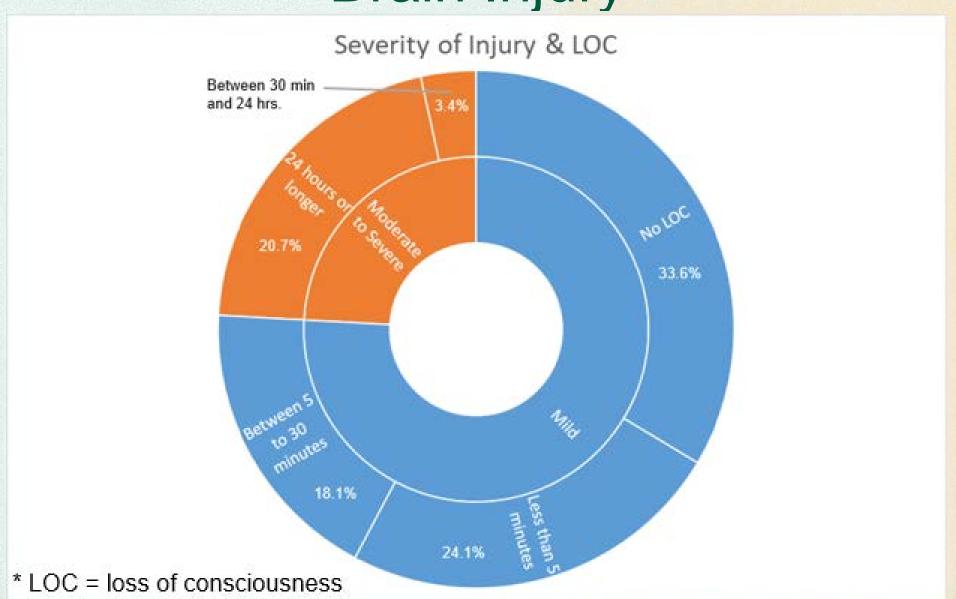
Location

Urban vs. Rural

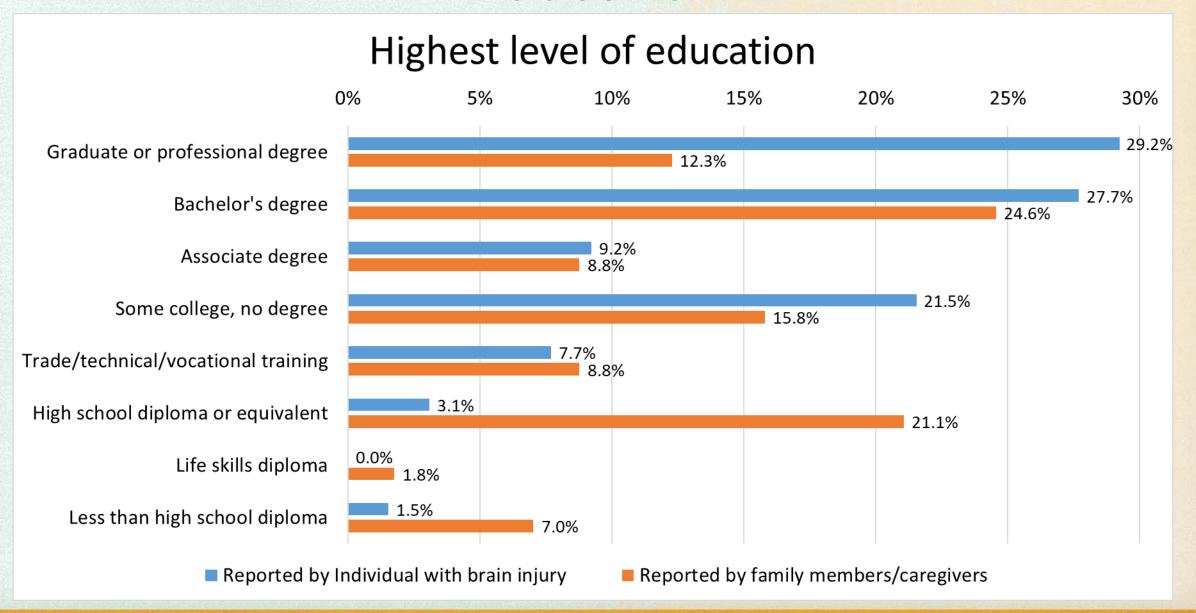


Individuals with a brain injury who were represented in this survey mainly lived in urban areas (reporting they were from Anchorage, Juneau or Fairbanks).

Brain Injury

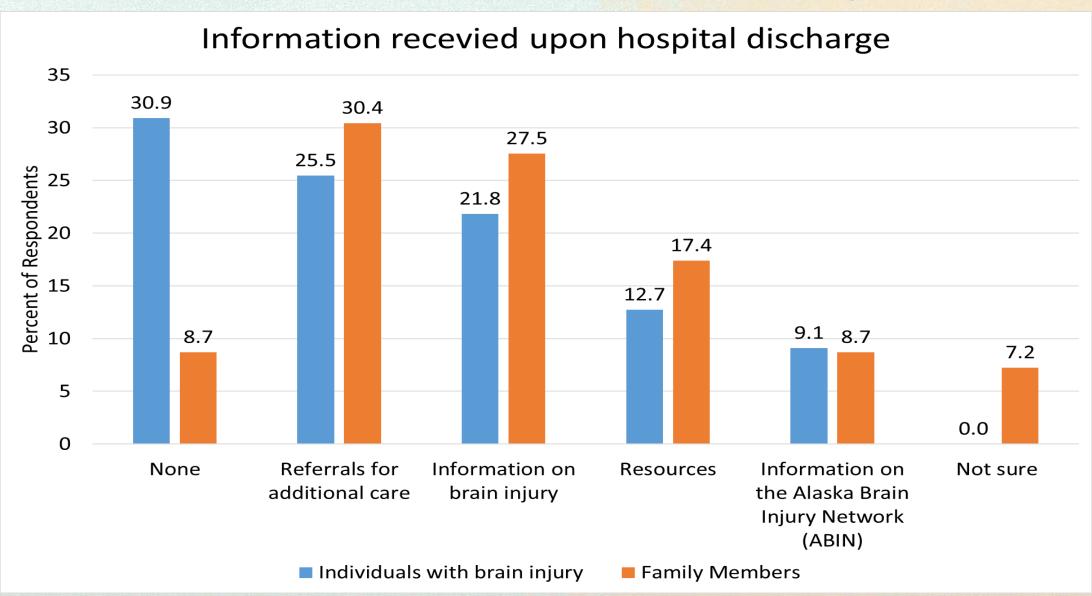


Education



BRAIN INJURY PARTICIPANT SURVEY RESULTS

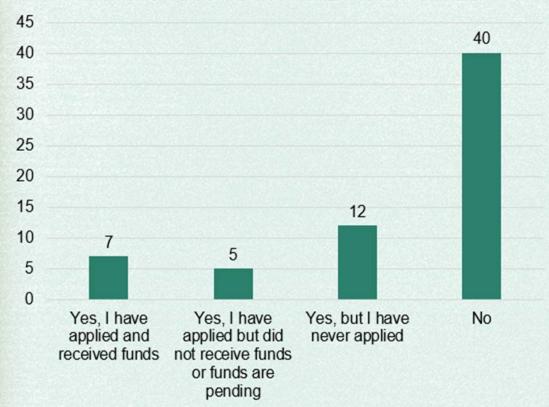
Experience upon discharge



TABI Mini Grant Program

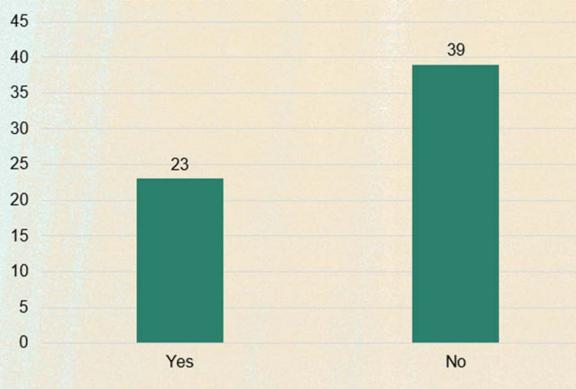
Individual with a brain injury

Awareness of the TABI Mini Grant



Family member/caregiver

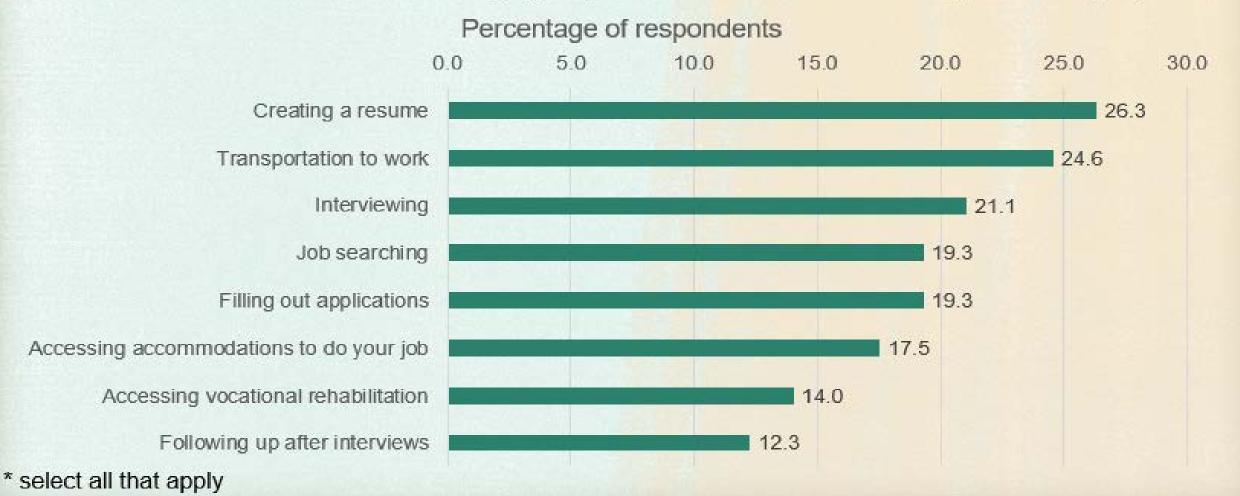
Awareness of the TABI Mini Grant



Employment

Individuals with a brain injury survey responses only

71.9% of individuals with brain injury reported at least one difficulty with employment



Housing

Individuals with a brain injury survey responses only

72.1% of individuals with brain injury reported at least one difficulty with housing

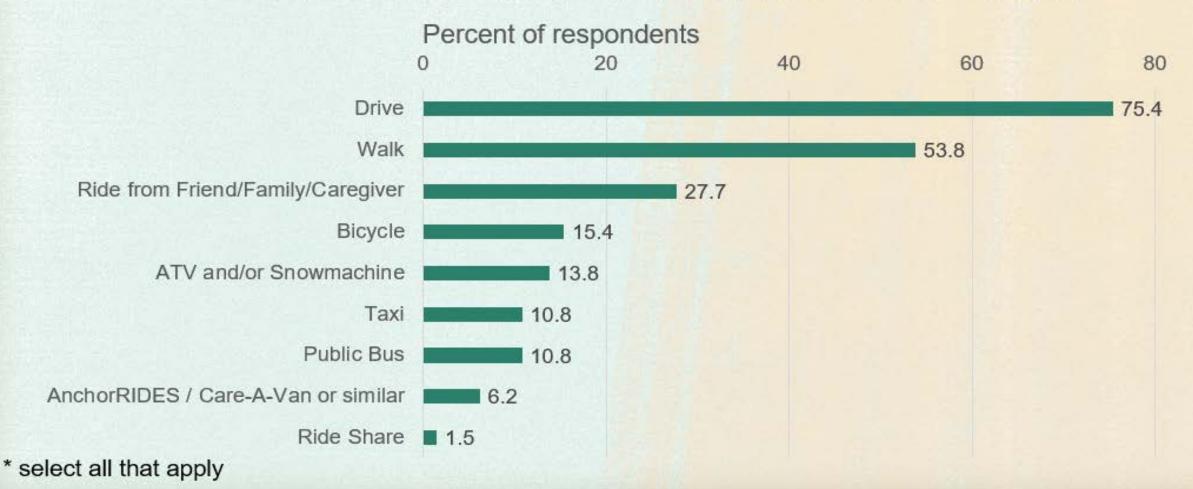
Percentage of respondents



Transportation

Individuals with a brain injury survey responses only

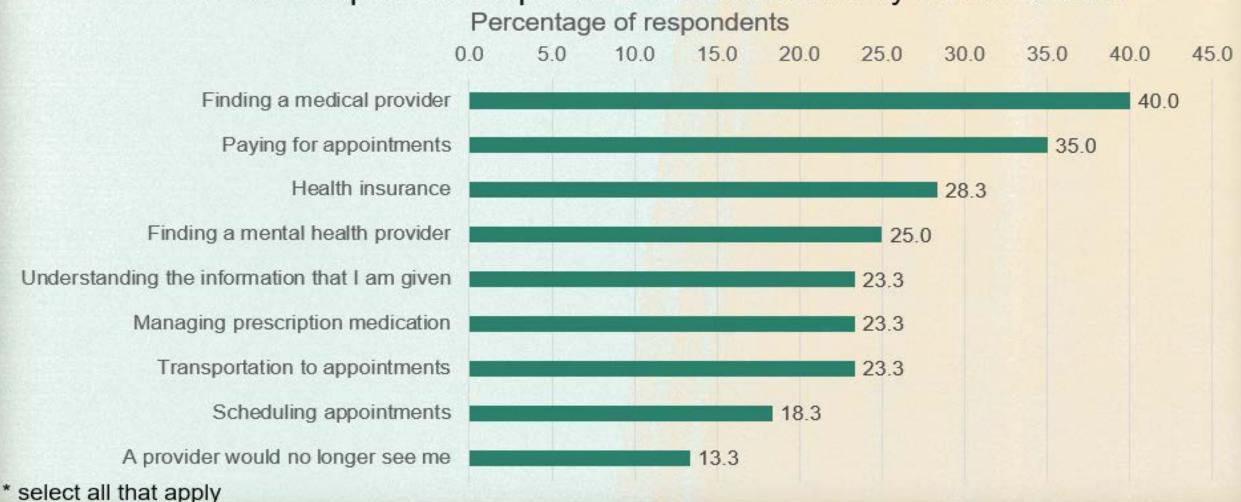
Mode of transportation – Reported by individuals with a brain injury



Healthcare

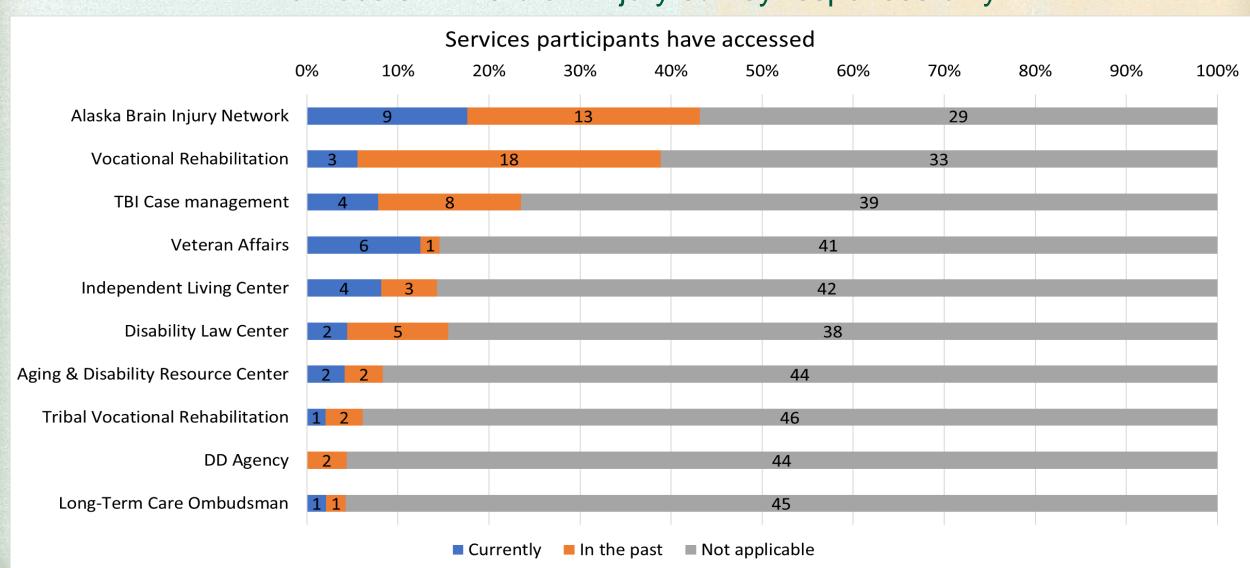
Individuals with a brain injury survey responses only

71.7% of respondents reported at least one difficulty with healthcare



Access to Services

Individuals with a brain injury survey responses only



Reasons unsatisfied with services

Participants were asked to explain why they were unsatisfied with services they had received. The main four themes identified for each participant track were:

Individual with a brain injury	Family member/Caregiver
Need help accessing services	Unclear how to access services / need one contact
Education is needed for Providers and communities	Education is needed for Providers as it can be harmful without
Financial difficulties with cost of care, housing, etc.	Financial difficulties with cost of care (e.g. need waiver)
Need supportive and compassionate Providers (e.g. sympathetic, patient, help with paperwork)	Providers need to understand patients may be difficult (e.g. behaviorally or not understand they need help)

Other areas of support

Participants were asked to describe what other areas of support they wish were available. The main four themes identified in answers were:

Individual with a brain injury	Family member/Caregiver
Need assistance but are left alone with no support	Need more access to services including mental health
Financial support would be beneficial	Need to educate Providers, families and communities
Need more access to services including medical and transportation to appointments	Financial support would be beneficial
More education for Providers as it can be harmful without this	Increase opportunities for individuals with a brain injury to socialize with peers

Additional comments for individuals with a brain injury

Individuals with a brain injury were asked to provide any additional comments. The four main themes identified in answers were:

- 1. Participants felt alone in this struggle
- 2. They wanted education on brain injury for Providers
- 3. Participants stated that anyone could have a brain injury and afterwards everything is suddenly different
- 4. Respondents said they needed more supports as Alaska has high Traumatic Brain Injury numbers

Additional resources for family members and caregivers

Family members/caregivers were asked if they wished that any additional resources were available. The four main themes identified in responses were:

- 1. Information and education for families
- 2. Opportunities for self care (e.g. Respite or Support Groups)
- 3. Access to more services for holistic care
- 4. Financial support (e.g. a waiver)

Additional comments for family members and caregivers

Family members/caregivers were asked if there was anything else they wished to share. The four main themes identified in responses were:

- 1. Education for Providers and communities is important
- 2. Individuals with a brain injury need access to coordinated care
- 3. Families are left alone with no information or support
- 4. Brain injury is linked to behavioral health struggles and suicide

Provider Track

Online, mail, and telephone surveys

Respondents:
165 Medical and Service Providers

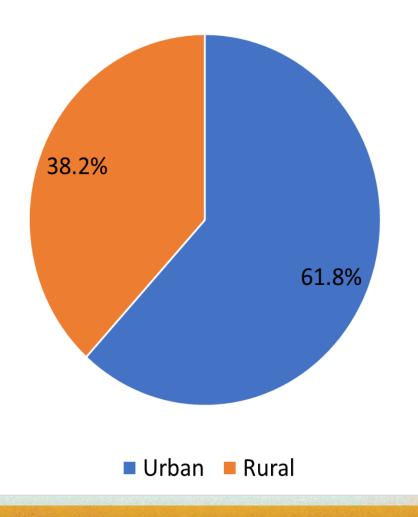
When looking at the data from this section please note:

 Results are based upon survey responses only and may not be representative of all Providers working in Alaska.

PROVIDER DEMOGRAPHICS

Provider Location

Where Medical and Service Providers work



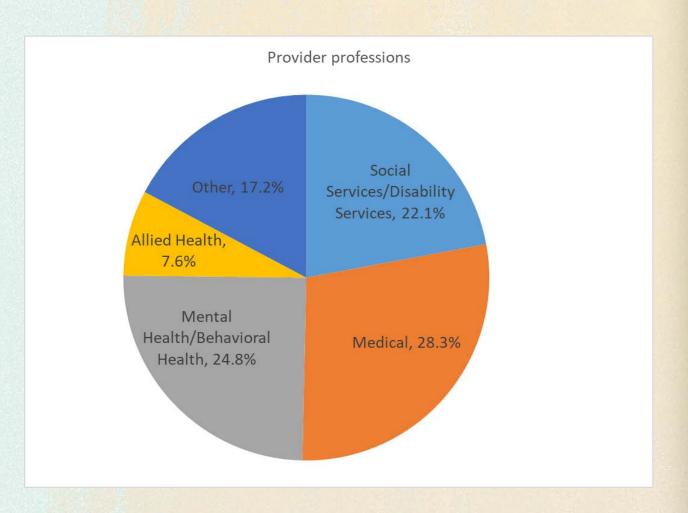
Providers who responded to the survey were mostly from urban areas (reporting they were from Anchorage, Juneau or Fairbanks).

Provider Professions

Top 3 Professions

Medical (28.3%)

Mental Health /Behavioral Health (24.8%) Social Services/ Disabilities Services (22.1%)

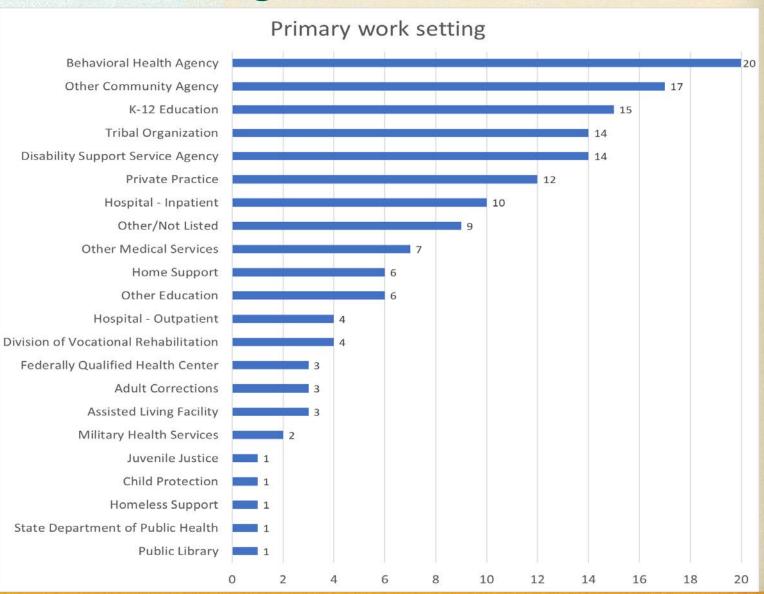


Work Settings

Top 3 Work Settings

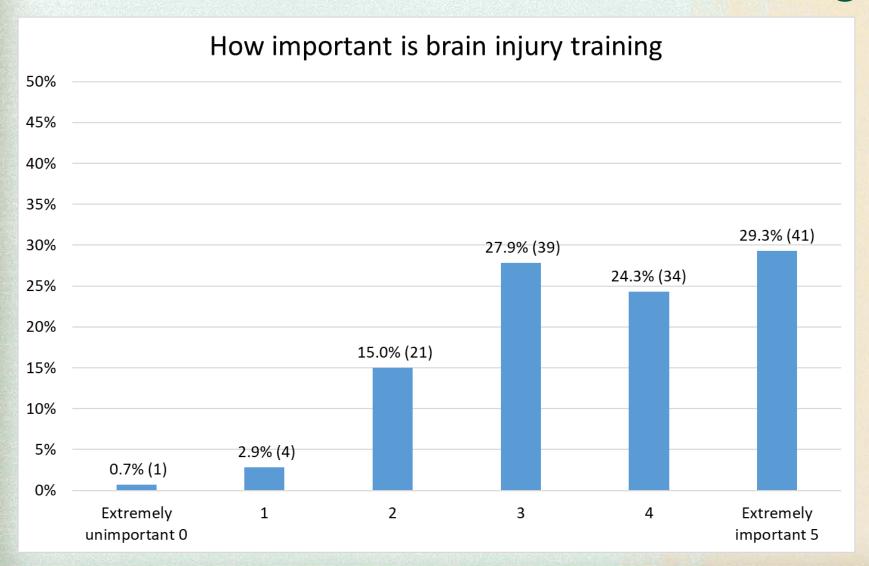
Behavioral Health Agency Other Community Agency

K-12 Education



PROVIDER SURVEY RESULTS

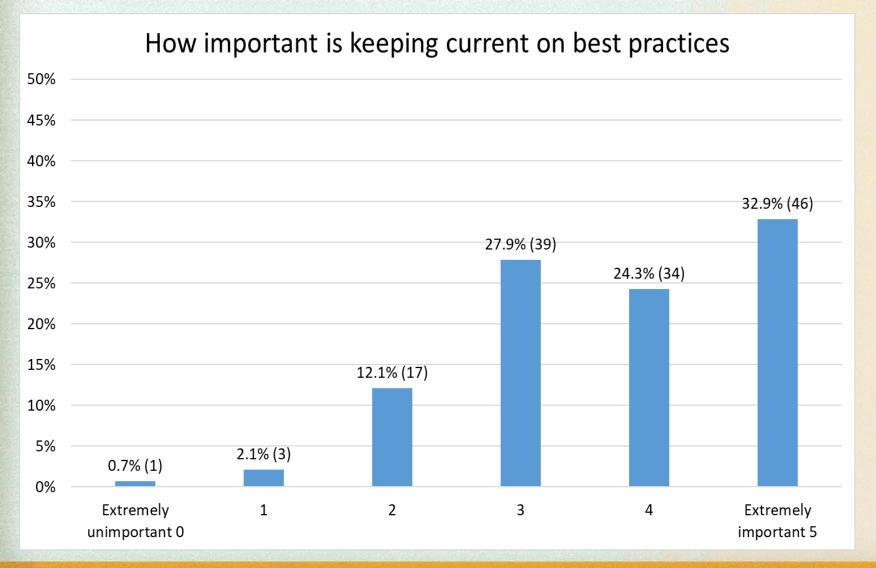
Provider Training



Graph on scale of 0 to 5, (0 = extremely unimportant, 5 = extremely important).

Over 75% of providers rated brain injury training as a '3' or higher in terms of its' importance to their job.

Provider Training Needs



Graph on scale of 0 to 5, (0 = extremely unimportant, 5 = extremely important).

Over 75% of providers rated keeping up on current best practices as a '3' or higher.

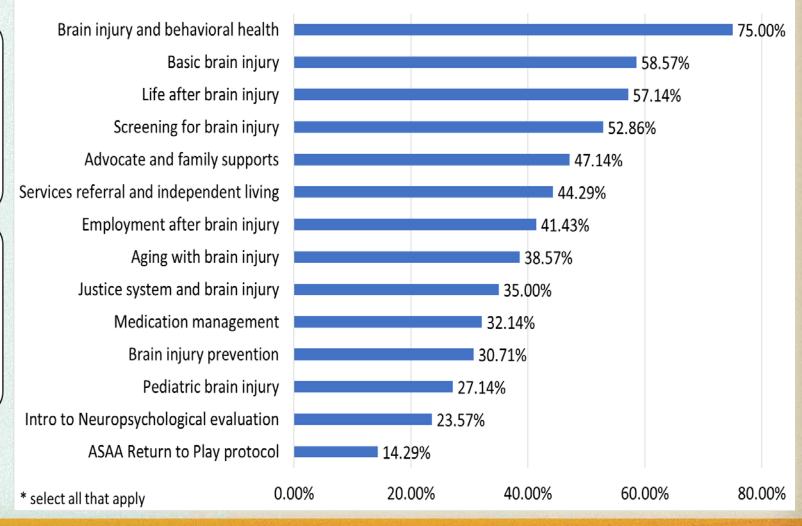
Training Topics

Brain Injury & Behavioral Health (75.00%)

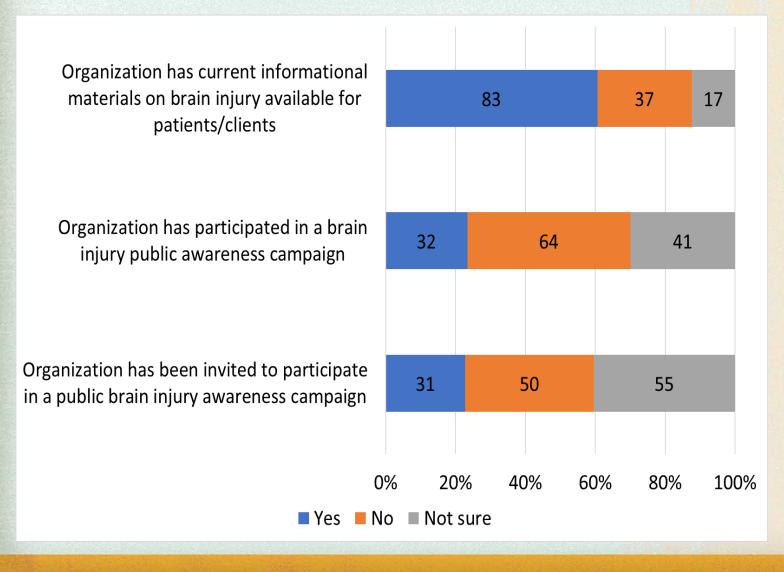
Basic Brain Injury (58.57%) Life after Brain Injury (57.14%)

Top 3 Trainings Providers Want





Provider Awareness

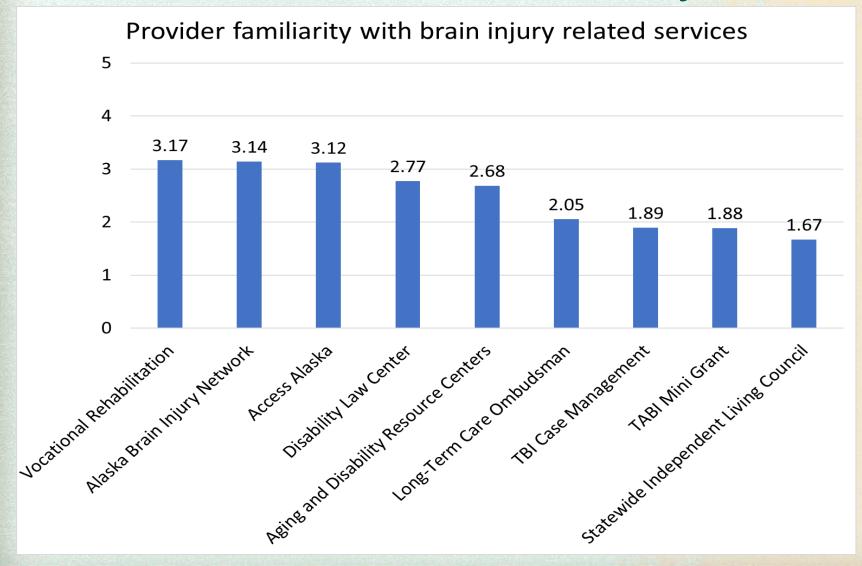


Over half of the providers have informational materials.

Almost half have not participated in a public awareness campaign.

Almost half were not sure if they had been invited to participate in a public awareness campaign.

Provider Familiarity with Services



Graph on scale from 0 to 5 (0 = not familiar, 5 = very familiar) showing the mean (average) score.

Providers as a whole group were most familiar with Vocational Rehabilitation and least familiar with the Statewide Independent Living Council.

Barriers for providing care

Medical and Service Providers were asked what barriers they faced in providing care. Four main themes were identified:

- 1. Lack of knowledge/education needed on brain injury
- 2. Difficulties accessing services
- 3. TBI not being identified/misdiagnosed
- 4. Cost of care preventing access to services

Solutions to navigate barriers

Medical and Service Providers were asked for solutions to navigate barriers they faced. Four main themes were identified:

- 1. Improve access to services
- 2. Provide education to Providers, survivors, and communities
- 3. Increase communication between Providers
- 4. Help with the cost of care

Other areas Providers wish were available

Medical and Service Providers were asked it there were any other areas they wished were available. Five main themes were identified:

- 1. Education for Providers, survivors, families, and communities
- 2. Supported housing for brain injury survivors
- 3. More TBI specific Case Management
- 4. Increased availability and follow-up in rural areas
- 5. Support to get survivors into employment

Further comments

Medical and Service Providers were asked if they had any further comments. Four main themes were identified in responses:

- 1. Education on brain injury is important
- 2. Brain injury is not supported by the state but funding is needed
- 3. Brain injury is linked to vulnerable populations (e.g. domestic violence, prison, homelessness)
- 4. It is frustrating and upsetting for Providers because they want to help brain injury survivors but barriers are present

Contacts

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