

# The Impact of Aphasia Camp on Partners of Persons with Aphasia

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The Power of **AND**

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## Aphasia Camp: What is it?

- **Purpose:** to study the experiences of partners at Chippewa Valley Aphasia Camp.
- Aphasia camps are an **alternative service delivery model** for chronic phase of recovery
- **Camps** are designed to increase engagement in participation as a **springboard** to social communication in home community



## Survey

- **Pre- and Post- online** Qualtrics survey.
- Questions examined **demographic information** and nature of interactions outside of camp
- Quantitative data includes tallies of the types of **social interaction experiences** before and after camp.
- Written responses yielded **10 pre-camp themes** and **12 post-camp themes**



## Partners at Camp:

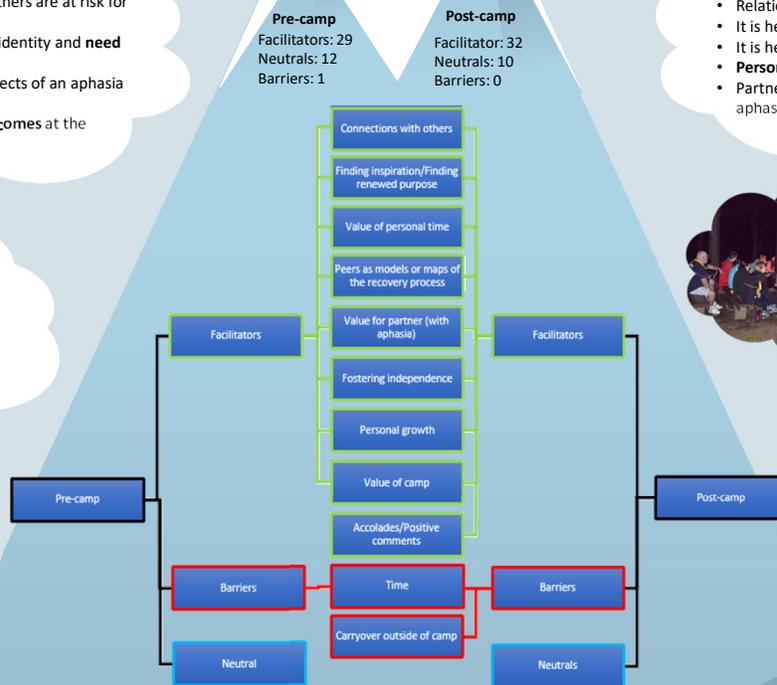
- Both individuals with aphasia and their partners are at risk for **social isolation** (Adelman et. Al. 2014).
- Therefore, partners also experience loss of identity and **need for peer support**.
- Fox and colleagues (2009) examined the effects of an aphasia camp experience on partners.
- The present study investigated **partner outcomes** at the Chippewa Valley Aphasia Camp.

## 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**

## Participants

- **Nine** partners completed the online survey.
- Attended the Chippewa Valley Aphasia Camp in 2017 with their spouse with aphasia.
- **7/9** partners completed the **pre-camp survey**.
- **6/7** partners who completed the pre-camp survey completed the **post-camp survey**.
- Mean age of 63.3, range of 47 to 72 years.



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## Camp Related Questions

Before your loved ones stroke/aphasia, estimate the frequency of YOUR interactions with the following people in YOUR social network:

	Daily	Several times each week	At least once a week	At least once a month	Rarely
Loved one with aphasia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Close family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Close friends (primarily "your friend")	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Close friends (primarily "person with aphasia's friend")	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People from your church	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People from your community group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People from fitness/health club	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People you meet while traveling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People from your work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People from your loved one with aphasia's work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Qualitative Methods and Coding Framework:

- Open-ended survey responses were coded using Granenheim & Lundman's (2006) dichotomous coding scheme.
- This allowed high inter-rater reliability (>90%) for initial binary coding (barriers and facilitators).
  - Categories were identified thematically, based upon nature of content.
  - Note overlap between pre- and post camp barriers and facilitators.

"We (both of us) have a connection through these people the caregivers, the aphasia people, the staff and we each have our connections for different reasons in different ways."

"I look at life not as we can no longer do this, but as if I'm going to do this, than I need to do it myself."

My spouse with aphasia comes home each year (this year was no different) with so much renewed energy and focus to be able to handle more of life with a gusto approach

"We continue to return to camp because I feel that it is the single best thing we have found for her."

"It's a terrific opportunity to socialize and be around people that understand the daily struggles of having Aphasia or being a caregiver of someone with Aphasia."

"This is a great opportunity for her to flourish and be herself without fear of judgement or worry."

"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."

## References:

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden. *Clinical Review and Education*, 31(10), 1052-1059. Retrieved April 30, 2017.
- Fox, L.E., Poulsen, S.B., Bawden, K.C., and Packard, D. (2004). Critical elements and outcomes of a residential family-based intervention for aphasia caregivers. *Aphasiology*, 18(12), 1177-1199.
- See authors for full reference list.