



BRAIN INJURY SPEAKS
Stakeholder Engagement Network of Ontario

A Voice for Survivors and Caregivers

Building a Provincial Stakeholder Engagement Network for the Brain Injury Community

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Ontario Neurotrauma Foundation¹

Ontario Brain Injury Association²

Agenda



What is *Brain Injury Speaks*?



Stakeholder Engagement Network Operations



COVID-19 Impact Survey Results

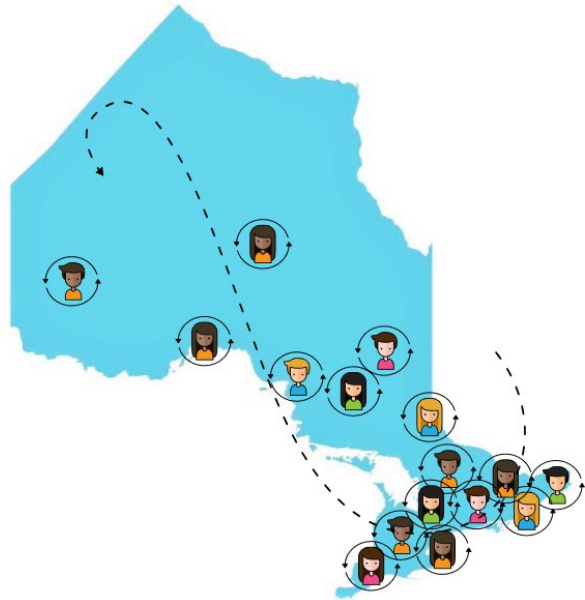


Next Steps and Future Direction



How to get involved

Brain Injury Speaks: What is it?



Active Engagement Network of persons with lived experience, caregivers and family members

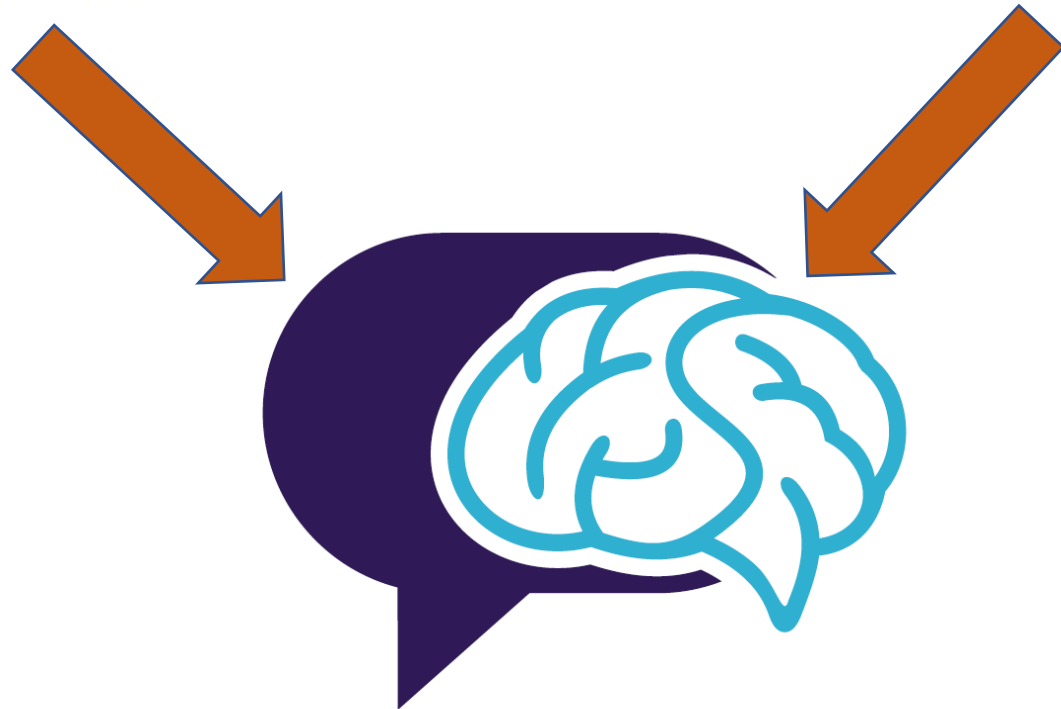
Need for a Provincial Voice

- Decisions are being made with little input from persons living with acquired brain injury and their family/caregivers
- The *Brain Injury Speaks* network aims to fill this system gap
- Systematic approach to inform brain injury priorities and services across the province

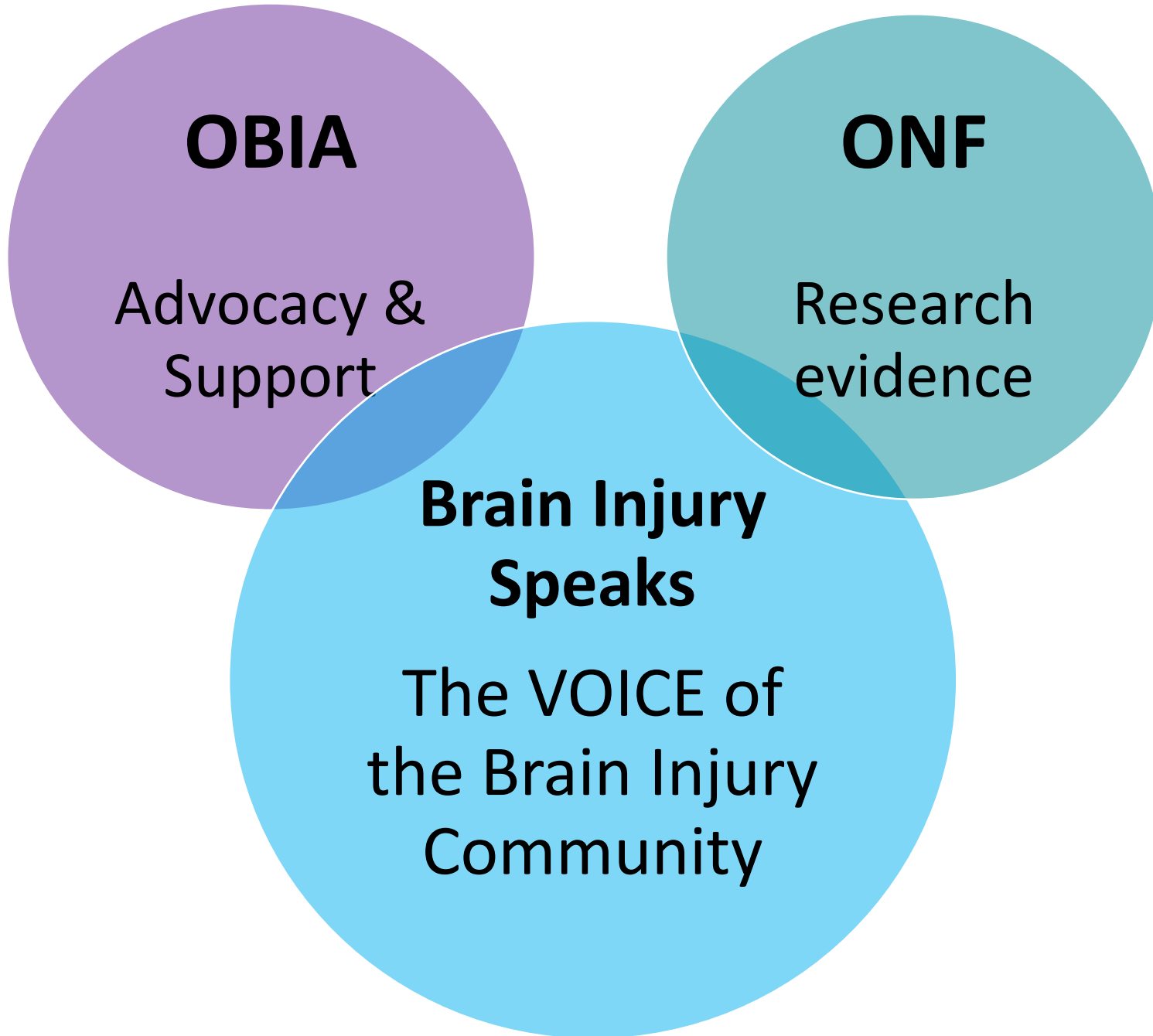




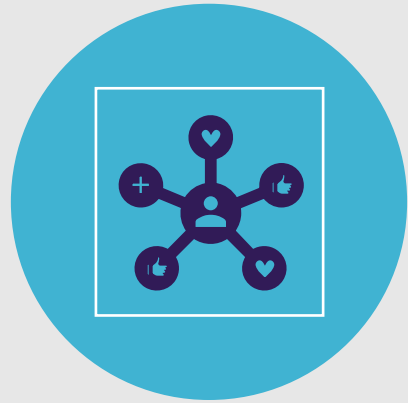
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Goals of the Network

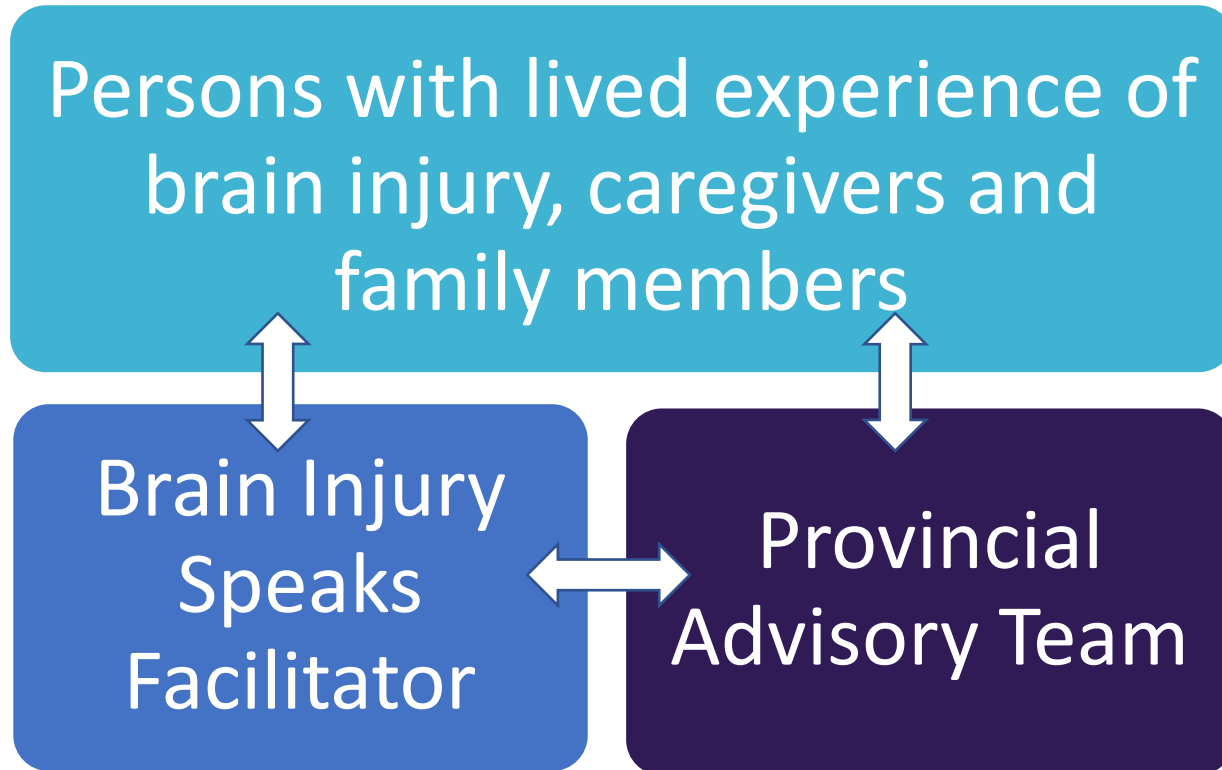


SHORT TERM: CREATE A COMMUNITY OF SURVIVORS, CAREGIVERS AND FAMILY MEMBERS WHO ARE OPEN TO SHARING THEIR EXPERIENCES



LONG TERM: INFORM THE FUTURE OF BRAIN INJURY CARE AND POLICIES ACROSS THE PROVINCE OF ONTARIO

Network Organization



Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie



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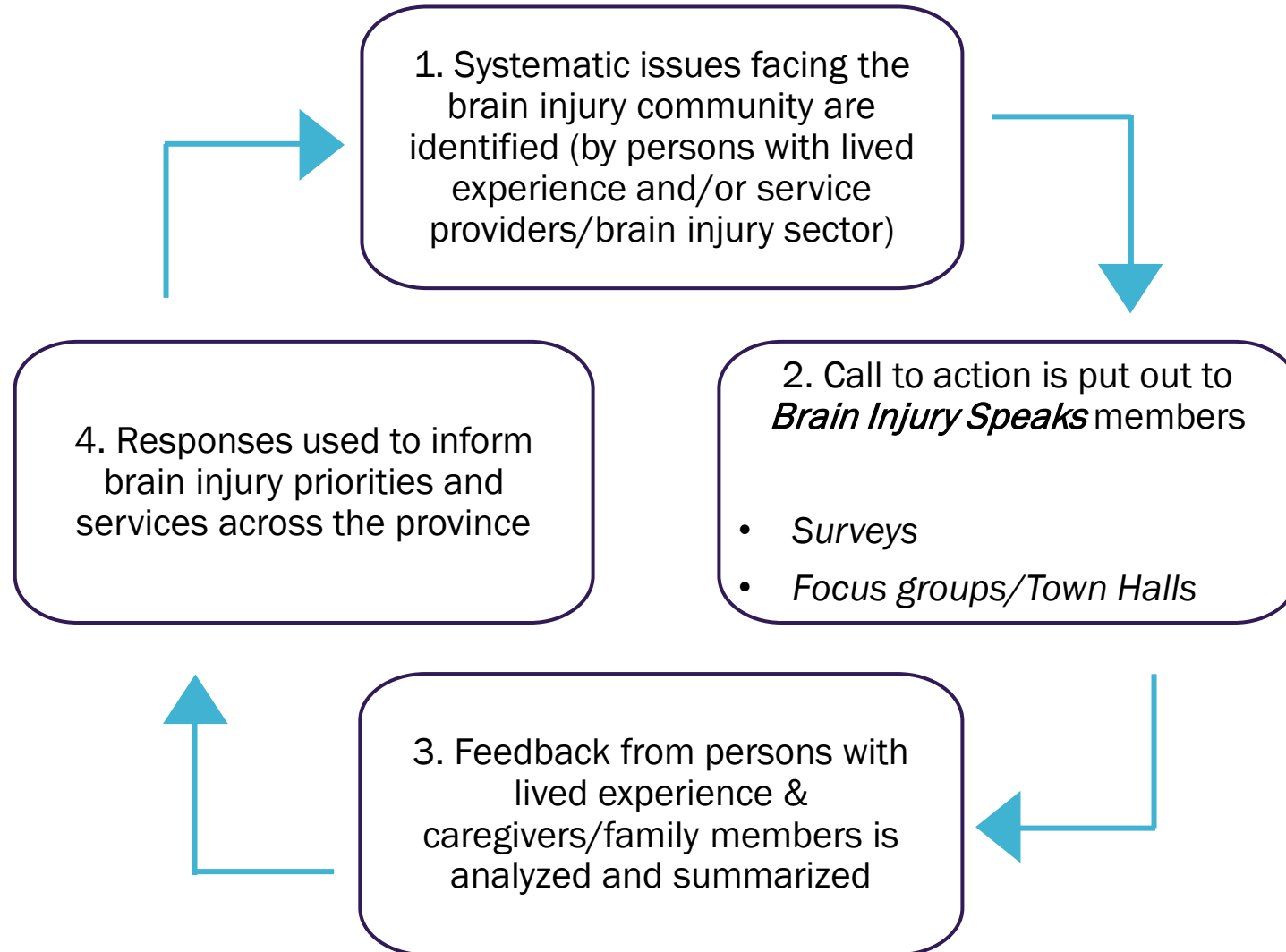


Stakeholder Engagement Network Operations

2-Way Communication Channel



Gathering Feedback



Choosing Topics to Address

- Awareness of broader issues at ONF/OBIA
- Through PABIN (Provincial Acquired Brain Injury Network)
- From previous surveys
- Feedback from the members of the Provincial Advisory Team
- Insights from Brain Injury Associations



Current Stakeholder Numbers

Total: 508

**Family members/
caregivers: 126**

**Persons with lived
experience: 382**

Data Matters

- We collect only the data we need and all data is deidentified

You are a (Survivor/Person with Lived Experience OR a Caregiver/Family member)	Do you wish to tell your story or why you decided to join this network? (optional)	City/Town of Residence	Type of brain injury	Date of the injury
Survivor (Person with Lived Experience)	I had my concussion in November of 2013...	Ottawa	Concussion/mild traumatic brain injury	November 2013
Caregiver/Family member	My son has had multiple concussions and as the primary caregiver...	Sudbury	Concussion/mild traumatic brain injury	April 2004
Survivor (Person with Lived Experience)	Since my car accident in 1998, my life has been very difficult...	Toronto	Moderate-to-severe traumatic brain injury	January 1998



COVID-19 Impact Survey Results

COVID-19 Impact Survey: Brain Injury Speaks

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

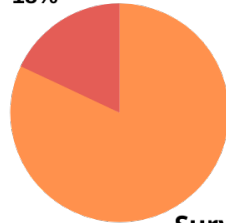
In June 2020, we asked members of the **Brain Injury Speaks** Stakeholder Engagement Network about the impact of COVID-19 social distancing measures on their brain injury supports and services.

210 survey respondents

Caregivers/Family

Members

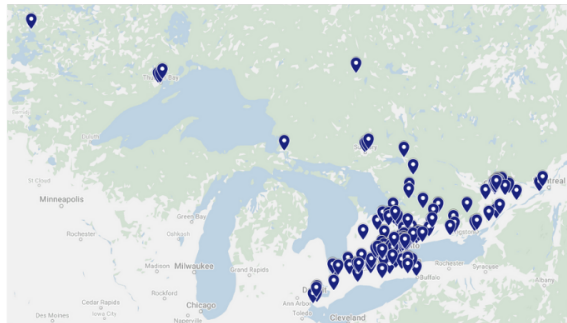
18%



Survivors*
82%

*10.5% of responses were completed by caregivers/family members on the survivors' behalf

Where do the respondents live?



Supports and Services



We asked whether brain injury survivors have been able to access the supports they need, how and where they accessed support, and the barriers to receiving support and services during COVID-19 social distancing measures.



1. **Healthcare** (medical appointments, crisis/emergency services & helplines)

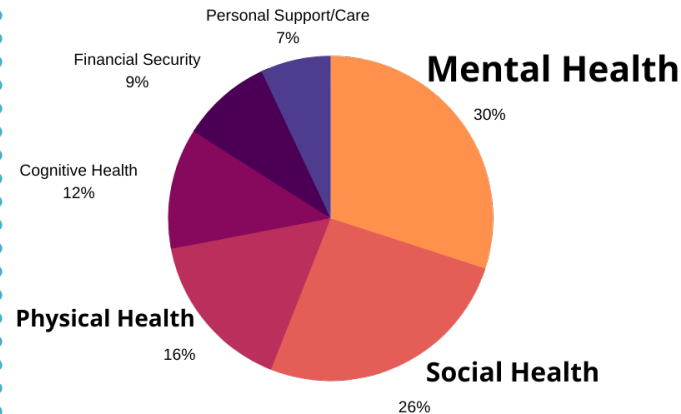


2. **Rehabilitation** (non-medical healthcare, personal support services, rehab therapist or community support worker)



3. **Community** (peer support groups, survivor support groups, family support groups)

Impacted by COVID-19 Social Distancing Measures



During COVID-19 Social Distancing Measures...



11% of survivors relied on their family member or caregiver to provide healthcare support instead of seeking formal healthcare services



16% of survivors relied on their family member or caregiver to take on the role of a personal support worker, community support worker, or rehab therapist because they have been unable to access those supports



14% of survivors were unsure what healthcare support was available to them



up to **37%** of survivors were unsure what community supports were available to them (e.g. support groups, day programs, etc.)

What has helped survivors the most during COVID-19?

Family and friends



Social/support groups

Yoga/exercise/walks



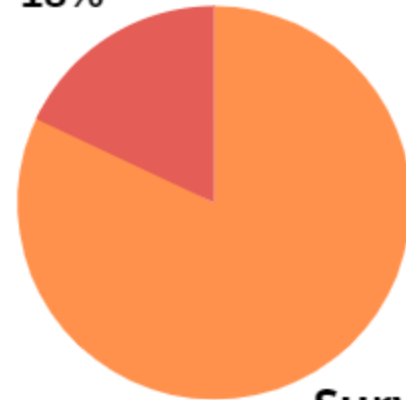
Mindfulness/meditation

n=210

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Caregivers/Family
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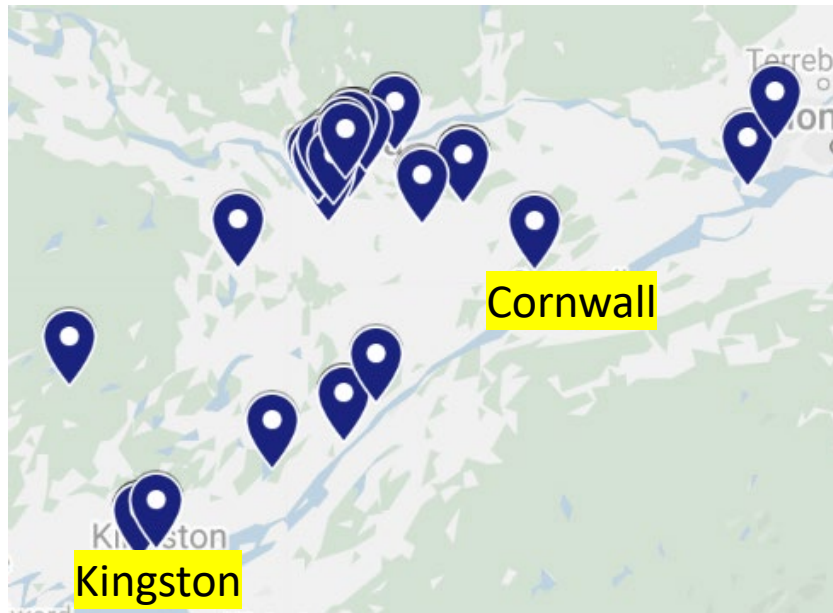
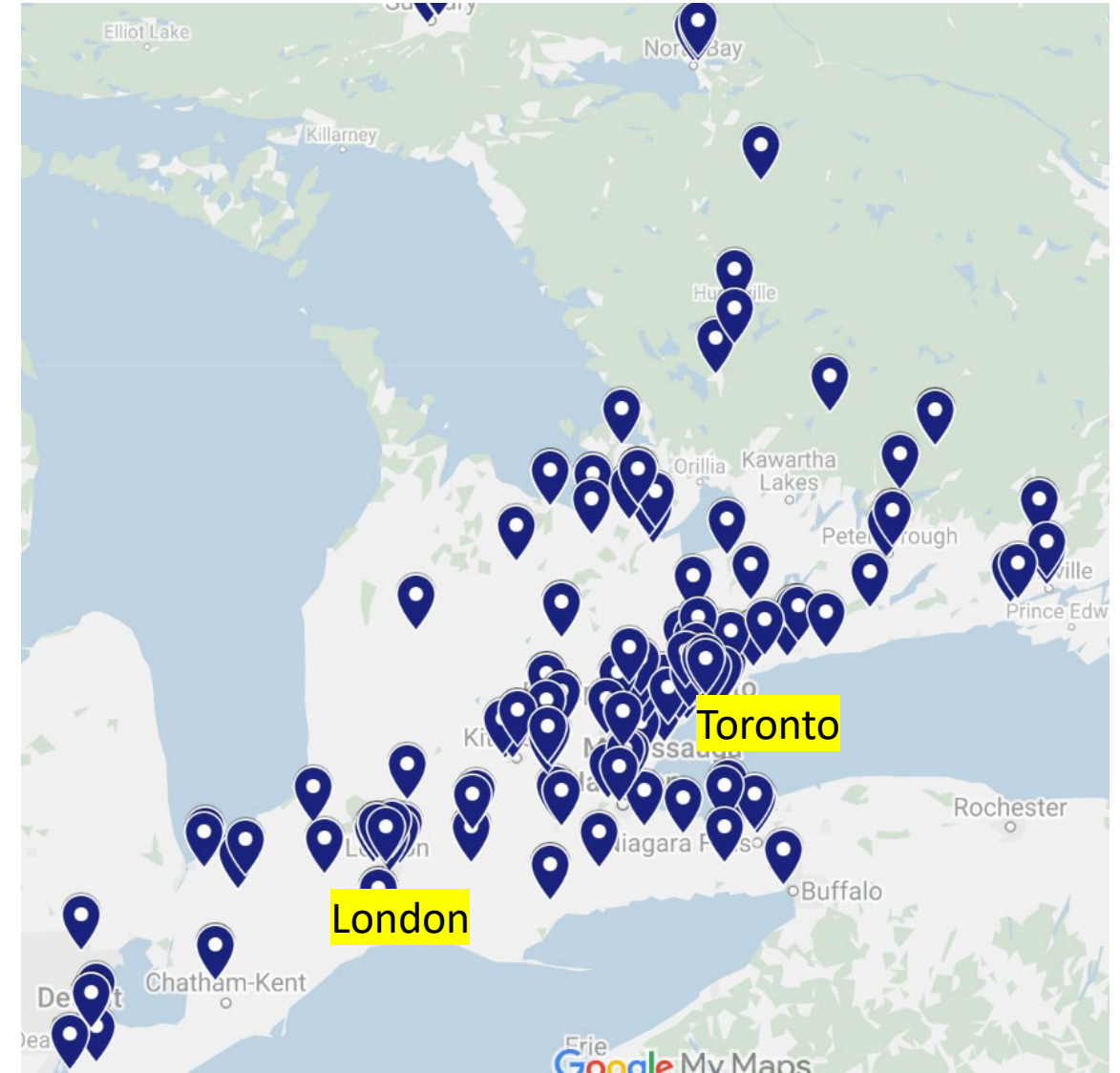
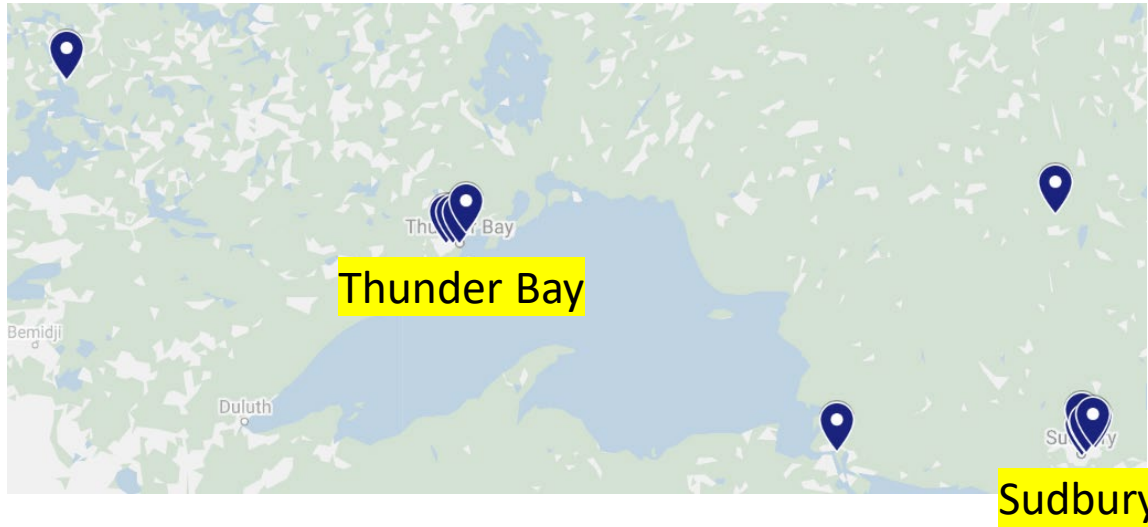
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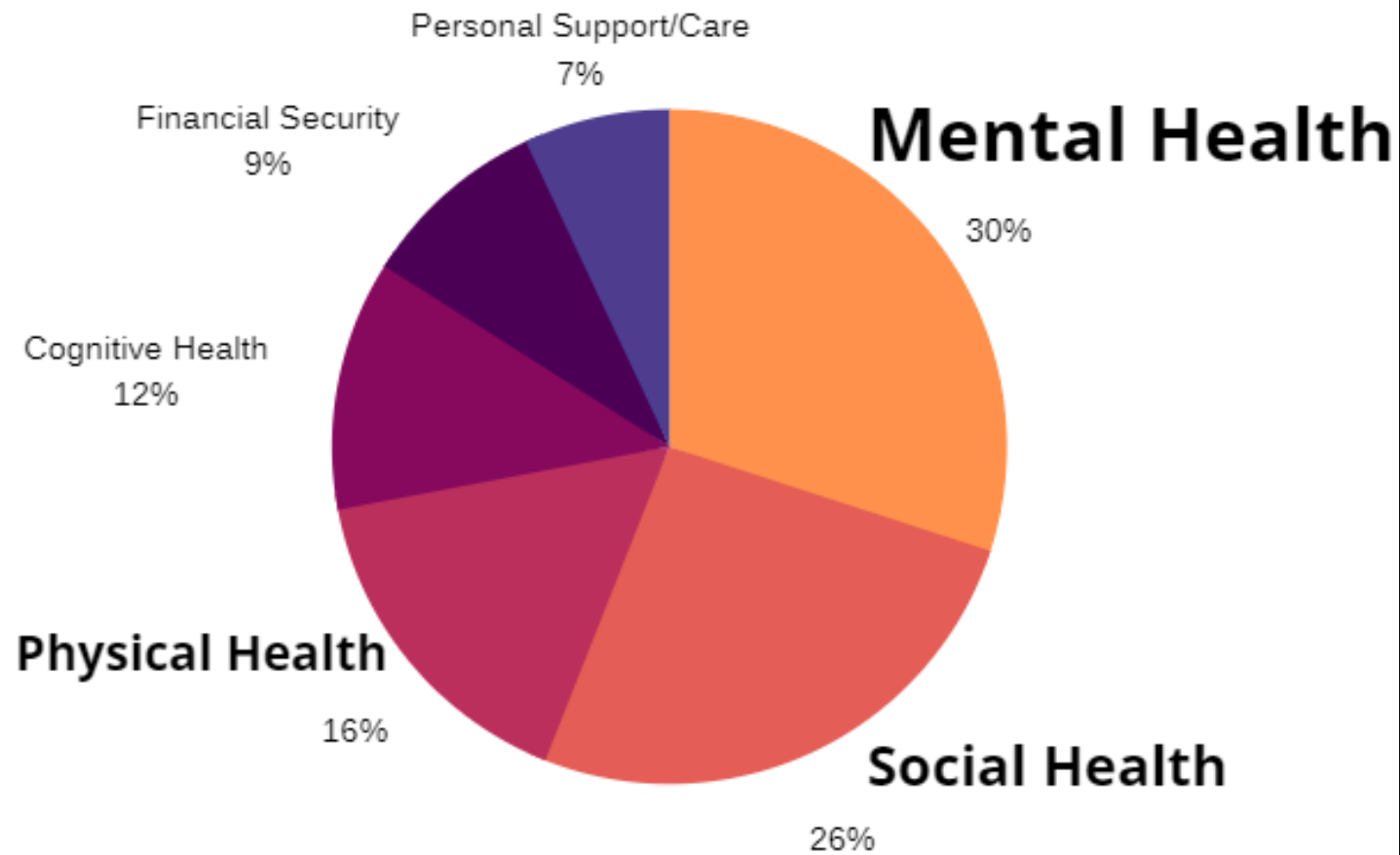


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Mindfulness/meditation



Next Steps & Future Direction

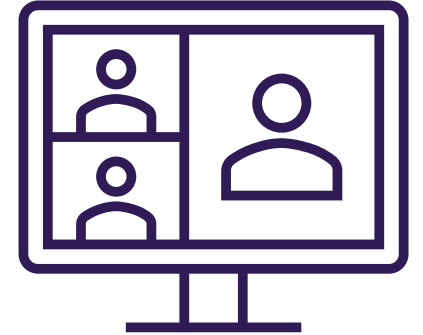
Sharing Knowledge

- **Survey summaries have been shared with a variety of individuals, organizations, service providers, Ministry representatives, etc.,**
- **Other communication vehicles:**
 - Published in OBIA Review
 - Packaged with PABIN data for the Ministry
 - Presentations at organizations/associations
- All survey summaries available on the ONF website (<https://onf.org/impact/brain-injury-speaks-2-2/>)



Next Steps: Provincial Advisory Team Function

- 5 members from different regions in ON – champions!
- Meet bi-monthly with BIS Facilitator
- PAT informs the future goals and direction of the ***Brain Injury Speaks*** Network – provide suggestions on topics to be addressed, feedback on communicating with the Network, etc.,



Next Steps: Strategic Direction and Planning

- Planning focus groups/town hall sessions in the New Year (Feb 2021)
 - TOPIC: social isolation/community supports
- Housing is an important issue that has been raised across multiple stakeholder groups
 - Housing survey teaser...



Why is it important to have a Provincial Voice for Persons with Lived Experience?

- The annual **incidence** of ABI is **greater than** that of **Multiple Sclerosis, Spinal Cord Injury, HIV/AIDS** and **Breast Cancer** combined
- Yet, brain injury doesn't have a presence on the map!
- Important to have a Provincial Network that is not connected with a particular service provider
- Important to understand lived experience
- We have seen that real life experience and sharing stories is impactful

This is just the beginning!

Let's Strengthen the Voice of the Brain Injury Community





How to Get Involved



Help is just a call away
1-800-263-5404
Calls answered Mon-Fri, 9am - 5pm EST



- Home
- About »
- ABI Training »
- Resources »
- Support & Services »
- Get Involved »
- Events »
- DONATE**

- › Helpline
- › Online Concussion Support Group
- › Caregiver Education Program
- › Peer Support Program
- › Local Brain Injury Associations
- › Dual Membership
- › Participate in Research Study
- › Directory of ABI Services
- › **Brain Injury Speaks »**

Get Involved

<http://obia.ca/about-brain-injury-speaks/>

OR

<http://obia.ca/>

Supports & Services >
Brain Injury Speaks

How to join:

**Are you, or someone you know,
living with a brain injury and want
your voice to be heard?**

**JOIN
NETWORK**

Brain Injury Speaks

The Stakeholder Engagement
Network of Ontario

smartsheet

Brain Injury Speaks, the Stakeholder Engagement Network of Ontario

Thank you for your interest in joining Brain Injury Speaks, the Stakeholder Engagement Network of Ontario. We hope to strengthen the voice of the brain injury community across Ontario. Please answer the following questions to provide us information about who you are and why you would like to join:

Stakeholder Information

Today's date

Your First Name

Your Last Name

You are a

- Survivor (Person with lived experience)
 Family member/caregiver

Your City / Town of Residence in Ontario

Your Postal Code

Your Email Address

Your Phone Number

Which type of brain injury are you or the person you care for affected by?

Contact Information

If you are interested in learning more about **Brain Injury Speaks**, please contact Gazal Kukreja (Stakeholder Engagement Coordinator)

Email: gkukreja@obia.ca



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