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## **AAC: Communication Options for Individuals with CdLS**

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# Disclosures

# Agenda

- What is AAC
  - What does the research say
  - Address AAC Myths
  - Types of devices & features
  - Paying for a device
  - General recommendations
  - Questions
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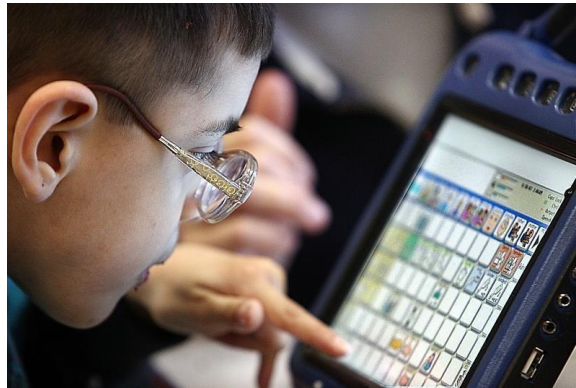
# What is AAC?

- Augmentative & Alternative Communication
  - Alternative to current communication
  - Supplement current communication methods
- Bridge the gap between *what I want to say* and *what I can express*




# What is AAC?

- AAC lets people communicate basic wants and needs, express feelings, state opinions, build relationships, and build language and literacy skills.



Who can use AAC?



**Anyone who  
cannot meet  
communication  
needs in all  
situations can  
benefit from  
AAC.**

# Communication "Gaps" in CdLS

- Speech
- Expressive language
- Social communication

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# Potential Benefits of AAC

- ↑ Speech-language abilities
- ↑ Vocabulary inventory
- ↑ Use of grammatical structures/multi-word utterances
- ↑ Understanding of language in young children
- ↑ Speech in autistic individuals
- ↓ Frustration/negative behaviors related to communication



# Minimal Research Specific to AAC & CdLS

- 23% (N=4) had early AAC assessment
  - Ages 2 – 13 years
  - Increased understanding and use of vocabulary
  - Improved attention skills

■ Ajmone, P. F., et al., 2014

# Recommendations

- Early AAC intervention
- Novel approaches needed given complexity of CdLS
- "Wide augmented communication input"
  - Language immersion approach
  - Whole life context
    - School, work, recreation, community therapy
  - Involving everyone – especially the family

■ Ajmone, P. F., et al., 2014

# Baltimore CdLS Clinic 2016 - 2019

20 individuals with CdLS

Ages: 2 - 30 years (mean = 15.5 years)

13 females, 7 males

# Caregiver Report

## Primary Communication Method(s)

12 – Sounds (Vocalizations)

7 – Speaking words or phrases

6 - Sign (+1 used to sign)

4 - Guiding partner to  
object/activity

3 – Gestures

1 - Facial expressions

1- Object box (at school only)

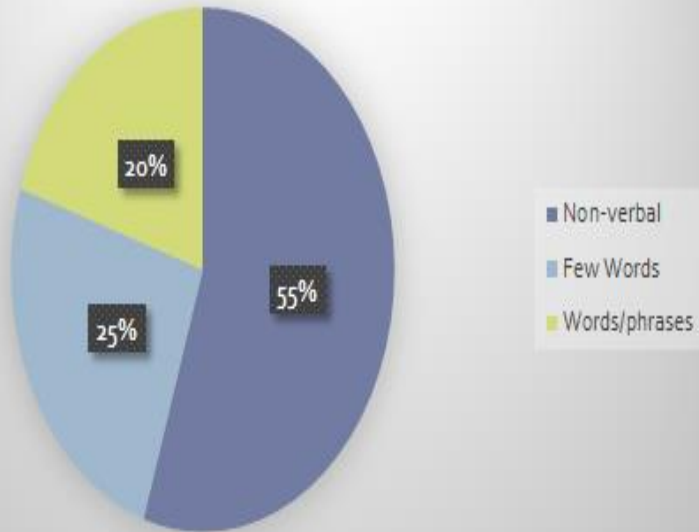
1- Modified PECS (fanny pack  
deck) regressed/no longer uses

1- Touch Chat App

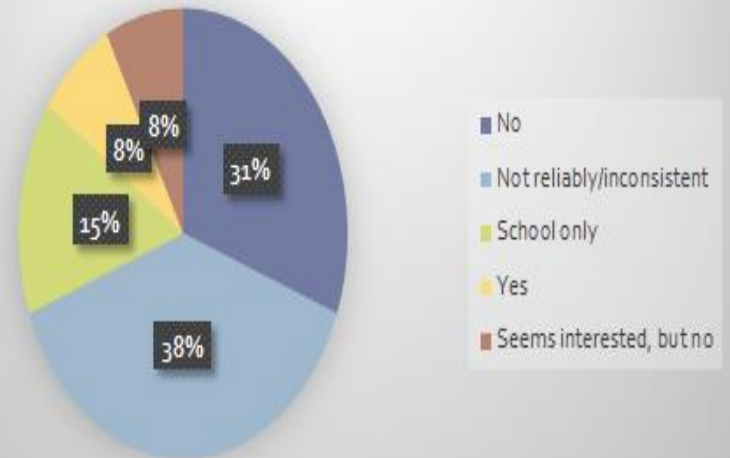
1 - Select between 2 items

# 80% Non-Verbal + Minimally Verbal vs 23% Device Use (15% School Only)

Verbal Communication Status



Caregiver Report of Device Use in Communication



# Recreational Device Uses

- ❖ iPad, tablet (Fire), iPod, smartphone, remote control
  - ❖ Finds camera icon and swipes through pictures/take photos
  - ❖ Finds/plays games
  - ❖ Selects music
  - ❖ Uses pictures/words on smartphone to make calls
  - ❖ Selecting YouTube icon and further selecting videos to watch
  - ❖ Use remote control
- ❖ Selects between 2 DVD cases

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# You May Have Heard

— AAC Myths —

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## AAC will keep someone from talking



## AAC and Speech

**Introduction and use of AAC will keep an individual from using or developing his or her natural speech.**



# What does the research say?

- Millar, Light and Schlosser (2006) reviewed several previously published studies & found:
  - 89% of individuals demonstrated increases in speech production after being introduced to AAC
  - 11% of individuals demonstrated no change in their speech product
  - 0% had no decreases in speech production

**The individual has some speech, so AAC is not needed.**



**AAC is not needed if the individual has a few words.**

# What does the research say?

- Limited speech does not allow for or encourage growth & independence.
  - By 18 months, a child can typically produce 50 words & combine words.
  - Typically developing preschoolers learn 9 new words a day.
  - The person with a severe communication impairment cannot effectively establish or deepen relationships with others or demonstrate new knowledge and thoughts.
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- Light, Collier, and Parns, 1985; National Research Council, 2001

# The child is too young to use AAC



“We should wait and see what happens.”

# What does the research say?

- AAC has a positive effect on speech production (Cress, et. al. 2003).
- There are no prerequisites for introducing AAC (Kangas & Lloyd).
- Communication and language development impact advancement of many other skills (e.g., literacy, cognition, etc.). AAC has an enormous potential to expand skills.
- AAC intervention should not be contingent on the failure to develop speech skills or considered as last resort (Ronski & Sevcik, 2005).

# Too many challenging behaviors



“The child has too many challenging behaviors to use a communication device.”

# What does the research say?

- Positive behavior supports are effective in reducing problem behavior in most cases.
- Success rates nearly doubled when intervention is based on a prior functional assessment.
- Positive behavior supports are widely applicable to people with serious disabilities who exhibit serious problem behavior.
- Positive behavior supports increase positive behavior.

■ Carr et. al., (1999)

# Identifying Individuals who may Benefit from AAC

## Communication Success Screening

If you know an individual who has difficulty communicating with others, the following checklist may help you determine whether you should explore some communication tools that could help. You can use this screening in a few different ways:

- Complete this screening on your own and then discuss with the appropriate individual (e.g., physician, speech-language pathologist, educator, etc.).
  - Have each member of the intervention team (e.g., speech-language pathologist, family members, educators, job coach, etc.) answer these questions individually and then come together to discuss.
1. Does the individual have a diagnosis (e.g., autism, CP, aphasia, ALS, etc.) that puts him/her at risk for speech and language challenges? Yes\_\_\_ No\_\_\_
  2. Does the individual have less than 20 words or signs/signals that can be understood by unfamiliar listeners? Yes\_\_\_ No\_\_\_
  3. Does the individual have difficulty communicating his/her ideas (e.g., asking for a desired item, telling a story, expressing an idea)? Yes\_\_\_ No\_\_\_
  4. Does the individual have difficulty having basic needs met? Yes\_\_\_ No\_\_\_
  5. Does the individual attempt to communicate verbally, but attempts are unintelligible to most listeners (e.g., Apraxia, dysarthria)? Yes\_\_\_ No\_\_\_
  6. Does the individual become frustrated and exhibit inappropriate behaviors when unable to communicate with others? Yes\_\_\_ No\_\_\_
  7. Does the individual show an interest in social interaction, but lacks the verbal skills to do so? Yes\_\_\_ No\_\_\_
  8. Does the individual have difficulty initiating interaction with others? Yes\_\_\_ No\_\_\_
  9. Does the individual use objects, photographs or picture symbols primarily for requesting but needs a way to increase language function? Yes\_\_\_ No\_\_\_
  10. Does the individual fall below either developmental milestones for expressive language or previous expressive levels? Yes\_\_\_ No\_\_\_
  11. Does the individual lack a reliable yes/no response? Yes\_\_\_ No\_\_\_

## Communication Success Screening

### What is it?

- A quick and easy screening tool
- Can be completed by professional staff and family.
- May identify candidates who may not have ever been considered.



# Types of AAC

- Communication Boards
- Buttons/Switches
- APPs (Non-dedicated)
- Speech Generating Devices (Dedicated)

# Obtaining a device

- Provided by public school
- Covered by Medicare

## **Durable Medical Equipment – Speech Generating Device**

- Most private insurances follow Medicare requirements
- Medicaid - covers with varied coverage per state
- Federal Employee Benefits variable – SGD Exclusion or dollar limits
- Insurance requires formal AAC evaluation with SLP
  - Document 3 or more methods/devices trialed & response

# Obtaining a device

- Assistive Technology Act of 2004
  - Technology centers in each state <https://at3center.net/state-at-programs/>
  - Specialists, lending libraries, information on funding
- ACA (2010) provided protections re. disability discrimination, including SGD access
- Steve Gleason Act - accessories (switches, etc) funded by 3<sup>rd</sup> party payers
- Limited public funding/grant streams – Maryland LISS

# Recommendations

- Seek out AAC specialist for evaluation
  - Individualized evaluation
  - Multiple communication options considered
  - Voice output feature
  - Interview prior to meeting
    - Ask about AAC experience (# of evaluations, how do you stay current)
    - Ask about types of AAC recommended and used
    - If AAC is recommended, what support is provided

# Recommendations

- If on a long waiting list, consider:
  - Contact a local university speech-language clinic
  - <https://www.asha.org/profind/>
  - <finder.ussaac.org/find-members/>
  - <https://isaac-online.org/english/home/>
  - State speech-language pathology association

# Recommendations

- Comprehensive plan to implement AAC use
  - Team in place (family, SLP, teacher, OT/PT, behavioral support)
  - Encourage AAC in all environments (home, school-work, recreation, community)
  - Motivating communication practice and partners
  - Select functional and motivating vocabulary appropriate to daily life
  - Accept all communication attempts (sign, speech, vocalizations, guiding, facial expressions)
  - Re-assess progress and make changes

# Survey: Individuals with CdLS & AAC

<https://www.surveymonkey.com/r/CdLSAAC>



Thank you!

