



Talking Points With Families

Rebecca Semke

Barb Weber

Setting the Stage for Discussions around Assistive Technology

- First visit
 - Discuss the difference between speech and language
 - Discuss the possible use of sign or picture use and the benefits for using these “other” language modes to promote development and speech
 - Discuss the importance of language development

Definition of Language

- A system of communication used by a particular community or country
 - Semantics – word meaning
 - Morphology – word endings or beginnings that change meaning
 - Syntax/grammar – combining words and ideas to share more sophisticated thoughts or stories
 - Pragmatics – language use (social aspects of using language)

Definition of Speech

- The communication or expression of thoughts in spoken words (Merriam-Webster Dictionary)
 - Thus, coordinating mouth movements to make sounds to express language

Speech vs. Language in Birth-3

- The main focus for therapy in the birth-3 population is on growth of language skills as there are only 6 or so sounds that should be developed in every child by the age of 3
 - P, b, m, t, d, n
- Reality: We are always supporting and addressing speech as we address children's language skills

Other Modes of Language

- Signs
- Pictures
- Gestures
- Behavior
- Nonverbal movement/body position
- Facial expressions

Benefits of Using Signs/Pictures as other Language Modes

- Ability to teach the child the relationship between an action (sign, touching a picture) and a desired outcome while continuing to model speech – teaches the power of communication
- Can provide a less transient form of communication
- Action imitation develops before speech imitation
- Research supports that the use of sign, pictures, or other forms of augmentative communication does not hinder the development of speech – in fact, it might support quicker development of speech

Importance of Language Development

- Decreased frustration
- Increased social engagement and interaction capabilities
- Increased understanding of the power of communication
- Importance for future literacy skill development

Case Study 1: Connor

Connor's Background

- Diagnosis of Cerebral Palsy
- At age 2, he had approximately 2-3 words
- Little babble, few sounds in general
- Had gross and fine motor difficulties associated with cerebral palsy
- Family was highly involved with his care

First Steps

- Introduced some pictures of preferred items
 - Songs
 - Cars, trucks, blocks
- Introduced some basic signs
 - More, done
 - Open, go

Moving to switches and other forms of Assistive technology

- Connor's family was skeptical of Connor's ability to use pictures/signs to communicate
- The therapist had to get some buy-in before the family was willing to explore other forms of assistive technology
- Started with some simple switches – Big Mack – to give Connor a way to get attention and participate in repetitive lines of songs/books

Use what the family has

- Connor loved family's iPad – explored some free communication apps on the iPad
 - Sounding Board
 - Go Talk Now Free

Currently....

- Connor is almost 4.
- He has developed much more sophisticated speech capabilities and does not require augmentation the majority of the time at home.
- He is waiting to receive an Accent 1000 device from PRC to supplement his speech capabilities mainly in educational and community settings.

Take-away points

- Start with what you have and explain the rationale to the family.
- Read the family's nonverbal cues – some families need to see some evidence of understanding/use before being willing to explore the next stage of AT.
 - Trials of devices/systems are important. They give the family a true feel for how their child can interact with the device/system.
- Use what the family has (iPad) even if that is not the “ending point” for AT.

Take-away points cont'd

- As the family started to see that Connor could use various pieces of technology to support his communication, they realized that they needed more features (greater vocabulary capabilities, better ways for their son to access technology for communication, etc.)
- This was the doorway to their willingness to explore new types of AAC.

Case Study - Bobby

Background Information

- Bobby was a child with CP with little mobility and imprecise, fistled hand control
- He was unable to use his index finger to activate a specific icon
- Batting at screen could slide or activate depending upon the app
- Positioning was important for technology use

First Steps

- Checked with family to gauge interest in eye gaze equipment
- Brought in consult to brain storm and have a second opinion
- Put in for equipment loan (took months to arrive!)
- Tried device for a two weeks

What happened

- Family decided against device
- Family had concerns that the technology would be outdated as devices are typically approved every 5-7 years
- Family had concerns that needs now would not be the child's needs in the future
- Family was surprised by learning curve and lack to immediate expansion into things Bobby could not say

Talking Points

- Cons:
- This is really hard work and has a big learning curve
- The wait was 3-4 months and the trial allowed was only 2 weeks
- Parents were responsible for most of the programming and data collection
- Like all tools, it takes time and work to use them to the child's advantage

Talking Points continued

- Pros:
- Parents are now informed consumers
- Parents are able to make better decisions in the future as needs become defined for Bobby
- Team does not have to “wonder” how AAC might help; we have our data

Lesson's Learned

- Help parents better understand pros and cons up front.
- Be aware of how parent's hope that the AAC will change their child's communication and present a balanced view.
- A child's communication problems don't magically disappear with a device. The problems will continue to interface with AAC.

Case Studies Perdue U.

Presented principles of Speakall at ASHA,2015

- In their studies, studied children diagnosed with autism
- App begins with very basic icon use on an iPad
- Goes into evidence based protocol in partner with PECS development
- Expands into shared activities such as reading a story and playing a game

Talking Points

- Cons
- Just one app and needs finger dexterity to use
- Feature match may not be what child needs
- Is not as robust as apps that have core vocabulary pages and pre-stored vocabulary

Talking Points, continued

- Pros
- Easy to use
- Protocol is evidence based
- Expands across many activities
- Low cost
- One “little” app can fit many needs, depending upon what the family wants

Take away points:

- App expanded with child's skills
- What family's in these studies really wanted were shared activities in daily routines, such as book time and family game night.
- Consider parent's priorities and what they truly want from the AAC

Case Study - Jenny

Jenny's Background

- No official diagnosis – presents similar to a child with cerebral palsy
- Some gross and fine motor concerns
 - Crawls, but needs support to walk
 - Some fine motor capabilities – can produce some signs
- Child has some sounds, but does not use them regularly in words
- Family does not trust doctors or therapists and has already been through several therapists

Background cont'd

- Jenny expresses frustration in which she can make herself throw up if not given what she wants or if she is not understood
- Jenny uses a combination of gestures (mainly pointing) and facial expressions to express communicative intent
- Some maternal depression is expected and Dad works long hours outside of the home

Baby steps

- Family was open to signs – so taught family signs that were important to them
- Pictures for Jenny's favorite TV shows were presented as this was a choice that mom was happy to provide to her daughter
- As she did well, family was open to learning more signs and to allow therapist to create picture boards for some of child's favorite activities

Introduced concept of voice output

- Family had a Samsung tablet which Jenny liked to use – so therapist shared free communication apps
- Family had difficulty getting them to download
- Family was able to obtain a free iPhone so downloaded Sounding board
- Jenny did not like the touchscreen and was not as willing to use it

High-tech AT exploration

- Therapist brought a Dynavox product to demonstrate to family as Jenny was imitating two-sign and two-picture combinations as well as creating some spontaneously
- Jenny required some prompting to activate her desired areas
- Family was unsure of the layout of vocabulary (some in digital scenes)

Family's ending decision

- Family felt comfortable with picture communication boards
 - Easier for them to transport, pull-out at a minute's notice, and wipe food/water/drool off of them
 - Easier to have multiple copies in different places around the house
 - A familiar adult was always around their daughter so she didn't have to communicate across space
 - Higher demand on child to get attention, but lower demand on parents

Take-Away Points

- Cons of high-tech AAC for this family
 - Had to ensure that it was plugged in and ready to go when the family already felt they had a lot on their plate
 - Time spent in programming boards
 - More difficult time accessing high-tech devices
 - Child would throw items if mad or frustrated – better likelihood that high-tech device would break

Take-home points

- Importance of providing information to the family, presenting options and rationales, but then following their lead and preferences
- Importance of being flexible in trying different AAC options
- High-tech devices are not the “right” decision for every family
- At times, decisions on the “right” AAC system may be more about the parents than the child



Summary of Take-Home Points

Review

- Set the stage early – the first visit, if possible
- Provide information, rationales, and demonstrations when possible – present all sides of the equation (pros and cons of high-tech AAC)
 - AAC can provide access to many capabilities.
 - AAC is not a magic box. There can be a significant learning curve to a device and adds additional skills that a child must learn.
- Follow families' lead. Sometimes this means baby steps and exploring “less-sophisticated” devices first to get buy-in.

Review

- Consider options that may already be in the family's home (such as an iPad) even if you are hoping that what they have is not the "end result"
- Consider families' priorities. These may be different than the therapist's and may end up with a different result.