# Creating a Framework for the First Alberta Aphasia Camp: Literature Review, Interview Results, Logistical Research, and Insights from a Visit to the Aphasia Camp Northwest

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Alberta Aphasia Camp Framework

## ABSTRACT

This paper outlines the authors' efforts in researching and laying the framework for the inaugural aphasia camp to be implemented in Alberta, the Alberta Aphasia Camp (ABAC). This includes a review of previous research discussing the benefits of non-traditional therapy for people living with aphasia (PWA) and their caregivers. Additionally, this paper includes summaries of interview results with local PWA and family members regarding their preferences for a camp, the selection process of a camp location, and information regarding the authors' visit to the Aphasia Camp Northwest (ACNW) in Portland, Oregon. This combination of findings provides the basis and rationale for the creation of the ABAC as well as recommendations for implementing the camp. The ABAC model is intended to provide an opportunity for PWA and their spouses, family and/or caregivers to enjoy respite in a therapeutic and supportive environment, aiming to foster re-engagement in life activities.

## BACKGROUND

Aphasia is an acquired language disorder that is primarily caused by stroke or brain injury. Approximately thirty percent of stroke survivors experience aphasia (Engelter et al., 2006; Flowers, Silver, Fang, Rochon, & Martino, 2013) but it is estimated that the number of people who survive a stroke and live with aphasia will increase due to increased medical advances in the future (Code & Petheram, 2011). Currently there are over 100 000 PWA in Canada (The Aphasia Institute, 2012).

The World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF) model does not view aphasia as solely a biological dysfunction (World Health Organization, 2001). Additionally, it recognizes the impact that the environment and personal factors can have on the extent of an individual’s disability. The ICF model includes the interaction of the following domains: Body Structure and Function; Activity Limitations and Participation Restrictions; and Personal and Environmental Contextual Factors. Kagan et al. (2008) acknowledge that understanding all of the elements in the ICF model can better help clinicians assess and provide interventions which target improvement in quality of life (QOL) for PWA and their families. However, Kagan et al. (2008) also recognized that QOL was not an element explicitly included within the ICF framework. Therefore, they re-organized the ICF domains into an overlapping schematic, termed the Framework for Outcome Measurement (A-FROM) which centrally highlights QOL. The A-FROM was also influenced by the Life Participation Approach to Aphasia (LPAA) which emphasizes and values client-centered care and re-engagement in life (LPAA Project Group, 2001). Client-centered group treatment consistent with the LPAA has been shown to lead to speech and language, psychosocial and health benefits (Elman, 2007). The values and philosophies of holistic client-centered care as described by the LPAA, A-FROM, and ICF models have helped guide planning of the ABAC.

The rationale for both the need and structure of the ABAC is discussed herein, focusing specifically on how it can address the Activity Limitation and Participation Restriction domains of the ICF while providing a supportive communication environment for PWA and their families. The following section has been divided into the domains of the ICF model. While the authors recognize the interaction between all domains, this has been done for ease of organizing information.

### *Body Structures and Function*

PWA vary greatly with their residual language processing skills and related cognitive functions and may have a combination of difficulties coded in the WHO ICF model under Mental Functions as Language (b16), Verbal memory (b14) and Attention (b140) (Simmons-Mackie & Kagan, 2007). Aphasia classification schemes are often described in terms of language impairments including difficulty with word finding, constructing syntactically accurate sentences, and understanding spoken words, phrases or sentences (Simmons-Mackie & Kagan, 2007). ABAC will be available to people with various types of fluent and non-fluent aphasia. Camp participants will likely have had previous individual speech-language therapy that has partly focused on aspects of aphasia relating to body structure and function. The ABAC, while not targeting the Body Structures and Functions domain specifically, will be designed to reduce communication barriers and provide an enabling communication environment.

### *Environmental Contextual Factors*

Registered speech language pathologists (SLPs) and trained SLP students will provide continuous conversational support and encourage the use of multimodal communication strategies within an interactive and naturalistic communication context. It is likely that caregivers will arrive with preexisting knowledge of communication strategies; however, resources and recommendations for services will be available. Additionally, the use of alternative and augmentative communication aids will be encouraged through the use of conversation books made specifically for camp, as well as aphasia friendly graphics focused on conversations about camp activities and mealtimes. Furthermore, daily conversation groups for PWA will be facilitated by a registered SLP and assisted by students. A variety of communication strategies will be used to help best address the communication needs of each individual camper and provide them with many opportunities for successful communicative interactions.

### ***Participation Restrictions***

Communication depends on the ability to engage with others, to interact, to share, and to maintain equality during interactions; therefore, anything affecting communication can impact a person's social participation (Lyon & Shadden, 2001). Research supports this notion, as PWA have reported decreased engagement in activities and lower QOL compared to people who have had a stroke and do not have aphasia, even when their psychological well-being, amount of social support and physical abilities were similar (Hilari, 2011). While some PWA find that they have satisfying social interactions with others, much of the research suggests that many PWA often have feelings of social isolation and feel excluded even when they are engaged in social activities (Dalemans, de Witte, Dale, van den Heuvel, 2010; Hilari & Northcott, 2006). PWA have noted a loss of friends, anxiety in meeting strangers, a loss of means for making social contacts and changes in the level of effort required to make new friendships (Le Dorze & Brassard, 1995). Thus intervention should focus on helping PWA to regain a previous social role or one that fits their new identity as a PWA (Dietz et al., 2013). Additionally, the research clearly indicates that PWA report a desire for increased social relationships (Dietz et al., 2013). For example, interviews of 50 PWA identified nine broad categories of goals which encompassed all of the ICF components, with the majority of the goals being focused on Activity Limitations and Participation Restrictions (Worrall et al., 2011).

The ABAC aims to directly address these major life priorities of PWA therefore, pre- and post-assessment and interventions will be focused on the Activity Limitation and Participation Restriction domains of the ICF model and improving overall QOL. Initial research has suggested that group service delivery can be beneficial to target improved group participation and community access; however, reviewers also noted that additional research is needed to solidify these findings (Lanyon, Rose, & Worrall, 2013; Ross, Winslow, Marchant, & Brumfitt, 2006). The ABAC will offer a supportive environment and opportunities to make social contacts with others who understand the impact of aphasia on communication. Scheduled icebreaker activities and clinician-led conversation groups will facilitate and ease some of the burden of meeting strangers. Anecdotal evidence from the ACNW in Portland, Oregon, acknowledges that returning campers have exchanged contact information and organized social events outside of the camp's administration. Therefore, likewise the ABAC offers a possibility for new friendships to develop and extend past the end of camp. Overall, providing a place where people who understand and/or have aphasia as well as providing access to partner training in supportive conversation techniques can facilitate a greater sense of support and community for PWA and their families.

### *Activity Limitations*

Similar to changes in social roles and relationships, PWA often cite changes in, and a reduced number of, leisure activities compared to before the onset of their aphasia (Davidson, Howe, Worrall, Hickson, & Togher, 2003; Dietz et al., 2013; Le Dorze & Brassard, 1995). A few identified positive coping behaviors post-stroke include becoming involved with other PWA or devoting oneself to a new task (Le Dorze & Brassard, 1995). A qualitative meta-analysis of the perspectives of PWA, family members, and SLPs on activity participation for PWA indicated that engaging in activities are important for experiencing independence, pleasure and well-being, and a sense of purpose or usefulness (Brown, Worrall, Davidson, & Howe, 2012).

This sense of independence, pleasure, and well-being will be fostered at ABAC through engaging activities incorporating both physical and communicative support as needed. The ABAC plans to be located at a site that offers a number of adapted physical activities such as wall-climbing and canoeing. Trained instructors from the facility will help to lead outdoor recreational activities. Students will also plan and lead both indoor and outdoor leisure activities that are aphasia friendly. On a more fundamental level, simply attending camp may help to achieve some of these results. Personal conversations with PWA at the ACNW revealed that some campers enjoyed being in an out-of town, outdoor environment, which some had not experienced in many, many years. Additionally, not having enough social partners to engage in leisure activities with has been cited as an activity restriction for some PWA – the ABAC therefore plans to address this need (Simmons, Mackie & Kagan, 2007).

While the ABAC aims to provide social interaction in a supportive environment, the goal of the camp would also be to promote generalization of participation beyond the camp setting. Research has shown that using Life Interests and Values Cards can be a viable tool for enabling PWA to communicate their current and preferred activities (Haley, Womack, Helm-Estabrooks, Lovette, & Goff, 2013). Such cards could potentially be used at ABAC to support discussion around activities that participants would like to get involved in, as well as generation of plans and goals to work toward after camp is over. Individual progress on these goals and/or barriers to progress may be evaluated at future camps with additional support provided as required.

### ***Caregivers***

Aphasia can also have wide ranging impact on the body functions, activities and participation of the caregivers of PWA (Grawburg, Howe, Worrall, & Scarinci, 2013). This has been termed third-party disability (Grawburg et al., 2013). Researchers have reported that coping strategies of friends and family members of PWA may include trying to make new friends with people who are familiar with aphasia in order to cope with changes in interpersonal relationships (Le Dorze &Brassard, 1995).

One study based on the work at the ACNW (Fox, Poulsen, Bawden, & Packard, 2004) shows that caregivers can benefit from camp by having: (a) a renewed sense of hope; (b) an improved ability to monitor their own well-being; (c) a greater acceptance of the families' altered state; (d) an improved ability to access their own social resources; and (e) an emergence of a new social support network. Additionally, researchers from the ACNW have outlined four critical elements that were identified by caregivers for a positive residential intervention experience: (a) the perception that the camp environment was a physically and emotionally secure experience; (b) respite from caregiving; (c) peer learning in a naturalistic setting through support sessions about their own experiences and coping strategies; and (d) peer mentorship between recent and experienced caregivers (Fox et al., 2004).

The ABAC will take these recommendations into account when planning the structure of the camp. For example, the camp plans to recruit PWA with various lengths of time post aphasia onset in order to promote peer-learning. Additionally, while PWA are engaging in recreational and conversational activities, caregivers will have the opportunity to participate in support sessions led by group facilitators with experience in leading support groups and with an understanding of the impact of aphasia on the family. Lastly, caregivers will also be invited to partake in recreational activities with other caregivers in order to promote new friendships, strengthen social networks, engage in leisure activities, and enjoy respite from caregiving.

### ***Rationale***

The literature has uncovered many perceived themes for what is required to live successfully with aphasia.  An analysis of published written accounts of PWA uncovered four main themes, two of which were having adequate social supports and looking to the future and setting new goals (Hinckley, 2006). The ABAC aims to address these by providing opportunities for social support as well as increased participation in activities and helping campers to set goals for their life outside of camp. While research regarding the impact of aphasia camp attendance is lacking from the literature, anecdotal evidence shows that attendance at an *"aphasia camp"* can improve QOL for PWA and their caregivers.

Currently, there are limited camps for PWA and their families in Canada, and none in Alberta. Our camp aims to provide improvement in the areas of QOL for PWA and their families, as well as support student clinician education and research in the area of alternative service delivery models, specifically a residential family-style camp.

## INTERVIEW RESULTS: APHASIA CAMP PREFERENCES

In order to design a local camp that provided the greatest benefits to participants, interviews were conducted with PWA and their spouses. The results aided in determining preferences for the focus, activities, social preferences and overall opinions of a camp structure.

### *Data Collection*

Five PWA (three male, two female) and two spouses (one husband and one wife) were interviewed either in their homes or at the University of Alberta. Participants ranged in ages and time post stroke (however inclusion criteria required that participants be at least six months post stroke). Table 1 details participant information.

| Participant | Age | Gender | Time Post Stroke | Fluent/Nonfluent |
|---|---|---|---|---|
| P1 | 63 | Male | 12yrs | Nonfluent |
| P2 | 55 | Female | 5yrs | Nonfluent |
| P3 | 43 | Female | 8yrs | Nonfluent |
| P4 | 67 | Male | 4yrs | Fluent |
| P5 | 44 | Male | 11yrs | Fluent |

**Table 1: Participant Information**

Given the purpose of this informal study, the interview approach was particularly useful because participants were asked to discuss their opinions and provide examples when needed. The interviewers anticipated that there may be some shared views regarding the focus of camp but also diverse views regarding specifics of the camp and personal communication methods. Interviewers also wanted to determine how to reduce barriers for participants to attend camp and if there was interest in accessing a multidisciplinary team at camp.

At the outset of the interview, participants were given some background on the existence and nature of pre-existing aphasia camps in North America and an explanation of the purpose of our interview. A semi-structured format was used along with checklists. Questions and interviewing techniques were made aphasia friendly by including pictures, reducing rate of speech, rewording questions, summarizing participant responses and providing additional written support. Participants were also encouraged to write, draw, gesture, describe, and seek clarification to help understand questions and express their opinions.

## *Results*

### I. <u>General Focus of Camp</u>

***Camp Focus should be both Fun and Therapeutic in Nature.*** The opening checklist was designed to gain a broad view of participant preference for the nature of the camp. The consensus was that participants would prefer a camp with an equal focus on speech therapy and fun activities. Spouses also provided input into the discussion of the nature of the camp. One spouse mentioned that “everyone will want to learn” but that it would be important to start the camp off with many fun group activities in order to help people relax and increase group cohesion, thereby allowing people to feel comfortable practicing their communication skills in later therapeutic sessions.

Goals most highly rated by participants included practicing communication strategies, learning from other people with aphasia, making new memories with family and friends, meeting new people, and trying new activities. Other highly ranked reasons for attending camp included the ability to relax and enjoy activities around people who understood aphasia and to have fun and get away. When asked for the main reason why participants would attend an aphasia camp, a variety of answers were provided. These included: learning new strategies, being social, talking and connecting with other people with aphasia, and relaxing. Participants also provided reasons for their preferences. Common themes included wanting to have the opportunity of a community of PWA and their communication partners (CP) and having access to SLP and other healthcare provider services (as most no longer did).

***Spouses Interested in both Structured and Unstructured Family/Friend Sessions with Other People Living with Someone with Aphasia.*** Both spouses interviewed expressed a desire to have a separate session with other family members/friends to express their personal experiences of living with a PWA and to attend a session facilitated by a health-care professional. Additionally, one spouse expressed the feeling that they did not think sessions should be called 'caregiver' sessions but rather family member/friend sessions.

## II. Recreational Activities

***A Variety of Individual, Group, Indoor, and Outdoor Activities Stated as Preferred Recreation.*** The second part of the interview focused around the preference for recreational activities at the camp. The initial discussion included general open-ended questions about what activities participants like to engage in for fun and relaxation in both indoor and outdoor environments. Some participants had difficulties coming up with specific activities and/or expressing them in these open-ended questions. However, some participants noted that they enjoy playing cards and board games, reading, attending social activities, camping, golfing, biking, and watching TV and sports. Specific games were mentioned by many participants including Risk, Crib, Jenga, Yahtzee, Checkers, Scrabble, and Monopoly. One participant mentioned that they preferred outdoor activities to indoor activities.

***Therapeutic Sessions, by SLPs and Other Health Professionals, and Adapted Outdoor Activities Preferred for Camp Schedule.*** Participants were then asked to rank specific listed activities on a 5-point scale that ranged from considerable interest (5) to no interest (1). Many participants expressed hesitations for some of the activities until it was explained that each activity would be made as adaptable as possible. There was considerable diversity in responses in this section of the interview. The majority of the participants indicated that they wanted the following activities to be included in the camp: discussion/support groups, canoeing, lawn games, hiking, and informational workshops led by other health-care professionals. Specifically, workshops led by physiotherapists, doctors, and psychologists were mentioned. Possible topics identified for workshops included future stroke prevention, home exercises, and recognizing depression. Additionally, many participants also expressed interest in having a nightly campfire and music.

Some interest ratings for activities were spilt between participants who had considerable interest and those who had no interest in them. These activities included fishing, pampering activities, golfing, archery, and swimming.  Activities that did receive strong preferences in either direction included baking, photography, biking, philanthropic activities, and crafts and scrapbooking. Lastly, activities that drew little interest (1) were painting and drawing. Therefore, providing a variety of choices and concurrent activities is recommended.

***Choice between Structured Activities and Unstructured Time Important.*** Many participants agreed that the option to have a choice between activities was important. Additionally, the possibility to not sign up for any activity and just enjoy some unstructured personal time was conveyed as important for some participants.

## III. Logistics

***No Overall Consensus for Camp Length.*** Logistics including the length, location, cost, and transportation options for the camp were also discussed with participants. Four participants stated a preference for an overnight weekend camp, one for a day camp, and two had no preference for either.

***Hold Camp Out of Town at an Overnight Facility.*** Overall, there was slight preference for having the camp out of town at an outdoor recreational facility. The other participants did not have a preference for attending camp in or out of town. One participant suggested that the overall findings of activity interests and focus of the camp should direct the location of the camp.

***Range of Perceived Reasonable Cost to Attend Camp.*** There was a wide range of opinions for what was considered a reasonable cost to attend camp. This ranged from $25-$100/person for a day camp (with a mode around $55/person) and $100-$200/person for a weekend camp.

***Transportation Not Likely a Barrier For Camp Attendance For Most, But May Help Some.*** All participants stated they would definitely or likely be able to get their own transportation to the camp. However, one participant noted that they would be more likely able to attend camp if transportation was provided.

## IV. Communication

***Communication Strengths, Challenges, and Strategies Vary Among Participants.*** An open-ended section of the interview focused on the individual communication strengths and challenges of the PWA as well as any tools or strategies that help them to communicate. Many participants stated that they were good at understanding others, writing and gesturing to communicate. A wide variety of other strengths were also mentioned including laughing and using humour, drawing, describing concepts, speaking in groups, oral spelling, speaking in another language and reading. Speaking in rushed/stressful situations, getting words out, word finding, finding the best word to describe something, communicating in public areas, and communicating in general were listed as participant challenges. Interviewers noted that the majority of PWA had a harder time recognizing their communication strengths than their challenges. It was discussed that perhaps this might be a good topic to address at the camp.

Many different strategies for communication were identified among participants. These included oral spelling, visualization, writing, and gesturing. Additional technological aids were also reported such as texting, using speech-to-text functions, and using specific aphasia apps. Participants also recognized using techniques with conversation partners such as asking them to slow down their speech and to repeat themselves.

## V. Social Preferences

***Provide Options for Small Group Settings and One-on-One Therapy.*** Most participants expressed the preference to spending most of their time in a group setting rather than interacting one-on-one. However, they did express that it would be important to keep the groups small. The preferred size of the group ranged from 4-7 people, with most participants wanting groups to be comprised of 4-5 people.

***Provide Options for Attending the Camp Alone or with Family.*** Involvement of family and friends at the camp was important to two participants while one preferred to attend alone and two had no preference. Both spouses interviewed were interested in attending the camp if their partner wanted them there. Participants who were interviewed without the presence of a family member/spouse mentioned that they were not certain if their family and friends would want to attend the camp with them.

### VI. Camp Reunion Dinner

***Some Initial Interest in Attending a Camp Reunion Dinner.*** While this topic was not initially included in the interview questions and not all participants were asked about the possibility of having a reunion dinner, those that discussed it expressed interest in it. Some participants conveyed that it would be nice if the camp provided them with an opportunity to develop a community with other people dealing with aphasia.

### VII. Overall Impressions

***Both PWA and Their Spouses are Interested in the ABAC.*** The primary reason of interest in attending an aphasia camp was the desire to improve communication skills while also having fun. Overall, participants were happy to provide their opinions and were interested in being contacted in the future about attending the ABAC.

## CAMP LOCATION SELECTION

After researching other aphasia camps across North America and gathering information from PWA on their preferences for camp, the next step was to determine where to hold the camp. A brief examination of the outdoor recreational facilities around the Edmonton area revealed three locations that prompted further investigation; Camp He Ho Ha, Camp Warwa, and YoWoChAs Outdoor Education Center. Representatives of each facility were contacted by phone to arrange tours of the camp. The following section details the information gathered during these visits that was used to help select the final location for the camp.

### *Camp He Ho Ha*

Camp He Ho Ha is located 90 km west of Edmonton on Lake Isle. The facility is comprised of a number of modern buildings that provide adequate meeting space. Accommodations available include a mix of shared and private rooms. Opportunities for recreational activities include a heated, indoor accessible pool, canoes, and a large field for lawn games. Meals are cooked by the facility's staff and served buffet style in a spacious dining room. One major benefit of this facility is that it is extremely accessible for individuals with physical limitations. Pathways are paved and many options for accommodation are designed for individuals with mobility issues. Furthermore, all washrooms are wheelchair accessible, and there are wheelchair accessible showers on-site. The costs for Camp He Ho Ha are variable based on several factors such as the type of accommodation, meeting spaces and recreational activities chosen. Because of this, the overall cost of renting the facility could become quite expensive. Furthermore, organizations that have rented the facility during the previous year have priority for booking and it was noted that September and October are often very busy times. Thus finding an available weekend to book could potentially be difficult.

### *Camp Warwa*

Located 80 km west of Edmonton on Lac Ste. Anne, Camp Warwa offers a range of recreational activities, although less options for meeting spaces and accommodations. Possible recreation packages available include icebreaker programming, canoeing (including group voyageur canoes), wall climbing, ziplining, playing archery, and using a low ropes course. While some of these activities may be modifiable for those with physical limitations (e.g. the low ropes course and canoeing) others, such as the zipline and climbing wall require certain levels of physical skill that may preclude some PWA from participating. In terms of accommodations, a dormitory style accommodation is available with bunk beds and in-building washrooms; however, these washrooms do not contain accessible showers. Another lodge style building is available, but campers must use a washroom that is detached from the building, which could be difficult to access, especially at night. Accessible showers are available in these washrooms. Family style meals are cooked by the facility staff and served in a dining room that seats about 120 people. Seating is comprised of long wooden table with benches, potentially a barrier for those with mobility issues. Meeting spaces are limited to a hall that seats up to 50 people, as well as an outdoor, covered picnic shelter. The estimated cost per person came out to about $116. This included accommodations, meals, access to all meeting spaces and three recreational programs run by camp staff. As with Camp He Ho Ha, preference for booking is given to returning groups and September and October were cited as very busy times.

### ***YoWoChAs Outdoor Education Center***

YoWoChAs Outdoor Education Center is located 80 km west of Edmonton on Lake Wabuman. It offers a large number of recreational activities such as canoeing, kayaking, ziplining, wall climbing, and participating in archery and a high and low rope courses that are run by facility staff. Impressively, all of these activities can be adapted for individuals with physical limitations (including those in wheelchairs). There is also a large field appropriate for lawn games and a campfire pit. Accommodations are shared rooms with bunk beds and access to accessible washrooms with showers. All meals are homemade and prepared by the facility's kitchen staff. The cost per camper is about $122 and includes accommodations, food, and recreational programming. There is also a discounted rate for adult leaders of $60, which can be used at a ratio of 1 adult leader to 5 campers.

***ABAC to be Held at YoWoChAs Outdoor Education Center in September, 2014.*** After comparing the benefits and limitations of each camp, it was decided that YoWoChAs Outdoor Education Center would fit best with the vision for the ABAC. YoWoChAs provided the greatest range of accessible facilities and recreational opportunities, a reasonable rental cost, and was perceived as easier to book in advance. Following this decision, a contract was signed and a $600 deposit provided to YoWoChAs to book the inaugural ABAC for Friday, September 12 through Sunday, September 14th, 2014.

## APHASIA CAMP NORTHWEST VISIT

As a final step in researching aphasia camp formatting and planning, the authors attended the 2013 Aphasia Camp Northwest (ACNW) at Mount Hood Kiwanis Camp, near Portland, Oregon. This camp is run by a partnership of Portland State University, Pacific University, and the registered charity, The Aphasia Network. Attendance at the ACNW was chosen for a number of reasons, primarily because it is well established – having run annually since 1998 and attracting stroke survivors from all across the Northwestern and Midwestern United States. Furthermore, their mandate and philosophies are most closely related to the planned ABAC. The four main areas of focus of ACNW are stated as graduate education, respite, supported communication strategies, and research. These are discussed in more detail in the sections below, which outline the authors' own experiences and interpretation of the camp.

### ***ACNW Philosophy***

Though not explicitly stated as an area of focus, ACNW's model fits the values and ideas put forth by the ICF model, LPAA and the A-FROM, and these frameworks permeate almost every aspect of the camp. From observing over the weekend, as well as speaking to PWA, caregivers, and the students and the faculty, it became clear that the main reason people keep coming back to camp is due to its powerful ability to foster a re-engagement in life.

The foundation for participation of course comes through the use of supported conversation strategies. Prior to camp, all students undergo a training session in supported communication techniques and are instructed on how to make conversation books, which all students and PWA will have during camp. Throughout the camp, activities are planned such that there is a high ratio of students to PWA. This ensures that help is always available when needed, and that there is always someone trained in supported communication strategies available to facilitate interactions.

This is particularly important when caregivers and spouses break off for their own activities. While the PWA are engaging in conversation groups and recreational activities, their caregivers and spouses are given a chance to connect with each other, and relax in a setting where they know that their spouse, parent, or friend is safe. The effects of stroke often have an effect not only on the survivor but also on their spouse or caregiver, as outlined above, and so ACNW places a strong emphasis on the quality of participation and activity available to caregivers. This year at ACNW was the first camp where caregivers ate some meals separately from PWA and had multiple recreational activities that were for caregivers only. Caregivers generally agreed that they appreciated the new changes as it gave them a chance to really relax and have fun, and develop better bonds with other caregivers. In addition to the meals and recreational activities, caregivers also had support sessions hosted by a psychologist and a social worker.

Of course, having a foundation for participation is only one component. The other reason ACNW is so effective is that it is fun, and this is due to a combination of many factors, including but not limited to the following. First, there is an immediate sense of camaraderie as many of the PWA and caregivers already know each other from the ACNW community, and the students and faculty are obviously well acquainted and also extremely welcoming. Second, while workshops and support groups are present, the focus is on activities. From ziplining to fishing to scavenger hunts, there is something for everyone. Finally, the students really go out of their way to make it a memorable experience. For example, rehearsing songs for the campfire, or planning a choreographed flashmob during the Saturday night banquet. While the majority of this section of this paper will focus on a few concrete principles, it is important to remember that there are many components to a successful camp.

### ***Student Training***

As mentioned above, all student volunteers are trained in supported communication strategies, but at ACNW these strategies also take physical form as “conversation books”. These books consist of small photo albums which can be carried on a shoulder strap or lanyard, and serve a number of purposes throughout the weekend. All conversation books contain several pages of communication aids – for example letter boards, pictographic representations of interests, activities, and common phrases, a map to discuss where you are from – and then many pages are left blank for personalization and for use throughout the weekend. Pictures are added of family members, and of other people, activities, or experiences that are relevant to the survivor or student. The conversation books were supplemented with larger communication aid binders at each table, and aphasia-friendly materials outlining the upcoming activities at each meal. All three types of materials were modeled by staff and used heavily throughout the weekend, simultaneously improving ease of social interaction as well as giving people a variety of ideas to improve their communicative function in the future.

Not only do the conversation books help when breakdowns occur, but they also serve as conversation starters. Over the course of the weekend, pictures are taken during activities and added to the book along with cards summarizing how the activity went for them, what they liked about it, and how they may be able to do something similar in their life outside of camp. This functions as a motivator to engage in more activities throughout the year, and also makes the book more useful outside of camp – encouraging its use when telling their family and friends about camp – which helps to transition the book, and other conversational supports, into everyday life.

### ***Conversation Groups & Caregiver Sessions***

The format of conversation groups for PWA varied throughout the weekend. Conversation groups always consisted of the same PWA, and they were matched based on their language strengths and challenges to ensure that everyone would have an equal opportunity to participate. Groups were also formed such that they contained both new and returning campers, to allow for peer-to-peer mentorship and so that the more experienced campers, who knew what to expect, could take the lead and increase support and comfort within the group. On the first evening, the conversation groups were designed to introduce PWA and family members and to begin to learn about each other. These conversation groups were centered on the past. Students led the PWA in their group in discussing where they came from, what they did before their stroke, and then describing how their stroke happened, what it was like, and how things have changed for them since. Student facilitators were provided with training and given materials to guide them in the types of questions that they could ask, but were also instructed to facilitate a natural flow of conversation. For example, one observed group had several members who were not comfortable talking in great detail about the emotional consequences of their stroke, and so more personal questions were omitted.

On day two the conversation groups were more social, and PWA were given an opportunity to lead the discussion. Unfortunately, the authors did not have the opportunity to observe one of these groups. On day three, once the PWA had all had a chance to get to know each other and have had experience interacting with each other, the final conversation group was aimed at having PWA set achievable and meaningful goals for the coming year. This conversation group was the most structured of the weekend and was primarily led by the SLP students, consisting of what the camp organizers called a ‘card sort’. Camp organizers had previously compiled a list of activities that have proven popular and meaningful among campers in past years, and created decks of cards with pictures of these activities. Student facilitators then worked with each survivor one-on-one to sort these activities into four groups: things that they “want to do”, “do now”, have “never done” or have “given up” on.

When each survivor has finished sorting their cards, a photograph was taken of their sorted deck and added to their conversation book. The student then helped them come up with a list of a 4-5 activities that were meaningful to them, and that they didn't currently do but would like to do. Once each participant has completed this activity, they came back together as a group and gave each other feedback on their top activities, helping each other to generate the beginnings of goals as well as sharing ideas as to how they could accomplish them. The students kept notes and between the morning conversation group and lunch, the notes were turned into a "challenge" for each camper – a specific, achievable goal for the next year – by faculty SLPs. Some challenges that came up this year included: inviting a brother to go camping; learning to play the piano again with one hand; using a software program to help compose emails to grandchildren; or even painting pictures for next year's camp silent auction. At lunch on the final day, the returning campers were each asked to give an update on how they did with last year's challenge. Immediately afterwards, students came up and read aloud each camper's new challenge for the coming year. In both cases, everyone showed their support with applause and encouraging words, and campers left with a concrete goal to work on in the next year, motivated by the knowledge that next year they can come back to camp and tell their friends all about how it went. This effectively ends the camp on a tone of motivation to continue putting effort into meaningful activities, as well as creating a social continuity from year to year.

The caregiver sessions came in two formats. The sessions on Friday and Sunday were open to all caregivers and spouses, focusing on general discussion guided by the psychologist and social workers. Major themes included remembering personal time and self-care, and challenges that arise in their relationships. On Sunday, the session also included discussion about the coming year and many returning caregivers created goals that they could report on next year. On Saturday, in contrast, the sessions included some workshops in yoga and relaxation techniques, and then the caregivers were split up into a men's group and a women's group. This again is something that ACNW did for the first time this year. Attendees were asked to comment on this change and to provide feedback. While the majority of people had positive comments, the men in particular found it was a valuable change. They reported that it provided an environment where men felt comfortable sharing and talking about things that they would otherwise have kept to themselves. While the authors only had the opportunity to observe the final session on the Sunday, the mood in that session was one of gratitude for the respite and friendship they had experienced, and positivity for the coming year.

### The Aphasia Network, and Camp Organization/Structure

While ACNW has been building on the concept of continuity and progression through conversation books and challenges, they have also recently founded the registered charity The Aphasia Network to assist this on a larger scale. This new arrangement takes some pressure off of the faculty in running the camp by implementing a unified board to help with fundraising and larger operational logistics. It also provides the opportunity to expand ACNW, and the community built through ACNW, beyond just a once yearly camp. Now that the camp organizers have the added capacity of The Aphasia Network, survivor and caregiver workshops as well as social opportunities and community outreach are implemented year round. While this format is still fairly new, it shows promise in continuing to bring people together in a supportive and therapeutic environment, which has the potential to further the community that ACNW has been building, as well as further increase QOL for PWA and their families.

As mentioned above, in addition to The Aphasia Network, the camp is, and was originally, run by faculty and students from Portland State University. More recently, Pacific University has joined in as well. For the first nine years of ACNW, the camp was run almost exclusively by speech-language pathology students and professors. Since then, the diversity of staff and volunteers has grown to include occupational therapists (OTs) and physical therapists (PTs). These disciplines help with activities, identify areas or activities where some campers may have trouble, and train all volunteers in the proper techniques for transfers. Additionally, a registered nurse available for any first aid or health problems, and social workers as well as a rehabilitation psychologist lead the support groups and caregiver workshops. This interdisciplinary format is something that helps make ACNW as unique and as effective as it is. However, as was mentioned by a number of the returning camp organizers, this is something that needs to develop over time and experience. There are many challenges that arise from coordinating people from so many different backgrounds and determining how to make best use of the unique skills that they offer.

### ***Research & Graduate Education***

As ANCW is run primarily by faculty and students from Portland State University (PSU), it makes sense that there would be a focus on research and education. It was impressive to see how inherently engrained education was throughout the course of the weekend for all people involved. While much of this is intentional, some of it also occurs naturally. ACNW is a very unique therapeutic and educational environment in which everyone is able to work together without barriers such as teacher/student or client/clinician, so that everyone learns and it is consistently revealed that everyone has something to offer. Much of this less structured learning is peer-to-peer. Due to the wide variety of professions present, differing levels of experience (e.g. new or returning, student, survivor, or faculty), and unique backgrounds of each survivor and caregiver, everyone truly does have something to share. Facilitated peer-to-peer learning occurs through recruiting “mentor” students who have attended camp before and shown exceptional leadership potential. It also occurs through pairing more experienced campers with new campers. A large proportion of peer-to-peer learning emerges naturally in the camp environment. In fact, a group of students attended camp this year with the sole purpose of investigating the mechanics of natural and planned peer-to-peer learning. Research is also carried out on a regular basis by the faculty at PSU with the goal of evaluating and describing the camp’s effects on graduate education, caregiver outcomes, and functional communication outcomes. This research may be used to optimize educational and therapeutic outcomes from year to year, and may also facilitate transmission of skills and knowledge learned at ACNW to the broader professional community through academic publications.

Another way in which ACNW contributes to the professional community is through a heavy emphasis on graduate student education. Students are encouraged to be active in the learning process from the beginning of their involvement through a pre-assessment of their skills and abilities in facilitating communication and interaction with people with aphasia. A framework is set up for student learning with the following objectives: “to learn about the lived experience of aphasia using a theory-driven approach; to master interdisciplinary teamwork and participation skills; to explore use of reflective writing and other qualitative research methodologies; and to explore methods for promoting normalcy, conversation, social engagement, safely taking risks, making choices, respite, and development of a community of support for families living with aphasia" (ACNW Student Handout). Before camp starts students are required to complete readings, modules, and quizzes on aphasia and supportive communication. Students also participate in two training days – one a week prior to camp and the other before camp starts on the Friday. The purpose of the training days is to review supported communication strategies, participate in transfer training, prepare for the upcoming activities, and review how to collect conversational data for future research. Brief training sessions and meetings continue throughout the course of the weekend. After camp there is a final debrief and students are required to complete an assignment reflecting on their educational and personal development.

While the weekend is obviously rich with opportunities for experiential and peer-to-peer learning, structured learning also comes through data collection during the conversation groups. While each group has a student leader, other students present take data for future research, according to a specific rubric. Not only does this engage students in the research process, but it also trains students to look for specific aspects of communication in real-time, which is an important skill for future clinicians. Students record data for one of two categories. The first is communication components. This consists of verbal content, nonverbal cues (e.g. facial expression), para-language (e.g. intonation, laughing), and context (e.g. lighting, noise, seating arrangement). Students who are not collecting data on communication components will be recording the communication and conversation process. This collection consists of who initiates conversation, how turns are taken, topic changes, and how each person communicates to or for others. Either category is challenging to record, as there is a lot of information to capture and multiple interactions and activities occurring simultaneously. Therefore, there are multiple students collecting data for each category; everyone has a chance to learn and a more complete picture of each person's communication, as well as the group's interactions, are captured. Following the conversation group, students are given feedback on their data collection for educational purposes. The data is then compiled for future use in research.

## RECOMMENDATIONS/DISCUSSION

Based on what was learned from the literature, from contacting other aphasia camps, from our interviews with PWA and their family, and through our relationship with ACNW and Portland State University, the following guiding principles are suggested for the future ABAC:

1. Utilizing a foundation of supported conversation strategies to enable quality social interactions in the context of engaging and self-relevant activities for PWA and their families
2. Emphasizing fun in a therapeutic context, rather than formal therapy
3. Providing caregivers a facilitated opportunity to connect and share experiences
4. Building continuity from year to year by helping campers create functional and enriching goals, as well as strategies to achieve them before next year's camp
5. Providing an opportunity for student clinical education in a unique environment
6. Improving the camp experience and contributing to knowledge of service delivery in the professional community through research focusing on functional outcomes and QOL

Additional suggestions from the organizers of ACNW included starting small and making only minimal changes from year to year, stating that their least successful years have been those where they tried to change too much. The integration of other disciples was emphasized including the importance of having a nurse on site, as well as to have physiotherapist and/or occupational therapist do a site visit to identify safety concerns areas and to train all volunteers in safe transfer techniques. They also stressed the importance of having someone specifically qualified to lead caregiver sessions, such as a psychologist or social worker. Finally, it was advised to have clear goals for camp, in order to provide a clear definition of success, and offer a framework for improvement from year to year.

It is also suggested that in order to best cater to the local population, camp should be held out of town at a campsite facility, with a mix of therapeutic sessions and adapted outdoor activities. Options for small group or one-on-one interactions are important as are a mix of structured activities and unstructured time.

## CONCLUSION

After examining the research, interviewing PWA and their spouses, visiting potential camp locations and learning from ACNW, four primary goals have been developed to support the framework of ABAC

The ABAC aims to:

1) Develop an aphasia camp in the Edmonton area to better support PWA and their caregivers in experiencing quality social interactions and in maximizing their communicative interactions and participation in activities that are important to them.
2) Provide respite, peer learning, and professional-led support groups for caregivers of PWA.

3) Contribute to the body of knowledge on the benefits and essential elements of running a successful residential family-style camp for PWA and their families.
4) Develop opportunities for student clinicians to gain experience in an alternative service-delivery model providing communicative support to PWA and their caregivers.

As part of this initial planning stage for ABAC, a number of resources were created for the camp including a schedule, packing list, funding proposal letter and poster detailing what camp participants could expect. These documents have been made available on a shared google drive file with all organizing members of the ABAC team. With this framework in place, students and staff will be better able to implement the first ABAC, currently scheduled for September 12th to September 14th, 2014.

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