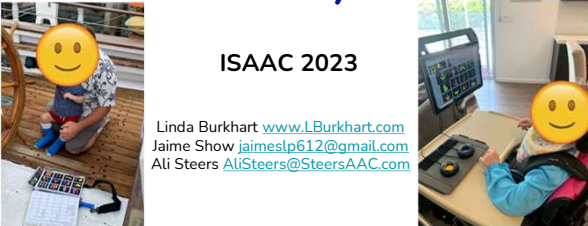


Young Children With Complex Physical and Visual Challenges Have Something To Say

ISAAC 2023


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1

Linda J. Burkhart - Financial Disclosure

- Self-Employed
- Paid Consultant and Trainer
- Small Home Business (books and software activities)
- Work with children, families and teams privately
- Volunteer consulting to AT Vendors and product developers



2

Rebecca Sobolevsky - Financial Disclosure


- Self Employed
- Private practice Team Speech working with children 0-18 in Denver metro area with children with complex communication needs
- Early Intervention SLP
- Assistive Technology Consultant for Early Intervention CCB's
- Paid Trainer and Consultant



3

Jaime Show - Financial Disclosure


- Full time pediatric speech-language pathologist at a rehabilitation hospital in the Chicagoland area with a heavy caseload of children with complex communication needs
- Performs AAC evaluations and treatment plans for the facility
- Early Intervention provider
- Guest presenter for college assistive technology classes
- Paid trainer and consultant



4

Ali Steers - Financial Disclosure

- Full time pediatric speech-language pathologist
- Self-Employed at Steers AAC Language & Speech, Inc
- Caseload exclusively comprised of children with complex communication needs
- Performs AAC evaluations, direct therapy and consults/collaborates with schools and teams
- Paid trainer and AAC consultant



5

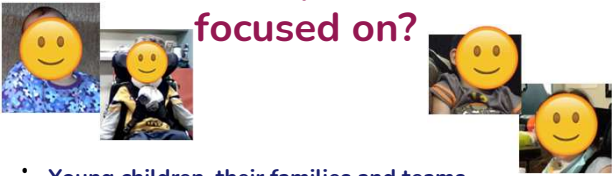
Children with Complex Physical Needs, CVI and CCN

So much we could teach / learn - what are the priorities?



6

Who is this presentation focused on?

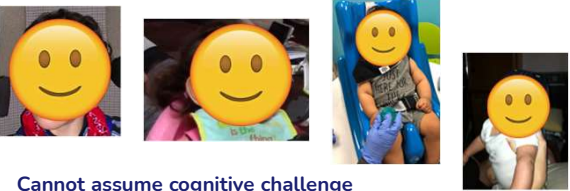


- Young children, their families and teams
- Children with significant physical challenges that limit their ability to directly select items on a display
- Children with CVI (brain-based visual impairment)
- Children who have Complex Communication Needs (speech abilities not sufficient to meet their communication needs)

7

When young children have significant physical and visual challenges, there is no way to know what they understand or are capable of learning

(Porter & Iacono)




- Cannot assume cognitive challenge
- May lack early gestures and visual attention
- Need to be given appropriate opportunities to learn first

8

Cortical Visual Impairment (CVI)

- 60-70% of children with cerebral palsy also have cortical visual impairment (Sandoval, Castlebury & Rice, 2020).
- CVI is often underidentified in children with CP
- Even when CVI is identified, it can be difficult to find appropriate services/professionals




Sandoval, M. A., Castleberry, K., & Rice, M. L. An analysis of the correlation between cerebral visual impairment and cerebral palsy severity at Cincinnati Children's Hospital Medical Center. Invest. Ophthalmol. Vis. Sci. 2020;61(7):2151.

9

Parents Wished AAC Was Introduced Earlier

- Instead, the focus was on physical needs
- In early intervention, an SLP was typically not part of the team unless for feeding
- If a child was referred for AAC in Early Intervention, they were referred closer to 3rd birthday



10


Parent Discussion



11

What parents told us they wish they knew...


- AAC could have been introduced earlier
- Physical piece and communication piece were more related
- Shifting to what child can do
- Connection and enjoying building the relationship between parents and child
- Communication early to support health and medical needs




12

Why Weren't These Children Introduced to AAC Earlier?

- Prerequisites?
- Challenges with access?
- Belief that motor was a priority?
- Never seen it before?



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Developing Shared Understandings

- Neurologically, the brain learns information via patterns.
- There are no prerequisites to AAC
- Not having speech is not the same as not understanding
- Assume the child has something to say
- See your role as the person discovering what the child wants to say - not as "trying to get them to say something"
- Respond to all communication as intent - build a sense of competence
- First assume an access to communication disorder

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Best Practices in all areas: Motor, Vision, Communication, & Literacy

- Natural contexts - integrated all day
- Partners developing good observational skills to set up and monitor adaptations on the spot
- Active learning and intrinsic motivation
- Challenging individual at just the right level for learning (Zone of Proximal Development)
- Develop goals as a team with the long-term outcomes in mind - Does it matter?

15

Learning is Connecting Intent with Movement/Action



Physical, Emotional and/or Cognitive Action

16

Beginning development of an active sense of self (agency)

- I can make things happen
- I have some control
- I can advocate for my needs and preferences
- I can move toward or move away from interactions with other people
- I can have an impact on other people




17

Learning is Enhanced by Attention to Relevant Components



18

What Might Attention Look Like?



19

Learning is Dependent upon Active Engagement

- Moving an individual's body through motor patterns multiple times is not as effective as the child having a reason to move
- Random visual stimulation done to the individual is not as effective as helping that individual develop visual curiosity
- Drilling or testing an individual on vocabulary or syntax is not as effective as modeling language with a full range of functions across the day in natural contexts
- Visual identification of letters and words is only one small part of robust literacy learning

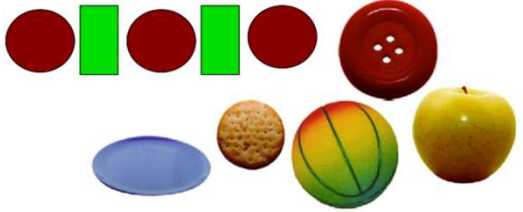
20

The Brain is **not** a Video Recorder



21

The Brain Builds Understanding Based Upon Patterns



The Brain Craves Patterns

22

Our Memory is Stored as Patterns

Get the "Gist"

Not All the Details

23



24



25

Our Memories are Stored as Patterns

Not Exact Details

26

Language is built upon patterns of interaction

- Without connection, interaction and relationships with other people, language/words have no meaning
- Interaction and contact comes first

Second Language Infant Studies
(Patricia Kuhl 2003)

27

Modeling in daily interactions

28

Patterns Can be Visual, Spacial, Auditory, Tactile, Kinesthetic, Temporal, Procedural, Cognitive, Linguistic, Multi-Modal, etc.

29

Language is a Pattern

30

Representational Hierarchy for Visual Development - Appropriate Strategy

When learning to use vision:

- Start with objects (single color simple shape)
- Move to photo of same object on plain background
- Increase abstractness of image through teaching salient



However, Not appropriate for teaching communication

31

Very Young Children Can Understand Abstract Symbols and Concepts As Long as they are Presented in a Consistent, Meaningful Pattern



32

Very Young Children Can Understand Abstract Symbols and Concepts As Long as they are Presented in a Consistent, Meaningful Pattern

Speech is Abstract

33

Representational Hierarchy

(starting with objects and moving to photos and then to abstract symbols)



- Used for development of vision in CVI, However, Not appropriate for teaching communication
- True for easier recognition of nouns without any prior learning, but speech is abstract
- Language is not recognized, it is learned
- Can not represent the early core language concepts that are not nouns: more, done, help, me, stop, uh oh, etc.

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Misuse of Representational Symbol Hierarchy for Language

- The individual may begin to see communication as passive - waiting for others to offer choices
- May limit the development of autonomous generative communication
- May limit the development of a wide range of pragmatic functions
- May limit the development of syntax

35

We need to choose appropriate symbols based upon the individual's ability to perceive differences between symbols

Do not need to be able to identify the symbols, before they are used receptively

36

We need to choose appropriate symbols based upon a child's individual requirements

Then, we need to present them in natural contexts with a consistent, meaningful pattern

37

Present these symbols in natural contexts with a consistent, meaningful pattern

- Similar to how typical kids learn a language through speech
- Not just vocabulary - vocabulary within a robust organization system that provides patterns for language usage of vocabulary

38



39

Does the individual actually have a language disability or an access to language disability? Accessible language must be used in the environment to be learned

40

Historical Strategies for Teaching Language: What were We Missing?

A collage of various communication symbols and icons. It includes a cracker, a glass of juice, a communication board with multiple icons, a red and yellow button, a communication board with icons for pudding, shake, spoon, and yummy, a communication board with icons for cow, pig, duck, farm, and tractor, and a communication board with icons for people and activities.

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Offered a Limited Set of Choices

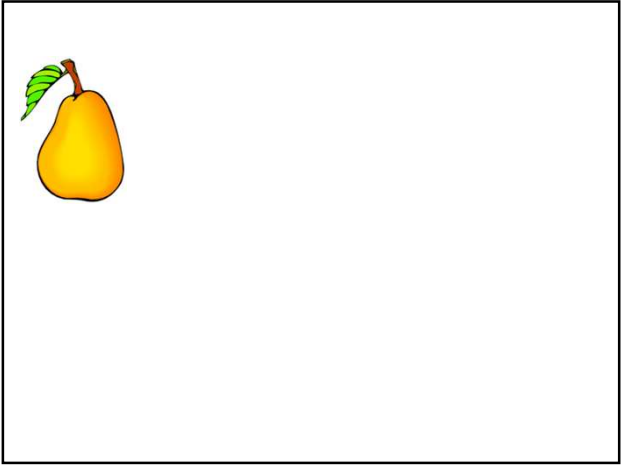
Two communication cards. The first card shows a cracker with the word "cracker" above it. The second card shows a glass of juice with the word "juice" above it.

42

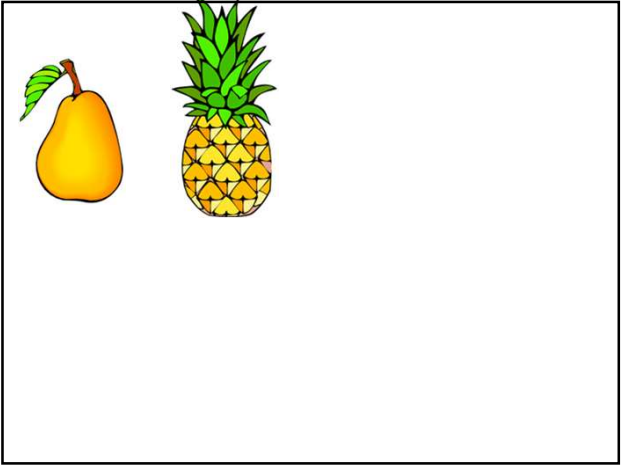
Neurologically, the brain needs a **large** enough set of experiences with **meaningful use of language** to recognize patterns and create meaning

Patterns are harder to recognize from a limited set

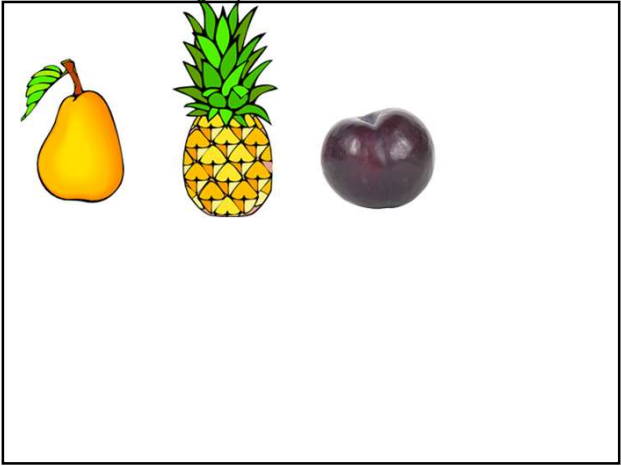
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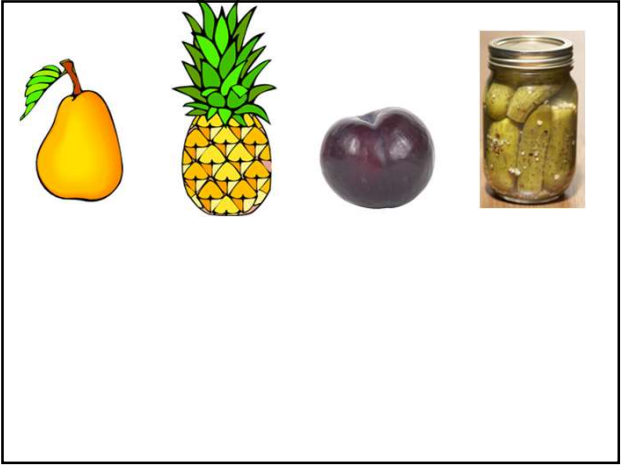
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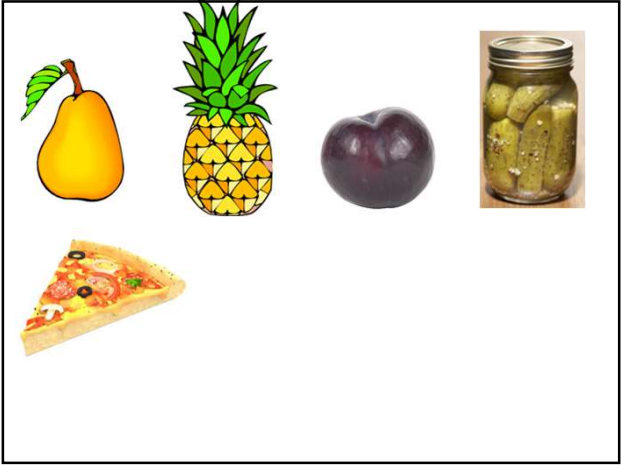
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48



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51



52

What would you like to eat
right now?

53

Here are your choices:




banana jello

54

Choices Help Provide a Means of Active Participation

But

- Being able to say what you want – when you want
- Not the same as making choices!
- Just Indicating a Choice that Someone Else Selects - Isn't Enough to Develop Language



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How Do Children Learn Language?

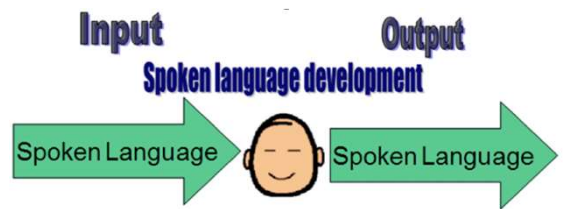


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Typical children learn language by being **immersed** in a native language learning environment, where they can freely interact with, and **try out** their developing skills

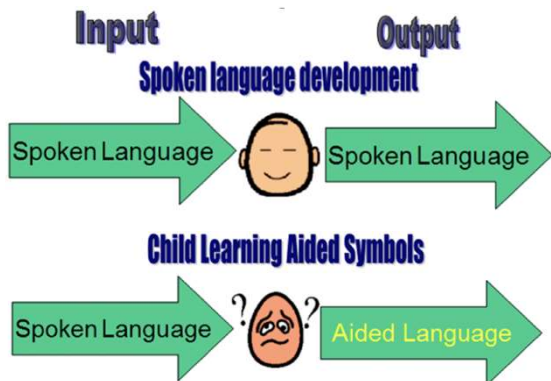


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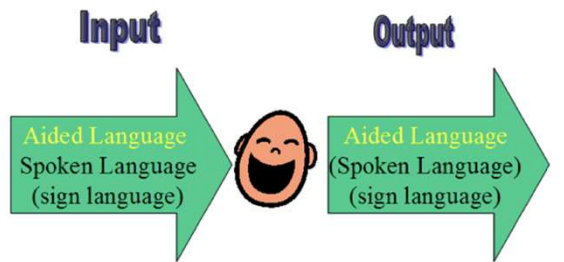
Gayle Porter, 2004

58



Gayle Porter, 2004


59



Gayle Porter, 2004

60


Children begin using language based upon their own agendas, long before they can talk about what we want them to talk about, so others providing options is not how language is learned



Try to maintain topic control when chatting with a typical two year old

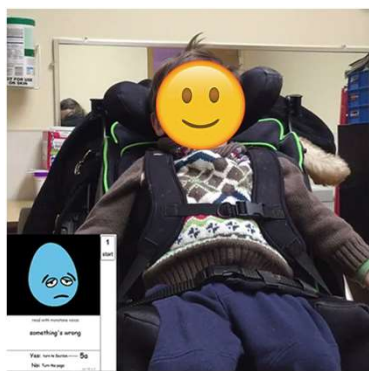
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We need to Provide Enough Vocabulary for the Child to Say What he Wants to Say When he Wants to Say it!



62


Early Message: "I don't like it-boring"



63

"Catch-22"


How do you test Language Skills before teaching Language Skills?



64

"Catch-22"


Motor skills may need to be developed or refined over many years



65

The Juggling Act Working Memory

- Many things to juggle for both the student and team working with the student
 - motor
 - vision
 - communication
 - interaction
 - academic learning
- Developing automaticity takes time!



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**Children with Significant Motor Challenges -
May Require a Great Deal of Cognitive Effort to
Move and Stabilize themselves**



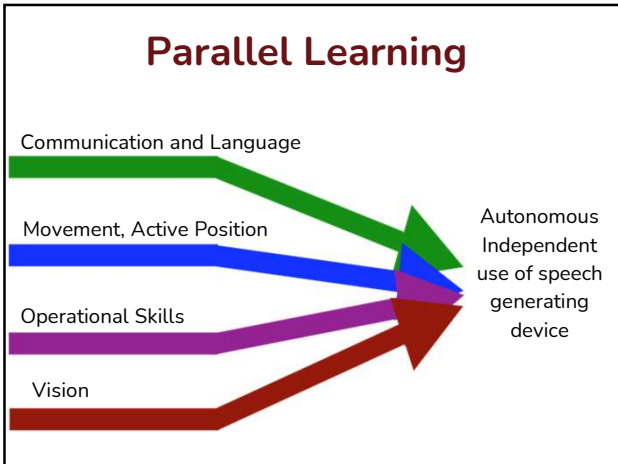
When a child needs to focus on movement and stabilizing, then there is very little working memory left for attention to the play, language or cognitive task

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**Juggling Explains Inconsistency of
Performance**



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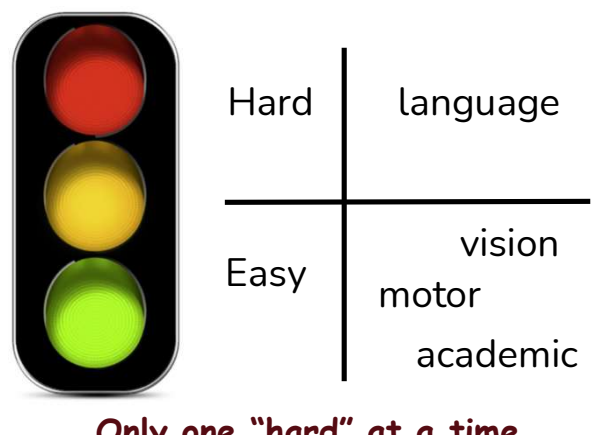


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**Focus on one component or skill within
each activity, or part of activity**

- Reduce motor load for difficult cognitive or language tasks
- Reduce cognitive load for motor learning tasks
- Reduce motor and cognitive load for vision tasks
- Teach access as a separate but parallel skill to language learning
- Only one "hard" at a time

70




Hard	language
Easy	vision motor academic

Only one "hard" at a time

71

Vision Development for CVI



- Appropriate adaptations based on current visual abilities
- Reduce motor, cognitive, and language demands

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Considerations for CVI

- Vision impairment caused by brain damage or brain difference - not problems with the eye itself (however the child may have both)
- Children's vision may improve with appropriate intervention in terms of materials used, how they are presented and environmental conditions
- Individual Assessment is critical, because characteristics vary for each child and change over time resulting in different intervention needs



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CVI Resources:

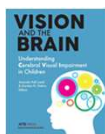
- Dr. Christine Roman- Lantzy's *CVI Range: Roman-Lantzy, C. A. (2007, 2018). Cortical Visual Impairment: An Approach to Assessment and Intervention.* New York: AFB Press) www.afb.org/store
- Numerous online webinars and videos by Dr. Christine Roman-Lantzy related to the CVI Range (both free and paid)
- Sensory Balance, Christine Roman-Lantzy and Matt Tietjen
- What's the Complexity? (Matt Tietjen)



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More CVI Resources:

- Gordon Dutton: CVI Scotland cviscotland.org - extensive website explaining CVI and appropriate strategies.
- Amanda Hall Lueck and Gordon Dutton, *Vision and the brain: understanding cerebral visual impairment in children*, New York, NY : AFB Press, American Foundation for the Blind, 2015)
- Visual Assessment Scale (Marjolein Wallroth and Marieke Steendam)
- The CVI Perspective: Understanding Cerebral Visual Impairment from the Inside Out <https://thecviperspective.wordpress.com/home/> (first person accounts of CVI) <https://thecviperspective.wordpress.com/?s=cvi>



75

Select symbols that the individual can perceive differences between

May need to use both Auditory and Visual representations before you discover the individual's developing abilities and preferences through use

Remember, do not need to be able to identify the symbols before they are used receptively

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Consider Mayer-Johnson PCS High Contrast (Between) Symbols

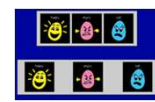
- High contrast from each other
- Requires less visual focus to discriminate and locate
- Significant differences in color and shape which often comes earlier
- Helps with discrimination without needing to look at detail
- Reduced complexity - Less detail - less demand on ventral stream processing
- High saturation of fewer colors
- Helps to select symbols from an array - don't focus on the iconicity of each symbol
- May use in combination with auditory cues



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Visual Complexity of the Array

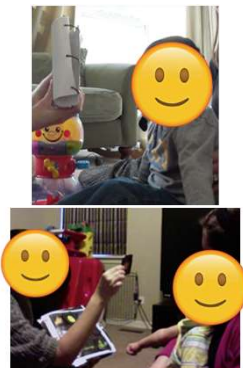
- Number of items on the display impacts complexity
- Spacing (crowding) of items on the display increases complexity
- Caution: may need to use Auditory plus visual scanning to support vision without holding back communication



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Some strategies to try through dynamic assessment process

- Position book in relation to individual's best visual field and distance
- Experiment with movement and light (or not) to help focus visual attention
- Reduce environmental complexity when practical
- Work closely with a Vision Specialist to problem-solve how much and what type of visual presentation to use



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When designing a communication system, some things are non-negotiable, and communication must be the priority, with vision taking a back seat during the communication exchange. Vision skills can be worked on at other times.



A communication system must support autonomous communication at the appropriate language level for that individual!

80

Importance of Seating and Positioning

"After spending time looking for pictures of Savana for Rebecca over the years, if I didn't SCREAM out that SEATING and POSITIONING was so important and something I really wish I paid more attention to early on, then I should have in this discussion. Also just wear the AFOPs and hand splints a lot more and have the feet stable/strapped in the foot plates. Just do it. It really helps and isn't mean (I remember how we felt/thought back then). Granted it helps a lot more to have an older parent/mentor telling you this but still. OMG."
-Shirley, parent of an AAC User



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Developing Motor Control and Active Positioning



- Reduce communication load
- Reduce vision load

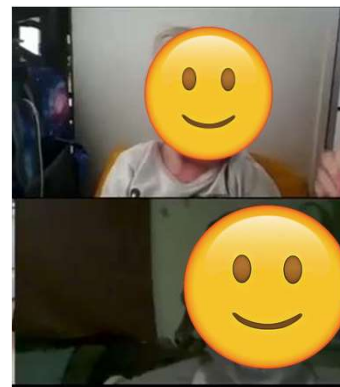
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Developing yes/no movements for partner-assisted scanning



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Yes/no for partner-assisted scanning



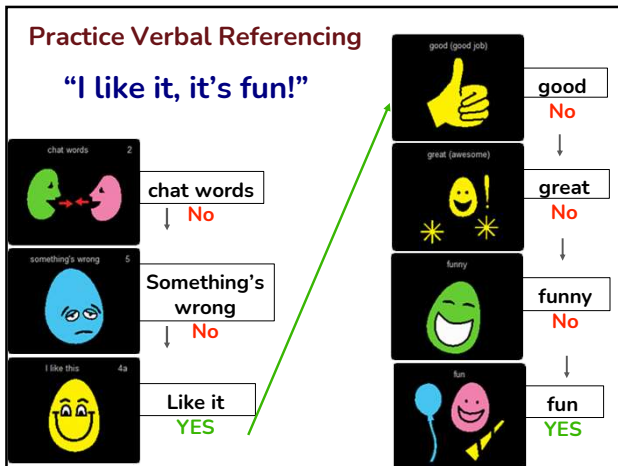
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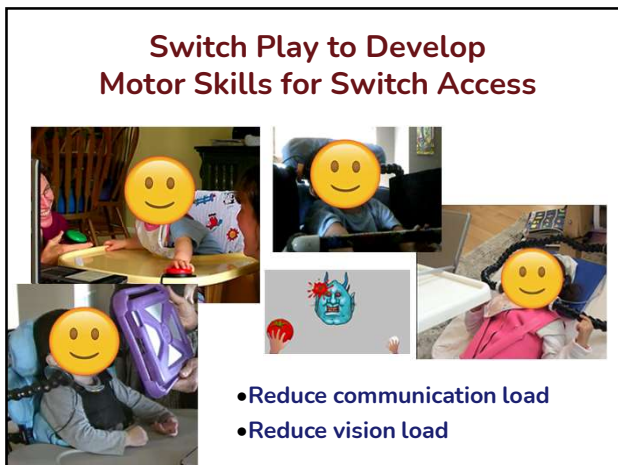
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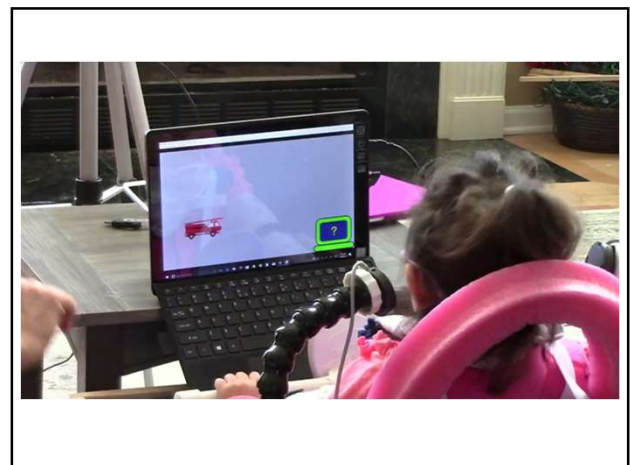
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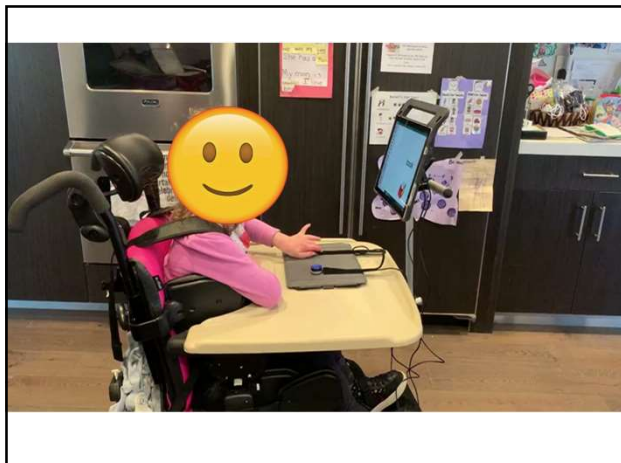
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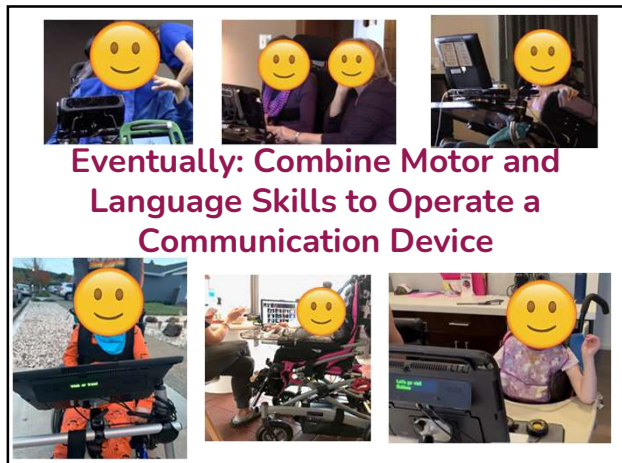
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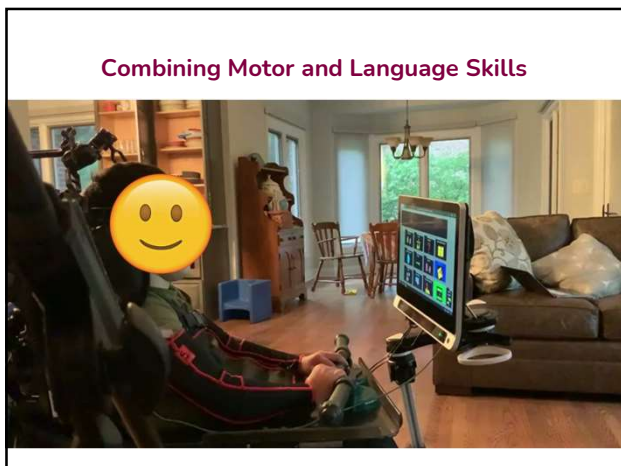


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Eventually: Combine Motor and Language Skills to Operate a Communication Device

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Combining Motor and Language Skills

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Team planning and coordination is critical. Everyone needs to be moving in the same direction for long term gains.

- Everyone needs to collaborate with other team members to:
 - Understand and use the individual's means of communication
 - Know how the person is learning to move and recognize helpful vs harmful positions and movements
 - Know what facilitates use of vision for this person
 - Recognize and address dysregulation - know how to address sensory needs on the spot
 - Incorporate what best facilitates learning for each individual (processing differences, learning needs)

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Introducing AAC: What parents felt they needed to learn

- Feel comfortable with system and modeling
- Understand their child may not "perform"
- Wait Time
- Understand their child's access and bodies

A photograph of a child sitting at a table, using a communication device. Two yellow smiley face emojis are overlaid on the image.

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Long Term Outcomes



"Communication is the most important life skill and transition skill. Knowing how to interact and communicate with a variety of people as an adult is essential to direct her personal care workers for meeting her needs and pursuing her interests. Showing she's an interesting person through communication will impact her quality of life!"

Shirley- Parent of an AAC User

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Case Study: Bradley

- Referred at 2 years 10 months
- Previously received services through early intervention
- Previously used a Big Mac switch
- Introduced to robust language with the PODD communication system during his AAC evaluation
- Started to use PODD expressively in his first few visits


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Goals, Strategies and Plan of Care

- Utilized strategies of verbal referencing and self talk scripts to target movements for communication, improved intelligibility of movements for communication
- Targeted expanding language using partner assisted scanning and trained caregivers
- Direct and indirect coaching techniques with mom, additional caregivers and school team staff
- Parallel learning with introduction of technology and switches



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Communication Growth Over Time

THEN:

- Vocalized/cried out to get attention
- Often upset
- Used facial expressions
- Selection via Big Mac switch
- Offered choices
- Caregivers often anticipate his wants/needs

NOW:

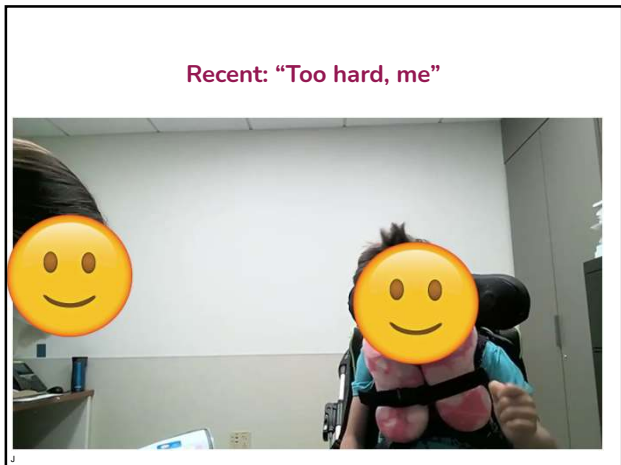
- Currently using an expanded key word auditory scanning PODD book
- Initiates 10+ messages in a session
- Uses correct grammar
- In Kindergarten general education setting—starting 2nd grade this Fall
- Using 2 step switch scanning to write cards and notes via Mind Express
- Electronic speech generating device



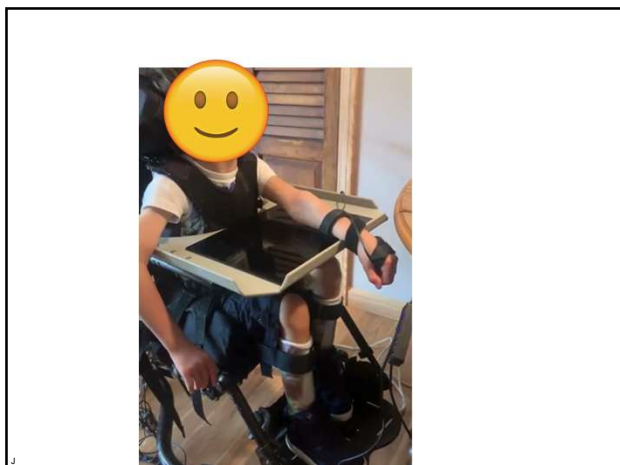

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Expanded key word auditory scanning PODD book

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Access to and use of a robust language system had significant impact on his school placement

BRADLEY'S AGE-5 KINDERGARTEN

The amazing thing about thinking outside of the box is you realize there never had to be a box in the first place.
- Victoria Young

VISION STATEMENT

Our vision for Bradley is for him to have all of the normal childhood experiences and opportunities alongside children his age of all abilities. That is understood that what is individual and he has access to an age appropriate academic curriculum. His communication is robust above all else, as this is the strongest way for him to develop relationships and be a fundamental part of the community.

For the disability skills to help pursue his own personal interests that reflect his own strengths and to be a person with knowledge. And that these interests are applicable in all social settings, not limited by where he is or who he is with. All goals will be brought around him being a valued member of the inclusive community. It will be a meaningful and fulfilling life.

WHAT WORKS FOR ME:
Peer and staff modeling, positive reinforcement, sensory time and feedback, promoting competence, time to create thoughtful/meaningful responses

WHAT DOESN'T WORK FOR ME:
Being asked to respond to things, talking/answering for me

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Parents wish they knew more about the schools

- Dynamic of team and who impacts decisions
- Inclusion: Understanding that the student is a part of the class not a "visitor"
- Thinking long term about education and how preschool may impact future decisions

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Dynamic of the Team in a School Setting

- Knowledge of how the school system works, who makes the decisions and language that is used in IEP meetings
- Acknowledgement that the speech-language pathologist "wears many hats"
- Expectation that the speech-language pathologist is often tasked with training the team

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Something to Think About

"In a segregated setting, bright children can just check out, which fuels the need to keep them segregated"

- Shirley, parent of an AAC User

Transition to preschool/early childhood is important because play is still a large focus.

Children learn from other children, including language and communication

There can be a positive impact on friendships

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What is Inclusion? Mom's Perspective

What we were told it would look like...	What we experience...
<ul style="list-style-type: none"> • "inclusion opportunities" • typically offered during "specials" - library, art, etc. • pull-out services for additional needs • offered morning multi-needs for therapeutic needs, afternoon gen-ed for "exposure" 	<ul style="list-style-type: none"> • 100% access to general education with supports • push-in classroom services • meaningful relationships • "normal" childhood experiences • true belonging

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Robust Communication

- Self Advocacy & Independence
- Demonstration of skills
- Participation in class
 - access to age-appropriate words and concepts
- Safety
- Exploration of Interests
- Connection

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Establishing Connections with Friends and Peers

The "Bestest" Friends



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What can we as professionals do to help?

- Provide families with resources
- Start robust AAC early
- Parent liaison
- Encourage parents to find mentors that support their vision
- Be a part of transition if possible



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Thanks For Joining Us

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