MORE STAKEHOLDERS WITH FEWER ISSUES INSTEAD OF FEWER STAKEHOLDERS WITH MORE ISSUES

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INTRODUCTION

- Close to 500,000 persons in Ontario have an Acquired Brain Injury (ABI) yet no provincial network exists to connect and represent the perspective of persons with ABI.
- Currently, only local/regional issues are being haphazardly addressed with little to no understanding of the brain injury community’s voice provincially.
- By connecting stakeholders to a central coordinated platform from each region within Ontario, the most common issues affecting the province can be identified and prioritized.
- Development of this network is the first step in an articulated provincial plan that supports the development of policy that meets the needs of persons with ABI.
- This approach is based on the Ontario Spinal Cord Injury (SCI) Alliance which has been effective in cultivating relationships with government and key stakeholders in Ontario.

NETWORK ORGANIZATION

The province of Ontario (pop. > 14 million) is organized into 14 health regions: West (1-4), Central (5-8), East (9-11), North (12-14).

The 3 Key components of the provincial stakeholder engagement network for persons living with ABI:

1) Regional Coordinators: to grow the network in their region and gather community feedback.
   - Coordinators have been established in each of the 14 regions to ensure broad representation of stakeholders across Ontario.

2) Steering Committee: to provide strategic oversight to the Stakeholder Engagement Coordinator regarding network growth, direction and sustainability while staying abreast of policy, system and industry developments which may directly or indirectly affect persons living with ABI.

3) Stakeholder Engagement Coordinator (SEC): to facilitate communication among the Regional Coordinators, Steering Committee and government policy developers and ministries.

- Brain Injury Speaks, the Stakeholder Engagement Network for Ontario has been established using the organizational structure above to represent the voice of persons living with brain injury (persons with lived experience, caregivers/family members) across the province.
  - The Ontario SCI Alliance is a key consultant.

NETWORK GROWTH

The Steering Committee meets every 2 months to decide which issues affecting persons living with ABI should be addressed by Brain Injury Speaks.

The SEC works with the Ontario Brain Injury Association (OBIA) to develop engagement strategies based on the Steering Committee recommendations.

The SEC then reaches out to the Regional Coordinators to start disseminating materials (social media, e-blasts, newsletters) to Brain Injury Speaks members within their respective region.

- Feedback is retrieved in the form of surveys, questionnaires, focus groups, teleconferences and committee meetings.

NETWORK OPERATIONS

The Steering Committee

Stakeholder Engagement Coordinator

Regional Coordinators

Provincial Brain Injury Community

- Regional Coordinators and brain injury service providers across Ontario advertised the Brain Injury Speaks Network.
- Interested persons filled out a survey and consent form to join the network.
- Brain Injury Speaks currently has 310 stakeholders (61 caregiver/family members and 249 persons with lived experience)
- Stakeholders are well represented within each region of Ontario including Northern, rural regions such as 13 and 14 (refer to Figure 2).

DISCUSSION

- Brain Injury Speaks has helped establish a unified voice for persons living with brain injury, caregivers and family members.
- Before this network, gathering responses from across the province from the brain injury community had not occurred.
  - Barriers were lack of resources, permanent structure and coordination.
- Having an active pipeline to engage with the brain injury community in a coordinated and sustainable way will allow for ongoing responses to pressing issues in the 5 key areas listed in Figure 4.

- The Terms of Reference clearly outline that Brain Injury Speaks will not be subject to outside influence i.e. industry, commercial, private marketing.

CONCLUSIONS

- Brain Injury Speaks supports the development of an articulated provincial strategy by coordinating and representing the voice of persons living with ABI across Ontario.
  - It has been effective in unifying the voice of brain injury stakeholders.
  - It is helping identify the most important issues for persons with ABI.
  - It is acting as a two-way communication channel between government and community.

- Brain Injury Speaks is expected to grow to over 1000 stakeholders by 2020.

For more information please contact Chad Debison-Larabie clarabie@obia.on.ca

Figure 1: Network Organization

Figure 2: Number of stakeholders in each region of Ontario

Figure 3: Connecting to persons across Ontario

Figure 4: 5 Key Areas

Figure 5: Brain Injury Speaks, the Stakeholder Engagement Network of Ontario logo