

Aphasia Camp: Meaningful participation in a rustic setting

Mary Beth Clark, MS/CCC-SLP

Tom Hintgen, MA/CCC-SLP

Jerry Hoepner, MS/CCC-SLP

Tom Sather, MS/CCC-SLP

**Luther Midelfort - Mayo Health
System**

**Department of Neurosciences,
Pediatrics and Trauma**

Eau Claire, Wisconsin

Luther Midelfort
Mayo Health System

Learner Outcomes

- **Identify three components of staff recruitment and training**
- **Identify six key components to successful aphasia camp implementation**
- **Identify outcome data that support aphasia camps**

Mission of Aphasia Camp

To offer individuals with aphasia and their significant others opportunities, activities and resources to gain confidence and facilitate success within a naturalistic environment

Aphasia Camp

- **Weekend retreat**
- **Rustic setting**
- **For people with aphasia and family members**
- **Participation focus**
- **Speech Pathologists, trained instructors, trained volunteers**
- **Third year running**

Core Values and Concepts

- **Respect**
- **Sharing**
- **Trust**
- **Confidence**
- **Admiration**
- **Honesty**
- **Naturalness**
- **Flexibility**
- **Mutual problem solving and exploration**

Core Values and Concepts

- Experience/participation focused
- Competent professionals
- Competent Volunteers
- Success

Philosophy of Camp

Atmosphere of Delight

How can I help?

Getting by isn't enough (Marshall)

Influences

- ❖ **Toronto – 2003**
- ❖ **Audrey Holland**
- ❖ **The Life Participation Approach to Aphasia Project Group (LPAA)**
- ❖ **The Scheme...Valerie Eaton-Griffith**
- ❖ **Lynn Fox and the Portland State University Camp**

Influences (con't)

- ❖ Jon Lyon- “Coping with Aphasia”...
- ❖ Robert Marshall- “Getting by isn’t enough”
- ❖ Mihaly Csikszentmihalyi, “Flow”

Images

Luther Midelfort

Mayo Health System

Participation



- “She was thrilled to have to make a choice between yoga and massage”
- “I went fishing and loved it.”
- “It is so much to be a part of, I couldn’t do it all.”
- “Everyone was so excited to do the things we used to do”

Relationships



- “People gelled incredibly in less than 48 hours, maybe as result of the opportunities within a non-threatening environment.”
- “Conversations in the cabin”
- “People sitting around the fireplace, talking about fishing”
- “Just sitting talking with Don. It reminds so much of talking with my grandpa.”

Enjoyment



Luther Midelfort
Mayo Health System

- “Another highlight was the bike ride this morning”
- “Lotta fun”
- “I was shuttling people out to the road to “watch others” and when I returned to the road they were not watching...”
- “I think Bob had a blast today with everybody else. He didn’t feel different.”
- “Wonderful”

Discovery



- “Jim like a real person...relaxed”
- “At spirituality, John cried because he was so excited about golfing...”
- “People initially were apprehensive and then joining in due to atmosphere and support.”
- “Aphasia, head injury can happen to anyone... It’s eye-opening to see first hand.”

Accolades



- “Speaker was great as usual”
- “Beautiful facility”
- “Low ropes – good idea. I think the team building between everyone was wonderful.”
- “The spiritual workshop was great.”
- “The nametags were great – great in terms of connecting...”

Comfort

- “Phyllis said she had one of the best conversations ever with Jim...”
- “I heard Phyllis say “This is the first time we haven’t stood out.”
- “...she knew he’d be okay and she could start to relax and have a break.”



Process and Development

Getting Started

Luther Midelfort

Mayo Health System

Development of Camp

- SLP's sitting around dining room table, talking camp,
- Dream to provide meaningful experiences
- Within nature

Speech Pathology Staff

- Two full time SLPs
- Two part-time SLPs
- Primary employment is Luther Midelfort – Mayo Health System



Planning Structure for Aphasia Camp

Aphasia Camp Board

Aphasia Camp Planning Committee

Volunteer and
Staff Training
SLP's and PT's

Facilities Planning
and Modification

Activities

Registration and Mailings

Luther Midelfort

Mayo Health System

Timeline

- **Recruitment**
- **Registration format**
- **Camp**
- **Training dates**
- **Resources**
- **Professional contacts**

Funding and partnerships

- **Chippewa Valley Aphasia Groups**
- **Luther Midelfort**
- **Gifts in Kind**
- **Scholarships**
- **Partnership with Universities**

Funding sources



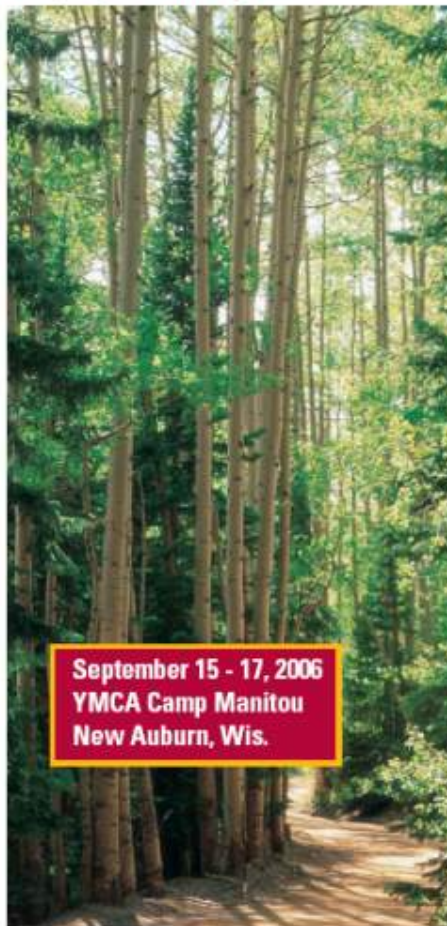
- Supported by Luther Midelfort
- Luther Midelfort does not solicit contributions for camp
- In 2004 fee was \$50/person for whole weekend
- In 2006, fee was \$100 for PWA; \$75 for family
- Day option added for \$50/day

Marketing

- **Corporate Communications**
- **2006-Audio Visual Luther Midelfort**
- **Fliers to hospitals**
- **Aphasia groups**

Aphasia Camp

A relaxing
weekend retreat in a rustic setting
for people with aphasia



September 15 - 17, 2006
YMCA Camp Manitou
New Auburn, Wis.

Luther Midelfort

Mayo Health System

Luther Midelfort

Mayo Health System

Attendance Data

	2004	2005	2006	Average
People with Aphasia	11	14	13	12.7
Caregivers	4	5	8	5.7
Student Volunteers	11	15	17	14.3
Community Volunteers	3	5	4	4
Professional Staff (SLPs, Ots, PT, etc)	7	5	7	6.3
Instructors	8	8	10	8.7

Registration









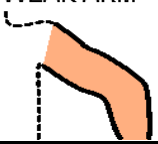



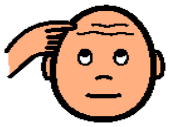







- OT helps create appropriate visual format
- OT/SLP together strive for aphasia friendly format
- PT leads the process

Forms

- Cover letter
- Brochure
- Interest survey
- Health history
- Camp Waiver
- Physical Needs survey
- Communication Survey
- Conversation ?'s

Physical Needs Survey

1. How much do your limitations interfere with your daily activities?





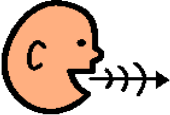







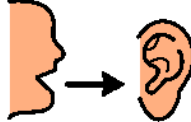



WALKING 	   <div style="display: flex; justify-content: space-between; width: 100%;"> ----- ----- </div> <div style="display: flex; justify-content: space-between; width: 100%;"> NONE SOME A LOT </div>
WEAK LEG 	   <div style="display: flex; justify-content: space-between; width: 100%;"> ----- ----- </div> <div style="display: flex; justify-content: space-between; width: 100%;"> NONE SOME A LOT </div>
WEAK ARM 	   <div style="display: flex; justify-content: space-between; width: 100%;"> ----- ----- </div> <div style="display: flex; justify-content: space-between; width: 100%;"> NONE SOME A LOT </div>
THINKING 	   <div style="display: flex; justify-content: space-between; width: 100%;"> ----- ----- </div> <div style="display: flex; justify-content: space-between; width: 100%;"> NONE SOME A LOT </div>
VISION 	   <div style="display: flex; justify-content: space-between; width: 100%;"> ----- ----- </div> <div style="display: flex; justify-content: space-between; width: 100%;"> NONE SOME A LOT </div>

2014-2015-2016

Mya's Health System

Communication Survey

Below are some questions regarding your communication.
How much difficulty do you have with:

<p>Reading</p> 	   <p>NONE SOME A LOT</p>
<p>TALKING</p> 	   <p>NONE SOME A LOT</p>
<p>Writing</p> 	   <p>NONE SOME A LOT</p>
<p>Understanding</p> 	   <p>NONE SOME A LOT</p>

© 2012 BSA

My Health System

The setting

Luther Midelfort

Mayo Health System

Facilities – YMCA Camp

- **Accessible bathrooms and buildings**
- **Rented golf carts for mobility limitations**
- **No phones in cabins, no TVs**
- **Main lodge is central gathering**
- **Meals buffet style w/ camp cook and campers**

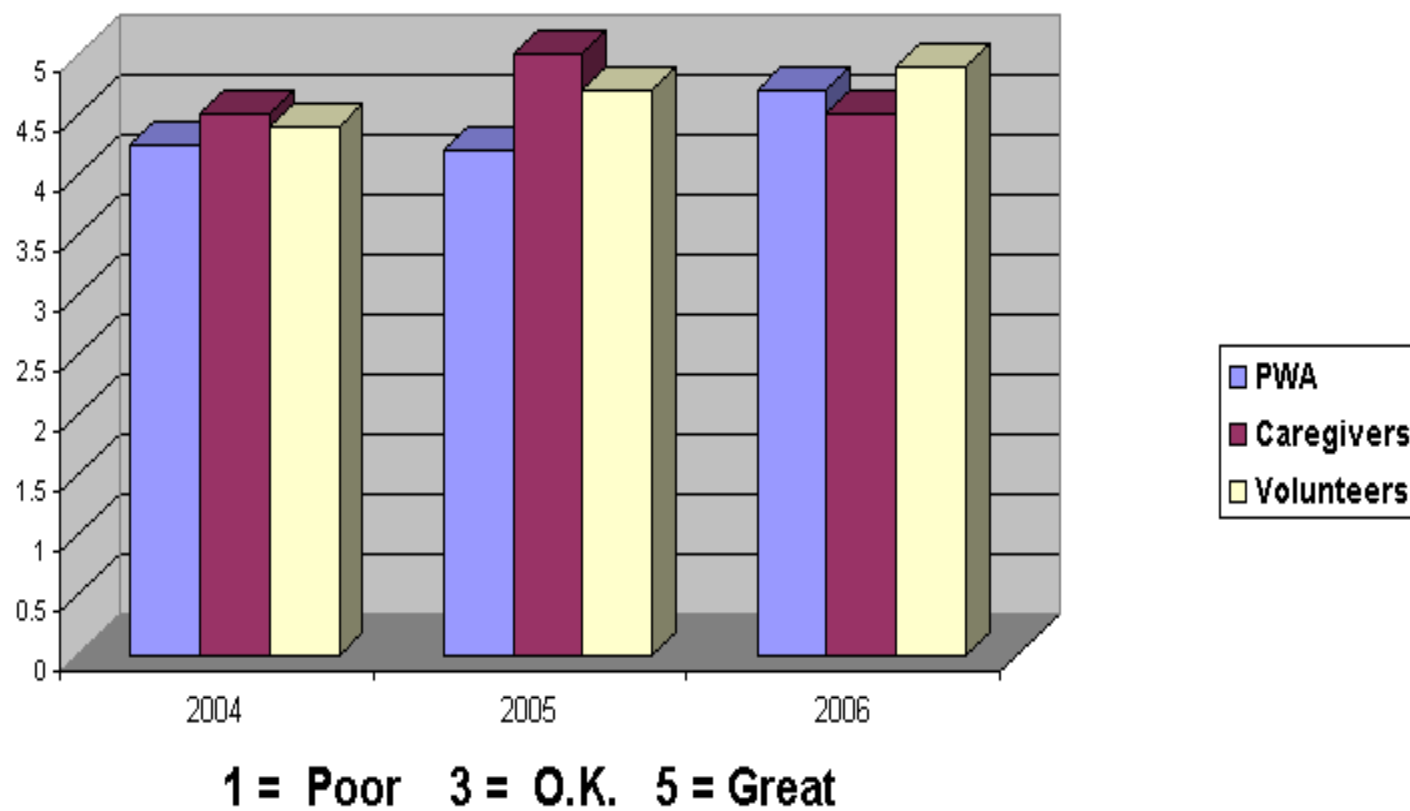
Camp Manitou



Luther Midelfort

Mayo Health System

Camp Setting



The facility is a crucial factor to the experience



Aphasia Camp Staff

Luther Midelfort

Mayo Health System

Staff at Aphasia Camp

- Includes health care staff, volunteers, professionals
- All staff function on transdisciplinary level
- Expected to have adequate skills and comfort for communication and interaction

Who are our volunteers

- **Community members**

- **Individuals with brain injury**

- **Spouses of members who have passed away**

Students

- **Undergrad and grad**

- **Comm Dis and other majors**

- **Aphasia group volunteers and “novel” volunteers**

Students come from...

- University of Wisconsin – Eau Claire
- University of Minnesota - Duluth
- University of Wisconsin – River Falls
- University of Wisconsin – Madison
- Purdue University



Volunteer and Staff Training

- **Mandatory 2 hour training session**
- **Information about aphasia**
- **Communication strategies – ramps, role plays, supported conversation**
- **Principles of camp**

Volunteer Training (con't)

- **Emphasis is placed on the role of conversation throughout camp**
- **Problem-based learning; collaborative discussion**
- **The camp experience**
- **Facilitating enjoyment**

Principles that Guide Volunteer Interactions

- Mutual benefit
- Meaningful conversation and relationships
- Participation
- Co-construction of meaning
- “Whatever it takes”
- Joint ownership and empowerment
 - “We did it”
 - “We figured it out”
- Confidence
- Compassion

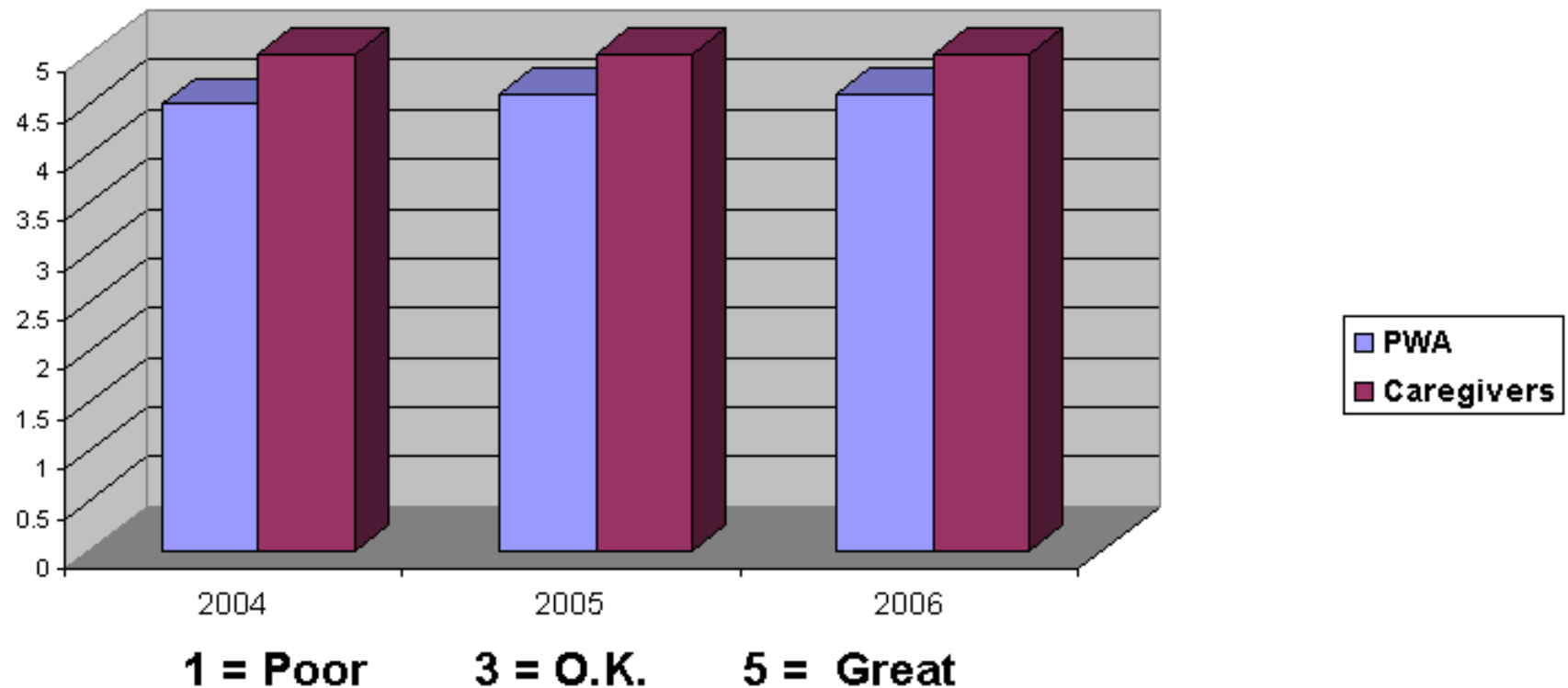
We expect our volunteers to

- **Be Caring**
- **Be Compassionate**
- **Be Confident**
- **Be Vigilant**
- **Be Comfortable**
- **Explore the Relationship**

Skilled Instructors

- **Experts – Professionals**
 - **SLPs lead very few sessions**
 - **Instructors complete training**
 - **Trained volunteers present in all sessions as well**
-
- **Instructors on equal level with campers – interact throughout weekend**

Quality and knowledge of staff



Activities

Luther Midelfort

Mayo Health System

Activities and Sessions

Criteria for Selection

- Interest in activity?
- Opportunity for meaningful participation?
- Can it be aphasia friendly?
- Financially reasonable?
- Enjoyable?
- Maintain safety?

Principles that guide activity and session development

- Opportunity to refine prior skills
- Opportunity to expand horizons and comfort level – try new things
- Choice





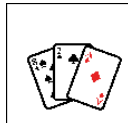






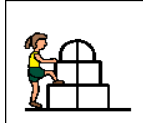
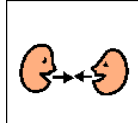
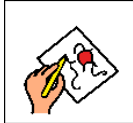


Examples of activities

- Adapted golf
- Woodworking
- Art
- Living with aphasia
- Spirituality
- Biking – 2 and 3 wheel
- GPS Geocaching
- Technology – email, practice,
- Murder mystery
- Low ropes course
- Fishing
- Crafts
- Songwriting and singing











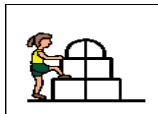
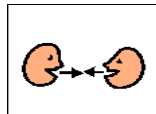
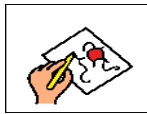

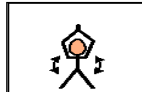
Activities (con't)

- **Hiking**
- **Yoga**
- **Massage**
- **Life history books**
- **Conversation groups**
- **Writing**
- **Card games**
- **Fantasy football draft**
- **Theatre**
- **Emotional wellness**
- **Conversation practice and coaching**

Schedule – people with Aphasia

Friday			Saturday Morning		
10 a.m. – Sign in			8 a.m. – Breakfast (dining hall)		
12 p.m. – Lunch (dining hall)			8:30 a.m. – Biking		
<u>Session 1 1:30 – 3 p.m.</u>			<u>SESSION 1 9:30 – 11 a.m.</u>		
					
Card Games (dining hall)	Computers (main lodge)	Hiking	Fishing (front patio)	Crafts Woodworking (outside/ dining hall)	Computer Practice (main lodge)
<u>SESSION 2 3:30 – 4:30 p.m.</u>			11 a.m. – Rest		
			12 p.m. – Lunch (dining hall)		
Low ropes	Conversation Practice	Art	Adaptive Yoga		

Schedule - Partners

Friday			Saturday Morning		
	8 a.m. – Breakfast (dining hall)				
	8:30 a.m. – Biking				
<u>Session 1 1:30 – 3 p.m.</u>			<u>SESSION 1 9:30 – 11 a.m.</u>		
					
Card Games (dining hall)	Computers (main lodge)	Hiking	Fishing (front patio)	Crafts Woodworking (outside/ dining hall)	Computer Practice (main lodge)
<u>SESSION 2 3:30 – 4:30 p.m.</u>			11 a.m. – Rest		
			12 p.m. – Lunch (dining hall)		
Low Ropes	Conversation Practice	Art			
			Adaptive Yoga		
					

2017-2018

Adaptive Health System

Schedules and Activities

- Schedules are somewhat different for PWA and family members
- Balance between rest and activity
- Typically two sessions in a.m. and two sessions in p.m. with evening activity

Schedule (con't)

- **Account for scheduling similar tasks at different times (art and crafts)**
- **Saturday evening – collaborative event that requires prep**

Nights

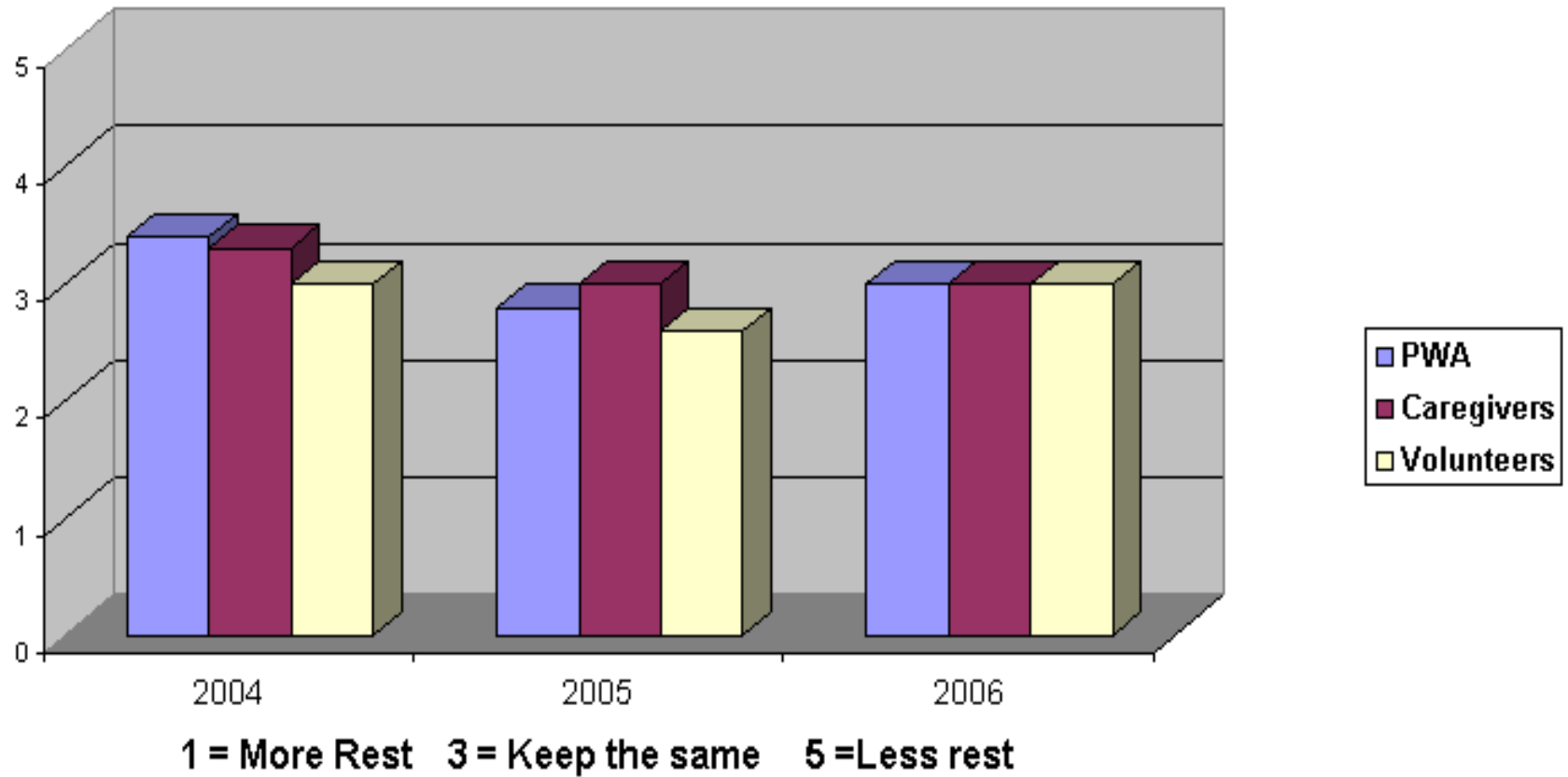
- Campfires
- Storytelling –
- Guitar and songs
- Kurt's stories



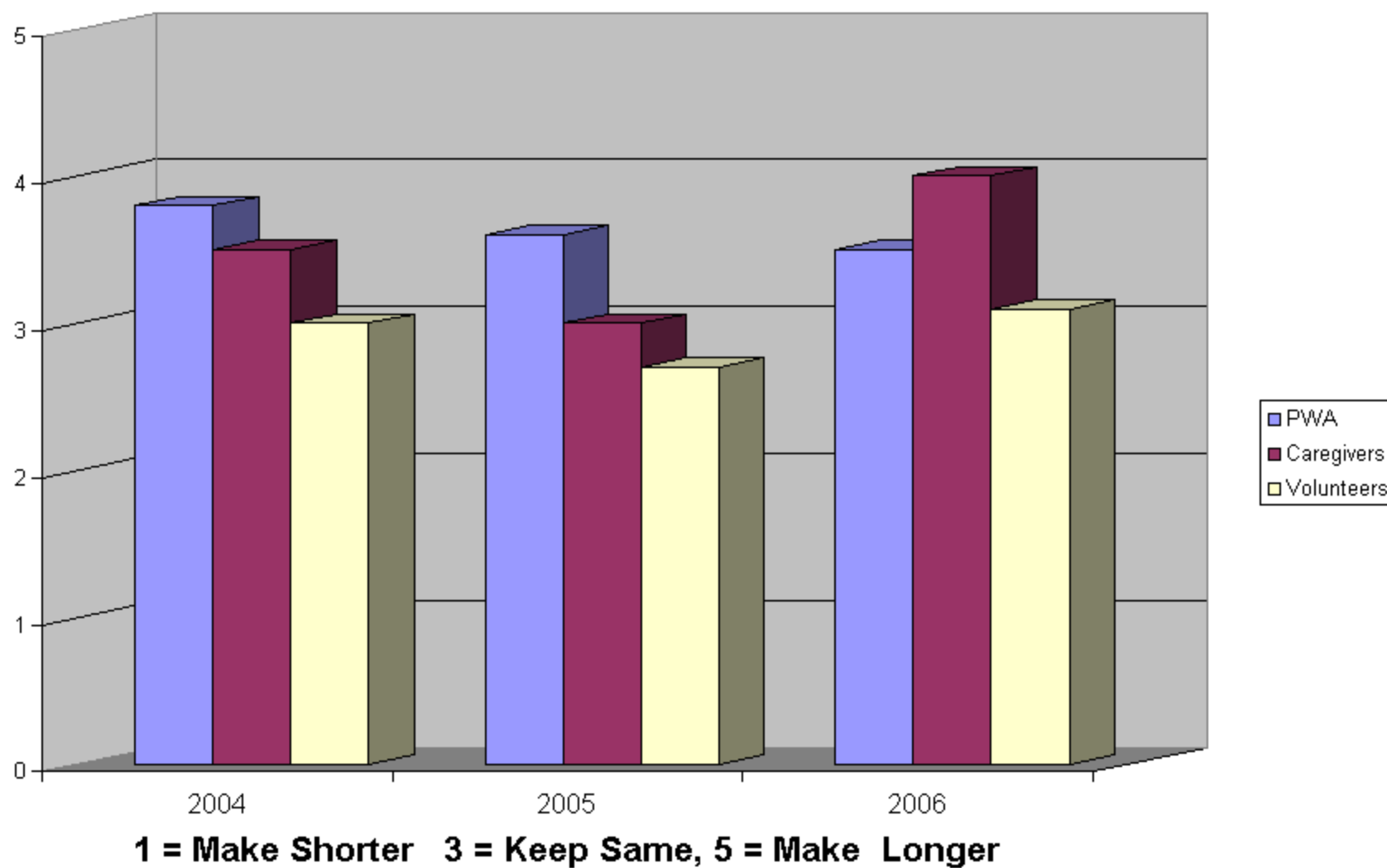
Evening de-briefing and journaling

- Discuss perceptions, events, challenges in forum setting
- Mutual problem solving
- Sharing, commonality
- Forum to discuss emotionally-charged events
- Facilitate reflection through guided discussion

Balance of Rest and Activities



Length of Camp



Outcomes

Qualitative Descriptions

Luther Midelfort

Mayo Health System

Qualitative Descriptions

- **Post camp debriefings**
- **Artifacts including letters, e-mails, notes**
- **Camper Images**
- **Journals**
- **Interviews**

Method – Focusing and analyzing data

- **Notes and journals reviewed independently and then collaboratively**
- **Reviews occurred on multiple occasions**
- **Themes and definitions created in response to data examples**
- **Themes reviewed and verified**

Themes

- Discovery
- Relationships
- Participation
- Enjoyment
- Accolades
- Suggestions
- Comfort

Discovery

- Learning
- Insights
- Inspiration
- Change in perspective or definition
- Answers to questions
- Process of learning
- Seeing aphasia and self in new ways

Examples

“Jim like a real person...relaxed.”

“Also took time to watch Mary Beth interact with someone today. I really enjoy taking a moment in the day to watch someone else interact.”

“Initially, I didn’t know how to start a conversation.”

Relationships

People's names

Family

Friendship

Inclusion

Meaningful interactions

Community

Together

Everyone, we, all, they

Examples

“People were exchanging addresses after the ecumenical service on Sunday.”

“I had a lot of good conversations about farms, dogs, and cats with Marlene.”

“Elaine helping Lenore as she arrived at camp.”

Participation

- Activity
- Choices
- Experiences
- Downtime
- Attempting something
- Achievement
- Helping

Examples

“Everyone singing together by the fire
This Land is Your Land and *Amazing Grace*.”

“Everyone was so excited to do the things they used to do.”

“Next was a campfire, where Bob proudly played guitar.”

Comfort

- **Ease**
- **Natural feeling**
- **Easy**
- **Compassion, hope, faith, kindness, care**

Examples

“... It was such a fun, safe atmosphere.”

“People hugging, tears packing up and saying goodbye.”

Enjoyment

- Flow
- Absence of communicative burden
- Absence of disability
- Great, fun, wonderful, awesome,
- Satisfaction

Examples

“Loved being on the water”

“On the way over to passage, she began to tell me that she never wanted to leave.”

“It was really cool. It was one of those times we were in flow, you know.”

Accolades

- Praise for campers and/or staff
- Environment
- Structure of camp

Examples

“Volunteers were on target.”

“I think Bruce was phenomenal!”

Suggestions

- “I wish...”
- “You should...”
- “Next time...”
- “There should be...”

Examples

“Cribbage tournament next year.”

“I know some about the computer, but I liked the information. I think it would be good to have a basic and advanced session for spouses.”

What have we learned from the qualitative descriptions...

Luther Midelfort

Mayo Health System

What have we learned from the qualitative descriptions...

- **Knowledge of aphasia does not always directly relate to positive volunteer experience**
- **Education paradigm affects volunteer's perceptions**

What we have learned (con't)

- **Volunteer journals provide rich information**
- **Camping environment contributes to communication context**
- **The process of analysis helps us to identify what we are looking for**

Volunteer characteristics or traits we are looking for:

- **Individuals who are willing to engage**
- **Individuals willing to learn**
- **Curious and interested in learning what it is like to live with aphasia**
- **Learn about people as individuals not “aphasics”**

Changes in our volunteer process

- Greater emphasis on relationship development
- Camp experience and expectations
- Training sessions with seasoned or veteran volunteers
- Small teams of volunteers accountable to each other
- Volunteers applying to be part of camp – looking at the fit of camp

More questions

- How are we gathering data?
- Is there a relationship between discovery, relationship and enjoyment?
- Is there a relationship between increased comfort and emerging confidence?
- Does this camp experience foster a paradigm shift in the individual's future of speech pathology?

The Value of Aphasia Camp

The long-term effects

Luther Midelfort

Mayo Health System

Campers

Meaningful real life outcomes

**Change in perspective of
identity, wellness, relationships**

Motivation for change

Luther Midelfort

Mayo Health System

Volunteers

- **Impact on career of speech language pathology**
- **Opportunity to experience life participation approach to aphasia**
- **Change in perspective**

Staff

- **Developing group opportunities...computer club, photography...**
- **Reading books recommended by the “Experts”**
- **Satisfaction of “Doing what is right”**

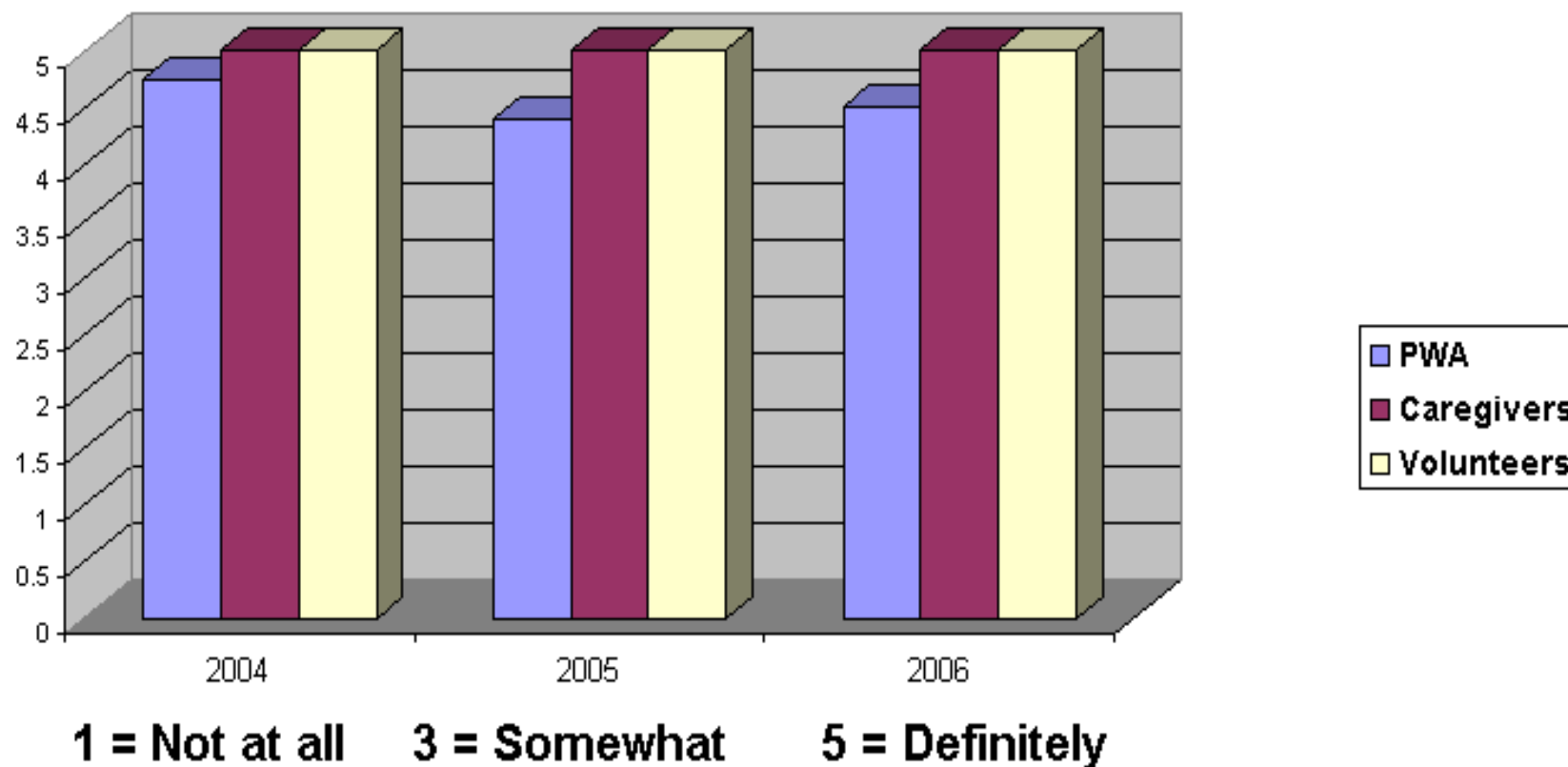
Instructors

- Relationships
- Opportunities for community programs
- Aphasia group involvement
- New learning about aphasia

Organization/Community

- **Increases knowledge base (“Way We Work”)**
- **Caring individuals**
- **Ripple effect**
- **Increases awareness**

Would you recommend camp?



The future of the Chippewa Valley Aphasia Camp

- **Volunteer recruitment/interview**
- **Mentoring/teams at camp**
- **Chaplain presence**
- **Competent relationship counselor presence**
- **Maintain naturalness, flow**
- **Establish more opportunities for success**

For more information...

**Next year's camp will be September 14-16th,
2007**

**If you are interested in volunteering with the
Chippewa Valley Aphasia Camp, or know
someone who would be interested in
attending camp, please contact us.**

Mary Beth Clark, MS/CCC-SLP

Clark.marybeth@mayo.edu

(715) 838-3258

Luther Midelfort
Mayo Health System

Bibliography

Chapey, R., Duchan, J., Elman, R., Garcia, L., Kagan, A., Lyon, J., Simmons-Mackie, N. (2000). "Life Participation Approach to Aphasia: A statement of values for the future." ASHA Leader, February, 2000.

Fox, L., et al., (2004). Critical elements and outcomes of a residential family-based intervention for aphasia caregivers. *Clinical Aphasiology Conference*.

Griffith, V. E. (1970). *A Stroke in the Family*. Penguin Publishing.

Holland, A. and Forbes, M. (eds) (1993) *Aphasia treatment: World perspectives*. London: Chapman and Hall.

Holland, A.L., Halper, A.S. (1996). Talking to individuals with aphasia: A challenge for the rehabilitation team. *Topics in Stroke Rehabilitation* 2 (4) 27-37.

Kagan, A. & Gailey, G. (1993). Functional is not enough: Training conversation partners for aphasic adults. In A.L. Holland & M.M. Forbes (Eds.), Aphasia treatment: World perspectives (pp.199-225) San Diego: Singular.

Light, J., (1997). "Communication Is the Essence of Human Life": Reflections on Communicative Competence. AAC Augmentative and Alternative Communication **13**, 61-70.

Lyon, J., Cariski, D., Keisler, L., Rosenbeck, J., Levine, R., Kumpula, J., Ryff, C., Coyne, S., and Blanc, M. (1997). Communication Partners: enhancing participation in life and communication for adults with aphasia in natural settings. Aphasiology, **11**, 693-708.

Lyon, J. (1997). Volunteers and partners: Moving intervention outside the treatment room. In Shadden, B.B. and Toner, M (Eds.). Aging and Communication for Clinicians By Clinicians. (pp. 299-323). Austin, Tx: ProEd.

Lyon, J. (1998). *Coping with Aphasia*. San Diego: Singular Publishing.

Marshall, R. C. (1998). *Group treatment for aphasia: Planning, Procedures, Documentation*. Boston : Butterworth –Heinemann

Simmons-Mackie, N. (2000). *Social Approaches to the Management of Aphasia*. In Worrall, L.E., Frattali, C.m. (Eds). *Neurogenic Communication Disorders: A Functional Approach*. (pp 162-187). New York: Stuttgart.

The Picture Communication Symbols
© Copyright 1981-2003 Mayer-Johnson, Inc