Overview

I. Intro to Speech/Language Disorders
II. Speech and Language in 17q12
III. What is AAC?
IV. The AAC Assessment Process
V. FAQs

Speech and Language Disorders

• Impairments in speech and language are the most common developmental problems of early childhood
  • Prevalence estimates range from 14.5% - 19% of 4 - 5 year old children (McLeod & Harrison, 2009; Betts & et al., 1986)

Speech & Language in 17q12 Deletions

• All who participated in 17q12 registry (6 responses) reported current speech therapy or speech therapy in past (Patient Crossroads - 17q12 Interest Group)
  • Most, but not all, individuals appear to have communication difficulties
    • Developmental area most likely to be affected
    • Delayed first words
    • Receptive and expressive language impairment into school-age
    • Speech sound disorder
    • In context of more global cognitive delay vs. speech delay only (Morano-de Luca et al., 2010; Nagamani et al., 2010; Roberts et al., 2014; Unique; Patient Crossroads)

Speech and Language Disorders

• Most children do eventually learn to talk
• Some children take much longer, and some will remain nonverbal or minimally verbal
• Complex communication needs
  • 12% of preschoolers enrolled in early intervention (Briner & Light, 2006)
  • 3 – 6% of school-aged children in special ed (Matas et al., 1985)

Speech and Language Disorders

• Speech sound disorders
  • Articulation or phonological disorder
  • Dysarthria
  • Apraxia
• Language disorders
  • Receptive
  • Expressive
  • Pragmatic
• Stuttering/ Fluency
• Voice or resonance disorders
Speech & Language in 17q12 Duplications

- Most, but not all, report speech/language delay
  - Range from normal speech to nonverbal
  - Most often, both receptive and expressive language affected
  - Several cases of speech impairment resulting from cleft palate or hearing loss
  - Several reports of stuttering/stammering
  - Often in line with more global developmental delay

(Hardies et al., 2013; Nagamani et al., 2010; Mefford et al., 2007; Unique)

Augmentative and Alternative Communication (AAC)

“All tools and strategies that are used to supplement or replace speech when it is not sufficient to meet a person’s daily needs”

What kinds of children could benefit from AAC?

- There is no “typical” user
  - Intellectual disability
  - Autism spectrum disorder (ASD)
  - Cerebral palsy
  - Severe motor speech disorder
  - Craniofacial differences
  - Tracheostomy

“Anyone who can’t rely on speech alone to meet needs”

Types of AAC

Unaided
- Facial expression
- Vocalization
- Gesture
- Sign language

Aided

Types of AAC: Aided

Low tech
- Single message voice output
- Pencil and paper, alphabet boards, pictures and photos

Mid tech
- Fixed display speech generating devices

High tech
- Dynamic display speech generating devices

1. Sign language
2. Picture Exchange Communication System (PECS)
3. Fixed display SGDs
4. Dynamic display SGDs- Dedicated vs. tablets
Types of AAC: Sign Language

- American Sign Language (ASL) is a “real” language
- Before 1990, was most common AAC strategy used with people with autism and/or ID
- Some argue it is easier for individuals with ID to learn signs vs. picture selection (Sundberg & Sundberg, 1990)
- Total communication approach- using both sign and speech simultaneously

Pros:
- Unlimited, generative vocabulary
- Portable/ accessible
- Inexpensive
- Fast rate of communication

Cons:
- Not all communication partners will understand signs
- Learning demands on communication partners
- Impossible if there are motor impairments

Types of AAC: PECS

- Picture Exchange Communication System
- Bondy and Frost (1985)- training protocol based on principles of ABA
- 6 distinct phases:
  1. How to communicate
  2. Distance and persistence
  3. Picture discrimination
  4. Sentence structure (sentence strip)
  5. Answering questions
  6. Commenting

Pros:
- Durable
- Inexpensive
- Easy to understand message
- Research support for kids with autism

Cons:
- Vocabulary and language complexity constrained
- No voice output
- Slower rate of communication
- Cumbersome

Types of AAC: Fixed Display SGDs

- Any device with voice output that has a static (unchanging) display
- Vary widely in terms of specifications, complexity, price
- Single message to multiple messages

Pros:
- Relatively cheap
- Durable
- Easy to program and use
- Voice output

Cons:
- Vocabulary capacity is very limited
- May require adult assistance to switch out overlays
Types of AAC: Dynamic Display SGDs

• High tech devices that change screens when activated, thereby introducing new vocabulary
• Vocabulary represented by pictures, words, or both
• Vocabulary may be arranged by grid or visual scene display

Types of AAC: Dynamic Display SGDs

• Can be dedicated, traditional devices or non-dedicated tablets, such as iPad

Dedicated/ traditional Tablets

Types of AAC: Dedicated vs. Tablet Technology

DEDICATED
• Used only for communication
• Fairly durable
• Good customer support
• Covered by insurance
• Very expensive
• Variable sizes

TABLETS
• Many purposes
• Breakable
• Variable customer support
• NOT covered by insurance
• Less expensive
• Lightweight

How to Get an AAC Device/System

1. Initial AAC Assessment
   - Speech-language pathologist
   - Gather information from family, teachers, therapists, doctors
   - Review current strengths and needs
   - Combination standardized and non-standardized measures
   - Identify situations where current communication is not sufficient to meet child’s needs
   - Identify possible solutions based on feature mapping

   You fit the AAC system to the child, NOT the child to the AAC system!

2. Trial multiple devices and strategies
   - Lending libraries
     • Assistive technology resource centers in each state (“Tech Act”)
       • http://www.resnaprojects.org/
   - Take data on how well different things work
   - Settle on a system that best fits child’s needs

3. SLP writes report and parent gets doctor’s prescription (if billing insurance/Medicaid)

4. Find funding
   - Private Insurance
   - Medicaid
   - If insurance will not pay, school districts must fund device if educationally necessary (documented in IEP)
   - Low interest loans
   - Local community service or charitable organizations
FAQs
Q: Will using AAC prevent my child from learning how to talk?
A: No, research suggests that introducing AAC does not keep children from learning to talk. In fact, some studies show an increase in verbal speech after the introduction of AAC.
Kasari et al. (2014); Schlosser & Wendt (2008); Millar, Light, & Schlosser (2006)

FAQs
Q: How can children with severe physical handicaps use an AAC device?
A: A variety of access technologies enable people with motor impairments to use AAC

FAQs
Q: How can I get an iPad or other tablet with communication software for my child?
A: Be creative!
• Ask the school district
• Look into low cost or no interest loans
• Research grant opportunities (disability organizations, etc.)
• Work with local charities
• Explore special deals and discounts

Final Thoughts
• Communication is multimodal; multiple AAC strategies should be employed
• Keep lines of communication open between family, teachers, therapists
• AAC strategy is only as effective as instruction program
• Time and commitment are required

AAC Resources
AAC-RERC
http://aac-rerc.psu.edu/

YAACK- Connecting Young Kids to AAC
http://aac.uml.edu/yaack/

National Dissemination Center for Children with Disabilities
http://nichcy.org/laws/ata

Apps for AAC by Jane Farrall
http://www.janefarrall.com/aacappslist.html

Questions?
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