Exploring the social experiences of people with aphasia

PROJECT REPORT

Erika Snowden
Elizabeth Russell

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TRENT UNIVERSITY
PSYCHOLOGY

Study Information

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Ethics

The research was approved by the Trent University Psychology Research Ethics Subcommittee: File #13868

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For more information about this research, please visit www.trentu.ca/aging/aphasia or email ruralaging@trentu.ca or elizabethrussell@trentu.ca

As Trent University researchers, we respectfully acknowledge that this research was undertaken on the treaty and traditional territory of the Mississauga Anishinaabeg. We offer our gratitude to the First Nations for their care for, and teachings about, our earth and our relations. May we honour those teachings.

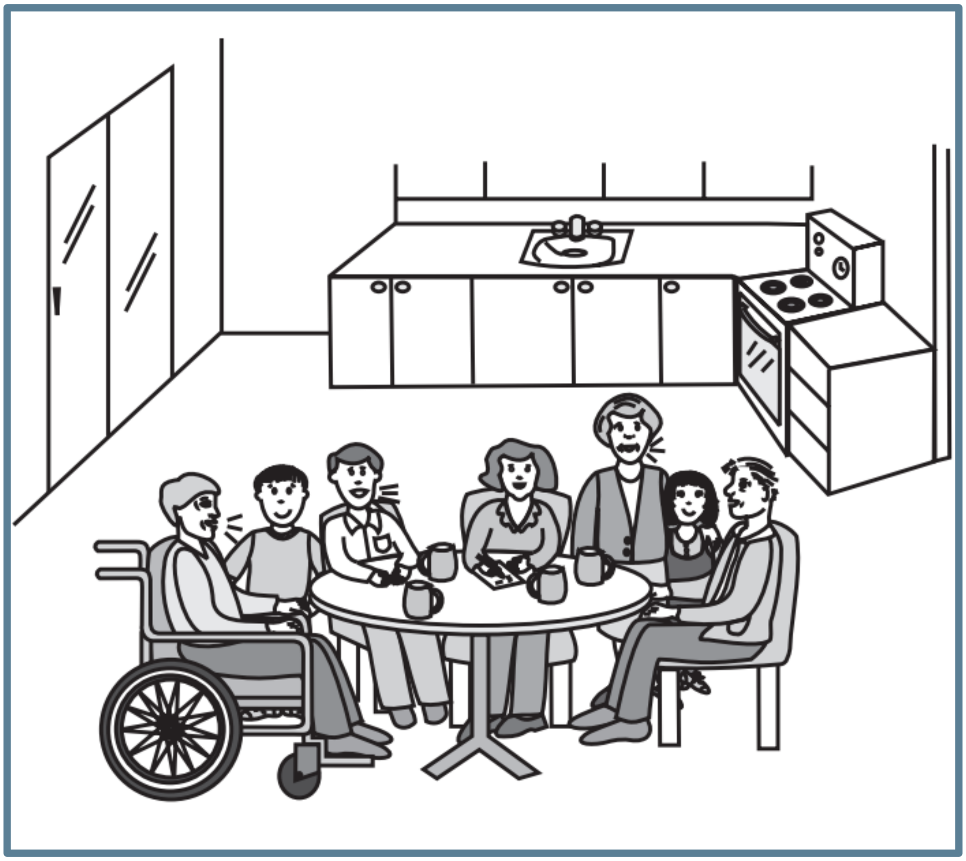
Acknowledgements

This project would not have been possible without the support of March of Dimes Canada and the Aphasia and Communication Disabilities Program (ACD). Their encouragement and cooperation allowed me to pursue a research topic that I am truly passionate about. My involvement with the ACD program has taught me so much about aphasia, community involvement, and inclusive communication.

I would especially like to thank Sara Piotrowska (SLP), Tahera Khalfan (CDA), and the clients of ACD Peterborough, who taught me everything I know about aphasia-friendly communication. Applying what this program has taught me in a research capacity is a dream come true.

Finally, and most importantly, I would like to express my sincerest gratitude to the participants of this project for sharing their stories with me. They welcomed me with warmth and laughter, contributed to how I adapted my methods, and encouraged me with their enthusiasm to be involved. I am immeasurably thankful for their trust. Their contributions were the driving force behind this project and their insight is invaluable. Thank you.

To learn more about the March of Dimes Canada: Aphasia & Communication Disabilities Program, please visit the program website.



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EXECUTIVE SUMMARY

It is estimated that **30% of people who have a stroke acquire aphasia**, a communication disability that impacts language and communication (Speech-Language & Audiology Canada, 2024). Challenges with communication can impact a person's **social participation**; specifically, their ability to take part in activities that provide meaningful interactions with others (Levasseur et al., 2022).

To better understand how social participation is impacted by aphasia, **this research investigated the social experiences of five adults with aphasia** attending a March of Dimes Canada: Aphasia and Communication Disabilities (ACD) program in **Peterborough, Ontario**, which is situated on the **treaty and traditional territory of the Mississauga Anishinaabeg**. Five semi-structured, **aphasia-friendly interviews** were conducted in February and March of 2024. A qualitative thematic analysis revealed **three key themes**: 1) living with aphasia, 2) barriers to social participation, and 3) facilitating social participation.

In line with previous studies, the present research found that participants' social participation was **significantly impacted by social support**. Negative social experiences emerged as a major barrier for participants' social participation; other people's low aphasia awareness was perceived by participants as a main contributor to their negative experiences. Based on the findings, organizations and policy makers can **improve social participation** for people with aphasia by implementing and promoting **three key goals**: 1) **increasing public aphasia awareness**, 2) **improving social interactions for people with aphasia**, and 3) **creating and maintain accessible community spaces**.

The present research adds to the body of knowledge exploring the complex social experiences of people with aphasia, and presents recommendations for communicative access, as identified by the participants.

RECOMMENDATIONS

Organizations and policy makers can **increase social participation** for people with aphasia by implementing and promoting three key goals: 1) **increasing public aphasia awareness**, 2) **improving social interactions for people with aphasia**, and 3) **creating and maintaining accessible community spaces**.

RESEARCH CONTEXT

This study was inspired and informed by the experiences of Erika Snowden, the **honours thesis researcher**, during her time as a **communication facilitator within the ACD program**, spanning from 2021-2025. Involvement in the ACD community fostered Erika's desire to elevate the perspectives of people with aphasia and contribute to **communicative access**, which became the basis for this study, and a strength of the research.

Erika's extensive **experience and training** in communicative accessibility, aphasia awareness, and the personal communication needs of this group heavily informed the **design and implementation of the research**, allowing her to best **support participation** for everyone involved.

To address **ethical considerations** associated with this study, as per our approval by Trent University's Research Ethics Board, **the voluntary nature of participation** was emphasized at every point of the research beginning with recruitment and continuing through to the end of participation.

BACKGROUND

Key Concepts

Aphasia

Aphasia is an acquired disability resulting from stroke, brain injury, or brain illness that impairs communication and language skills. **It is estimated that approximately 1/3 of people who have a stroke will live with aphasia** (Speech-Language and Audiology Canada, 2024) which can impact speech, understanding, reading, and writing abilities.

It is often said that aphasia **"masks competence"** due to the breakdown between what an individual knows and their ability to express themselves through speech. Despite its prevalence, **public knowledge about aphasia is consistently low** (Code, 2020; Simmons-Mackie et al., 2020), which influences how people with aphasia are treated by others and what resources are available to them (Simmons-Mackie et al., 2020).

Social Participation

Social participation examines how people's voluntary participation in activities at the individual level (e.g., interpersonal relationships), the community level (e.g., participation in community programs), and the institutional level (e.g., membership in political groups) contribute to wellbeing and help people give meaning to their life (Levasseur et al., 2022).

Meaningful interactions with others have been found to **improve quality of life across ages and abilities, including in people with aphasia** (Archer et al., 2023; Blonski et al., 2014). However, taking part in such activities is more challenging for individuals with disabilities, whose needs are often not well met by their environment (Griffith et al., 2016; Levasseur et al., 2024).

Personal, social, and environmental factors all play a role in people with aphasia's ability to **participate socially**. People with aphasia often experience social isolation (Hilari & Northcott, 2017; Kim et al., 2023), while deteriorating social networks, fewer opportunities for community involvement, changes to social roles (e.g., from caregiver to care receiver), and less independence compared to before their diagnosis (Manning et al., 2021) create barriers to social participation.

Understanding how social participation is impacted by communication disability is vital to supporting the social and psychological wellbeing of people with aphasia.

PRESENT STUDY

The present study sought to explore how people with aphasia **described** their experiences with social participation, to **identify** challenges and supports to social participation for these individuals, and to **gain insights** into communicative accessibility, all informed by **participants' lived experiences**.

Study Objectives:

- ***Describe*** the day-to-day communication experiences of people with aphasia attending ACD Peterborough;
- ***Investigate*** how these experiences contribute to or challenge people with aphasia's social participation;
- ***Identify*** barriers and support for participating socially with aphasia;
- ***Highlight*** recommendations from people with aphasia for improving communication access, thereby facilitating social participation.

Study Goals:

To better **understand** the **communication experiences** of people with aphasia, to gain their **insights** into **communicative access**, and to contribute to **aphasia awareness**.

RESEARCH DESIGN

Collaboration with March of Dimes Canada (MODC)

The study was undertaken in collaboration with the **March of Dimes Canada: Aphasia & Communication Disorders (ACD) Program** in Peterborough, Ontario. The ACD program is a weekly group which services adults with aphasia and other communication disorders in Peterborough and the surrounding area. At the program, clients meet to **practice** communication skills, **participate** in conversation with peers, and **engage** in a community. The program's mission goals are to improve communication, enhance quality of life, support independence, encourage participation in community life, and provide communicative access (March of Dimes Canada, 2022).

Development of Research Materials

All materials used were newly created for the purpose of this study. The goal was to take an **informed, evidence-based approach** to designing a qualitative study that would meet the needs of a participant sample with aphasia and be comfortable for participants of the ACD group.

Based on an extensive review of literature on the accessible inclusion of people with aphasia in research, adaptive communication techniques, and the researcher's prior experience creating content for the ACD group, materials synthesized recommendations from the literature and ACD content delivery formatting. Information and consent forms were created based on a template from the Collaboration of Aphasia Trialists (CATs), a working group dedicated to facilitating aphasia research (The Collaboration of Aphasia Trialists, 2023).


If someone wanted to make their **organization** more **aphasia-friendly** what **advice** would you give them?

Along with the accessible information and consent forms, **PowerPoint slides** were developed to deliver recruitment information and support conversation during the research process. Using ACD program materials as a template, these slides took an evidence-based approach through the inclusion of **Participics**: pictographic tools developed by the Aphasia Institute to facilitate communication for people with aphasia.

Participics are free to use and fit a variety of conversation topics. The searchable database can be found here.

METHODOLOGY

Recruitment

Upon receiving ethics approval, a **recruitment presentation using Power Point slides** was delivered to each ACD Peterborough group (morning and afternoon). ACD clients who expressed interest in the research were sent a follow-up email by the program speech-language pathologist, encouraging them to communicate directly with the researcher to obtain more information and arrange participation.

Data Collection

Data collection consisted of five individual, aphasia-friendly interviews. Using supportive communication strategies, the interview procedures were adapted to each participant's communication needs; communication was an ongoing, collaborative process between the researcher and the participant.

Interviews were 60-90 minutes in legnth and were held either in-person in private meeting rooms at Northminster United Church (where the ACD program is held) and Trent University, or over Zoom. Interviews covered **topics** such as participants' **experiences living with aphasia**, their **experiences interacting with others in community spaces**, and the **challenges and supports they faced to participating socially with aphasia**.

Participants

Participants were **five adults with aphasia** attending ACD Peterborough at the time of recruitment. The **average age of participants was 55 years old**; consistent with Ontario stroke survivor demographics, participants were mostly over 55 years old. **Four** participants identified as **female**; **one** participant identified as **male**.

Participants' communication **support needs varied greatly**. For example, some participants had limited speech and relied almost exclusively on non-verbal communication methods, while other participants had more verbal expression and required support with receptive communication.

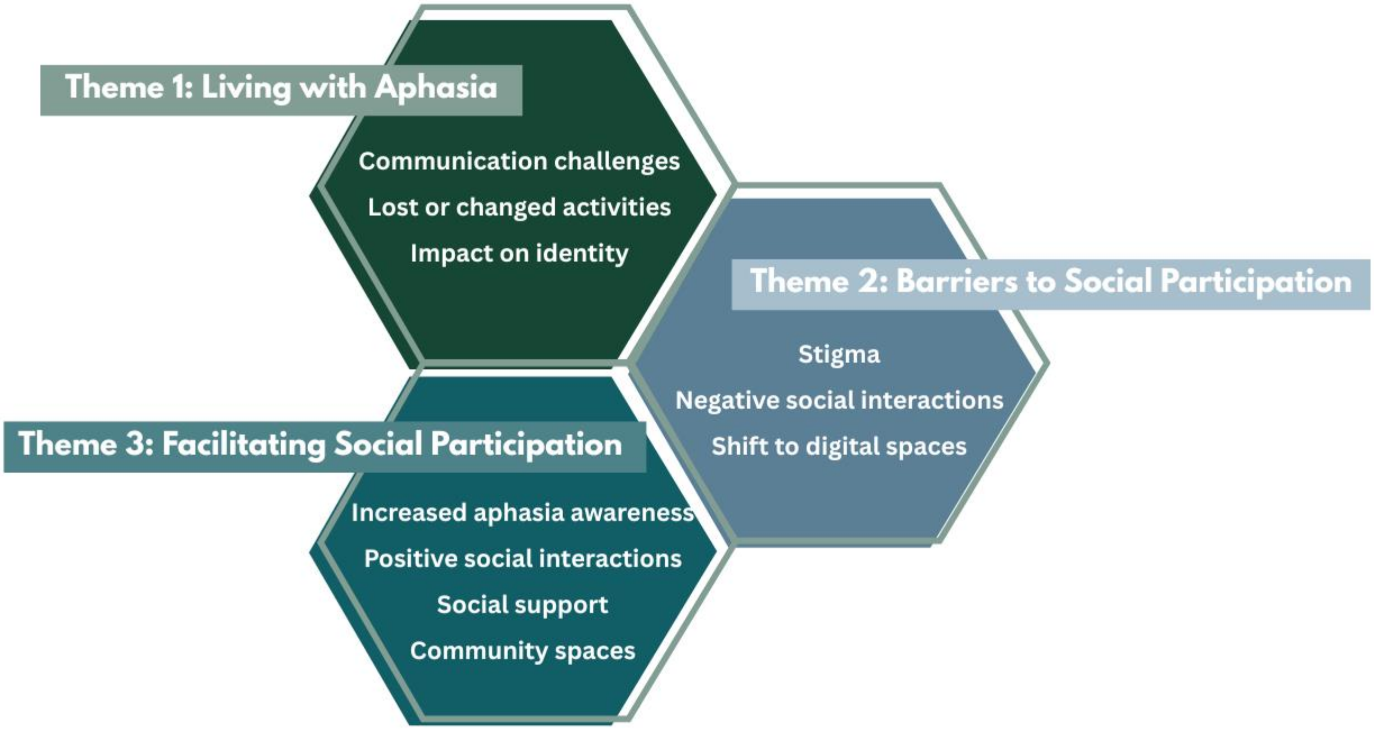
Data Analysis

With participants' informed consent, **interviews were audio and video recorded and transcribed**. To ensure the transcripts accurately represented data from all participants regardless of verbal expression, both video and audio recordings were incorporated in transcription: **non-verbal communication** such as **gestures** and **writing** were described and included in the transcripts for analysis.

Following **a thematic analysis process**, the transcripts were reviewed and holistically analyzed, revealing **three emergent themes**: 1) **living with aphasia**, 2) **barriers to social participation** and 3) **facilitating social participation**.

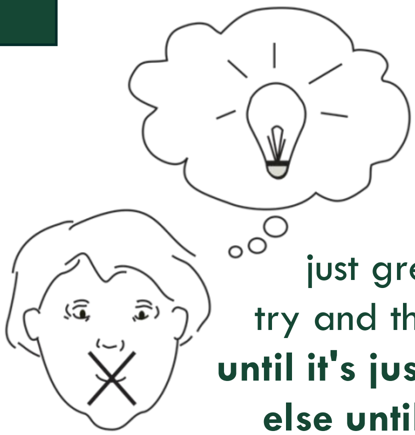
FINDINGS

Three key themes emerged in how participants described their experiences: **living with aphasia**, or how participants described their personal experiences living with a communication disability**, barriers to social participation** that negatively impacted participants' opportunities for interacting with others, and **facilitating social participation**, which described the ways that participants felt their social experiences could be improved.



Participants are quoted verbatim to enhance the analysis, however, to preserve their privacy, **identifying information has been removed** and participants have been assigned **pseudonyms**.

> ***"The person [you] spoke to before and person [you] speak to now is not that different. […] I'm still the same person."***
>
> - *Louise, she/her*



Theme 1: Living with aphasia

> "When there's something in my head, I picture this **grey bubble.** I can see **there's something in the bubble** but it's just grey enough that **you can't read what it is.** And the more you try and think about it and struggle with it, the darker the bubble gets **until it's just gone** [...] you're so stuck on it that **you can't do anything else until you get it.** And it can feel like you're gonna lose control of everything"
>
> - *Rebecca, she/her*

Participants described the **personal communication challenges** that resulted from their aphasia such as difficulty with reading and writing, word-finding, expressing thoughts with speech, and following conversations. Despite individual differences in symptoms, the experience of having a disconnect between intact thoughts, emotions, and opinions and the ability to communicate these with others was felt by all participants.

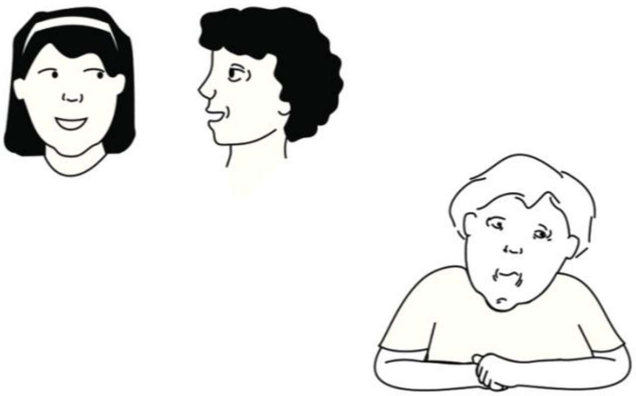
> ***"I know [Ruth puts hand to her chest, makes motion outward, she is teary] but it is hard to say how it is for me"***
>
> - *Ruth, she/her*

Feelings of hidden competence impacted participants' **sense of self and identity.** Participants felt that aphasia prevented others from seeing who they really were, which affected their confidence. Participants emphasized **the importance of feeling recognized as individual people after the occurrence of their stroke**. Participants felt that due to their aphasia, people were more likely to avoid or minimize the life they had before the stroke.

Participants expressed strong **desires to make meaningful contributions in society**, and these desires were often integral to how they viewed themselves. Participants spoke of **helping others** who had aphasia, **breaking down barriers to accessibility**, and **contributing their knowledge**.

For many participants, **the loss of, or changes to, recreational activities or sports** that they had enjoyed pre-stroke was a significant aspect of their experience. Some participants coped with these changes by finding new ways to socialize, such as attending swimming lessons or going on neighborhood walks. However, replacing old activities with new ones seemed to be dependent on how much family support participants could access. Ruth and Henry, who lived with their respective families, had other activities they were currently involved with, while Anna, who lived alone, felt she had no one to socialize with and limited transportation to attend ongoing activities in her community.

Theme 2: Barriers to Social Participation



> “[Henry gestures to indicate **a person in front of him,** gestures to indicate **a person beside him,** then looks between them: **he is acting out being left out.** He shrugs his shoulders with his hand on his chest, eyebrows raised and mouth **frowning –** expression looks like ‘**I’m right here!**’]”
>
> - *Henry, he/him*

Negative social experiences emerged as the main barrier participants faced when interacting with others, including when trying to access support and community services. In some cases, this meant being perceived as incapable of communicating or being left out socially altogether. **Stigma** was a major concern for participants, who used words like **“weird”** (Rebecca) and **“stupid”** (Louise) to describe how others treated them. Participants expressed that most people that they encountered had a poor understanding of aphasia and mostly blamed this low knowledge for the lack of respect they experienced from others.

> ***“[After the stroke] I went home, I have no friends. They disappeared. Disappeared! […] Hugely [difficult]”***
>
> - *Anna, she/her*

A noteworthy finding was that these **negative experiences appeared unrestricted by the type or formality of the service participants attempted to access**. Many participants experienced negative interactions, stigma, or ignorance in spaces that they expected to be more supportive (e.g., accommodation services, government offices, disability-specific programs). To try and account for this gap in knowledge, most participants felt comfortable informing others about their aphasia and explicitly asking for the support they needed. Unfortunately, this did not always work as intended. Some participants described how their attempts to self-advocate often ended poorly, as conversation partners minimized, misunderstood, or ignored their needs.

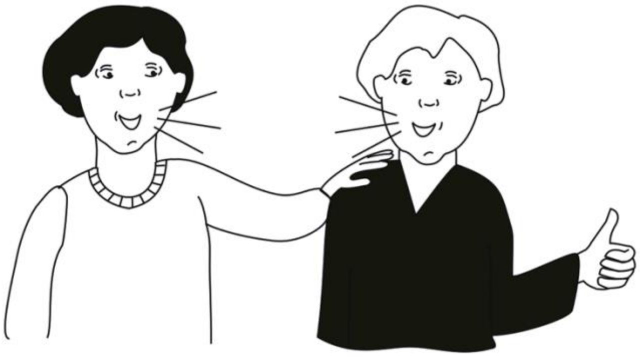
> ***“[People] say, ‘Oh, that happens to everyone.’ It makes me want to scream. I wish the world could look into our aphasia group to just understand what it actually is”***
>
> *- Rebecca, she/her*

Frustration and discouragement led some participants to feel that increasing knowledge and understanding about aphasia would make no difference to the amount of **stigma** they faced. Anna felt the real reason others mistreated or excluded people with aphasia was because **"They don't care […] Sorry to say it. [She waves her hand dismissively] They don't care"**. Whether participants blamed a lack of knowledge or a lack of consideration, they all felt that their social participation was hindered by the treatment they received from other people.

The **shift to digital and online spaces in society**, particularly during and following the COVID-19 pandemic, was a complex issue due to the different needs among participants in this study. For some participants, a shift to digital spaces **represented a loss of opportunities for social participation**. Participants who relied on self-advocacy for successful interactions felt that their ability to identify their specific challenges and needs was hindered with phone and digital communication, particularly in cases where visual strategies (e.g., writing, aphasia wallet card) were used. Furthermore, some participants expressed feelings that since the COVID-19 pandemic, socializing has become increasingly reliant on technology (e.g., videoconferencing) which did not offer the same engagement as socializing in-person.

> ***"I don't really have anyone to communicate with like, speech. We can chat [on a device]... I can type it, but it's not the same"***
>
> *- Louise, she/her*

Critically, for some participants, the availability of remote digital spaces **enabled social participation**. Participants who had limited support or issues with transportation relied on videoconferencing options to engage with others, for example in the Zoom portion of the ACD group. Taken together, these findings suggest that a shift to digital spaces can be a barrier or an enabler for the social participation of people with aphasia, depending on personal circumstances**. It is important that options for both in-person and remote activities exist**, so that individuals may choose what best suits their needs.



Theme 3: Facilitating Social Participation

> "Even if I only say a **few words,** it's nice. It's really happy to say 'Oh, **I'm still in this community** with these people'"
> - *Louise, she/her*

Increasing aphasia awareness among others was the main way that participants felt social participation could be facilitated for people with aphasia. Participants emphasized that for specific supports such as communication strategies to be effective, people with aphasia needed **"[increased public] awareness before you can get to anywhere else"** (Rebecca). Improving recognition for aphasia was considered the first step in creating a more inclusive environment and noted that even minimal awareness prompted people to be more flexible and ask questions like "how can we help you?". Most participants felt motivated to use their experiences with aphasia to raise awareness **"for myself and for people [with aphasia] who are out there"** (Ruth) through being visible in their community, participating in research projects such as this one or through **"programs with a teacher [who has] aphasia. […] for normal [i.e., without aphasia] people"** (Anna). Participants felt that if people were more knowledgeable about aphasia, they would treat people with aphasia respectfully and be open to adjusting communication to support them. Increased knowledge would provide the basis for more concrete actions to improve social interactions, such as the use of communication strategies.

> ***"When you approach the people, you should speak to them normally. You should use normal voice"***
> *- Anna, she/her*

Participants described how **improving social interactions** would facilitate their social participation and inclusion. Participants emphasized that everyone's challenges with aphasia were different, so communication would take time and consideration but felt that **"everyone should know to speak clearly to everybody, whether they have aphasia or not"** (Louise). Although most participants wished people would be mindful of how quickly they spoke, they noted with some humor that speaking in slow-motion or raising your voice was unnecessary:

> Henry, when asked if people often raise their voice around him: ***Yeah. Yeah. Oh. [Henry rolls his eyes with a groan, laughs]***
>
> Interviewer: ***So, speak clearly not loudly?***
>
> Henry: ***[Henry is laughing, he touches his ear and winces as if it rings]***
>
> - *Henry, he/him*

In general, participants wanted people to be more considerate in their interactions with others, to pay attention, and to be flexible when communicating. Participants recommended that others **"be patient and be light"** about communication breakdowns, and to **"keep in mind how frustrating it is for us"** (Rebecca). Since many people with aphasia lack opportunities to socialize, **participants felt it was most important for people to know they could approach and include them, even without being experts in accessible communication**.

Communication strategies like those outlined in Supported Conversation for Adults with Aphasia (SCA) helped to facilitate their social participation. Some strategies, such as pacing speech and giving time, were things participants felt should be incorporated across the board, while implementing more applied communication strategies, such as keywording or offering numbered choices, usually came with getting to know a person's specific communication style. However, participants did stress that that employees in service jobs should have some communication strategy training, so that they could offer specific support when requested.

Social support played a major role in the opportunities participants had to engage in the activities that were meaningful to them. Although all participants described changes to their social experience since the occurrence of their stroke, the degree to which they had been able to reclaim opportunities for engagement differed drastically. **Participants who had regular access to family and friends described having more opportunities for socializing, being involved with more groups, and seemed more engaged in activities that brought them satisfaction and fulfillment**. In some cases, this was due to practical support, like having someone who could drive them to places, advocate for their needs, or help them with grocery shopping. In other cases, friends and family offered emotional support, or validated participants' sense of competency.

> ***"They know I can do something […] I feel well, I feel good when I'm with my friends"***
>
> *-Ruth, she/her*

Having support reduced the perceived impact of aphasia on social participation among most participants. This was especially true for Louise, who expressed having a strong support network which included family, friends, and community members who she described as "okay with aphasia":

> ***"They say things in a different way sometimes if they're speaking to me […] not like it's talked down to me, but they rephrase their words, to make it easier for me to understand. And that's the thing makes me feel like [aphasia] doesn't have an effect in my day-to-day life, which is great"***
>
> *- Louise, she/her*

In contrast, participants who did not have as robust social support had very little opportunity for social participation, were involved in minimal groups or activities, and expressed feelings of loneliness and isolation. They felt abandoned by friends from before their stroke, lived alone, and felt they had no one to go out with:

> ***"Friends are a huge part of my life. Now? I don't see anybody. Difficult. Difficult. [Anna has an upset expression]"***
> *- Anna, she/her*

In these cases, **supportive community spaces**, such as the ACD program, which participants described as being "like family" became particularly important. Anna, in particular, felt that the ACD program was one of the few opportunities she had to "meet people" and "to speak" on a regular basis. Other participants identified different post-stroke or disability groups as safe spaces they attended, such as Life After Stroke, or Diabetes conferences.

The ability to walk or roll around the neighborhood, say hello to neighbors, and visit familiar community spaces such as the public library played an important role in the lives of participants in this study. **Feeling supported and safe among neighbors and community members contributed to participants' opportunities for meaningful interactions**. Participants frequently used the word "familiar" to describe the places and people in their community who made them feel included. Participants described familiarity as feeling they were known or recognized, that their communication needs were understood, and that they felt comfortable being **"open with my aphasia"** (Rebecca).

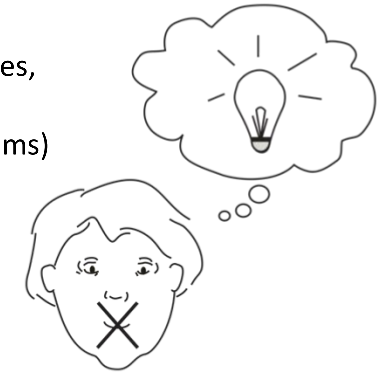
RECOMMENDATIONS

This research aimed to examine how participants with aphasia described their social experiences, including the challenges and supports to their social participation, and to gain their insights into improving communicative access. Based on our findings, organizations and policy makers can **improve social participation** for people with aphasia by implementing and promoting **three key goals**:

1

Increasing public aphasia awareness

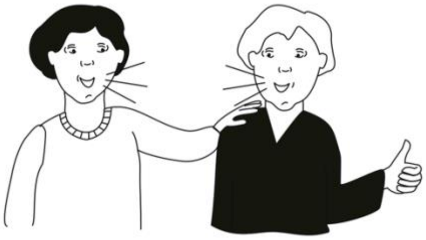
- Focus on **increasing knowledge of aphasia** outside of aphasia-specific spaces, particularly in **settings** where people with aphasia are most likely to **access services** (e.g., government offices, medical settings, stroke recovery programs)
- **Including and centering** people with aphasia in **the development and delivery of aphasia awareness initiatives**
- **Promoting** the message that aphasia masks **competence** (e.g., speech does not equal intelligence)



2

Improving social interactions for people with aphasia

- Prioritizing **communicative access** through **policies**, **procedures**, and **planning**
- Making **training** and **workshop opportunities** (e.g., [SCA training]) broadly **available and accessible** (e.g., at local libraries, public institutions, online)
- Speaking in a **normal tone of voice** and remaining **flexible** when communicating
- Using **supportive communication strategies** if you are able
- **Asking** people with aphasia **how they would like to be supported**



3

Creating and maintaining accessible community spaces

- **Providing both in-person and remote options** for participation in community groups, programs, and activities
- Delivering and promoting **aphasia-friendly programs** (e.g., ACD, Life After Stroke) where people with aphasia can **interact meaningfully** with others, **meet people**, and **form social connections**
- **Improving the accessibility of community spaces** through visuals, labeling, and sensory-friendly settings

For more information and to access the full honours thesis, please visit:

www.trentu.ca/aging/aphasia

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