

Bringing Aphasia to Life: A volunteer's perspective

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As a group of speech-language pathologists working on a neuro-rehabilitation unit, we have found it invaluable to have volunteer support for our programs. During the past year, these volunteers have allowed us to offer enriched programming for our clients with aphasia.

We started with one undergraduate volunteer and interest from other students grew immensely. To date, we have had six volunteers involved with our program.

The volunteers have participated in our weekly aphasia group and observed individual assessment and treatment sessions. In addition, some of them have had the unique opportunity to serve as conversational partners for clients with aphasia – an experience the clients would otherwise not have had.

With the help of our volunteers, we have been able to develop a resource binder for the aphasia group, which we have also shared with our colleagues in community-based programs for people with aphasia.

The following reflections from four of our volunteers illustrate how accessing volunteer support has been a mutually beneficial experience and has added value to our programs:

“One of the most exciting things I witnessed while volunteering with the aphasia group was how clients would use their communicative strengths to help others with areas or moments of difficulty. This really highlights the truth that language is a social phenomenon and is facilitated by social situations. Additionally, since I knew that aphasia could be a devastating impairment, I guess I never thought that treatment would be so fun. I always look forward to working with the aphasia groups because smiles are sure to be had. I started volunteering to see if a career in speech-language pathology was an appropriate path for me and to meet admission requirements. The challenge and reward of interacting with clients with aphasia has made me certain that I've chosen the right career path. I've met my requirements, and now I volunteer just for the joy of it.”

Catherine Knott
BA Linguistics, BA Psychology

“Despite numerous exposures to aphasia in my courses and textbooks, being offered the experience to actually work with patients with aphasia has provided me with new insights and understandings of the disorder. Observing the different kinds of aphasia was a totally different experience than simply learning the

definitions from a textbook, and this greatly enhanced my learning. Working with patients with aphasia led me to develop compassion and understanding for all the hard work they do in order to improve their communication. Realizing the impact therapy can have on the daily life of a patient with aphasia has really fuelled my passion to pursue speech pathology as a career.”

Kimberly Freed
B.Sc. Honours Psychology

“My initial intention, just like every student volunteer, was to get a reference letter for grad school. Prior to this volunteer experience I had volunteered at a hospital gift shop and emergency department. Even though I had learned a lot of skills and gained experience in the health care environment, everything I learned was passive.

“I had previously taken an introductory course to speech-language pathology, however, volunteering on the neuro-rehabilitation unit made my textbook and course notes come to life! Aphasia is the disorder that has by far intrigued me the most. I have been actively involved in developing a resource binder filled with activities that would aid in aphasia group therapy. I have observed strategies used by S-LPs to ‘get through’ to the aphasic patient.

“In addition, I had the opportunity to observe individual treatment with aphasic patients and assist with preparation of therapy materials. I also spent time helping patients with their speech-language homework and became familiar with using BoardMaker® to make communication boards and books.

“In summation, the desire I have had since Junior High to become a speech pathologist has only been confirmed by my experience as a volunteer. I had initially thought I would not pursue speech pathology further than a Masters degree, but with the experience and knowledge that I have gained, I am intending on pursuing a PhD in speech pathology.”

Veena Kallambettu
BA Linguistics

“Volunteering has allowed me to witness the amazing opportunity S-LPs have to help clients with aphasia rise to their fullest communicative abilities through therapy, compassion and support. The experience that has impacted me the most was creating a *Go Talk* communication board for a client with global aphasia. When we handed her the board she realized that she now had nine sentences to communicate, when she previously had none; the joy on her face made this a priceless experience for me.”

Lindsay Rowe
BA Linguistics



L to R: Lindsay Rowe and Heather Tomlinson



Aphasia Camp 2008

Jan Roadhouse, MSLP, Reg. CASLPO
Speech-Language Pathologist
Aphasia Program Co-ordinator, ARTC
Brantford, Ontario

*"I have learned more than I could have imagined.
I was inspired by everyone at the camp"*

—UWO S-LP student

*"There was a great emphasis on keeping a positive
attitude while living with aphasia, which
helps with the coping process"*

—family member

"#1 weekend of my life"

—Stephen Goff, person with aphasia and inspiration
for Aphasia Camp

Aphasia Camp 2008 was a weekend camp for people with aphasia and their caregivers from September 19–21, 2008, at Tim Horton Onondaga Farms near Brantford, Ontario. It was sponsored by the Adult Recreation Therapy Centre (ARTC), a community-based adult day program for individuals with stroke and other acquired conditions. The mandate of the ARTC is to help individuals to maintain an optimum level of physical ability, intellectual function and social interaction, and to offer support, respite and information to caregivers.

The Camp program included:

- a session for people with aphasia, facilitated by a stroke survivor and an S-LP;
- a session for caregivers, facilitated by an S-LP and social worker;
- adapted physical activities including golf, biking (recumbent bikes, trikes), hiking, fishing, music, art, crafts, campfire songs, mocktails and games night, and chat; and
- time for caregivers to meet for informal and facilitated discussion, support and sharing.

The camp was intended to help people with aphasia and their caregivers to *live more successfully with aphasia* through participation in physical, social and educational activities. Aphasia training for staff, students and volunteers ensured that all aspects of camp were communicatively accessible and "aphasia-friendly." To our knowledge, an Aphasia Camp has never been offered in Ontario or elsewhere in Canada.

Our campers included 36 people with aphasia and 29 family members/friends from across southern Ontario. More than 30 staff, students and volunteers worked at Camp. We had an innovative and mutually beneficial partnership with the University of Western Ontario. Taz Moosa recruited, trained and supervised eight first-year speech pathology students, who earned clinical placement hours through this unique opportunity. The following quotes from the students' feedback illustrate how their experience at camp took them beyond the classroom:

- *I've learned much more here than I think I ever could in the classroom (as an S-LP student). Thank you for including us from Western U.*
- *I'll think more outside of the therapy room to things and activities we did at camp.*
- *It will be easier to keep in mind that people live day-to-day with aphasia.*
- *Building relationships and learning from those with aphasia built a sound clinical foundation for me to work within school.*
- *I will feel more comfortable working with people affected by aphasia and those with other communication difficulties.*
- *I will not avoid issues I feel might emotionally impact a patient, e.g. talking about their stroke.*
- *I will also work towards building connections with their caregivers.*
- *It was a great experience and I learned so much about people with aphasia. It is a great segway [sic] into clinical practicum to interact with people with aphasia in a recreational setting to become comfortable with supported conversation.*
- *It was great to put the theoretical to practice.*
- *A truly life-changing experience. I've become a better listener, a better communicator, a better clinician and above all a better person because of Aphasia Camp 2008. Please do this again – people with aphasia (and their families) need it.*
- *My experience was AMAZING!*

Feedback from campers

Feedback from campers was overwhelmingly positive. Survey results indicated that the majority of people with aphasia felt that the camp experience would help them to live more successfully with aphasia and that they intended to become more socially and/or physically active in their own community as a result of Aphasia Camp. One respondent wrote "maybe even dance."

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Aphasia Camp 2008 participants and staff



Aphasia camp

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Comments from people with aphasia included:

- *Fantastic!*
- *Treated us so well, normal*
- *I learned more patience*
- *Great experience*
- *I can ride a bike!*
- *Relaxed*

Comments from family members included:

- *Inspired by other caregivers in similar situations.*
- *It was excellent!*
- *I enjoyed everything.*
- *The cost was right for me. I have a small income.*
- *I do not see how Aphasia Camp could be improved.*
- *We would return. Great quality of volunteers, well thought out program and good schedule.*

Another important partnership was with the Ontario March of Dimes. We benefited from their expertise in offering summer camps to people with physical disabilities. Together we have created a comprehensive manual for running a weekend camp. It is available free of charge to S-LPs who are interested in running a camp. On a personal note, Aphasia Camp 2008 was a most rewarding way to mark my 20th year in speech pathology!

Services offered to clients with chronic aphasia

By Allison Baird, MA, CCC-sp
Speech-Language Pathologist
Speechworks Inc.
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During the last five years I have enjoyed the opportunity to develop a community-based service for people with cognitive-communication impairments secondary to acquired brain injury. This has occurred within the context of my private practice, Speechworks Inc. I believe that a continuum of care is essential when dealing with adults with chronic communication disorders and so we offer a range of services each requiring varying levels of commitment from myself and my clients. In this article I will discuss some of the services I offer to people with chronic aphasia.

For clients interested in speech/language practice and drill skills, we offer individual treatment that is rooted in a constraint-induced treatment model. Constraint-induced language therapy is characterized by forced use of verbal language and massed practice. The best outcomes we have been able to achieve given the limited contact we have with clients have been accomplished with the use of computers and appropriately assigned software. Computers provide an opportunity to experience a rapid and repetitive type of stimulation and the independence in the task encourages client-centered therapy.

After assessment and interview, the client is introduced to a laptop computer loaded with a range of software options. A starting point is selected and the client is sent home with the laptop and recommendations for daily computer-based homework. Sometimes family or health care aides are trained

to assist with computer use. It is common for a client to select a goal that is not a goal that I would have selected. I have been astonished with the outcomes associated with this self-directed therapy. Recovery that I was certain would not occur does occur to a level that is satisfying for the client.

I have not yet encountered a client who is unable to interact at least minimally with a computer. Most of my clients have been discharged from public services after having reached a plateau in treatment and yet 90 per cent experience a measurable treatment effect and are seen only once a week. Of course the client decides when to discontinue treatment, and as they adjust to the disabling aspects of aphasia, different services are required.

Group treatment through Speechworks Inc. has been available for just over a year and is based on a life participation model. Our group, which is heterogeneous for severity, aphasia type and communication disorder (i.e., anyone with a communication impairment related to acquired brain injury is encouraged to join), meets biweekly for 1½ hours. At every session we introduce ourselves, greet one another (sometimes in unison) and then listen to two to three stories told by professional storytellers who have no communication disability. The stories always prompt storytelling by group members. As I have known most of the clients for many years, I am able to support them well in conversation and demand a level of interaction that is almost a threshold point for conversation.

This group has been as much fun for me as it has been for participants. It has been remarkable how the stories and the reduced emphasis on verbal production and attention have allowed personalities to emerge more fully and increase participation. My role as a therapist is to request the best possible production and never ignore a turn. I have had a chance to teach the storytellers about communication disorders and acquired brain injury, and I think this has done something for the confidence of everyone in the group.

Our newest service started six months ago. I am not aware of any other service like this one which has a mixed goal of restoration and life participation. Group size is limited to six people. To start, all group members are seated at a laptop computer. For the first thirty minutes, each person practices their speech and language by listening to audio files through head phones and responding verbally to the computer as directed. For the last half hour, group members are paired together and act as each others' therapist. Each has the opportunity to help the other by presenting verbal stimuli the best way possible. The feedback provided is very straightforward. Either the listener "gets it" or they do not. And if they do not, the speaker must revise the message. The changes witnessed in group members with chronic and severe communication disorders seem greater than changes documented in individual treatment. Again, personalities emerge in a very natural fashion and confidence is built as people become familiar with one another. The therapist moves from one dyad to the next, providing input about how to try things in a different way and encouraging the clients to try harder.

As I gain experience and my clients gain communicative competence and confidence, the programs change to better meet the needs of the participants. It has been a most rewarding opportunity to participate in designing goals and treatment for this group of people who believed they could improve and who in most instances have.

If there are any questions about these services, please see our website at www.aphasiaworks.com or email me. I would be glad to exchange ideas that would help me help people with aphasia. Email: aphasiaworks@shaw.ca.