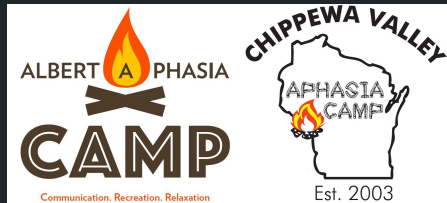


More than a get-away: The Aphasia Camp experience

Aphasia Access 2019



Who are we

Alberta Aphasia Camp

Esther Kim, PhD, CCC-SLP, R.SLP

Co-founder of Alberta Aphasia Camp

Communication Sciences and Disorders

Faculty of Rehabilitation Medicine

University of Alberta

esther.kim@ualberta.ca

Andrea Ruelling, MA, CCC-SLP, R.SLP

Co-founder of Alberta Aphasia Camp

Communication Sciences and Disorders

Faculty of Rehabilitation Medicine

University of Alberta

ruelling@ualberta.ca

Chippewa Valley Aphasia Camp

Mary Beth Clark

Co-founder of Chippewa Valley Aphasia Camp

Mayo Clinic Health Systems - Eau Claire

clark.marybeth1@mayo.edu

Jerry Hoepner

Co-founder of Chippewa Valley Aphasia Camp

University of Wisconsin - Eau Claire

hoepnejk@uwec.edu

Tom Sather

Co-founder of Chippewa Valley Aphasia Camp

University of Wisconsin - Eau Claire

Mayo Clinic Health Systems - Eau Claire

sathertw@uwec.edu

Outline

Overview of Aphasia Camps

Guiding Principles

Camper Roles

Service Delivery Model

Outcome Measures

Potential Layout for Camps Roundtable

1. Camp philosophies - LPAA, participation based, relationships (5-7 minutes)
2. What happens at a camp/what does camp look like at Alberta/in Wisconsin (Alberta 5 minutes; Wisco 5 minutes)
3. Pertinent outcomes - what happens that we feel is important, during and outside of camp (7 minutes)
4. Applying the camp concept - to a weekend camp, a half day program, a saturday rehab outing; applying the WHO-ICF (5 minutes)
5. Questions to bring to the audience - including use of Discussion prompts (see next page) (10-15 minutes)

A day (or weekend) in the life...

Alberta Aphasia Camp

- **Inaugural camp:** 2014
- **Partnership:** University of Alberta and March of Dimes Canada
- **Personnel:** Leaders (SLP, PT, OT), Lead volunteers, Student volunteers, Camp staff, Community volunteers (i.e., activity leaders)
- **Numbers:** Campers both PWA and Care partners (70); Leaders (8); Student Volunteers (24)
- **Format:**
 - Weekend (Friday evening - Sunday afternoon)
 - Rustic camp location / Shared cabins / Mostly accessible
 - 6 concurrent streams of activities (recreation, self-care, therapy)



Chippewa Valley Aphasia Camp

- **Inaugural camp:** 2004
- **Partnership:** YMCA, UWEC, Mayo Health System, Chippewa Valley Aphasia Network
- **Personnel:** Leaders (SLP, PT, OT), Community professionals, Lead volunteers, Student volunteers, Camp staff, Community volunteers (i.e., activity leaders)
- **Numbers:** Campers both PWA and Care partners (80); Leaders (12); Student Volunteers (25)
- **Format:**
 - Weekend (Friday evening - Sunday afternoon)
 - Rustic camp location / Shared cabins / Mostly accessible
 - 4 - 5 concurrent streams of activities (recreation, self-care, therapy)

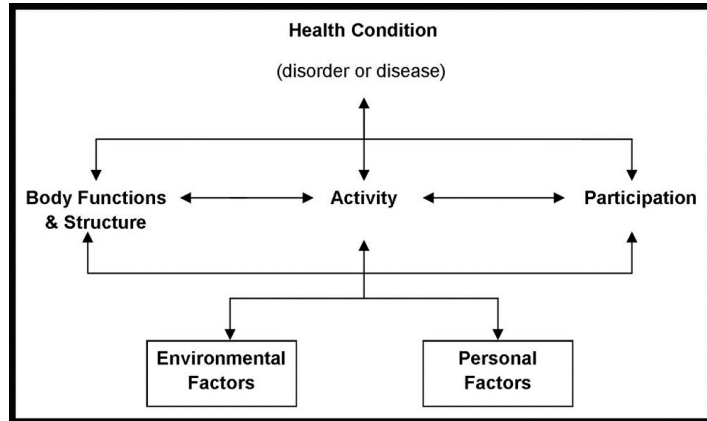
Sample Schedule

- 4 Activity slots (2 morning, 2 afternoon)
 - Recreational (e.g., Hike, Canoe, Kayak, Low ropes, Rock climbing, Archery, Painting, etc.)
 - Therapeutic (e.g., Conversation Groups, Apps & Technology, Active Living Workshop, Sleep Hygiene, etc.)
 - Self-care (e.g., Manicure/Pedicure, Yoga, Meditation, etc.)
- Campers choose from several activities throughout day
- All-camp activities (e.g., drum circle, concert, dance, fireside, scavenger hunt)

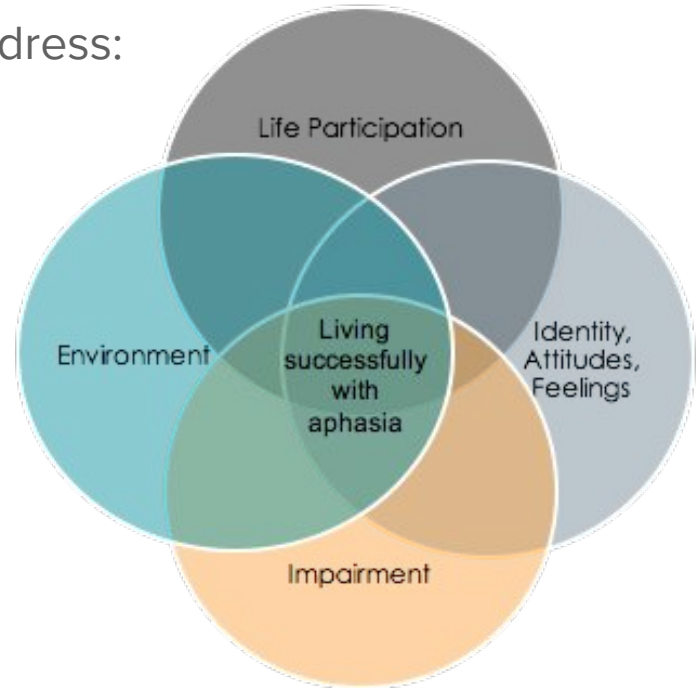


The Aphasia Camp philosophy: A-FROM (Aphasia Institute, 2008)

Camps that enhance living with aphasia address:



www.icfeducation.org/what-is-icf



Camps Provide Peer-to-Peer Learning Environments

Learners may include:

- Persons with aphasia (all severities & all ages)
- Care Partners (spouses, siblings, parents, children)
- Students (SLP, PT, OT, Recreation Therapy, Social Work, Psychology)
- Staff (SLP, PT, OT, Nurse, chaplaincy, community members)
- Other Volunteers (various activity leaders)



Camps Enhance Personal & Community Growth

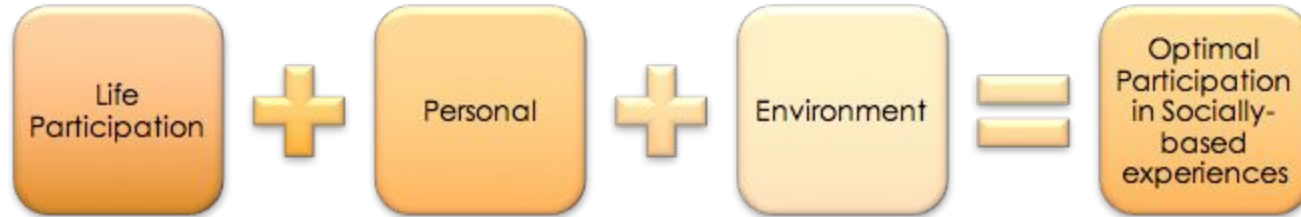
- Create meaningful social contexts (activities, meals, conversation groups, etc)
- Provide a safe environment that encourages personal sharing
 - PWA + PWA
 - Care partner + PWA
 - Care partner + care partner
- Promote self-discovery & challenge with peripheral to central participation



How are campers involved

- Advisory board / planning committees
- Co-lead sessions / activities
- Coaching
- Networking / Recruitment

Socially-based Experiences (A-FROM components)



Provide activities that are socially relevant & build a sense of community

Provide activities that are socially relevant & build a sense of community

Utilize natural partners and natural environments



Outcomes

Camper Outcomes

Table 2. ALA pre- and post-camp means and standard deviations

ALA Domain	Pre-Camp	Post-Camp
Aphasia	2.61 (0.44)	2.68 (0.48)
Participation	2.74 (0.50)	3.00* (0.40)
Environment	3.06 (0.45)	3.13 (0.30)
Personal	3.07 (0.38)	3.30* (0.22)
'Wall Question'	2.83 (0.79)	2.89 (0.66)
Total	2.82 (0.33)	3.05** (0.31)

* $p < .05$, ** $p < .01$

Kim, Ruelling, Garcia & Kajner (2016). *Topics in Stroke Rehabilitation*.

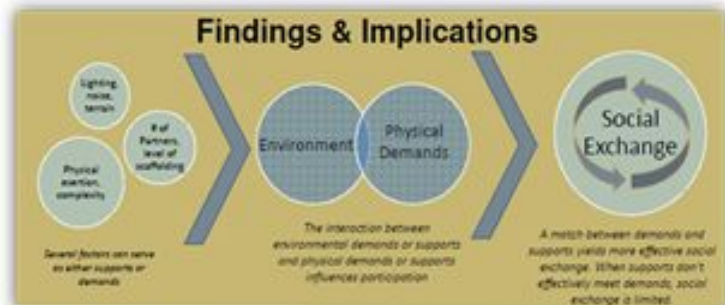
Camper Outcomes

- Measures:

- Physical activity: descriptions and accelerometer data
- Communication output: Clinical Discourse Analysis (CDA) % errors
- Partner support: Measure of Skill in Supported Conversation (MSC)
- Social exchange: Measure of Participation in Conversation (MPC)
- Environment (physical context): ICF environmental factors (barriers & facilitators)
- Environment (partner context): ICF environmental factors (barriers & facilitators)

- In broad terms...

- As demands rose (across physical, environment, or communication demands), output dropped
- However, demands could be overcome or at least counterbalanced by effective partner or environmental supports

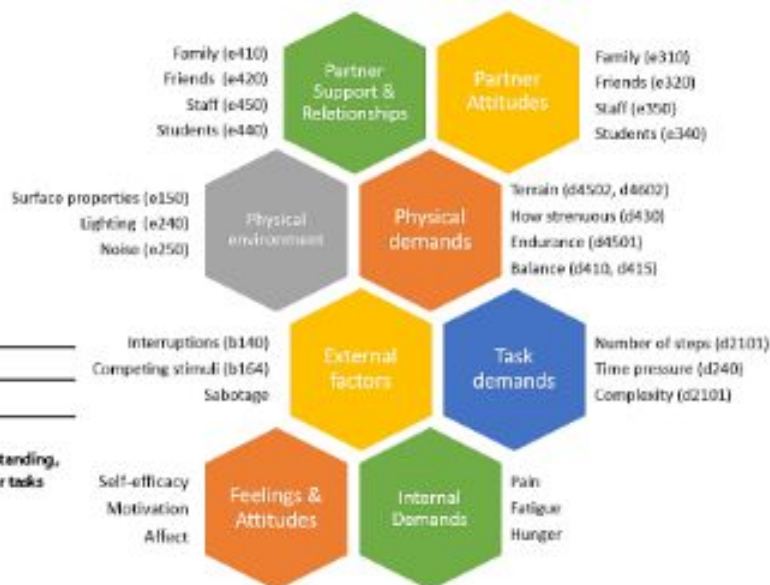


Just a snippet...

N of 4

Table 4. Profile of P1s performance and environmental context across activities.

Performance measures	Activity			
	Technology	Fitness assessment	Frisbee golf	Night activity
Time in activity	83 minutes	20 minutes	71.5 minutes	103 minutes
Physical activity description	Primarily sitting	Balance, strength, flexibility and range of motion, bending, reaching	Walking outdoors, standing, and throwing Frisbee	Walking outdoors, standing, throwing, fine motor tasks
Accelerometer (activity count)	Sedentary: 98% Light: 2% Moderate: 0%	Sedentary: 55% Light: 35% Moderate: 10%	Sedentary: 20% Light: 80% Moderate: 0%	Sedentary: 48% Light: 43% Moderate: 9%
CDA (percent errors)	12.5% (n = 32)	41% (n = 51)	64% (n = 17)	50% (n = 6)
Social exchange (MPQ)	Interaction: 3.0/4.0 Transaction: 2.0/4.0	Interaction: 3.0/4.0 Transaction: 2.0/4.0	N.A. multiple partners	Interaction: 1.5/4.0 Transaction: 1.0/4.0
Partner support (MSC)	Acknowledges: 3.0/4.0 Reveals: 2.5/4.0	Acknowledges: 2.5/4.0 Reveals: 1.0/4.0	N.A. multiple partners	N.A. multiple partners
Environment (physical context)	e125.+1 (Pad) e240.0 (lighting) e250.3 (sound)	e120.+2 (AFO) e150.+1 (building) e250.1 (sound)	e120.+1 (AFO) e120.1 (terrain)	e120.+1 (AFO) e150.2 (ground) e240.2 (lighting) e250.2 (sound)
Environment (partner context)	e320.+1 (friend) e325.+2 (student) e320.+2 (friend) e360.+2 (SLPs)	e360.1 (trainer) e455.+1 (trainer attitude)	e320.+1 (friend) e325.+1 (student) e360.+2 (SLPs) e420.+1 (friend attitude) e440.+1 (staff attitude) e455.+1 (student attitude)	e320.+1 (friend) e325.+1 (student) e455.+1 (student attitude)



Camper Outcomes

Hoepner, Baier, Sather, & Clark, 2017
Baier, Hoepner, & Sather, 2018



- Participant generated photography – Snapchat exchanges as an expression of experiences
- N of 20 – qualitative photographic coding



174 snaps

- Heavily focused on sharing about people (154/174; 89%) vs objects (20/174; 11%)
*note difference at home
- Relationships & participation (113/174; 65%)



Camper Outcomes



The people were very friendly and helpful.

Meeting the other campers and visiting with them.

It gave me a chance to try thing it wouldn't of tried before. In a non-threatening environment.

FUN! Tiring, but still fun.

People asked "where do you want to go": instead of just sitting here"
Everything was just perfect.



Wonderful, positive experiences. In a supportive environment. This is our second year and returning was even more productive and enjoyable to get to know people that I did not get a chance to get know last year. Renew friendships and build on them.

He'd have dragged me if I hadn't been willing—it's the highlight of his year

It helps reinforce some of the practices I forget about. It also has a respite effect for me and I feel refreshed and more patient. It is also very helpful to talk with others that face many of the same challenges.

Partner Outcomes



The experience increased my partner's enthusiasm for life and willingness to try things he's been hesitant to do.

Hearing stories from others. Learning from others. Inspired by how others have handled recovery and moved on with their new lives.

Absolutely, we have been coming for 3 years. This year we had a big breakthrough -you may not ever get an opportunity have one IF you don't take risk and go to something like this.

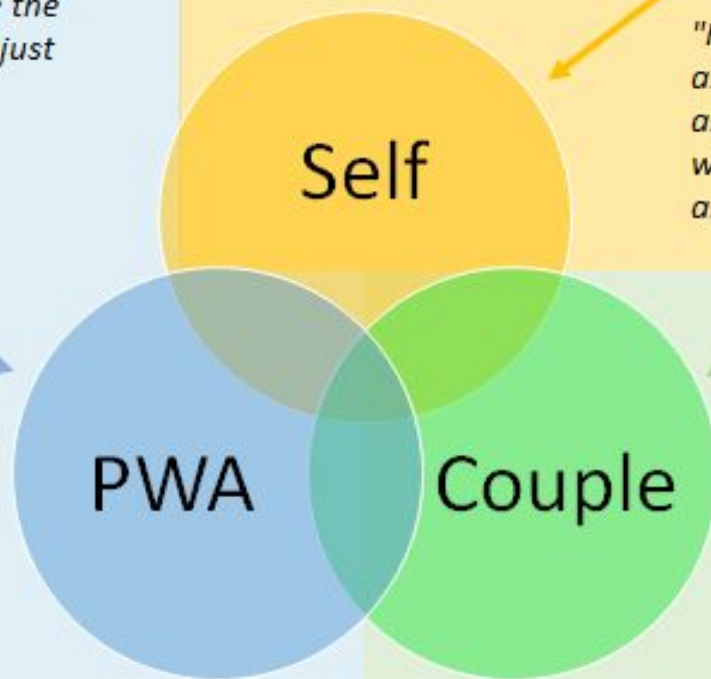
Partner Outcomes

N of 9

"And this camp has given my wife the confidence to try new things and just be herself."

Still looking at camp from the **lens of a partner** – impact on person with aphasia

The main reason for going there is their loved one with aphasia



Even though the survey focused on partner outcomes, not all reflections were about self

Their **identity is "caregiver"** vs. being a partner (couple)

Transitioning back to being a spouse – rather than fully caregiver identity

"For me as a caregiver, this weekend allows me to relax and not have to worry about her as much because I know that when we aren't together, there will always be someone there to help her."

Joint identity

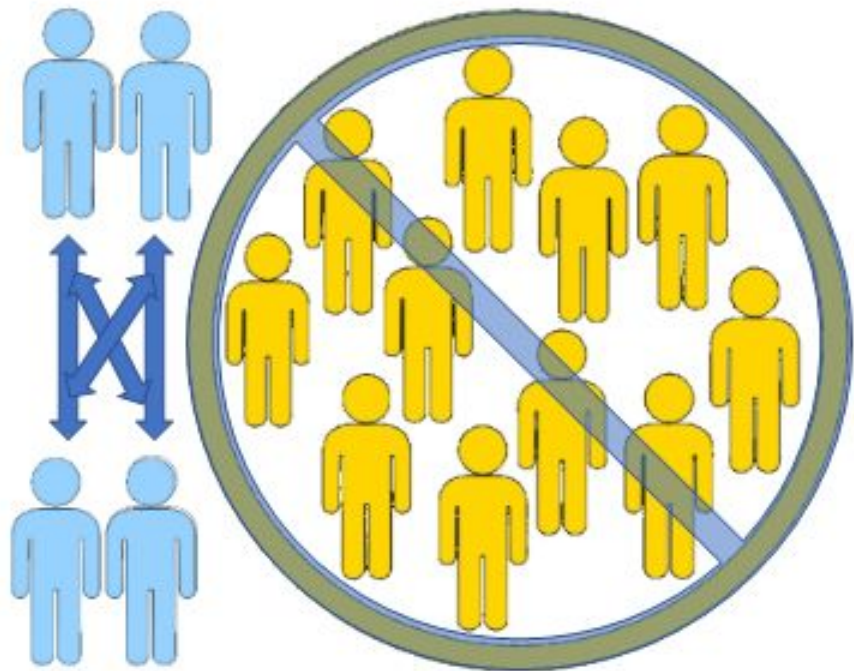
"My wife and I will continue to come to camp for as long as we can."

"...touch base with our 'aphasia' friends again..."

Partner Outcomes

Central to value of camp: Maintaining ties

- It will be nice to touch base with our "aphasia" friends again and is always exciting to meet new and help talk with other caregivers that might be new at the whole experience.
- "We continue to return to camp because I feel that it is the single best thing we have found for her."
- Sure, we'll be there next year. Even if it doesn't directly change anything in our day to day lives at home, it is a nice weekend get away from the same old daily grind.



Caregiver vs. Life Partner Continuum

Refer to self as caregivers
"me as a caregiver"

Refer to loved one with aphasia
as "my wife (husband)"



Full caregiver mode
(Don't really act as a
life partner)



Hat switchers – can
step out of
caregiver role at
times, really be a
life partner at times
and be themselves
at times

Full life partner
mode (Don't really
act as a caregiver)

Refer to partner as "my
person with aphasia"

Refer to partner as "my
spouse with aphasia"



Partner Outcomes: Implications

- **Value** for partners as well as campers with aphasia
- Relationships forged can foster **ongoing peer support**
- It is helpful to **see people at different stages** of recovery
- It is helpful to see **models of living successfully** with aphasia
- **Personal time** to decompress and take care of self
- Partners learn to give up (reduce) control of camper with aphasia and thus **nurture independence**





Student Volunteer Outcomes

1. Building relationships*
 - a. Campers, Team, Facilitators
2. Communication
 - a. Peers, Campers with Aphasia, Family/caregivers
3. Interdisciplinary environment
4. Lived experience
5. Personal and professional growth*
6. Practice within the context*



Student Outcomes

Hoepner, Clark, Sather, & Knutson, 2012

- N of 90 students (144 experiences)

Commitment to having an impact as a professional, continuing to engage in service
Strive to meet the challenges they encounter
Personal rewards & inspiration



Extends & fosters course-learning

Increased application of content knowledge

Commitment-Altruism



In-their-shoes

Evolving perspective of living with aphasia



Training matters



Increased self-confidence and self-efficacy

Peers matter

Collaborative learning, peer mentoring & shared experiences foster learning



Cultural competence



Developing meaningful, genuine relationships with campers, partners, staff, & peers

Student Outcomes

Hoepner, Sather, Homolka, Clark, & Knutson, in prep

Table 4. Clinical experience scheme, categories, and exemplars.

Clinical Experience	Increased confidence/ self-efficacy	<p>"So, um, I don't know, just a really positive experience today. I feel like I'm learning to communicate with people with aphasia in a lot more of an effective way, I guess. Um, so I'm hoping that I'll continue this into the rest of the weekend."</p>
		<p>"[sighs] It's sad to leave [emotional, voice cracking slightly], um... (2 sec) I just feel so comfortable now. I wish we had more time [smiles], but um, hopefully in the future, who knows, maybe I'll be here again [smiles]."</p>
	Inspirational/rewarding	<p>"I also challenged myself a little differently than last year. Last year I was very comfortable speaking with the people with aphasia. As long as their caregivers were around, I was very comfortable but I really strayed away from talking just one on one with someone [shakes head slightly]. I was scared of having that communication breakdown and I avoided it. So this year, I went in and really wanted to have a one on one conversation right off the bat and I did [smiles] and I just found that it was a very positive [smiles] and it was, it was just a great conversation [smiles]."</p>

Student Outcomes • N of 22

Hoepner, Sather, Homolka, Clark, & Knutson, in prep

Table 2. Applied Learning scheme, categories, and exemplars.

Applied Learning	Increased application of content knowledge	<p>"Today was a really great experience. I communicated with some people who have more severe aphasia, so I actually got to practice [smiles] some of the communication techniques that we've been working on in, um, our prep sessions."</p> <p>"And I used a lot of written choice. I even used my own (raises sheet of paper) rating scale, which was really exciting. And I was just able to connect with a lot of the campers and their spouses. And I didn't really feel afraid to talk to anybody because I was able to communicate in some fashion. And it was just really exciting to have the opportunity and when we get stuck on words or stuff, it was – it was cool to troubleshoot that."</p>
	Evolving perspective of living with aphasia	<p>"They (the campers) are just so intelligent and loving [emphasis]. So, it's amazing at the relationships that they each have and how involved they are and how willing they are to do everything."</p>
	Collaborative learning	<p>"I've had a good time seeing some of the students who have been here before, some of the older students, using some of their communication strategies with the campers. Um, I've learned a lot from them just from observing them and from seeing how they interact with the campers. Some of them are just really good at it and I can just tell that they are going to be really good speech pathologists, so that's really cool to see as well just being a junior and watching the seniors."</p>

Student Outcomes

Hoepner, Sather, Homolka, Clark, & Knutson, in prep

Table 3. Service scheme, categories, and exemplars.

Service	Commitment to making a meaningful impact	<p>"Yeah! And it was a great time [smiles] so once again I'm just um, gonna take all the experiences with me and ya know, have this experience now and use it in my future and ya know, as a resource to look back to and make connections with."</p> <p>"I think, I mean even though we were only here for three days, I think we really did impact their life and that's, that's huge. That's a big thing. Um, I feel like if you do one nice thing for somebody your entire life, then you've done your job. And I feel, I feel really satisfied, I feel fulfilled being here. I feel like I've helped people. Um, even if I only made somebody smile once, I feel like I've done my job."</p>
	Interpersonal relationships	<p>"It was really [emphasis] emotional. Um, you don't realize how connected you become with the campers and it felt really good [smiles]."</p>
	Meeting the challenge	<p>"I guess if I had to say, my favorite thing about today was really talking with people who had aphasia. I had never talked with someone who had aphasia, so I really didn't know what to expect and I didn't know what to do really [smiles]. But it's really not as bad as it seems [smiles] and um, made some great connections and had a great time."</p>

Facilitator Outcomes

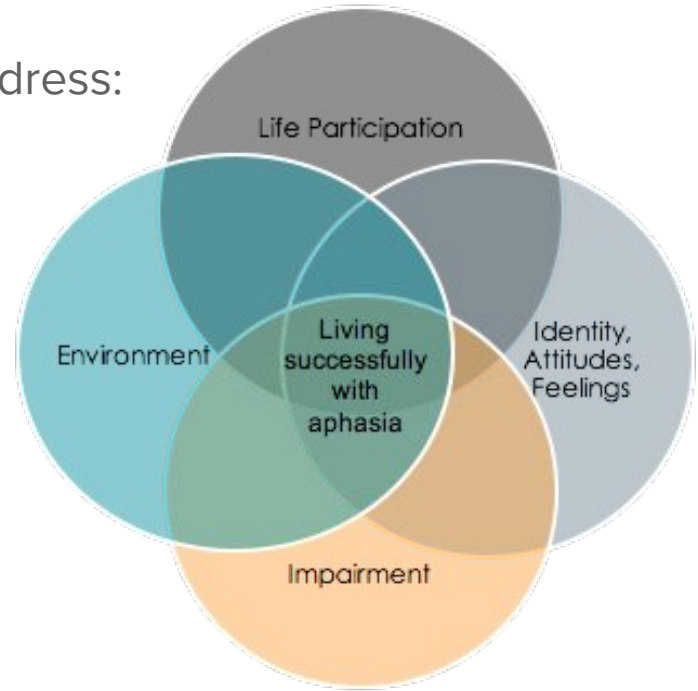
1. Educator Characteristics/Philosophy
 - Learning as a process
 - Open to feedback
 - Flexible (okay with “grey”)
 - **Secure in own knowledge (don’t need to ‘know it all’)**
 - Trust
 - **‘Guiding from the sideline’** → giving up control
2. Environment
 - **Students have autonomy, ownership**
 - Structure but flexibility built in
 - Students feel safe to take risks
 - **Absence of evaluation**
 - Flattened hierarchy
 - Clear expectations



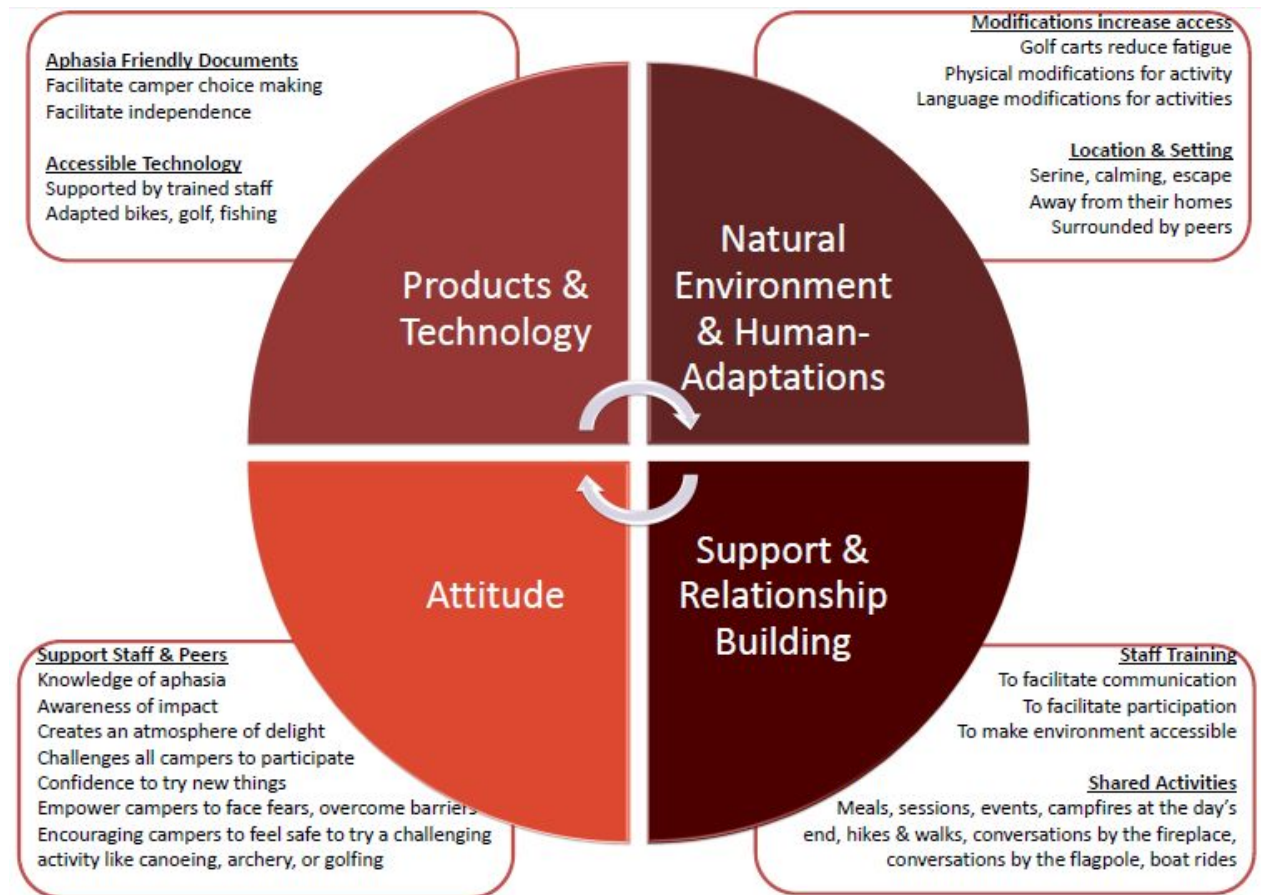
Applications of the LPAA within the aphasia camp environment

The Aphasia Camp philosophy: A-FROM (Aphasia Institute, 2008)

Camps that enhance living with aphasia address:



The environment...





Identity



Applying the aphasia camp framework
to a variety of service delivery models

Potential discussion prompts/questions

1. What is the role of non-traditional environments in aphasia therapy?
2. How do you authentically foster/support/facilitate participation?
3. How do you incorporate the partners?
4. Should there be a camp that doesn't explicitly address aphasia? "Just" a weekend getaway for people that happen to have aphasia?
5. What do people with aphasia want?
6. What's the role of big health systems and hospital/SNF/rehab company clinicians in these kinds of programs?
7. Is this just a university program that's totally irrelevant to the real world?
8. Is a weekend too short? What about the rest of the year?