Preparing Learners with Complex Communication Needs for Life after School: New Approaches to Supporting Communication and “Building Community”

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Transition Goals

1. Have a safe place to live
2. Participate in meaningful activities
3. Access to services
4. Develop friendships and intimate relationships

Goals drive development of communication (AAC)

Communication (AAC) supports achievement of goals

Plan for the future

• Visit the future
• Talk to someone who is already there
  • Success stories and challenges
Transition Goals

1. Have a safe place to live
2. Participate in meaningful activities
3. Advocate for services
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Personal Care Attendants

• No matter where someone lives, their quality of life depends to a great extent on the degree to which they can direct the services of the person who provides attendant care
  1. Direct care
  2. Give positive and constructive feedback
  3. Deal with conflicts and dangerous situations
• Barbara Collier, 2005

Documenting Service Routines

• Identify important contexts
  • Transfers, mealtimes, toileting
• Document Service Routine
  • Step-by-step description
  • Binders, pages on wall, programmed into devices
    • Photos
  • Practice use in role-playing situations

Service Routine for Nail Care

(Collier et al., 2006)

• When cutting or cleaning my nails, it is important to know that my hand may clench. This is due to my spasticity. It does not help to ask me to relax or open my hand. I cannot control it.
• The best thing to do is
  • Gently pry open each finger
  • Hold each nail firmly when cut or clean the nail
  • Cut my nails short
  • File any jagged nails because I might scratch myself
Teach Needed Strategies:
Dealing with problem
(Collier, 2007)

Use role plays to teach needed strategies
• Describe problem
  • I have a problem with my nails
• State significance
  • It hurts when they have jagged edges
• Communicate what needs to happen
  • Please follow the service routine in my book

Communication (AAC) supports achievement of goals

Communication and Self-determination

Encourage children and young adults to
• Communicate what they want and how they want it done (requires specific vocabulary)
  • Give polite feedback
  • Problem solve
• Develop a sense of personal privacy
  • Say “no” when appropriate

Goals drive development of communication

Crime and Abuse
(Bryen, Carey & Frantz, 2003)

Survey of 40 adults who use AAC

• 45% have experienced crime or abuse
• 97% knew the perpetrators
• 71% victimized multiple times
• 28% reported abuse to police
### My Student:

<table>
<thead>
<tr>
<th>Goal</th>
<th>Teaching opportunity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduce AAC system</td>
<td>• peers without disabilities during group projects/ongoing activities</td>
</tr>
<tr>
<td></td>
<td>• restaurants, community trips</td>
</tr>
<tr>
<td>Document and teach service routines to others</td>
<td>• classroom volunteers</td>
</tr>
<tr>
<td>Give polite feedback to staff, problem solve</td>
<td>• “sabotage” opportunities (wrong coat)</td>
</tr>
<tr>
<td></td>
<td>• Communicate “no”</td>
</tr>
</tbody>
</table>

## Communication (AAC) supports achievement of goals

### “Reach for the Stars”:

*Five Principles for the Next 25 Years of AAC*

- (a) The time for AAC is now
- (b) One is never enough
- (c) My AAC must fit my life
- (d) AAC must support full participation in all aspects of 21st century life
- (e) Nothing about me without me
(a) The time for AAC is now

- The Right to Communicate is a Basic Human Freedom
- Less than 5% of adults with severe disabilities have access to appropriate AAC services
Jackson – 2 years 9 months

- Acquired >1,000 words
- Expresses 45-80 different concepts in 20 minutes of interaction
- Expresses wide range of semantic relations
  - agent, action, object, entity, attribute, adverbial, recurrence, locative, greetings, demonstrative, quantifier, question, affirmation, negation
- Typically uses single words
  - Increased use of 2-3 word combinations
- Navigates aided AAC system independently

(b) One is never enough

- Individuals with complex communication needs require more than
  - One Device,
  - One Communication Partner,
  - One Communication Strategy,
  - One Communication Environment
- Too often we focus on supporting requests with familiar partners (if we focus on partner at all)

(c) My AAC must fit my life

- AAC Systems Must Be Highly Individualized and Appropriate to Individual Needs
- Too often we focus on systems that are “easy” for us
  - We recommend what we know best
  - We provide the vocabulary we “think” they need
- Need to be easy for person who uses AAC!

(d) AAC must support full participation in all aspects of 21st century life

1. Have a safe place to live
2. Participate in meaningful activities
3. Advocate for services
4. Develop friendships and intimate relationships
(e) Nothing about me without me

- Individuals Who Use AAC Have a Right to be Meaningfully Involved in Every Aspect of AAC Research, Development, and Intervention

“Reach for the Stars”: Five Principles for the Next 25 Years of AAC

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Goals drive development of communication

Communication (AAC) supports achievement of goals

Transition Goals

1. Have a safe place to live
2. Participate in meaningful activities
3. Maintain a reliable source of income and access to services
4. Develop friendships and intimate relationships
Transition Goals

1. Have a safe place to live
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Participate in Meaningful Activities

• Work
• Volunteering
• Post-Secondary Education
• Recreation and Leisure

“Reach for the Stars”: Five Principles for the Next 25 Years of AAC

(a) The time for AAC is now
(b) One is never enough
(c) My AAC must fit my life: easy to learn
(d) AAC must support full participation in all aspects of 21st century life: Support learning new skills
(e) Nothing about me without me: Individuals who use AAC have a right to be meaningfully involved in every aspect of AAC research, development, and intervention

Video VSD

• Automatic pausing of the video at key events provides opportunities for participation, and provides the necessary vocabulary within the VSD to fulfill the communication demands at that point.
• Video VSDs capture the dynamic routines within the learner’s life (e.g., school, work, community activities) and cue the learner through the activities, one step at a time, fostering greater participation and communication.
Robert

- 18 year old male with autism
- High school student
- No functional speech
  - A few signs – mostly yes/no, thank you
- Prompt dependent in activities
  - Vocational training: Local elementary school library
  - Checking in books, putting away/sorting books, and making dye cuts

Task Analysis: Putting Books Away

1. Pick up the box of books
2. Bring the box to the table
3. Empty the books on to the table
4. Sort the books into piles based on categories
5. Pick up the books and take them to the bookshelves
6. Put the books in the correct place on the shelf
7. Return the box

Results: Putting Away Books/Sorting

[Graph showing data]
Task Analysis: Putting Books Away

1. Ask to put the books away: Can I put the books away?
2. Pick up the box of books
3. Bring the box to the table
4. Empty the books on to the table
5. Sort the books into piles based on categories
6. Ask a staff member to check your work: Can you check my work?
7. Tell a staff member you are going to put the books away: I’m going to put the books on the shelf
8. Pick up the books and take them to the bookshelves
9. Put the books in the correct place on the shelf
10. Return the box
11. Tell a staff member you are finished: I am finished putting the books away

Results: Putting Away Books/Sorting

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Visit future
Sample future living environments
• LifeLink (State College, PA)
  • High school program
  • Students plan all week for a weekend “visit” to an apartment
    • Plan menu
      • Nutrition, math, meal preparation, transportation
    • Laundry
    • Recreation
    • Community living and problem solving

Tara
• Riding bus

% Steps correct in public transportation

• A very different way of thinking about AAC
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Participate in Meaningful Activities

• Work
  • Volunteering
  • Post-Secondary Education
  • Recreation and Leisure

Key Components of Employment

1. Developing employee knowledge and skills that are valued in the workplace
2. Identifying and developing jobs that are a good match for the skills and interests of the AAC user
3. Ensuring that needed supports are available to maintain employment success

Benefits of Volunteer Activities

• Financial support
• Opportunity to interact socially
• Enhanced self-esteem
• Contributing to society
• A very different way of thinking about AAC

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"Reach for the Stars": Five Principles for the Next 25 Years of AAC

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My Student: Participate in meaningful interactions

<table>
<thead>
<tr>
<th>Goal</th>
<th>Teaching opportunity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be a guide/greeter</td>
<td>• Parent nights</td>
</tr>
<tr>
<td></td>
<td>• Visiting sports teams</td>
</tr>
<tr>
<td>Be a book partner</td>
<td>• Listen to books read by others</td>
</tr>
<tr>
<td>Document for social media</td>
<td>• Take pictures of school activities</td>
</tr>
<tr>
<td>Assist others in work</td>
<td>• School library, community building</td>
</tr>
</tbody>
</table>

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Goals drive development of communication

Need for trained partners

Communication (AAC) supports achievement of goals

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Cullowhee 2018
Transition Goals

1. Have a safe place to live
2. Participate in meaningful activities
3. Advocate for services
4. Develop friendships and intimate relationships

What do doctors expect?

• Typical medical appointment: ____ minutes
• Time for patient to talk before being interrupted? ____ seconds

Medical Services (McNaughton, Balandin, Kennedy, & Sandmel, 2010)

<table>
<thead>
<tr>
<th></th>
<th>Children</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents coordinate care</td>
<td>Individuals are responsible for managing their own health care, including identifying service providers and advocating for needed services</td>
<td></td>
</tr>
<tr>
<td>Children’s rehabilitation facilities often provide “one-stop” coordinated services</td>
<td>Individuals may need to interact with and coordinate information between • general practitioners, • medical specialists and • habilitation / rehabilitation specialists</td>
<td></td>
</tr>
<tr>
<td>Government guarantees of health and rehabilitation services</td>
<td>Individuals need to be able to advocate for adult services</td>
<td></td>
</tr>
</tbody>
</table>

Needed skills

1. Introduce oneself and one’s communication system;
2. Use appropriate vocabulary and language to communicate concerns and needs;
3. Use appropriate communication strategies to ensure that previous health care and current health concerns are understood by the health professional.
Communication Passport
http://www.accpc.ca/pdfs/passport.pdf

Needed skills

• **Children**
  - How AAC equipment should be set up and why it is important
  - Ask for AAC device
  - Make sure it is charged

• **Adolescents**
  - Be familiar with names of medication, schedule
  - Take leadership role in medical appointments, school meetings

My Student: Advocate for services

<table>
<thead>
<tr>
<th>Goal</th>
<th>Teaching opportunity</th>
</tr>
</thead>
</table>
| Advocate for AAC              | • “Ask” for AAC
                                   • “sabotage”
                                   • Direct charging schedule           |
| Prepare for appointments      | • Booking transportation
                                   • roleplay                            |
| Develop leadership skills in  | • “Speak for self” in appointment     |
                                   | appointments                          |
                                   • roleplay                            |

Transition Goals

1. Have a safe place to live
2. Participate in meaningful activities
3. Maintain a reliable source of income and access to services
4. **Develop friendships and intimate relationships**
   - Meaningful activities lead to friendship opportunities
   - Friendships lead to opportunities for meaningful activities
Effect of an AAC App-based Video Training on Peers’ Accuracy Identifying Communicative Behaviors in Presymbolic Middle Schoolers with Multiple Disabilities

Christine Holyfield
Arkansas University
(Proud Penn State grad!)

The Problem

• However, school-aged and older individuals with multiple disabilities who are presymbolic communicators interact with wide range of communication partners throughout their day (Wilcox, Kouri, & Caswell, 1990).

• Inconsistent responsiveness, including inconsistent linguistic mapping, can make symbolic communication much less attainable for individuals with multiple disabilities (Grove, Bunning, Porter, & Olsson, 1999).

• Symbolic language emerges through the “linguistic mapping” (Yoder, Warren, Kim, & Gazdag, 1994) provided by more expert communication partners in response to presymbolic communicative behavior.

• In typical language development, parents are largely responsible for providing these linguistic maps (Carter & Iacono, 2002).

Communication (AAC) supports achievement of goals

Goals drive development of communication

Need for trained partners

• School-aged and older individuals with multiple disabilities who are pre-symbolic communicators interact with a wide range of communication partners throughout their day (Wilcox, Kouri, & Caswell, 1990).

• Inconsistent responsiveness, including inconsistent linguistic mapping, can make symbolic communication much less attainable for individuals with multiple disabilities (Grove, Bunning, Porter, & Olsson, 1999).

• Symbolic language emerges through the “linguistic mapping” (Yoder, Warren, Kim, & Gazdag, 1994) provided by more expert communication partners in response to presymbolic communicative behavior.

• In typical language development, parents are largely responsible for providing these linguistic maps (Carter & Iacono, 2002).
The Current Study

• Evaluate the effects of a short, AAC app-based video training on:
  • Participants’ accuracy in judging video clips documenting the behavior of presymbolic communicators, and
  • Participants’ self-reported level of certainty when making those judgments.

Students with Multiple Disabilities

• Three middle-school students with multiple disabilities – Alyse, Van, & Frankie (pseudonyms) – provided the communicative behavior serving as the content for teaching and testing in the current study.
  • All students communicative predominately through presymbolic means.

Students’ Identified Communicative Behaviors

<table>
<thead>
<tr>
<th>Alyse</th>
<th>Van</th>
<th>Frankie</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication Behavior #1</strong></td>
<td><strong>Communication Behavior #1</strong></td>
<td><strong>Communication Behavior #1</strong></td>
</tr>
<tr>
<td>Linguistic Map Operational Definition</td>
<td>“That’s funny.”</td>
<td>“Yes, I want it.”</td>
</tr>
<tr>
<td></td>
<td>• Smiles</td>
<td>• Moves head down</td>
</tr>
<tr>
<td></td>
<td>• Moves hand/arm</td>
<td>• Hums</td>
</tr>
<tr>
<td></td>
<td>• Extends arm toward person/object</td>
<td>• Extends arm hand/leggers</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Alyse</th>
<th>Van</th>
<th>Frankie</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication Behavior #2</strong></td>
<td><strong>Communication Behavior #2</strong></td>
<td><strong>Communication Behavior #2</strong></td>
</tr>
<tr>
<td>Linguistic Map Operational Definition</td>
<td>“I’m unhappy.”</td>
<td>“Ball”</td>
</tr>
<tr>
<td></td>
<td>• Moves eyebrows down and together</td>
<td>• Vocalizes a sound that starts with a “buh”</td>
</tr>
<tr>
<td></td>
<td>• Moves hand/arm</td>
<td>• Extends arm with palm out to push person/object away</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alyse</th>
<th>Van</th>
<th>Frankie</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication Behavior #3</strong></td>
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</tr>
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Probes

• 18 unique clips showing the communicative and non-communicative behavior of the students with multiple disabilities.

Video Training

• The training contained multiple clips of communicative and non-communicative behavior.
• The training was housed on the videoVSD software (Jakobs, Invotek).
• The software allowed the clips to be made into videoVSDs with hotspots.

Gain Scores

• Results from the ANOVA suggested the gain scores of the two groups differed significantly ($F(1, 22) = 78.907, p < .001$).

Discussion

• Peers do not always pick up on the idiosyncratic communication of individuals with multiple disabilities;
• often ascribe meaning far different than the meaning interpreted by expert communication partners
• The video training seemed to be an effective approach to increasing middle school peers’ performance in identifying communicative and non-communicative behaviors in individuals with multiple disabilities.
The Effect of a Checklist on School-Based Speech-Language Pathologists' Plans for Augmentative and Alternative Communication (AAC) Assessment

Julia Birmingham Karnezos, MS, CCC-SLP
Janice Light, PhD
Department of Communication Sciences and Disorders
The Pennsylvania State University

AAC decisions take time, and a team
- team members have individual expertise
- few teams have learned “team” skills
- high pressure/high stakes event
  - “obvious” issues get forgotten

Method

Design
A pretest-posttest control group design was used to determine the effect of a checklist on school-based SLPs’ plans for AAC assessment.

Participants
Twenty school-based SLPs with certification from ASHA and the Pennsylvania Department of Education.

Method

Procedures
Pretest. Participants in both groups were asked to think-aloud while they planned an assessment for a boy with cerebral palsy (CP) and CCN.

Intervention. Participants in the experimental group received the checklist.

Posttest. Participants in both groups were asked to think-aloud while they planned another assessment for a boy with CP and CCN.
All of the participants reported that they will use the checklist again.

Nine reported that they liked the content of the checklist: “I like that it walks you through communication needs, student skills, partners and environments—partners especially.”
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aac.psu.edu