Introduction to Augmentative and Alternative Communication for Children with Down Syndrome

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Presenter Information

- Bachelor in Science from University of South Dakota
- Master in Science from University of Nebraska-Lincoln
- Previous/current working experiences
- Specialty interest areas

Financial Disclosures

Financial Disclosure:

- I have received financial support for providing this presentation.
- I have not received any financial support from any assistive device company nor endorse any single assistive device discussed in this presentation.
- I am an employee of the University of Nebraska Medical Center (UNMC) and provide speech-language and sensorimotor feeding services at the Scottish Rite RiteCare Clinic in Lincoln, Nebraska.

Nonfinancial Disclosure :

- None

Presentation Objectives

- Audience will understand communication difficulties/delays associated with a diagnosis of Down Syndrome and why early AAC intervention is key.
- Audience will learn what encompasses AAC, become familiar with various AAC systems, and understand general terminology associated with AAC use.
- Audience will understand why AAC is frequently utilized for individuals with a variety of communication disorders.
- Audience will learn common AAC myths or mispercetions and learn the facts behind AAC use.
- Audience will learn about current research findings regarding the use of AAC for children with Down Syndrome.
- Audience will understand the process of introducing AAC and use of AAC techniques.
- Audience will view examples of how we use AAC in our clinic's preschool setting, learn more about our parent training opportunities, and understand how to become involved in our RiteCare Total Communication clinic.

Introduction

- Audience Questions
- Definition of Speech and Language (ASHA, 2016):
  - Speech: How we communicate VERBALLY (e.g., articulation, fluency, voice)
  - Language: Socially shared rules (e.g., vocabulary, sentence structure) which may be verbal or nonverbal
    - Expressive: sharing thoughts, ideas, and feelings
    - Receptive: understanding others
- AAC Questions
- Partner Sharing:
  - Turn to a neighbor and tell them one thing you must do this weekend without using your voice
  - Turn to a neighbor and tell them about one member of your family using no voice and no sign language

Speech Characteristics Associated with Down Syndrome

Speech difficulties for children with Down Syndrome are often persistent due to:

- Smaller oral cavity may impact articulatory placement
- Low muscle tone impacts the coordination of all muscles involved in speech including: respiration, phonation, resonation, and articulation
- Cognitive and language difficulties
- Dysfluencies impact up to 45% of individuals with DS, particularly those with more advanced expressive language skills (Berkowtiz, 2016)
- Other possible comorbidities (e.g., cleft palate)

How Speech Characteristics Impact Development & Early Intervention

Delays in speech may negatively impact other aspects of development :
- Functional communication
- Social development
- Language development
- Learning/cognitive development
- Literacy development
- Quality of life

Therefore, early intervention is crucial to set children up for a means to communicate while developing speech and language skills

This helps to keep developmental gaps from becoming greater, developing learned passiveness, and/or unwanted behaviors as a means to communicate

(Light & Drager, 2010)

Where Does AAC Come In?

- AAC empowers communication!
- AAC may serve as a supplement to current communication skills or as a primary means of communication
- AAC may help with unwanted behaviors which stem from communication challenges

Definitions: AAC and Other Associated Terminology

- AAC means **A**ugmentative and **A**lternative **C**ommunication
  - Augmentative: in addition to user's speech; supplementing and/or supporting
  - Alternative: instead of speech; replacing speech
- Unaided Communication: nonverbal means of natural communication
  - Examples: gestures, facial expressions, ASL
- Aided Communication: A system that is external to user
  - Examples: picture board, speech generated system

Definitions: Types of AAC Systems by Technology

No Technology: does not require technology (e.g., gestures, ASL, facial expression)

Low Technology: nonelectronic forms of supplementation (e.g., pictures, books, pointer stick)

High Technology: battery/electronic forms of communication (e.g., Big Mac, Computer, iPad, other Speech Generating Devices)

AAC Systems Demonstration

- Tech Talk
- Big Mac
- Preschool Board Books:
  - Emerging
  - Intermediate
  - Advanced
- IPad Apps:
  - Compass App
  - Snap Scene Lite
  - TouchChat HD
  - AnswersHD
  - SPEAK (Tom Taps Speak)

Definitions: Core and Fringe Vocabulary

- Once we have decided the right type of AAC systems to use, how do we decide what messages to use?
- It is important to start with "core vocabulary".
- Core vocabulary: a set of words (nouns, verbs, adjectives, adverbs) which can be used across a variety of activities
  - Examples: "go," "like," "more," "I," "you"
  - Preschool Book Example
- You may also incorporate what are considered "fringe vocabulary" words.
- Fringe Vocabulary: words that are specific to a certain activity
  - Examples: "Paw Patrol" or "spaghetti"

How Do We Choose Core Vocabulary?

- Choice of core vocabulary words come from various studies

  •Example Study: Banajee, M., Dicarlo, C., & Stricklin, S. B. 2003
  - In this study, a list of 26 "core words" were determined based upon those used by most typically developing toddlers

- Below is an example of a 36 word core vocabulary list (PrAACtical AAC, 2016)

What if my child has some words? Does s/he need AAC?

- "Any child whose speech (alone) is not effective to meet **ALL** communication needs (at any time) is a candidate for AAC."
- "Any child whose language comprehension skills are be claimed to be 'insufficient to warrant' AAC training is a candidate for aided language stimulation and AAC."
- Maslow's Hierarchy:
  - Physiological needs
  - Safety
  - Love, affection, belongingness
  - Esteem
  - Self-actualization
- Children need to be able to communication for a variety of reasons, including social purposes.

(Berkowitz, 2016, Maslow 1943)

We use sign language. Is that enough?

- Unaided forms of communication (such as sign language) can be a great communication resource (and is one form of AAC) but may be difficult for a child
  - in unfamiliar environment
  - when fine motor skills are still developing and signs are approximations
  - with new communication partners (e.g., at McDonald's, in emergency room)
- Aided forms of communication (such as a device) allow a child to communicate with a variety of partners as these forms are more universal (device says message, pictures and words have more universal meaning)
  - Think of sign language as learning Spanish in a predominantly English-speaking country

Let's Answer More Questions & Discuss Myths and Misconceptions...

- AAC is only for nonverbal children.
- Use of AAC will prevent children from developing speech.
- There are prerequisite skills that must be developed before AAC.
- Access to AAC eliminates all communication challenges.
- AAC will make my child look "different."
- AAC use is only an SLP's responsibility.

Debunking the Myths: Myth #1

"AAC is for only children who are nonverbal."

- Students with some speech are often not provided AAC system access because it is believed intervention should only focus on speech.
- Children with a few words or phrase need to increase vocabulary and communication functions.
- We do not know the future prognosis for each individual child (Beukelman & Mirenda, 2005). Therefore, child may be at risk of greater cognitive, social, emotional, and behavioral problems (Ballinger, 1999).
- Children need to be able to communicate in a variety of situations.
- Children need to be able to generate novel utterances.
- Children will always choose the easiest means to communicate. If a child can communicate with speech, s/he will use that over a device.
- Research shows that any intervention delayed beyond a child's first three years has less significant impact, and that children-including those with disabilities-learn faster and more easily when they are young.
- Waiting too long to provide a mode of communication denies the child opportunities to learn language, acquire vocabulary, and express him/herself appropriately." (Berkowitz, S, 2016)

Debunking the Myths: Myth #2

"AAC will prevent my child from using speech."

- Children need access to appropriate and effective modes of communication as soon as possible (or may see frustration and inappropriate behaviors).
- Children with access to AAC **increase** verbal skills (Millar, Light, Schlosser, 2006)
  - **89%** of children increase verbal skills
  - 11% maintain current skill level
  - **0% show decline** in verbal skills
- Why is this the case? Likely because demands are reduced, and AAC provides a constant visual cue and speech modeling.
- AAC considered an evidence-based practice for facilitating speech in nonverbal children. (Berkowitz, 2016)

Debunking the Myths: Myth #3

"Children must have certain prerequisite skills (e.g., joint attention, understand cause/effect) to use AAC"

- Everyone communicates (even newborns) no matter his/her skill level.
- No child is too young to use AAC.
- Research shows very young children learn signs and symbols before they learn to talk (why signing can be very effective too).
- No sufficient evidence to support that individuals cannot use AAC because of difficulty paying attention, understanding cause/effect, limited desire to communicate, unable to acquire skills (Kangas & Lloyd, 1988)
- Research does not support a hierarchy of AAC systems—what is most important is a stable vocabulary system (e.g., same location every time on device) (Berkowitz, 2016)
- Intervention builds learning as it strengthens neural pathways through these experiences

Debunking the Myths: Myth #4

"Access to AAC limits all communication challenges."

- AAC is simply a tool---it doesn't do anything without the person communicating using it (Beukelman & Mirenda, 2005)
- This depends on the training of the child AND communication partners
- Children and caregivers BOTH need appropriate instructions on how to use a system and develop effective communication to further language skills—if not used consistently, AAC learner is likely not to progress

Debunking the Myths: Myth #5

"AAC will make my child look "different" from others."

- "Acceptance of an AAC-user by peers increases significantly with full inclusion and active participation in regular school- related activities. (Baillinger, 1999)
- Among young children, acceptance appears not to be related to the type of AAC (e.g. voice output communication device versus sign language versus communication board)" (Ballinger, 1999).
- "In the long run, a child is at greater risk of being perceived differently when he or she does not have the ability to adequately express him- or herself. Teachers and parents often judge a child with communication impairments as socially and cognitively less capable than their peers. This results in lowered academic expectations and, frequently, decreased academic achievement." (Ballinger, 1999)
- "AAC may help in reducing the discrepancy, both real and imagined, between the child's actual and perceived cognitive and social capabilities." (Ballinger, 1999)

Debunking the Myths: Myth #6

"AAC is the responsibility of the speech-language pathologist only."

- We need to use the expertise of a variety of team members when determining a child's AAC use.
- This team may include but are not limited to: child, family, physician, speech-language pathologist, occupational therapist, physical therapist, general education teacher, special education teacher, etc..
- Those most familiar with the child's communication needs are an integral part of the decisions and should be familiar with and comfortable programming for his/her child. (Tobii Dynavox, 2010)

Research Supporting AAC Use for Children with Down Syndrome

- 95% of parents report that their children with DS had difficulty being understood by persons outside their immediate social circle at school-age (Kumin, 2006)
- Limitations often occur in speech production, associated with characteristic oro-facial dysmorphologies including a small oral cavity, dental issues, low muscle tone, and possible apraxia (Kumin, 2006)
- Speech that was previously adequate in home environment is often not sufficient for academic communication with unfamiliar partners (Roberts, Price, & Malkin, 2007)

Research Continued...

- AAC provides opportunities for language development even when speech is not yet most effective means of communication.
- During early years, children fall further behind in language as not able to find adequate means to express themselves (Light & Drager, 2010)
- Aided AAC can not only enhance existing communication modalities (for children with DS), but may help to minimize barriers related to audience (not all community communication partners will understand signed forms) and to production difficulties associated with fine motor challenges (Berkowitz, 2016)

Research Continued...

- Dr. Janice Light Quote: "It is not a question of choosing between AAC or natural speech. Rather, AAC is used in conjunction with intervention to maximize speech development."
- Study presented at ASHA convention in 2010
- Children with Down Syndrome ages six months to three years in age (from start to completion of study)
- One hour/week in family's home using play activities and daily routines
- Children demonstrated increased rates of turn-taking, sustained longer interactions, used many modes of communication, **acquired spoken words earlier, and increasingly relied on speech over time, all demonstrated significant vocabulary growth**

(Light & Drager ASHA, 2010)

To Recap... Why use AAC for a child with Down Syndrome?

- AAC may enable a child to have all communication means met
- For most children with Down Syndrome, AAC supplements the development of speech and increases verbal expressive language skills.
- AAC assists child in reducing frustrations, especially when language skills are higher than verbal expressive skills.
- AAC is a visual means of communication to assist with comprehension skills (receptive language).

Where do I begin?

- Contact speech-language pathologist or other AAC specialist for an evaluation to determine if a device is appropriate and what device would be most appropriate should a device be deemed appropriate
- If able, initial AAC exposure around 6-9 months-3 years appears most beneficial for success (Light & Drager, 2010)
- Training is crucial (for child and family)
- The form of AAC **MUST** be used in all communication environments.

Techniques to Make AAC Successful

- Aided Language Input
- Focused Aided Language Stimulation
- Peer Mediated AAC Intervention
- Other General Strategies

Aided Language Input

- Aided language input (ALI) is a communication strategy, where a communication partner teaches symbol meaning and models language by combining his or her own verbal input with selection of vocabulary on the Augmentative and Alternative Communication (AAC) system. This is done by simultaneously selecting vocabulary on the AAC system and speaking.

(AAC Language Lab, 2011)

Aided Language Input Research Support

- With AAC Modeling, we are seeing:
  - Increased communication turns
  - Increased length of sentences
  - Increased vocabulary (both known and used)
  - Increased morphology (go, goes, going)

(Sennott, S.C., Light, J.C., McNaughton, D., 2016)

Aided Language Input Procedure

PROCEDURE

- Attention:Make sure that the individual is attending.
- Message & Icons: Create a message by selecting icons on the individual's AAC device. This step helps the individual to learn the system display, vocabulary items, and word order. White selecting the icon, also say the word (icon meaning).
- Complete Sentence: Create a complete sentence with the selected icons and repeat it verbally to the individual.
- Response: Ask the individual a follow-up question to keep the process going.

(AAC Language Lab, 2011)

Aided Language Input Examples

Example for "WANT TOY"

- - Make sure individual is attending to AAC device.
  - Select "WANT" and "TOY." Say, "Want toy."
- Grab toy item
- Ask: "What do you want?" Or "Your turn"

Aided Language Input Example

Aided Language Input Example

Aided Language Input Example

Demonstration

Let's Practice!

Now I would like to give you a chance to practice using this skill.

Focused Aided Language Stimulation

- General language strategy applied to AAC in which you use a new vocabulary word over and over in several contexts and several forms
- Involves repetition which studies show help a child with DS learn best
- Used in addition to aided language stimulation

Focused Aided Language Stimulation Procedure

STEP 1: Introduce the new word(s) using focused AIDED language stimulation

STEP 2: Teach the new word(s) with explicit instruction activities

STEP 3: Elaborate on the new word meanings with engaging practice activities

STEP 4: Provide repeated exposure to the new word(s) on an ongoing basis

STEP 5: Check for understanding and reteach, as necessary.

(PrAACtical AAC, 2016)

Focused Aided Language Stimulation Examples

Vocabulary target "ball"

- Using object with direct actions and AAC, may say:
  - "want ball"
  - "roll ball"
  - "green ball"
  - "ball bounce"
  - "your ball"

Focused Aided Language Stimulation Examples

Demonstration

Let's practice!

Now I would like to give you a chance to use this skill.

Peer Mediated (Modeling) AAC Intervention

- Newer method being used and has foundational research for children with Autism
- Use of typically developing peers to model use of AAC device by using it themselves during communication interactions
- Helps to generalize skill use when communicating with peers and siblings and may further increase language skills

(Barker, Akaba, Brady, & Thiemann-Bourque, 2014)

Peer Mediation Research Support

Studies show improvements in:

- Turn-taking
- Requesting
- Commenting
- Receptive and expressive vocabulary
- Length of utterances
- Phonological awareness
- Reading/writing

(Light and McNaughton, 2012; Lancioni et al., 2007; Schlosser et al., 2009)

Peer Mediation (Modeling) Examples

Teaching a peer how to interact with device and friends using a device:
https://www.youtube.com/watch?v=A18zyePCT_0

Practiced use of peer mediation with a friend using the device:
https://www.youtube.com/watch?v=6jC56iJ61QU

Vanderbilt EBIP YouTube Channel

Note: social component missing here which is commonly seen with an Autism diagnosis

Other General Tips for AAC Implementation

- Provide short, but complete verbal models.
- Use an enlarged Communication Board Wall Chart and marker to point out words and provide more information on the topic (definition, synonyms, antonyms, etc.).
- No matter what the individual selects on the board or device, the rule for communication partners is: RESPOND,RESPOND, RESPOND. Provide natural consequences to whatever the person said, even if it seems like a mistake.
- After the person communicates something, expand upon it.
- You do not have to model everything you are saying using ALS. Model the type of language you hope the child will produce. Determine the person's current expressive language abilities and model 1 or 2 words beyond that level.
- Model "definitions" and "word altering" strategies (e.g., "go" "going" "gone") as part of your on-going communication process.

(AAC Language Lab, 2011)

About our clinic

- One of four RiteCare clinics across the state: Lincoln, Omaha, Hastings, and Kearney
- All services provided at NO costs to families at this time with donations always appreciated.
- We specialize in feeding/swallowing therapy, augmentative and alternative communication, and speech/language therapy.
- Two primary SLPs: Carrie Kenny, M.S., CCC-SLP and Holly Schlautman, M.S., CCC-SLP

About our clinic

- Location-Barkley Memorial Center on UNL's East Campus
- Waitlist Information:
  - State contact information, dx, and mention AAC preschool program
  - Contact Rose: (402) 559-6460
- Indicate if would like to participate in parent training program

Our AAC Preschool Program

- AAC preschool group runs throughout the year (with short breaks intermittently following UNL's graduate calendar).
- Children with a variety of complex communication needs (e.g., Down Syndrome, Traumatic Brain Injury, Autism, Cerebral Palsy)
- Variety of communication modalities (e.g., ASL, speech, pictures, devices)
- UNL Graduate Students involvement
- Provide services at NO cost to families in thanks to the generous support of the Scottish Rite masons and donations from the community.
- Current regulations: children are eligible to participate in the preschool program for up to two years of service between ages 2-5 OR until reach kindergarten eligibility (whichever comes first)

Parent Training Program

- We also have a general parent training program to teach language enhancement skills, particularly for children who are preverbal or using single words to communicate.
- 12 week program
- Available in person or via telehealth
- Undergraduate students watch child during presentation, child practice with feedback during other portion

Where we hope to go next...

- Evaluate each child for AAC needs prior to entering program to determine most appropriate modalities of AAC (6 months-3 years)
- Provide 1:1 coaching for parents to learn to navigate and program (birth-kindergarten)
- Provide services in preschool setting (as well as outings) with peer models to practice and build skills (ages 3-kindergarten eligibility, or two years of service)
- Specific parent training program for parents AAC users to increase opportunities for AAC use in home environment (birth-kindergarten)

Questions

- Time for questions
- RiteCare program participation:
  - Call Rose at: (402) 559-6460 and indicate interest in preschool program
  - Note: may also contact about feeding/swallowing therapy services or Augmentative and Alternative Communication (AAC) evaluation
- My contact information:
  - Carrie.kenny@unmc.edu

Thank You

Special thanks to the families who are currently participating in our AAC Total Communication Preschool program. Thank you for allowing us to use video examples in this presentation.

Thank you all for attending this presentation and allowing me to speak about this topic of interest.

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