

# Adults with Aphasia as Change Agents: Experiences in advocacy and co-design

Authors: Kathy Smith<sup>1</sup>, Brenda Adams<sup>2</sup>, Gwen Brown<sup>3,4</sup>, Karen Donaldson<sup>5</sup>, Robyn Donaldson<sup>5</sup>, Adam Hedberg<sup>6</sup>, Shelley Huffman<sup>3,4</sup>, Lynda Lennox<sup>2</sup>, Cally Martin<sup>3,4</sup>, Jennifer Mills<sup>1</sup>, Amelia Morris Mathany<sup>6</sup>, Catherine Nicol<sup>7</sup>, Lorraine Pyle<sup>8</sup>, Tom Walsh<sup>5</sup>, Lynda Walsh<sup>5</sup>, Shell-Lee Wert<sup>8</sup>

1. Quinte & District Rehabilitation 2. VON Canada Greater Kingston 3. Stroke Network of Southeastern Ontario 4. Kingston Health Sciences Centre 5. Person with Lived Experience 6. Kaymar Rehabilitation Inc. 7. South East Local Health Integration Network. 8. Community Care for South Hastings

## Background

- One in three stroke survivors is diagnosed with aphasia.
- Adults with aphasia (AWA) can self-isolate contributing to psychosocial distress including negative impacts on family relationships, limited social interactions and decreased self-esteem.
- In 2015, a community support service (CSS) agency (Community Care for South Hastings) and a community rehabilitation agency (Quinte & District Rehabilitation) collaboratively developed the Aphasia Conversation Group (ACG) intervention model for AWA to fill a gap in communication supports that were virtually non-existent in this rural region.
- Initial program goals evolved to integrate advocacy and mentorship, as positive shifts in self-confidence were realized.
- ACG groups spread to Kingston supported by a local CSS agency (VON Greater Kingston) and rehabilitation provider (Kaymar Rehabilitation Inc.) in 2018 and subsequently to a third rural geographical area in 2019 leveraging the results of the first site and the advocacy efforts of its members.

## Methodology

- In the ACG model, AWA were pre-assessed by a speech-language pathologist (SLP) and then participated in an assigned group on a weekly basis for 8 weeks.
- Groups were facilitated by a SLP and supported by trained volunteers.
- Conversations within the ACG included topics along the continuum of simple to complex.
- Surveys were conducted pre/post sessions asking participants to evaluate the effectiveness of the ACG across several domains including well-being, communication and general quality of life.
- In 2018, participants were also asked to comment on the role(s) they might play in raising aphasia awareness.
- AWA participated in stroke awareness activities at a local mall, created a video and spoke to healthcare leaders about aphasia and the benefits of ACG.



Stroke Awareness Day, 2018  
Kathy Smith, SLP  
Sandie Varcoe, AWA  
Mitch Panciuk, Belleville City Mayor



Stroke Awareness Day, 2019  
Tom Walsh, AWA

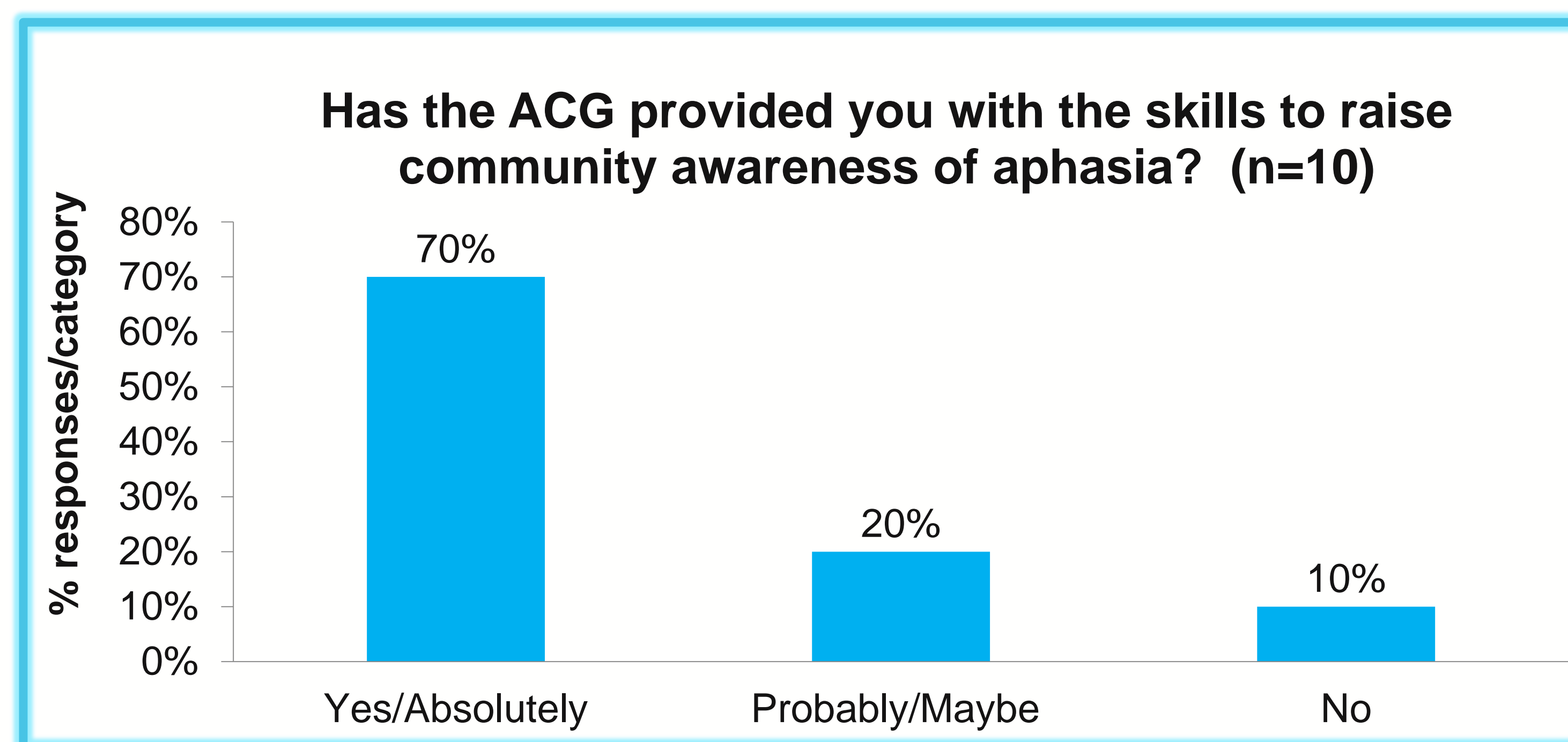
## Findings

Pre/post evaluation findings have consistently demonstrated positive, self-reported findings since inception in 2015.

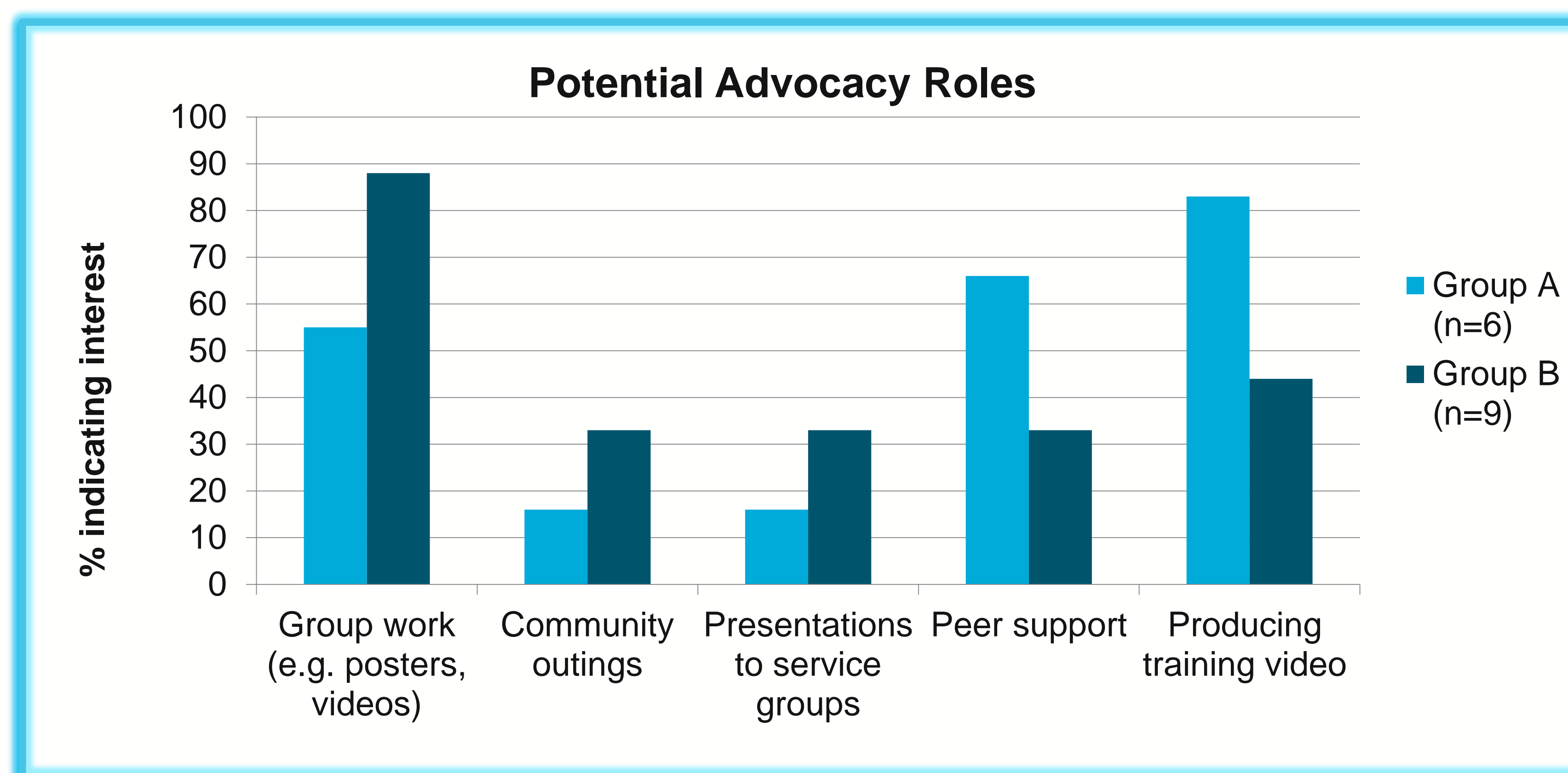
Participants reported improvements in the areas of:

- ✓ self-knowledge of aphasia
- ✓ feelings of acceptance
- ✓ ability to participate in simple & complex conversations
- ✓ degree to which aphasia is seen as a barrier in daily life

In 2018, advocacy questions were added to evaluations. AWA responses are displayed in Graph 1 and Graph 2.



Graph 1



Graph 2

*"[My wife] attends the Aphasia Conversation Group and [we have] found out we were not alone in our challenges. We noticed that people were not only looking for information in helping with their needs as a stroke survivor but also a place to get some much needed companionship [as they were] experiencing the same experiences as we did with loneliness and depression."*

- Spouse of AWA

## Evolving Roles and Services

Opportunities for advocacy and mentorship have led to successful spread of both the ACG itself and advocacy roles.

- ✓ Informing health care planning through letter writing and in-person meetings with decision-makers at the regional health planning authority (i.e. South East Local Health Integration Network). This resulted in the expansion of the ACG throughout the southeast.
- ✓ Creation of an advocacy video to enhance public and health care provider awareness and understanding of aphasia.
- ✓ Informing the initial and expanded ACG model through ongoing anecdotal and formal evaluation processes.
- ✓ Bringing the AWA voice to the tables of district and regional community stroke advisory committees.
- ✓ Promoting the ACG and providing mentorship for AWA new to the group.
- ✓ Participation in stroke support groups and activities not specific to AWA.
- ✓ Presenting lived experience stories at regional education events.
- ✓ Volunteering, co-designing and speaking at public stroke awareness days.
- ✓ Co-designing informational resources (e.g., Patient Journey Map, Stroke Information Packages, Transition Checklists and self-help questionnaires).

ACG facilitators provided the supports, linkages and supported conversation as needed to ensure that opportunities for advocacy and mentorship were accessed by interested AWA.



Use QR code reader to access AWA Advocacy Video  
Aphasia Knowledge Exchange Day, 2018



Aphasia Advocacy Group, Stroke Awareness Day, 2018

## Conclusions

- ✓ Participation in ACG increased self-confidence and helped to expand the goals and expectations of participants.
- ✓ As participants continued to engage with peers in SLP-facilitated groups (i.e. a 'safe' environment), their meaningful engagement in advocacy and mentorship roles was enhanced.
- ✓ As successes were realized both individually and as a group, horizons continued to expand and self-confidence and community involvement were further developed.
- ✓ AWA as change agents had a direct impact on health service improvements.