# Supporting Individuals with Complex Communication Needs to Capture and Share Active Recreation

Doctoral Student AAC Research Think Tank
David J. Hajjar, M.S., CCC-SLP
Ohio University
May, 2017

## Background

- People with CCN have limited opportunities for full participation & engagement across natural settings
  (Light & McNaughton, 2015; Balandin, 2011)
- Partners can have a positive impact on communication for people who use AAC
  (Kent-Walsh, Murza, Malani, & Binger, 2015)
- People with lifelong disability have limited social networks, difficulty making friends, report loneliness & a lack of meaningful activity in their lives
  (Ballin & Balandin, 2007)

2

## Background

- Participation Model: Opportunity and access barriers for people who use AAC
  (Beukelman & Mirenda, 2013)
- ICF/WHO: Consideration of body structure & function; activities & participation; contextual factors & personal factors
  (WHO, 2013)
- Recreational settings provide enhanced social connections, improved quality of life, and enjoyment
  (Datillo et al., 2008; Zabriskie, Lundberg, & Groff, 2005 )

3

## Why Collaborate with Recreation?

- May define one's life like work or school
- Physical barriers are eliminated
- Settings accessed by the general public
- Rich opportunities for communication, social interaction & participation
- Enhance the experience

4

## Developing a Line of Inquiry

**Interview Volunteers**
Active Recreational Settings

**Train Volunteers**
Therapeutic Horseback Riding

**CAPTURE & Share**
Distance Training & Application

5

## Interviews with Volunteers
### Conclusions

Volunteers:

- Reduce physical barriers
- Motivated communication partners
- Enhance social interactions & facilitate participation
- Serve as community ambassadors
- Report challenges with communication and limited use of aided AAC systems across the experience

6

# "You Get More Than You Give"

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION, 2016
VOL. 32, NO. 2, 131–142
http://dx.doi.org/10.3109/07434618.2015.1136686

Taylor & Francis
Taylor & Francis Group

RESEARCH ARTICLE

**"You Get More Than You Give": Experiences of Community Partners in Facilitating Active Recreation with Individuals who have Complex Communication Needs**

David J. Hajjar, John W. McCarthy, Joann P. Benigno, and Jennifer Chabot

Communication Sciences and Disorders, and Child and Family Studies, Ohio University, Athens, OH, USA

**ABSTRACT**
Recreation is an essential part of life that provides enriching experiences that may define one's life course similar to careers or other interests. An understanding of the role of volunteers in active community-based recreational programs can help to generate ways to enhance participation and contribute to additional communication opportunities with people who have complex communication needs. Nine volunteers from two adaptive ski programs and one therapeutic horseback-riding program in the Northeast region of the United States participated in semi-structured interviews. Audio-recordings were transcribed and analyzed and resulted in five thematic areas: (a) benefits, (b) why individuals volunteer, (c) barriers, (d) successful program supports, and (e) who are the riders and skiers using AAC. The findings provided insight to support the notion that active community-based recreational activities foster an environment for communication, meaningful engagement, and social relationships between volunteers and people with complex communication needs.

**ARTICLE HISTORY**
Received 11 February 2015
Revised 12 December 2015
Accepted 23 December 2015
Published online 8 February 2016

**KEYWORDS**
Augmentative and alternative communication; complex communication needs; recreation; leisure; volunteers

7

# Volunteers Provide Critical Support

8

# Take-home Program

9

# Training Volunteers
## Conclusions

- All volunteers reached criterion when using the program with riders
- Riders increased in the number and type of responses during pre & post lesson periods
- Volunteers provided positive feedback about the training

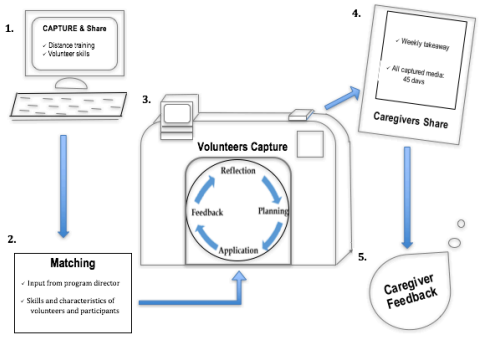
10

# Dissertation Research
## Overview

- Active recreational settings
- Volunteers as communication partners
- Capturing & sharing digital media
- 2 experiments:
  - Experiment 1: Distance training for volunteers (SSD)
  - Experiment 2: Application of program in natural context (Participatory Action Research)

11

# Research Process




12

## CAPTURE & Share Training: Experiment 1

What is the effect of the distance training on the volunteers' acquisition of the CAPTURE and Share program?

13

## CAPTURE & Share Method: Experiment 1

- Single-case research: multiple baseline design with replication
- Six volunteers completed five phases
- Independent variable: Distance training program
- Dependent variable: The percent accuracy of the targeted training elements as measured by the volunteers ability to generate a complete plan in a written response to repeated probes

14

## The Plan

| Program Steps | Action Item *Say or Do* | Barriers/ Supports *Participant* | Barriers/ Supports *Volunteer* |
|---|---|---|---|
| *1. Choose Camera* | | | |
| *2. Adapt* | | | |
| *3. Practice* | | | |
| *4. Take Photo and Video* | | | |
| *5. Use Context* | | | |
| *6. Review* | | | |
| *7. Edit* | | | |
| *8. Share* | | | |

## Results

- All volunteers successfully learned the program
- Improvement Rate Difference (IRD): 1 or 100%
- Stable baseline with no upward trend
- Gradual improvement during intervention phase
- Post, generalization, & maintenance probes over 80%

16

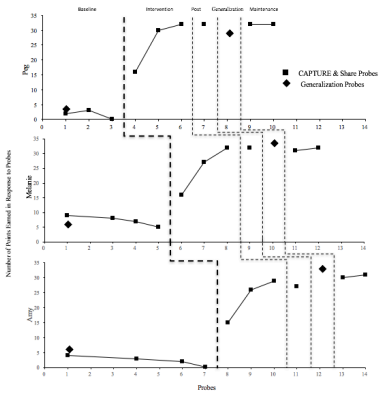



*Figure 1.* Total number of points earned by volunteers responding to hypothetical probes across five phases. The dotted line between baseline and intervention phases is bolder than the other lines to indicate that volunteers started to receive instruction. During the intervention phase, volunteers periodically responded to probes.

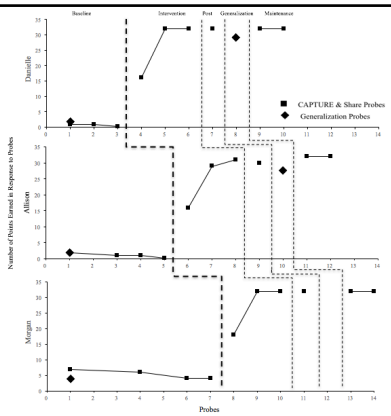
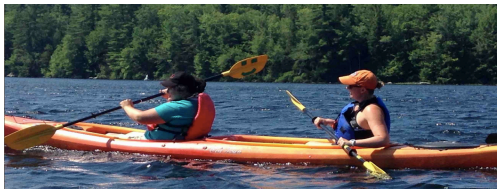



*Figure 2.* Total number of points earned by volunteers responding to hypothetical probes during replication. The dotted line between baseline and intervention phases is bolder than the other lines to indicate that volunteers started to receive instruction. During the intervention phase, volunteers periodically responded to probes.

18

# CAPTURE & Share
## Application: Experiment 2

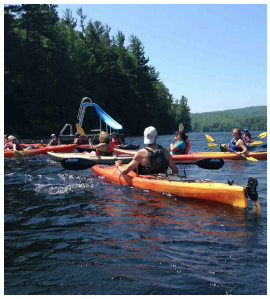
Aim: What are the perspectives of volunteers, participants, and caregivers relative to the application and use of the CAPTURE & Share program during active recreation?



19

# CAPTURE & Share
## Participatory Action Research

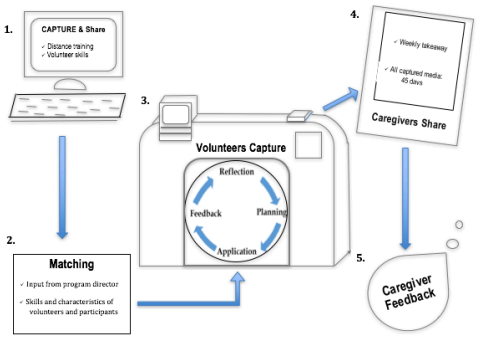
- Input from program director
- 3 feedback sessions with volunteers
- Pre/post interviews with caregivers & participants



(Hebblethwaite & Curley, 2015)

20

# Research Process




21

# Data Analysis & Results
## Volunteer Feedback Sessions

- Thematic analysis (Creswell, 2007)
- 5 Primary themes
  - Steps of the program (CAPTURE & Share)
  - Feedback (application, modifications, & training)
  - Barriers (technology & stakeholder)
  - Supports
  - Benefits

22

# Results
## Caregiver & Participant Pre-Lesson Interview

- Functional Communication Profile Revised (FCP)
- Pre-lesson capture & share experience:
  - J.V.-limited capture and share, email photos
  - J.V.-limited capture and share, some Email
  - S.A.-has tried Facebook in the past, Email
  - M.M.-print out photos
  - C.A.-limited capture, some Email

23

# Results
## Caregiver & Participant Post-Lesson Interview

- J.V. - New Facebook page, new Go-Pro camera
- J.V. - New Facebook page, personal review
- S.A.- Add to existing social media & share with sister and brother on west coast, create photo book
- M.M.- Social media, share with brother, print out
- C.A. - Share photos with her father, sisters, coach; mother did not want social media

24

# Impact
## CAPTURE & Share

- Empower volunteers to facilitate participation, enhance social interactions, and increase opportunities for communication
- Provide digital artifacts to caregivers and participants for sharing & personal review
- Support the development of psychosocial factors
- Consider application in other practice settings
- Collaborate with SLPs and related professionals to engage in program

25

# Research: Future Directions

- Participation, social engagement, quality of life, & supporting communicative competence
- Supporting communication partners across community based settings
- Consider AAC systems & other technology to support communication, capture, & preferences for sharing
- Collaborate with SLPs and related professionals across practice settings
- Focus on psychosocial factors to support communication and participation

26

# Acknowledgements


- AAC lab at Ohio University: Dr. John W. McCarthy, Jamie Boster, Jessica Apsley, Shelby Roberts, Alicia Swain, Lyndsey Welch
- T.A.L.K. lab at Ohio University; Dr. Joann P. Benigno & Bridget Gornichec
- Gary S. Neiman Award, Ohio University
- Community Engaged Research Grant, College of Health Sciences and Professions, Ohio University
- Original Works Grant, Graduate Student Senate, Ohio University
- 2016 New Century Doctoral Scholarship, ASHFoundation
- Participants with CCN, caregivers, guardians, volunteers & related professionals


27

# References


Beukelman, D.R., & Mirenda, P. (2013). *Augmentative and alternative communication: supporting children and adults with complex communication needs* (4th ed.). Baltimore: Paul H. Brookes Publishing Co.

Ballin, L., & Balandin, S. (2007). An exploration of loneliness: Communication and the social networks of older people with cerebral palsy. *Augmentative and Alternative Communication*, *32*(4), 315-326

Creswell, J. (2007). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage.

Datillo, J., Estrella, G., Estrella, L. J., Light, J., McNaughton, D., & Seabury, M. (2008). "I have chosen to live life abundantly": Perceptions of leisure by adults who use augmentative and alternative communication. *Augmentative and Alternative Communication*, *24*, 16-28.

Hajjar, D., McCarthy, J., Benigno, J. & Chabot J. (2016). "You get more than you give.": Experiences of community partners in facilitating active recreation with individuals who have complex communication needs. *Augmentative and Alternative Communication*, *32*(2), 131-142.

Hebblethwaite, S., & Cusley, L. (2015). Exploring the Role of Community Recreation in Stroke Recovery Using Participatory Action Research and Photovoice. *Therapeutic Recreation Journal*, *49*(1), 1.

Kent-Walsh, J., Murza, K.A., Malani, M.D., & Binger, C. (2015). Effects of communication partner instruction on the communication of individuals using AAC: A meta-analysis. *Augmentative and Alternative Communication*, *31*(4), 271-284.

Light, J., & McNaughton, D. (2015). Designing AAC research and intervention to improve outcomes for individuals with complex communication needs. *Augmentative and Alternative Communication*, *31*, 85-96.

World Health Organization (WHO) (2013). How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. Geneva, Switzerland: WHO.

~~Zabriskie, R.B., Lundberg, N.R., & Groff, D.G. (2005). Quality of life and identity: The benefits of a community based therapeutic recreation and adaptive sports program.~~ *Therapeutic Recreation Journal*, *39*(3), 176-191.


28

# Discussion & Research Challenges

29

# Discussion & Challenges

- *Participation:* What are the most meaningful and effective methods to measure participation when conducting research?
- *Training communication partners*: What are the most effective methods to train, evaluate, and provide feedback to partners across community and recreational settings? What are the best practices for incorporating distance learning into partner training?
- *Psychosocial skills to support communicative competence*: How do we investigate the factors of motivation, confidence and resiliency for people with CCN? What types of activities best support the development of these skills? Recreation sector?
- *Support for sharing*: what are the options and how to support caregivers to build an infrastructure for face-to-face and digital sharing?
- *Digital artifacts:* How to effectively use personalized media for storytelling and communication, use of video VSDs? Photo VSDs?
- *Promoting community based recreation:* Collaborate with stakeholders in recreation, How can SLPs support AAC across settings?

30