

# Brain Injury Speaks: Growing a Stakeholder Engagement Network for Survivors of Brain Injury and their Family Members/Caregivers

Gazal Kukreja<sup>1,2</sup>, Ruth Wilcock<sup>2</sup> & Judith Gargaro<sup>1</sup>  
Ontario Neurotrauma Foundation<sup>1</sup>  
Ontario Brain Injury Association<sup>2</sup>



## What is *Brain Injury Speaks*?

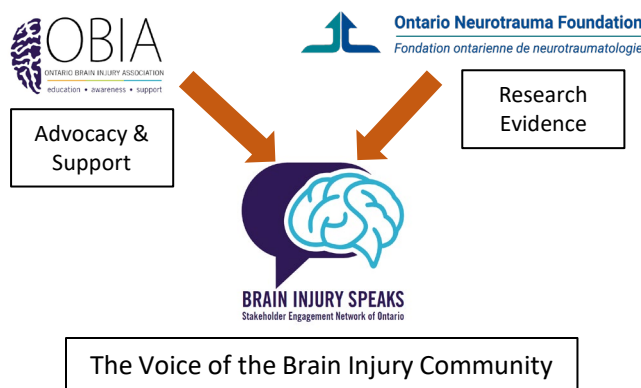
→ **Active Engagement Network** of persons with lived experience of brain injury, caregivers and family members

**Brain Injury Speaks (BIS)** is a new centralized, coordinated, and province-wide initiative aimed at identifying the most pressing and common issues faced by the brain injury community. This active engagement network provides a platform for persons with lived experience, caregivers and family members to express their needs and provide feedback on issues that are important to them.

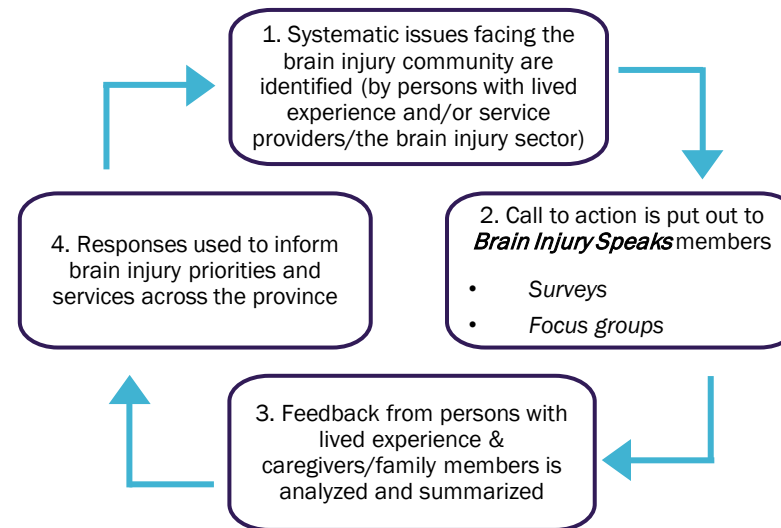
The long-term goal of BIS is to inform future service delivery and brain injury policies to improve the quality of life for those living with the effects of brain injury. The network will promote fluid communication among policy makers, allied healthcare providers, organizations representing persons with lived experience and the brain injury community.

This stakeholder network is being cultivated by two provincial organizations (Ontario Brain Injury Association [OBIA] & Ontario Neurotrauma Foundation [ONF]). To date, over 500 stakeholders spread across each region of Ontario have joined **Brain Injury Speaks** and the network continues to grow.

## Organizations Involved



## How does it work?



## Network Communications

The purpose of **Brain Injury Speaks** is to understand the needs of persons with lived experience and their family members/caregivers. In the past year, the following topics have been addressed by surveying members of the network:

- Barriers to accessing community supports and services
- Accessing primary care/virtual care & primary care doctor's level of knowledge about brain injury
- Impact of COVID-19 on brain injury supports and services
- Housing issues

Results of these surveys have been shared with brain injury associations, community organizations, service providers, members of the Provincial Acquired Brain Injury Network (PABIN), and Ministry of Health representatives. Survey summaries are accessible at <https://onf.org/impact/brain-injury-speaks-2-2/>

## Survey Results Overview



### Community Support

The number one barrier was the lack of services, or lack of knowledge about services/finding services in the community.



### Primary Care

More than 50% said that their primary care doctor has very limited knowledge about brain injury.



### COVID-19 Impact

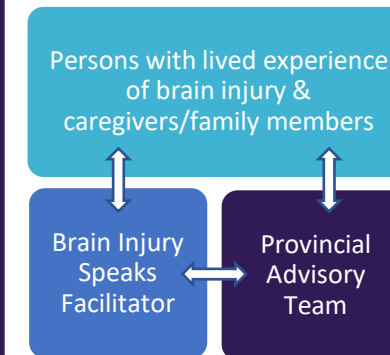
During COVID-19 the mental health and social wellbeing of persons with lived experience were impacted the most.



### Housing

More than 60% of respondents faced housing challenges, primarily due to financial constraints.

## Network Organization



## Roles

**Brain Injury Speaks Facilitator:** manages the stakeholder engagement network & coordinates the input of OBIA and ONF

**Provincial Advisory Team (PAT):** champions in different regions across the province who inform the future goals and direction of the network. The PAT members meet with the BIS facilitator regularly to provide suggestions on topics to be addressed, feedback on communicating with the network, direction on network goals etc.,

## Summary

Bringing the brain injury community together and representing their voices to effect change at the policy level is important. Through surveys and focus groups, the needs of the brain injury community are being identified and communicated to healthcare providers, brain injury organizations, policy makers, and government representatives. A stakeholder engagement network is an effective way to gather important information and data from stakeholders to inform future policies, programs and system changes to improve the quality of those living with brain injury.

To join **Brain Injury Speaks**, visit: <http://obia.ca/about-brain-injury-speaks/>