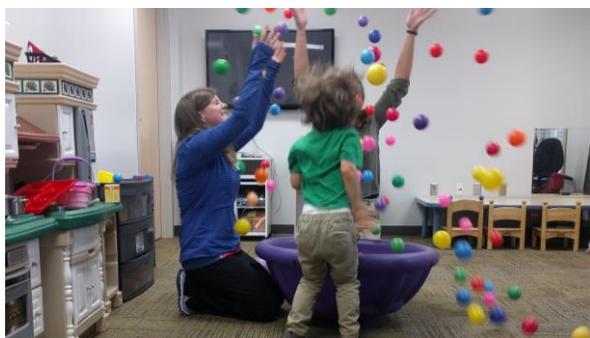# AAC and Autism:

From Joint Attention to Self- Advocacy

Melissa Pouncey MS CCC-SLP, United Ability

Words that come to mind as you look at the picture...

	But also...
▶ Joy	
▶ Connection	▶ Learning
▶ Choice	▶ Opportunity
▶ Pleasure	▶ Repetition
▶ Enjoyment	▶ Routine
▶ Happiness	▶ Complusion
▶ Play	▶ Language
▶ Fun	▶ Sensory

Why do we think we need to separate joy from learning?
Connection from communication?
Enjoyment from opportunities?

This presentation starts from a place of joy. I'd love to open with a discussion of how joyful your participants with Autism are, and some examples of the things that make them joyful.

From a place of joy, let's review the diagnostic- based challenges of Autism...

- Social skills
  - Joint Attention
  - Engagement Differences
  - Atypical presentation of emotions
- Communication skills
  - Limited or delayed speech
  - Using restricted language
  - Lack of generalization for communication
  - Segmentation of speech sounds
  - Apraxia of Speech
- Repetitive and restricted behaviors
  - Atypical interests
  - Need for routine and ritual
  - Atypical object use

A few words on RSB...

- First hand perspectives on Autism are invaluable to us as practitioners.
- Temple Grandin:
  - Read interview with Medscape
  - http://www.medscape.org/viewarticle/498153
  - Behavior is communication!
- Judy Endow:
  - Anxiety and Autism: Fear response
  - http://www.judyendow.com/advocacy/fear-anxiety-and-autistic-behavior/
  - Importance of using language to describe shared experiences
- Rhema @ Rhema's Hope
  - https://rhemashope.wordpress.com/
  - something i want to say is one of the hardest things about having an autistic mind is that directions get so ignored by your autistic body . my mom tells me to put on my socks and i want to but my body gets too stuck . it is like i cant tell my hands from my feet . my mind says one thing my body does something else . this is so frustrating because then people think you dont understand what a sock is. i want to get better at body control. i thank god for my body even though it fails me every day. it makes me pray a lot . love rhema.
- Amanda Baggs:
  - RSB and movements are a "conversation" with environment
  - https://www.wired.com/2008/02/ff-autism/
  - Importance of allowing user to shape their own communication

Repetitive behaviors and play often offer a way to cope with unpredictability or negative sensory experiences. As practitioners, we should be spending lots of time understanding a world view much different from our own.

So what does this mean for those of us utilizing AAC as a means for teaching communication for this population?

We…

▶ Engage in repetitive play and interests, rather than avoid them
▶ Build learning opportunities INTO this engagement
▶ Spend time building relationship and understanding each individual, especially if they are non-verbal
▶ Give tools for success, including as much repetition as needed/ desired

Engage in repetitive play and interests, rather than avoid them

▶ Ayden, 5 years old
▶ Complex birth hx and suspected ASD dx
▶ Visually impaired
▶ Non-verbal, struggles with seated work and toy play
▶ New device user
▶ VERY motived by active play and movement activities
▶ Co-treat with OT for feeding

Build learning opportunities INTO this engagement

▶ Jeremy, 14 years old
▶ Dx of Autism at 4, presently only using PECS to request
▶ New device user

Give tools for success, including as much repetition as needed/ desired

▶ https://www.youtube.com/watch?v=G-gHO0NQ0TA&index=3&list=PL9lxDYblspD2Q4dJ_UhvgD-3jKg3F3tKZ
▶ Henry: 4 years, ASD dx
  ▶ Second appointment with LAMP
  ▶ Typically struggles to sit and engage. Needed deep pressure (boundaries with arms, compression vest, weight across shoulders) to maximize success.
  ▶ Initially wanted to request color words only for crayons- shaped across session into requesting using core words
  ▶ Really thrives on repetition- could have done this the entire session.

Spend time building relationship and understanding each individual, especially if they are non-verbal

▶ Vanya, 7 years (3 at the time of video)
▶ Currently verbal
▶ CP, BPD, Amniotic banding, Adopted at 18 months from Ukraine
▶ Dx of Autism recently
▶ Device user exclusively for 2 years, developed verbal speech
▶ Very sensory driven and routined

Building joint attention:

▶ Use their interests!

▶ Imitate them as much as possible.

▶ Build vocabulary on top of imitation, using the device.

▶ Offer opportunities to use vocabulary as their turn arises, as you're able to build turn- taking out of imitation.

▶ MODEL! And allow of device exploration, avoiding HOH as much as possible.

▶ Your priority is to build connection and communication opportunities.

▶ Remember: The device is the language modality you're layering onto your joint attention based therapy!

Resources for Joint Attention Based Therapy:

▶ http://www.hanen.org/Programs/For-Parents/More-Than-Words.aspx

▶ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3749903/

▶ http://www.ucdmc.ucdavis.edu/mindinstitute/research/esdm/

▶ Remember, while some of these techniques are written and tested for young children, there are MANY people of all ages on the Autism Spectrum that these principles still apply.

▶ I would argue that ALL successful learning opportunities begin with building some level of joint attention in them.

Why is this approach best practice for children on the Autism Spectrum?

▶ Research on joint engagement:

    ▶ Intervention that utilize activities that promote joint engagement offer greater language and play gains.

    ▶ Kasari, Connie; Freeman, Stephanny; Paparella, Tanya. (2005). "Joint attention and symbolic play in young children with autism: a randomized controlled intervention study." Journal of Child Psychology and Psychiatry. 47: 611-620.

    ▶ Kasari, Connie; Paparella, Tanya; Freeman, Stephanny; Jahromi, Laudan B. (2008). "Language outcome in autism: Randomized comparison of joint attention and play interventions." Journal of Consulting and Clinical Psychology. 76: 125-137.

▶ Research on child directed interventions:

    ▶ Kouri (2009) reports positive impacts of child- led interventions on development of communication skills (signs and spoken)

▶ AAC literature is beginning to look the same:

    ▶ Kasari, Kaiser et al 2014 found that a blended approach of joint attention, play skills, and a speech generating device brought greater gains in spontaneous language

What does this mean for us? Practically and clinically?

We spend a LOT of time in child (or young adult)-directed play to begin.

And we begin with the end in mind.

Remember Vanya?

What was he missing?
But really…
What was I missing?

Answer: A ROBUST language system

► What do we mean by a robust language system?
► Robust:
  ► **strong and healthy; vigorous.**
  ► synonyms: strong, vigorous, sturdy, tough, powerful, solid, muscular, sinewy, rugged, hardy, strapping, brawny, burly, husky, heavily built
  ► (of an object) sturdy in construction.
  ► "a robust metal cabinet"
  ► synonyms: **durable, resilient, tough, hardwearing, long-lasting, sturdy, strong**
  ► "these knives are robust"
  ► antonyms: fragile
  ► **(of a process, system, organization, etc.) able to withstand or overcome adverse conditions.**
  ► "California's robust property market"

As speech therapists choosing and developing language skills in our clients, we should first ensure the language system we're choosing is ROBUST.

▶ Three **IMPORTANT** questions we need to ask each time we make this type of decision:

▶ Can the language system we're choosing withstand the test of language development and time?

▶ Does the language system we're choosing allow that user to engage in communication whenever THEY want to?

▶ Does the language system we're choosing cover ALL of the functions of language?

Can the language system we're choosing withstand the test of language development and time?

▶ Choosing a language system for our users on the Autism Spectrum is especially important.

▶ We can't see in the future- **a AAC choice MIGHT be with them long term**...

▶ and **change. is. hard.** (Remember our RSB slides from earlier).

▶ Jeremy
  ▶ Changing from PECS system to LAMP
  ▶ Struggling with engagement and functions of speech
  ▶ Behavior increasing

Does the language system we're choosing allow that user to engage in communication whenever THEY want to?

▶ From day one of AAC, we should be handing that system over to the user.
  ▶ **It's never ours- its theirs.**

▶ Choosing words and phrases that THEY want to say, and using our joint attention experiences with them to guide us.

▶ Example: Ezra and "This Blows!"

▶ Example: Andrew and the "eraser"
  ▶ Wish I had a video!
  ▶ Was on LAMP, now considering Word Power.

Does the language system we're choosing cover ALL of the functions of language?

- ▶ Interjecting, Narrating, Questioning, Greeting, Directing, Commenting AND Requesting
- ▶ If we only teach requesting- **Oh the opportunities we're missing to teach LANGUAGE.**

- ▶ Example: Vanya: LOOK!
- ▶ Example: Joint book reading, which we'll see videos of and talk about later REQUIRES that kids know and grasp how COMMENTING works.
  - ▶ Tough for this specific population.
- ▶ Example: Negation
  - ▶ Research tells us negation is the earliest developing function for phrases.
  - ▶ Bloom, 1968
  - ▶ What is early developing communication without negation?!

How do we know a robust language system is best practice?

- ▶ Research tells us that AAC is best utilized through modeling use of that language system and its symbols in natural communication exchanges.
  - ▶ Brady, Thiemann-Bourque,, Fleming and Matthews, 2013; Cafiero, 2001; Drager et al, 2006; Romski and Sevcik, 1993; Sennott, Light and McNaughton, 2016)
  - ▶ You can't have natural communication exchanges without a very robust language system!
  - ▶ These studies point to the need and necessity for high vocabulary availability so that communication partners can model and respond.

One characteristic of a robust language system?
CORE WORDS!

- ▶ Core words (ASHA Leader Article: Cannon, Edmund "A Few Good Words")
  - ▶ "Core vocabulary" describes a small set of basic words in any language that are used frequently and across contexts (Cross, Baker, Klotz, & Badman, 2006).
  - ▶ Core words tend to be pronouns, verbs, and demonstratives because they represent words that generally do not change (Stubbs, 1986).
  - ▶ Words like "big," "little," "give," "eat," "go," and "you" are examples of core vocabulary terms used every day in many situations.
  - ▶ Research shows that 80% of what we say is communicated with only the 200 most basic words in our language (Baker & Hill, 2000).
  - ▶ We use core words to make ourselves understood. For instance, one would say "give" instead of "bestow," or "smart" instead of "perspicacious."
  - ▶ Lists of core words are widely used when writing textbooks and training manuals to be sure the materials are readable by a broad audience (Stubbs, 1986).

More on Core

▶ Giving access to core vocabulary allows users on the Autism Spectrum to hear and attune listening to words across contexts, as well as use words across contexts.

▶ Ex: GO = go in the car, go around the ball pit, run across the room (ready set…), go away, and go up the steps

▶ When teaching a core word, having activities that teach the same word in multiple contexts is essential.

▶ This gives you lots of opportunities to follow your child's lead while building their vocabulary.

Some examples of core:

▶ fun/ funny
▶ girl/ woman/ mama
▶ have/ has
▶ he/him/ his
▶ hungry/ thirsty
▶ over/ under
▶ play
▶ she/her/hers
▶ sing
▶ sleep/tired
▶ we
▶ friend (names)
▶ again/ more
▶ all done/ finished/ all gone
▶ good/bad
▶ do/did
▶ help
▶ I/me/mine (name)
▶ Look/see
▶ Not/don't
▶ Go/stop

▶ That/ this
▶ want
▶ you/your
▶ big/ little
▶ come
▶ drink/ eat
▶ get/ give
▶ like
▶ happy/ sad
▶ here
▶ make
▶ put
▶ turn
▶ off/ on
▶ open/close
▶ read
▶ sit
▶ slow
▶ some
▶ up/ down
▶ watch
▶ work

Group Activity:

Split into groups of 3-5. Choose a core word and come up with 5-7 activities for that word.

The activities:

1. Must be something your AAC users will LOVE!
2. Must be an opportunity to build joint attention.

Questions?

Now let's EXPAND! Into the FRINGE!

Let's list some examples of fringe words.

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Fringe gives us an opportunity to phrase build, as well as teach concepts.

▶ How does this work?
  ▶ You might build engagement in an activity with a core word like: give, make, get, see, that, want.
  ▶ And expand into fringe as you continue through the activity with: colors, shapes, numbers, animals, body parts (you get the idea).
  ▶ https://www.youtube.com/watch?v=MwR1nCBTszE&list=PL9IxDYbIspD2Q4dJ_UhvgD-3jKg3F3tKZ&index=1
  ▶ https://www.youtube.com/watch?v=dkLAa7DUHNw&index=2&list=PL9IxDYbIspD2Q4dJ_UhvgD-3jKg3F3tKZ
  ▶ Let's go back to your core activity and add fringe to each one.
  ▶ For example:
    ▶ go (swing): high, low, fast, around, push, pull, stop
    ▶ go (getting pushed on a rolling chair): numbers, fast, don't, stop, places
    ▶ go (with a spinning toy): me, you, help, animals/ colors/ shapes (if more than one)
    ▶ go (running): to sight words, to colors, to pictures

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Independent Vocabulary Acquisition: Core + Fringe

- ► Rule 1: All "hits" are true words and should be rewarded as tangibly as possible.
- ► Rule 2: Give your user access to as much language as possible.
- ► Rule 3: Find opportunities to build engagement into this type of conversational exchange.

The value of generalization…

- ► Several studies have pointed to the importance of core vocabulary based on the frequency of use and flexibility across contexts and partners.
  - ► Banajee, DiCarlo, and Stricklin, 2003; Beukelman, Jones, and Rowan, 1989; Dennis, Erickson, and Hatch, 2013; Marvin, Beukelman, and Bilyeu, 1994; Trembath, Balandin, Togher, 2007
  - ► Generalization is KEY in learning multiple meanings and using language across multiple contexts, so a core based vocabulary system is the way to go!
- ► As you expand and model more complex ways to use core, really use the language system to help your user with generalization.

Joint Book Reading: the BEST place for Core + Fringe

- ► Joint Book Reading- opportunities for literacy, joint engagement and building that natural ability to engage in that input/ output loop
- ► Work of Karen Erikson: https://www.med.unc.edu/ahs/clds/new-faculty-page/karen-erickson
  - ► Look for books with a story, high interest for user.
  - ► Focus on Interaction first.
  - ► CAR strategy
    - ► The CAR strategy (Notari-Syverson, Maddox, and Cole, 1999) encourages adults to support students during shared reading by 'following the car':
    - ► Comment on what the student is doing e.g. "Oooh, a dog" (then wait 5 seconds)
    - ► Ask a question e.g. "Do you like the dog?" (then wait 5 seconds)
    - ► Respond by adding more e.g. "I like the dog. He looks very friendly".
- ► https://www.youtube.com/watch?v=IhJPeqtKqgc&list=PL9IxDYblspD2Q4dJ_UhvgD-3JKg3F3tK7&index=5
- ► https://www.youtube.com/watch?v=CE6uk-GVkDA&index=4&list=PL9IxDYblspD2Q4dJ_UhvgD-3JKg3F3tK7
- ► Resource: Center for Literacy and Disability Studies (UNC)
  - ► http://www.med.unc.edu/ahs/clds
  - ► Project Core

A word on prompting...

- Remember that your job is to TEACH a language, not TEST! Let's talk about the difference between those two.
- Teaching: TONS of modeling, using peers to model, modeling the word and its meaning many many times before expecting a independent hit, using lots of pauses to wait for a hit
- Testing: asking a child to "find me _____", asking a child "where is ___ word", asking a child to match symbol to symbol or word to word
- Bottom line is: MODELING and PROMPTING in the right ways are ESSENTIAL parts of learning AAC, just as they are for typical verbal speech communicators.
- PLEASE USE PROMPTING.
- BUT...

A word on prompting...
Some guidelines. And lots of WAITING.

- State
  - Make a very general statement about the situation. "You love to GO"
- Suggest
  - Be a little more direct, but general. "You can say GO so I know you want to GO"
- Say
  - State what the child needs to do. "Say GO so we can GO"
- Assist
  - Give a visual cue, point to the motor plan for the word.
  - Give a tactile cue.

  - Inspired by Rachael Langley, EATON RESA and #Talking AAC

Some final thoughts on prompting...

- Remember how we've talk about the importance of independent learning?
- Be sure you don't get caught up in "correctness" and miss REAL communication.
- Use prompting intentionally and ALWAYS respect the intentional communication you are seeing in front of you!
- Prompting is a dance. Be sure you're respecting your partner and reading cues as you go.

How do I write goals about all this?

► As an outpatient SLP, I've enjoyed the ability to write and work on family driven goals. BUT I realize we need to have a discussion about goals for other settings.

► Some goal ideas:
  ► Goal about increasing contextual vocabulary
    ► The client will utilize words (or phrases) to comment on objects and actions with fading prompts.
  ► Goal about increasing spontaneous use of core words
    ► The client will spontaneously use known core words in multiple contexts with minimal prompting.
  ► Goal about replacing challenging behaviors with intentional communication
    ► The client will utilize negations to protest and express displeasures during unfavorable activities with fading prompts.
  ► Goal about describing sensory needs
    ► The client will describe sensory needs and request action of a communication partner with minimal assistance.
  ► Goal about using AAC socially
    ► The client will engage in turn taking with a communication partner when playing games or during play activities with fading prompts.
  ► Goal about using AAC to increase joint attention
    ► The client will engage with a communication partner by initiating use of their device or imitating a partner during pleasurable play experiences.

Let's practice that!

Split into groups and write three goals for a user on your caseload.

Exploration: The KEY to AAC development for your users for Autism

► What do we mean by exploration?
  ► Built in opportunities, both at home and school to engage with their device completely unprompted.
  ► Using "Full LAMP" as much as possible, if that's the language system you choose. Meaning, hiding/ showing very little.
► Why is it important to let a user forge their own path into their system?
  ► Motivation and social reward/ consequence are natural language development teachers.
  ► Opportunities for independent learning.
► What does this mean for SLPs working with them?
  ► Socially and conversationally rewarding EVERY hit as much as possible!

Perspectives on Autodiadatic Learning for AAC

Lance McLemore, AAC user

Let's Review:

► Begin with joy and connection. It is never a wasted session if you get to know your AAC user better.
► Use activities that engage your user as ways to build communication opportunities.
► Begin here with core words.
► Move into fringe words as a way to expand into phrases.
► Continue to teach from a place of joint engagement.
► Reward and encourage independent exploration of the device. Conversations build real opportunities to learn.
► Use as little prompting as possible, which will create more independence in your user
► Write goals for you AAC user that give them opportunities to practice practical skills

Questions? Comments?