

## Background and Purpose

Aphasia centres provide:

- **Participation-based services** for people with aphasia (PWA)
- **Education** for both PWA and their communication partners
- **Support** for both PWA and their communication partners

Existing aphasia centres have been found to:

- Help PWA **overcome feelings of isolation** (Woelder et al. 2018)
- Extend **social networks** (Rose & Attard, 2015)
- **Increase engagement** in meaningful activities outside of therapy (Fink & Schwartz, 2000)

Edmonton is home to potentially thousands of individuals affected by aphasia. No such centre currently exists in Edmonton or the surrounding area. These centres can provide a stepping stone for PWA to participate in their community.

The purpose of this study was to explore the current services for PWA in Edmonton and the need for establishing an aphasia centre in Edmonton. This goal was achieved by meeting the following three objectives:

1. Conduct a **needs assessment**.
2. Produce a **written report** of results of the needs assessment.
3. Establish the **non-profit organization** C.H.A.T. Society (Communication Health and Therapy).

## Methodology

Data was collected through an **online survey** and **in-person interviews**.

- Discipline-specific surveys were sent to speech-language pathologists (17 questions), managers within Alberta Health Services (14 questions), allied healthcare professionals (16 questions), and individuals working in community-based programs (e.g., Brain Care Center, WJS; 14 questions). Survey recipients were asked to forward the survey to co-workers who work with PWA. Only responses from **Edmonton and area** were included in analysis.
- Interviews were conducted with PWA (24 questions) and their primary communication partners (17 questions).

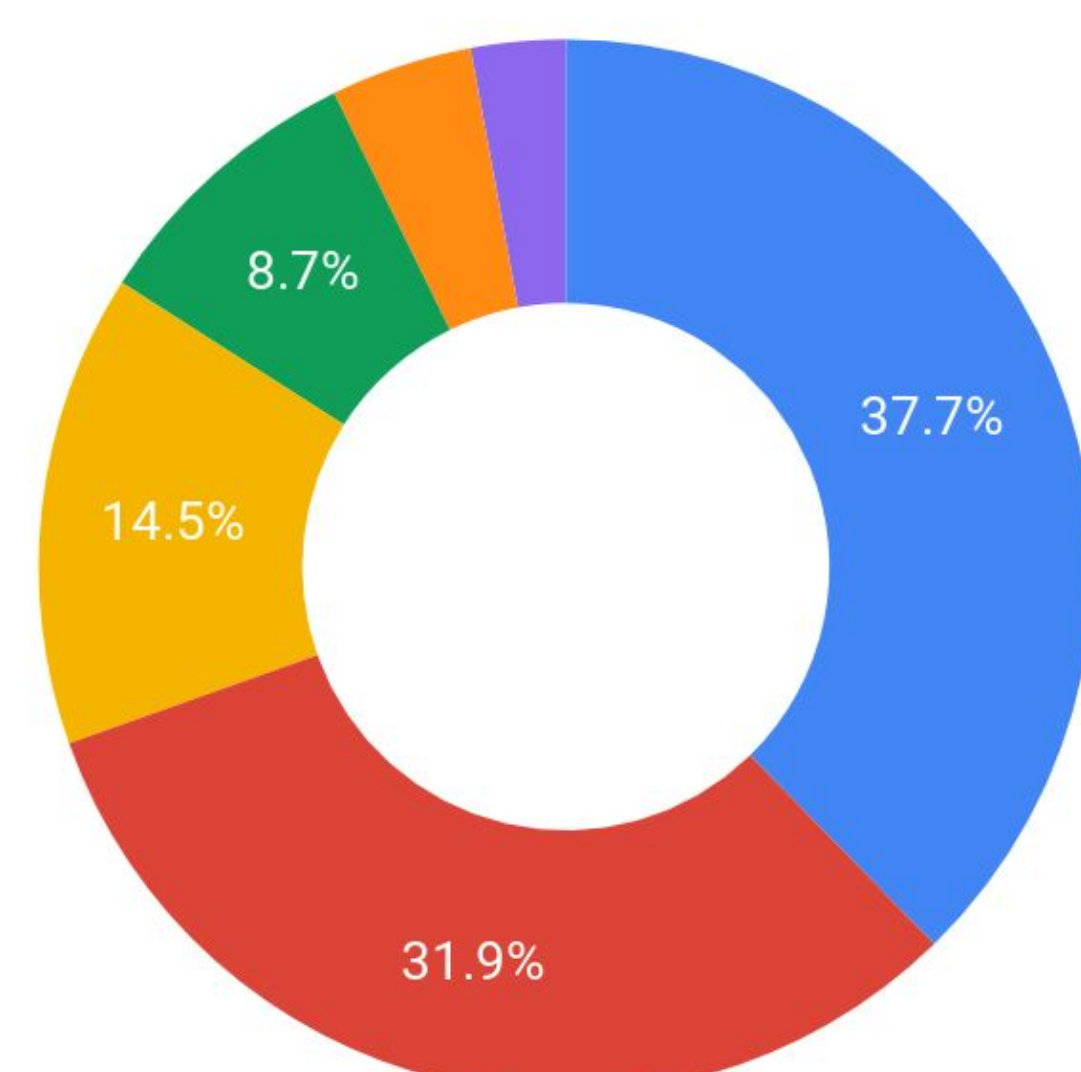
Survey responses N=56; Interview participants N=13

## Demographics

Participants

N = 69

- Speech-language pathologists (37.7%)
- Allied healthcare workers (31.9%)
- People with aphasia (14.5%)
- Community-based practitioners (8.7%)
- Communication partners (4.3%)
- Managers within AHS (2.9%)



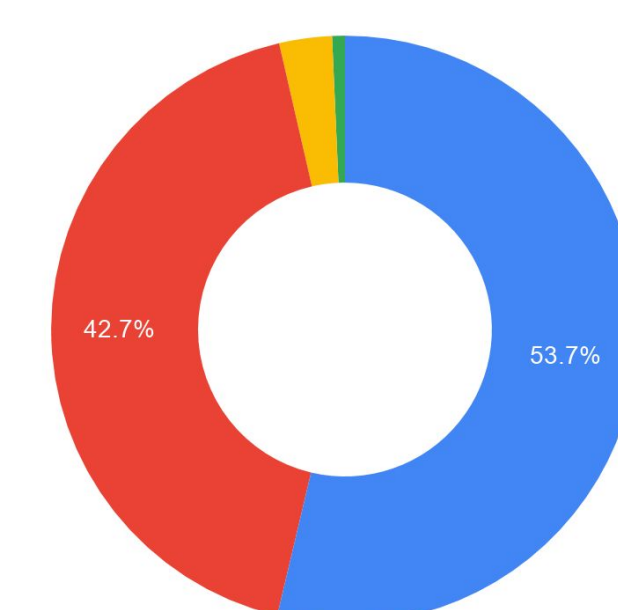
## Current Services for PWA

Survey respondents were asked to identify the services that they were aware of in their community, as well as identify the organizations that these services were provided by.

- Healthcare professionals identified a **variety of resources** for PWA in Edmonton
- Responses from healthcare professionals suggested a **lack of shared knowledge** regarding **current services** for aphasia

Organizations in Edmonton for PWA

- AHS Programs (53.7%)
- Community Programs (42.7%)
- Private Practice SLPs (2.9%)
- Unsure (2.9%)



## Service Gaps for PWA

Survey respondents were asked to identify what services they would like to see in the community for PWA. PWA were asked about their views on the amount of services they'd received.

- Responses from healthcare professionals suggested a lack of services for PWA in **rural settings**, and a general lack of support for these individuals outside of hospital care.
- The majority of PWA interviewed perceived the amount of speech therapy they'd received since their injury as **"a little"** or less.
- All PWA expressed interest in receiving **more speech therapy** in the future.



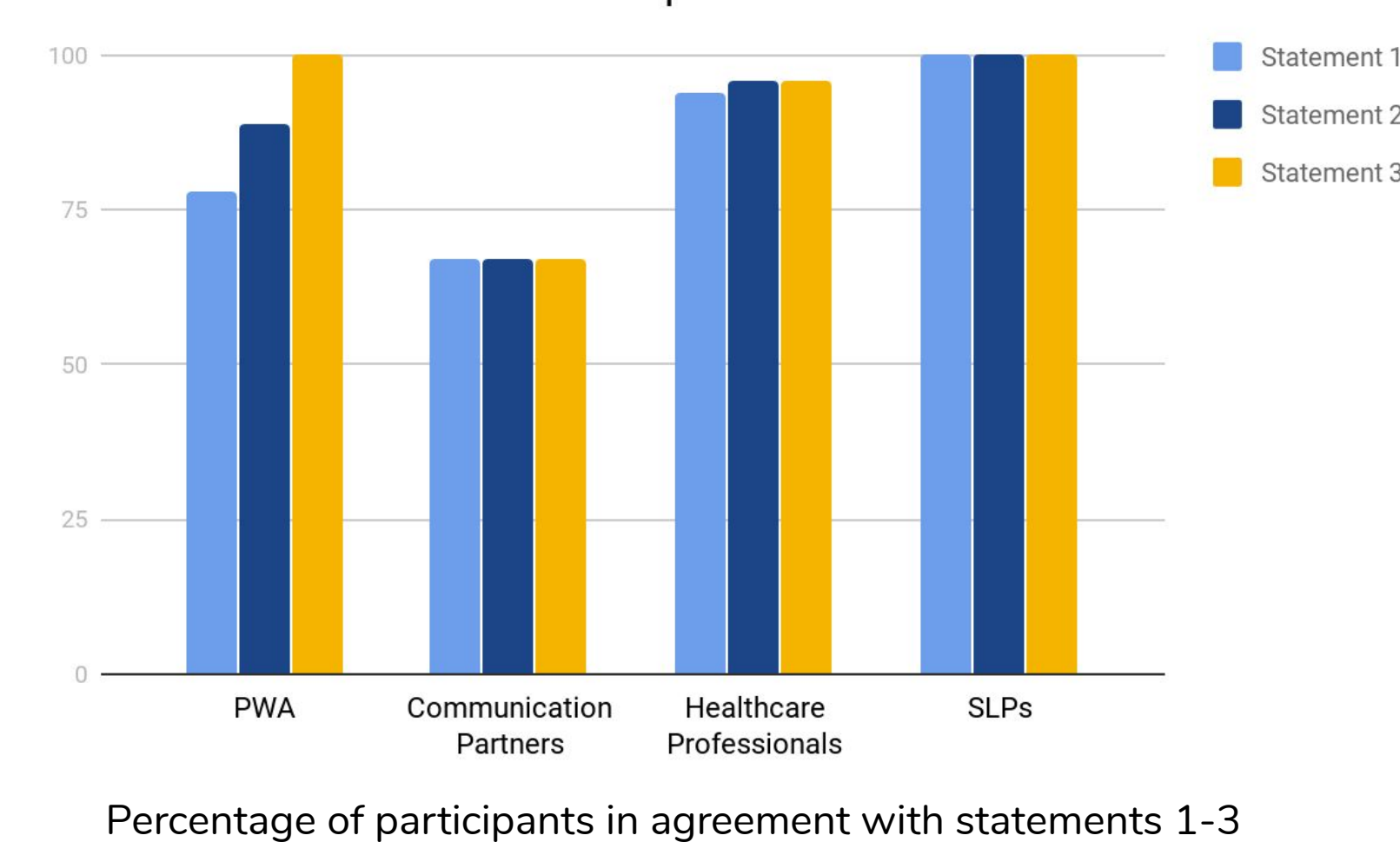
**"Lack of aphasia support is a large gap in our system outside of hospital care." - OT in Edmonton**

## Perceived Benefits of an Aphasia Centre

The majority of participants believed access to ongoing communication services would:

1. Increase the ability of PWA to **participate in activities of daily life**
2. Allow PWA to take a **more active role in their healthcare**
3. **Improve the quality of life** for PWA

Perceived Benefits From All Respondents



In a follow-up question solely for PWA, **all respondents** indicated they **believed they would benefit from access to ongoing communication services**.

## Vision for A.C.E.

The ACE will follow the **Life Participation Approach to Aphasia (LPAA)** service delivery model (Chapey et al., 2000). The core values of the LPAA include:

- Enhanced Life Participation as an Explicit Goal
- All Those Affected by Aphasia are Entitled to Services
- Personal and Environmental Factors are Intervention Targets
- Services are Available at all Stages of Aphasia

The ACE will be a brick and mortar facility designed to provide ongoing services and education for PWA, their communication partners and professionals. Through individual and group therapy services, the ACE will:

- Create **community** for PWA and their primary communication partners
- Provide **education** about aphasia
- Serve and **hub of resources** for healthcare professionals
- **Advocate** for PWA and **Communication Access**
- Provide unique **research** and **training** opportunities.

Participants identified conversation groups, education about aphasia, individual speech therapy, and advocacy groups as the highest priority services.

## Conclusions and Future Steps

The results of all the surveys and interviews indicate the following:

1. A **lack of centralized services** for aphasia in Edmonton
2. There are many **perceived benefits** of ongoing communication services

**A.C.E. (Aphasia Centre of Edmonton)** would provide both centralized services and ongoing communication services for aphasia.

- Limitations include small sample sizes for interviews
- Future studies should **pilot programs** that would be offered by an aphasia centre in order to demonstrate the impact that such programs have on quality of life, activities, and participation.



Photo from Alberta Aphasia Camp, 2019

## References

- Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons Mackie, N. (2000). Life participation approach to aphasia: A statement of values for the future. *The ASHA leader*, 5(3), 4-6.
- Fink, R.B. & Schwartz, M.F. (2000). MossRehab Aphasia centre: a collaborative model for long-term rehabilitation. *Topics in Stroke Rehabilitation*, 7(2), 32-43.
- Rose, M. L., & Attard, M. C. (2015). Practices and challenges in community aphasia groups in Australia: Results of a national survey. *International journal of speech-language pathology*, 17(3), 241-251.
- Woelders, S., van der Borg, W., Schipper, K., & Abma, T. (2018) The meaning of aphasia centres from the perspectives of PWA and their relatives: understanding participation in the Dutch context. *Aphasiology* (32)12, 1490-1512. doi: 10.1080/02687038.2018.1441364