

# 2019 Living with Brain Injury Survey

## Brief Summary

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### What is the Living with Brain Injury Survey?

- Three unique needs assessment surveys of (1) individuals with a brain injury, (2) their family members/caregivers, and (3) brain injury service providers.
- The survey was conducted online with a paper option. Surveys were collected the help of numerous partners working in brain injury.
- The survey was primarily administered in January and February of 2019. Surveys continue to be collected through a link on the Brain Injury Advisory Council's website.

### The purpose of the Living with Brain Injury Survey is to answer questions such as...

- What services are individuals with a brain injury and their family members needing right now?
- What are the barriers to those services?
- And ultimately, how can we address the needs, gaps, and/or barriers facing individuals with a brain injury, their family members, and service providers?

### Survey Response

- 114 individuals with a brain injury
- 68 family members/caregivers of individuals with a brain injury
- 46 brain injury service providers (includes those whose organization provides a variety of services, including services to brain injury)

### Key Findings for Individuals with a Brain Injury

1. *Regardless of the service, individuals with a brain injury feel that service providers do not understand brain injury.*

- ➔ Across seven different types of services for individuals living with a brain injury, the top barrier reported by individuals with a brain injury was "providers do not understand brain injury".

*"Agencies and people find it hard to believe that I am disabled and have a TBI because I look in their eyes "normal".  
– Individual living with a brain injury*

2. *Care coordination services are the most needed types of services as reported by individuals with a brain injury.*

- ➔ Among the top services most commonly reported as being currently needed by individuals living with a brain injury are the care coordination services of general information/referral, education and resources about brain injury, service and funding application assistance, and case management.

*"It is my impression that a person with a mild brain injury has to figure things out on their own."  
– Individual living with a brain injury*

- ➔ These same services are also reported as having high barriers among those with a brain injury who have tried to obtain them.

## Key Findings for Family Members of Individuals with a Brain Injury

3. *Family members of individuals with a brain injury experience significant financial and emotional hardships and are in need of support services.*
  - ➔ 79% of family members have been prevented from gaining employment as a result of being a family member/caregiver of an individual with a brain injury.
  - ➔ 97% of family members reported experiencing emotional stress in their role as a family member/caregiver or an individual with brain injury.
  - ➔ 79% of family members agree or strongly agree that accessing services for their family member with a brain injury has been stressful.
  - ➔ Family members indicated “support group” and “educational events” as the top two services that would be most helpful for them as a caregiver.

*“My son is falling through the cracks of support system.”  
– Family member/caregiver*

## Key Findings for Brain Injury Service Providers

4. *Many service providers do not consider themselves to be knowledgeable of brain injury and most service providers perceive staff at their agency as lacking in knowledge of brain injury.*
  - ➔ 53% of service providers rate themselves as knowledgeable or very knowledgeable about the needs of individuals living with a brain injury. Just 34% rate staff at their organization as knowledgeable or very knowledgeable.
5. *Brain injury service providers perceive considerable gaps in most services for individuals with a brain injury.*
  - ➔ Most service providers perceive that some or many individuals with a brain injury are unable to access the wide array of services that they need. For example...
    - 93% of service providers perceive that some or most individuals with a brain injury who need affordable housing are unable to get it.
    - 90% of service providers perceive that some or most individuals with a brain injury who need service and funding application assistance are unable to get it.
    - 87% of service providers perceive that some or most individuals with a brain injury who need cognitive and behavior supports are unable to get it.
    - These percentages remain relatively high for a list of 30 unique services.
6. *Brain injury service providers are prepared to provide those services that are most needed for individuals with a brain injury and their family members if more funding is made available.*
  - ➔ With increased funding, high percentages of brain injury service providers report that they are prepared to offer services such as care coordination and support groups, which are the services that individuals with a brain injury and their family members report needing most.

*“If we are educated, we can help educate individuals and families.”  
– Service provider*

*“There are organizations doing this work that lack funding.”  
– Service provider*