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

Doctoral Student AAC Research Think Tank
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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, & Briger, 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)

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)

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

Developing a Line of Inquiry

Interview Volunteers
Active Recreational Settings

Train Volunteers
Therapeutic Horseback Riding

CAPTURE & Share
Distance Training & Application

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
“You Get More Than You Give”

Volunteers Provide Critical Support

Take-home Program

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

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)
CAPTURE & Share Training: Experiment 1

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

**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

**Program Steps**

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<tr>
<th>Program Steps</th>
<th>Action Item</th>
<th>Barriers/ Supports</th>
<th>Barriers/ Supports</th>
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<tbody>
<tr>
<td>1. Choose Camera</td>
<td>Say or Do</td>
<td>Participant</td>
<td>Volunteer</td>
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<td>2. Adapt</td>
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<td>3. Practice</td>
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<td>4. Take Photo and Video</td>
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<td>5. Use Context</td>
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<td>6. Review</td>
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<td>7. Edit</td>
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<td>8. Share</td>
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**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%
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?

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CAPTURE & Share
Participatory Action Research

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

(Hebblethwaite & Curley, 2015)

Research Process

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

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

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
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

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

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Discussion & Research Challenges

- Training communication partners: What are the most effective methods to train, evaluate, and provide feedback to partners across community and institutional settings? What are the best practices for incorporating distance learning into partner training?
- Psychosocial skill to support communication partners: 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 settings?
- Support for sharing: What are the systems 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 VISION? Phone VISION?
- Promoting community-based recreation: Collaborate with stakeholders in recreation, How can SLPs support AAC across settings?