The goal of Brain Injury Speaks is to empower those who are living with brain injury to share their experiences and hopefully inform the future direction of brain injury care in Ontario.

In October 2020, we asked members of the Brain Injury Speaks Stakeholder Engagement Network about their housing needs and experiences with accessing appropriate housing. Respondents of the survey included both persons with lived experience as well as caregivers and family members.

It should be noted that this survey was sent to current Brain Injury Speaks members who have been primarily recruited from OBIA (Ontario Brain Injury Association) and local brain injury associations across the province. These respondents are likely to be longer post-injury and also more likely to be stable in the community with housing and access to computers and the internet. As such, these respondents should not be taken as representative of the full sample of persons living with a brain injury either recently after the injury or after a period of time. Even given the relative housing stability that these respondents are experiencing, they still reported some challenges with housing and rely on considerable family/caregiver support.

Respondent demographics:
- 174 survey respondents
  - 71% persons with lived experience; 29% caregivers/family members
  - 56% persons with moderate-severe brain injuries; 44% persons with concussion/mild TBI
- 28% of respondents have had difficulty accessing safe, affordable, appropriate, and meaningful housing

Persons with lived experience rely on the following people for care related to their brain injury at home

Caregiver Impact
Results from this section of the survey highlight the role of caregivers and family members in supporting persons with brain injury at home. Many caregivers/family members report not having access to in-home care or support, putting additional burden on caregivers and family members to take care of their loved one who has a brain injury. This is an important factor in the discussion about housing considerations for persons living with brain injury.

For more information, please visit http://obia.ca/about-brain-injury-speaks/
More than 70% of caregivers/family members reported that they do not have access to in-home care/support for their loved one.

Reasons for caregivers/family members not having access to in-home care/support for their loved one with brain injury:

- **Unable to afford**: 16.3%
- **In-home care/support not needed**: 30.6%
- **Loved one is not open to outside services**: 16.3%
- **Not eligible for support provided by community organizations**: 14.3%
- **Inconsistency in personnel delivering services**: 12.2%
- **Other**: 16.3%
  - COVID
  - Family member is the primary caregiver
  - Outpatient services

“Every person deserves to live in a safe living environment where the sanctity of one's mind and body are respected. While I don't blame anyone for the situation in which I find myself, appropriate and meaningful housing or subsidies for a person recovering from several mTBIs like me would be a GODSEND. For now, such things remain an unrealistic dream. I will continue to try to make my situation work because I have no choice, but the gift of independence for someone like me could have a major impact on my ability to heal, get off ODSP, and return to the workforce. Please don’t forget that people with mTBIs and mental health challenges need housing too.”

- **Brain Injury Speaks**, Housing Survey Respondent (person with lived experience)

“First we need to realize that just because someone doesn’t score high on the Glasgow Coma Scale doesn’t mean they don’t have life altering changes to their ability to function a decade after their injury. Then we need to tailor housing supports around the person’s individual needs so that care can increase and decrease based on their functioning.”

- **Brain Injury Speaks**, Housing Survey Respondent (caregiver/family member)

**Greatest Housing Challenges Identified**

**Affordability** & **Availability of appropriate options**

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