

Communication and Learning Strategies for individuals with Rett Syndrome

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Rett Syndrome

A neuro-developmental, genetic disorder found mostly in girls - There is a phase of degeneration, but over-all it is Not a degenerative disease. After that phase, children do make progress and learn

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Experience Rett

- Person one, move forward in your chair, raise legs (reduce feeling of stability), and sit on hands (or hold them up in the air) to simulate Rett Syndrome
- Spell word on next page, by eye-gazing to each circle in turn for each letter of the alphabet until you get to the desired letter. (say letters in your head, not out loud)
- Reverse directions for next letter
- Person two: read one instruction to your partner every 5 seconds

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Spell Rett

- Person 2: read one prompt below every 5 seconds:
 - That's it, you can do it!!
 - Wait a minute, I didn't see where you were looking, do it again
 - Remember to say the letters in your head as you go
 - Slow down, too fast
 - Remember R comes after Q
 - That is LMNOPQ - R
 - Oops I missed that, maybe you better start again
 - You need to look at all corners
 - Is that the one you wanted?
 - Don't forget to go back the other way for the next letter
 - etc.

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How did that feel?

- Did you need to start over when interrupted?
- Did your eye's fatigue
- Did you feel unstable and focused on your balance as well as the spelling
- Did you find yourself wanting to say the letters outloud instead of in your head
- Were any of the prompts helpful?

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Dyspraxia and/or Apraxia?

Apraxia is the inability to reliably connect thought to action

Dyspraxia: the signal gets through some of the time, but may be delayed or misdirected

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Dyspraxia and Apraxia in Rett Syndrome

- Neurological connections are formed, but not as strongly
- Compare to using the back roads instead of the main highway
- Signals may get off track and have trouble finding the right connections to produce the desired action

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Efferent Kinetic Dyspraxia (motor) They have the cognitive intention, but not the motor intention

- Difficulty with voluntarily initiating, sequencing and/or coordinating movements
- Difficulty finding the 'on' ramp to the freeway
- Difficulty with motor planning (moving from intention to action, despite a physical ability to produce that movement). Getting from intent to action takes **more time!**

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Driving Analogy



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Inability to Move Increases with Demand

- The harder the child tries, the harder it is for her to perform on demand
- She may need to move (herself or her head) away before moving toward what she intends (this can be misread by others as refusing, non-compliance or not understanding: none of which may be true)

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Neurological stereotypes

- Caused neurologically - not intentionally
- May be movements that are also sometimes intentional (just like eye blinks can be voluntary or involuntary)
 - Hand wringing, washing
 - Hands in mouth or in hair
 - Other hand movements
 - Other body movements, kicking
 - walking in circles

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Neurological stereotypes

- Varies with day, stress, anxiety, pain, fatigue and other unexplained reasons
- May change with age
- Masks intelligence
- Often confused with sensory processing or cognitive challenges

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Neurological stereotypies are different from sensory processing challenges

Sensory processing

- The neurological process of organizing information we get from our bodies and from the world around us for use in daily life.
- Can only occur if the information we receive is accurate.
- With optimal processing of all the senses, the child then has the ability to interact successfully with the environment - to plan, organize and carry out a sequence of unfamiliar actions, and to do what he needs and wants to do. This is called PRAXIS or MOTOR PLANNING.
- Afferent kinetic dyspraxia (motor)



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Neurological stereotypies are different from sensory processing challenges

- Sometimes occur along with Rett Syndrome
- Problem is not as much getting the information into brain as it is for getting it back out
- Strategies that work for children who have sensory challenges often don't work well for girls with Rett Syndrome
- Strategies that do help are usually related to helping with stability or calming

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The Child Must Over-Ride the Stereotypies to Perform a Motor Task for Communication

- Wait, wait, wait for a response beyond the stereotypy with patient anticipation
- Arm wraps may break up movement and allow more intention (also sometimes just holding one hand down)
- Music / Rhythm
- Intention/Interest

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- Dyspraxia/Apraxia also affects movements that control speech
- Difficulty moving as intended affects other communication skills - non-verbal social signals and sustained eye contact (She may appear disinterested)
- May make it difficult to maintain eye gaze and move eyes efficiently

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Breathing and Alerting Abnormalities Affect Ability to Move as Intended

- Difficulties with autonomic nervous system controlled by the brain stem
- Breathing dysrhythmias
- May get too much or too little oxygen and/or carbon dioxide due to breathing
- Impacts ability to move on demand

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Use Encouraging, Quiet Wait Time

Don't keep "re-booting" her system

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Attentive / Respectful Wait Time

- They know when someone is waiting for them or not
- They often learn which people will likely take the time to wait, so they can decide if it is **worth the effort**

(Note: When the child produces spontaneous movement, no one can see the time it took between initiation and movement)

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Sometimes, you can facilitate faster attention to you or materials:

Movement, Proximity and Moving Your Face or Materials into the Child's View so she doesn't need to move herself to watch / attend

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Strategic Feedback and a little Assistance when Stuck

- Move them a little (shoulder, pelvis, trunk)
- Separate hands
- Only help once child shows intent
- Allow child to complete movement on her own

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Very Sensitive to Non-Verbal Communications and Attitude of Others

- Very tuned into what you are thinking and will reflect your hidden emotions
- Will often have certain people that they work well with - people who view them as capable and treat them with respect

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Additional Challenges with Autonomic Nervous system

- Temperature regulation
- Circulation (sometimes to one extremity randomly)
- Sleep cycle disruptions
- Swallowing
- Gastro-intestinal movements
- Anxiety
- Agitation

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Weak parasympathetic (automatic calming) response

- More easily alerted
- More difficulty calming themselves down
- Easily become dysregulated
- fatigue

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Observe for Sensory Regulation and Readiness for Learning

- Identify signals of dysregulation and regulation for each child
- Work with OT, family and others to make a list of strategies that help with regulation - Apply as needed
- Take advantage of teachable moments when child is regulated

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Provide Individually Designed Mini-Breaks

- a quick nap
- a bite to eat
- short music break
- change of activity
- get up and move
- etc.

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Regulate your own state first then lend the individual your state

These children often have trouble with typical skills that we classify as early communicative behaviors

- Early communicative gestures
- Directed or coordinated eye-gaze for joint attention
- Non-verbal signals

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Therefore, they may get incorrectly labeled as "pre-intentional, Reflexive" or "low functioning" and not provided with appropriate language (AAC) tools, supports, and learning environments

It is Easy to Make the Wrong Assumptions about Cognitive and Language Potential for Children with Rett Syndrome

NOTE: We cannot see intention, so for children older than the age where typically developing children start showing intention we should not use the term "pre" or "low"

Some individuals with Rett are reading, doing math, and other academic work at grade level

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Motivation is Critical

- Motivation assists with regulation
- Makes it easier for the individual to overcome dyspraxia
- Neurons fire more effectively
- Internally drive motivation is the most powerful

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Motivated by Connection with Others:

- Most powerful motivation is social connection
- Dyspraxia increases during individual sessions away from peers. Movements are easier and participation increases in classrooms, kindergarten, with peers, and siblings
- Teach the child next to them

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Motivated by Connection with Others:

- Be interactive - socially engaging
- Take turns, laugh, tease and share pleasure in little things

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Teach Peers to be Friends, not "Helpers"

- Teachers and other adults often set the tone of the classroom
- Discourage "helping"
- Encourage "doing things together"
- Friendships are formed through common interests, not forced
- Naturally talk to other children around her, using her AAC
- Encourage peers to use her AAC by moving it toward them using it to talk to them and responding to them
- Assist with operation of AAC without taking over the conversation between child and her peers

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The Power of Modeling!
Take a Turn
Have Peers Take a Turn

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Children Need to See a Reason for Doing Something

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When a child wants to do something, her brain actually acts more efficiently and that task becomes easier for the child

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Withdrawal or passivity may be the child's way of protecting themselves from further failure

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Prompting and Helping Too Much Can Lead to Learned Helplessness

Provide strategic feedback vs. prompting

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Role of teacher, therapist, and para-professional is to facilitate independence, active engagement, and support for problem solving

Not just "get the answer right"

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Discovery Learning - Problem Solving in a Scaffolded Environment

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Limit or eliminate hand-over-hand assistance - try to support movement initiated by the child, instead of moving their hand for them

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External rewards and reinforcers can reduce mastery and shift child's attention away from task toward the reinforcer



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Empty praise is NOT helpful



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Meaningful feedback vs. praise for performance

- Less general "cheering"
- She knows when she did something or when someone just put her through the motions (hand over hand)
- Focus meaningful praise and feedback on what she does do



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Who Likes to be Told What to Do?



What do we do to kids all day?

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Entice, instead of telling them what to do

- Interact and then wait with attention, but not demand
- Sometimes look away to free their gaze
- Limit asking questions
- Make comments, describe

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Provide Strategic Feedback instead of Direct Prompts

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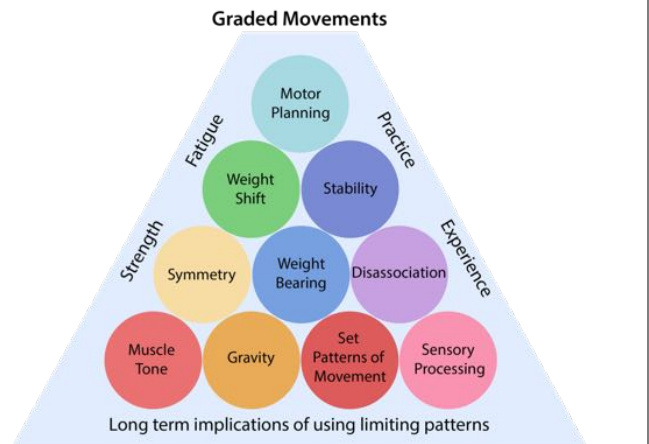
Key movement issues

- Key movement issues are movement skills that develop spontaneously in typical development
- Teach children with physical challenges how to move in a variety of positions – concepts of movement
- Support children to generalize this skill in a range of environments and positions
- Need to link concepts of movement to function



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Key movement issues



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Stability

- Stability enables a child to: weight-shift, weight-bear, disassociate and maintain symmetry
- Stability is required in all positions to enable movement
- Verbally reference what support is required and why
 - For individual
 - For partners



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Stability

- Support at shoulders, arms, hands, or pelvis (if standing)
- Ankle weights
- Arm wraps
- Grasp bars with 'houdidni' hand grips
- Lateral supports
- Second skin (supportive compression clothing)
- body and arm splints



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Disassociation

Learning to disassociate movements, that is to move one part of the body while keeping the rest of the body still, enables the person to control movements and be more successful



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Symmetry

- Children need to be in sustained symmetrical positions to prevent musculo-skeletal deformities
- Need to teach children to use both sides of their body
- Awareness of middle and active weight shifting to achieve symmetry need to be taught



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Weight-bearing

- Children need to learn to weight-bear through aligned limbs.
- Weight-bearing assists in providing the child with stability. E.g. flat feet in standing, WB through hands to keep body stable

Weight-bearing ensures:

- Elongation of muscles
- Improves bone density
- Improves joint strength



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Complex Communication Needs

Begin with Receptive Input - Aided Language Stimulation

Use a robust aided language system

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Selecting a Robust Aided-Language System

- Clear language organizational structure that builds to increasing levels of language sophistication
- Full range of communicative functions
- Can be always available - 'non-electronic' and 'electronic' tech options
- Designed for autonomous communication

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Imagine:

- You are a teenager with Rett Syndrome
- Mom is dressing you and talking about what you are going to do this weekend
- Going to little brother's soccer game
- Going to the park and watch the kids playing
- You would like to go to the mall and buy new shoes - How do you say that?

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Activity - Please find a partner

- First person - take a secret message
 - look at secret message to communicate (don't show partner)
 - hold your legs up to simulate instability
 - sit on hands (no gestures)
 - answer only with yes or no head nod - but count to 5 each time, before you move to nod or shake your head
- Second person
 - Ask yes/no questions to guess the message
- Switch roles and repeat activity

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All of those messages can be easily said using a yes/no access method for partner-assisted scanning with PODD

- Sample messages:
 - I'm going on a train
 - Leave me alone
 - That is a boring book
 - Mom is going on a plane
 - I want to show you something I made
 - I don't like chocolate

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Communication Autonomy

(von Tetzchner & Grove, 2003)

- Must be the Child's Message - Even if She Needs Help to Communicate it
- Not Just a Response to the Options Provided by Others
- Responsible for her own message

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AAC System Design - NEEDS

(Goossens, Crain & Elder 1992)

- Sufficient vocabulary
- Similarities between individual systems
- Built for development
- Selection techniques which are not too physically taxing to promote meaningful communication
- Built for growth

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Long Term Outcome?

Being able to say
what I want to say,
to whoever I want to say it to,
whenever I want to say it,
however I choose to say it

Gayle Porter

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Will she take it to a party?

Gayle Porter

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Features to Support Autonomous Communication in PODD

(Pragmatic Organization Dynamic Display)
(Gayle Porter 2006)

- Aided language development is supported - multiple page sets (communication books)
- The range of page sets reflects a developmental process as reported in the literature on both typical and aided language development
- Page sets are designed to facilitate the use of aided language stimulation
- Similarities of patterns across access methods - 'non-electronic' and 'electronic'

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Organization of vocabulary within PODD

(Pragmatic Organization Dynamic Display)
(Gayle Porter 2006)

- According to the individual's communication function and discourse requirements
- Combines the advantages of a wide variety of organizational systems: pragmatic intents, categories, activity specific, topic and anecdote organizations can all be used
- Includes scaffolds for supporting aided language development
- Efficiency to meet communication requirements is the overriding factor
- Tested and refined through use in a range of natural contexts

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No pre-requisites for aided-language input

- **Myth: Children must have a certain set of skills to be able to benefit from AAC (Ronski and Sevcik, 2005)**
- **Typical children hear the language that they will use for a full year before the first expressive word**
- **Children need to be exposed to a large number of language models in natural context to be able to learn language patterns**

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It's about building Language and Interaction

Not just learning vocabulary
or
answering questions correctly

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Begin with Receptive Input - Aided Language Stimulation immediately

Parents teach typical kids their first language so when possible they need to be heavily involved

However, parents don't need to do "speech therapy". They just need to talk to their kids using their child's language mode

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Supporting Parents to take the Lead

" The changes in my daughter's communication profile were largely facilitated through my involvement, resulting in a great increase in communication opportunities throughout the day - at home, at school, and at extended family gatherings. Now that the family sees her with her communication tools and know that she has a way of responding to them, they talk and relate to her differently. Once I saw and understood her communicative abilities, I was able to involve others in these experiences. I see this as a process that is on-going, the more others relate to her communicative abilities, the more she actively relates to them...."

Look for, and respond to subtle communicative signals the child uses to start babbling

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Work Towards More Intelligible Communication

- Teach movements that will be understood by others
- Support the child's Intent
- Provide and use a robust AAC system that will enable autonomous communication

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Recognize that communication is multi-modal

Any Attempts at Communication are Accepted as Valid and expanded upon

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Develop your own fluency for speaking with AAC - over time

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Teach Movements For Communication

- Initiation
- Multi-modal gestures
- Selection of messages from robust communication system (partner-assisted scanning, eye gaze, switch access, etc.)
- Access methods for independent and autonomous communication on an SGD

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Initiation

- model and verbally reference possible forms of initiation
 - Vocalization - "I hear your voice, do you have something to say?"
 - Vocalizing and looking toward book
 - Looking back and forth between partner and book
 - Raise arm or look at wrist with wrist band "I have something to say"
 - Noisy environments - supplement with voice-output switch, but don't replace non equipment dependent methods

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What Does Research Say About Learning a Motor Task?

- Initiation of intent must come from within the child
- Problem solving opportunities for trial and error
- Practice and repetition with a purpose
- Thousands of repetitions with variation

Hanser and Burkhart

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Developing Automaticity
takes practice:
Thousands of Repetitions
with **Intent**, **Purpose**, and
Variation

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Motivation Provides Intent

Natural Context Provides
Purpose and Variation

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

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Touch Points (Dale Gardner-Fox)
Co-Planned Sequenced Social Scripts -
experience conversational turn taking

- Touch one shoulder saying one option
- Touch the other shoulder saying a second option
- Whichever way the child turns her head is the selection
- No response? Give 2 different choices
- Record selections on a voice-output sequenced device (See Lburkhart.com click on handouts)
- 4 Points: shoulder, head, shoulder, chest - option 1, 2, 3, and none of those

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Teach Movements for
Communication

Learning **Yes/No** as an
Alternative to Pointing
- NOT for Responding
to Random Questions

Partner-Assisted Scanning

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Never Teach Yes / No with
Random Questions

- Understanding the language of the question has to come first
- Developmentally, expressing yes and no appropriately comes after the child has developed some expressive vocabulary
- Yes/No for confirm and reject is an earlier skill than answering questions

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Why is Yes / No So
Hard and Often Seen
as Inconsistent?



Gayle Porter

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Time for a snack?



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Would you like an apple?



Yes or No?

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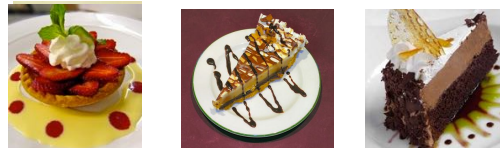
Would you like this?



Yes or No?

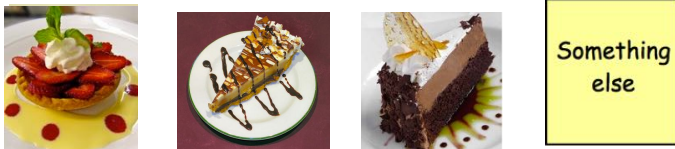
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Another Approach



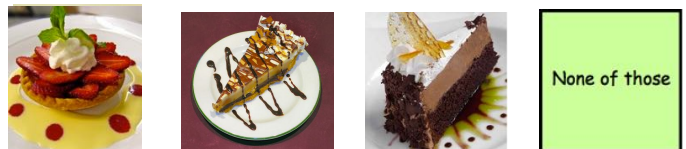
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Another Approach



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Another Approach



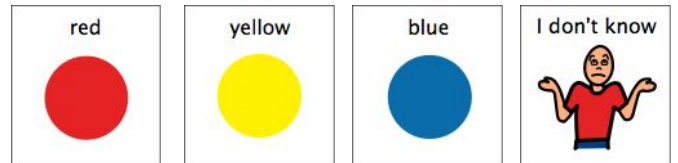
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Model First

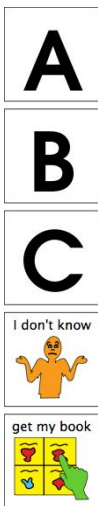
- List at least 3 items and "none of those" or "something else" (touching an empty part of the table at the end of the array of items)
- Go back and say each one out loud to yourself and model head movements no or yes
- Don't add extra verbal clutter
- Use a simple rhythmical voice for scan and social voice for your selection
- Model 3rd choice more often for a clear demonstration of how the process works
- Only offer to give the individual a turn, if she seems very interested and wants to try it - not as work to get something

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Testing and Direct Questions last item always: "I don't know"



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Testing and Direct Questions

"I don't know"
and
Please get my
communication
book / device

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Two movements to reject & accept - differentiated "YES" / "NO" signals

- Dyspraxia - Less skill required from the partner by eliminating the timing element
- Allows the child to control the speed of the communication

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Two movements to reject & accept - differentiated "YES" / "NO" signals

- Reduces partner influence and misreading of social responses within a scan
- Increased activity may cause physical fatigue for some children

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One movement to accept One signal to indicate "YES"

- The child does nothing until the required option is indicated
- Partner needs to provide an appropriate pause time between each item familiar partners often feel more confident of the child's responses

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One movement to accept
One signal to indicate "YES"

- The child needs to be able to reliably produce their "YES" movement within the identified pause time
- Experience suggests that less familiar partners often feel less confident of the child's responses

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Problems with
"look at me for yes"

- May work for a quick shared thought, but breaks down with longer autonomous communicative messages
- Apraxia / Dyspraxia increase with any timing demand
- How long do you wait for "no response"?
- Great variability in time required to produce movement

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Problems with
"look at me for yes"

- Eye contact and smiles are social connection and may get misinterpreted as "yes" when used to engage
- Not responding takes effort and child must inhibit looking during a scan or list
- Some children begin to look more autistic, because they actively inhibit eye-contact to prevent accidentally saying "yes"

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Long term goal: to use a natural gesture that will be readable by many communication partners down the road

- Yes/no head movements
- Who will be able to read it without training?
- Doesn't require extra steps for the partner to hold up cards to look at for each scan
- Children are perceived as smarter if they use a more typical means of saying yes and no
- May be worth the cost of learning over time

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Motor Cognitive Learning for Access to Partner-Assisted Scanning

Learning to intend head movements in group with Rhythmical Intention

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Teach Yes/No Head Movements with a Target - If Child is not in a motor learning program such as CPEC

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Remember to Attend to Position and Teach Key Issues of Movement

- Stability
- Alignment
- Weight bearing
- Weight shift
- Disassociation
- Self-talk to intend movements
- Verbal reference after movement

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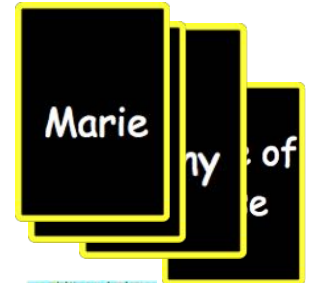
Hand Held - Talking yes/no switches used as a target and feedback for head movements (not mounted)

Fade the use of Switches Goal is to use head movements for Yes/No - without switches

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Practice Yes/No in Fun Ways

Objects, Books, Dry-Erase Boards

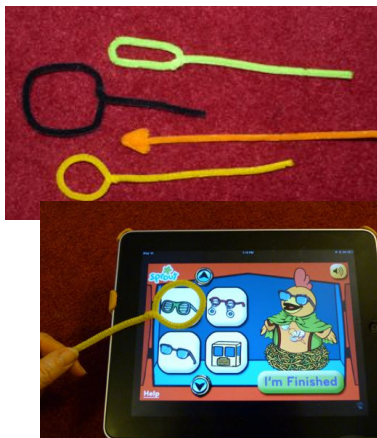


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Pipe Cleaner Pointers

- Won't activate touch screen
- Clarifies what is being scanned
- Helps focus visual attention



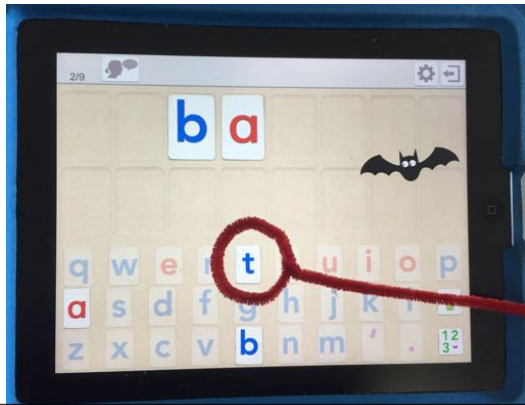
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Partner-Assisted Scanning with iPad Apps



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Partner Assisted Scanning on Apps - Word Wizard



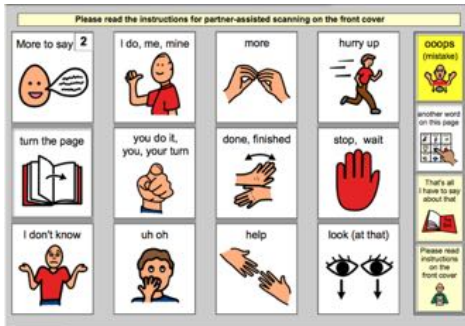
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Wikki Sticks to Make a Grid to Scan



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Partner-Assisted Scanning with Robust Language System



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Pragmatic Organization Dynamic Display

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Visual Scanning

- Best Option if child has good vision
- Consider specific customizations for the design of the robust communication system for use with scanning
- Visual scanning as first choice
- Visual plus auditory scanning slows down the process and adds verbal clutter to the working memory

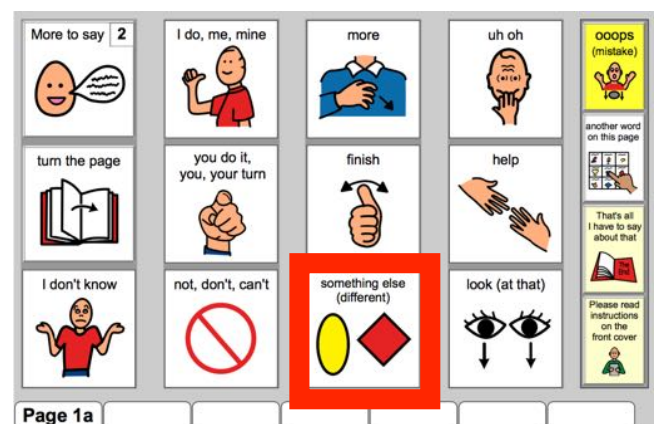
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Visual Scanning

- Visual scanning helps individual learn the symbols, which makes transitioning to more advanced levels of language easier
- Alternative to pointing
- Keep rhythm even and monotone: this column, this one, etc.

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Visual Scanning



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Auditory-Plus-Visual Partner Assisted Scanning used Rarely for individuals who have good vision

- Don't get in the habit of naming items as part of the scan
 - slows down the process
 - reduces chance of learning the symbols
 - adds verbal clutter that detracts from holding the message in mind
- Ok to use occasionally, when child is stuck and looking puzzled on a new or infrequently used page

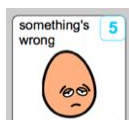
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Scanning is Not a Series of Questions

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Scan vs. Series of Questions

↓
something's wrong



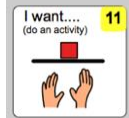
↓
"Is something wrong?"

Let's go



"Do you want to go somewhere?"

I want



"Do you want something?"

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Visual Partner-Assisted Scanning

Navigation for control of utterance length and more complete messages



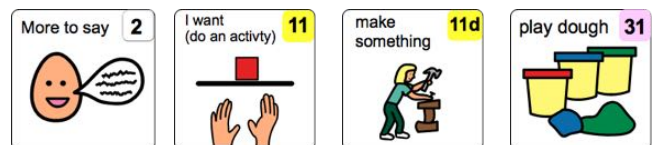
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Start with Direct Models

- Increase range of functions, messages modeled by communication partners
- Teach linguistic, social, strategic competencies
- Put emphasis on interaction and pragmatics
- Model full scan some of the time

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The pattern that you are modeling with a direct model is the key word on each page that the child will eventually select to communicate



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Non-Electronic and Electronic Not Either One or the Other

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Said with PODD Communication Book

- "I think it's, you, fun, not, school" (She is home schooled)
- "I want, want, hug, it's about now"
- "Let's go, in the car, you, me, can't, it's about now, I love you." She said this on a snowy day when we had been planning to go to the library, but it was too bad out!

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Said with PODD on Tobii: Eye-Gaze

- "Let's go, in the car, visit, pappy"
- "I don't want to do it, let's do something else"
- "I want, our, garden, yummy"
- "Have, pain, my, tummy, tired, I don't like it"
- "Lucy, yours, play, music, loud, yours, loud, song" (Her favorite song is "I'm Yours")

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"Non-Electronic" Systems Advantages

- Portability / Usability
- Multiple environments
- Multiple positions



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"Non-Electronic" Systems Advantages



- Reduced motor demands
- Face to face connection
- The use of a 'smart partner' operating system

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"Non-Electronic" Systems Disadvantages

- Size and weight of the system to provide a large vocabulary that is matched to the child's needs
- The need for partner-training for operating the system correctly

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"Electronic" Systems Advantages

- Speech: computer generated voice that can be spoken out loud
- Initiate and communicate independently (when set up for use)



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"Electronic" Systems Advantages



- Independence in message generation
- Access to extensive vocabulary without adding weight as with a paper system
- eye-gaze systems better at reading eye-gaze for communication than another person

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"Electronic" Systems Disadvantages

- need for more refined motor access skills
- limited environments (has to be set up to be used)
- dependence on battery power
- Some partners tend to take a more passive role



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"Electronic" Systems Disadvantages

- equipment failure
- Need for higher levels of language competencies - increased time needed to prepare messages which are morphologically correct
- May block visual fields and face to face communication

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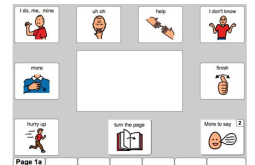
Needed features for both 'Non-Electronic' and 'Electronic' Tech AAC systems

- Robust language system (including core vocabulary, but not just core)
- Designed for efficient use of alternative access method such as partner-assisted scanning or Electronic eye-pointing
- Designed for conversation (both parts)
- Designed for pragmatic use at any time

131

Eye-Gaze - Non-Electronic

- Dyspraxia makes it difficult for partners to read more than a few points accurately (at least 9 on a page are needed for even a beginning robust system)
- More tendency for partner influence
- Difficulty with sequencing movement for clear signals
- Electronic displays don't have these issues



132

Eye-Gaze - Electronic

- Looking to locate and looking to select are different
- Need to develop motor skill for selecting with increasing accuracy
- May need to look away to reset vision when stuck



133

"Electronic" eye-pointing

- Start with play
- Build access skills
- Avoid high cognitive load when learning access
- Focus learning based on child's intent, not following directions
- Can not use for testing until access is automatic



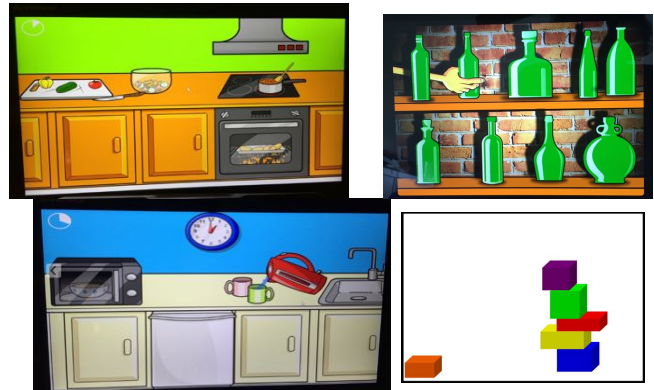
134

Eyegaze Exploring and Playing Look to Learn (Smartbox) (Inclusive Technology Ltd)



135

Manipulate the Environment Pretend Play



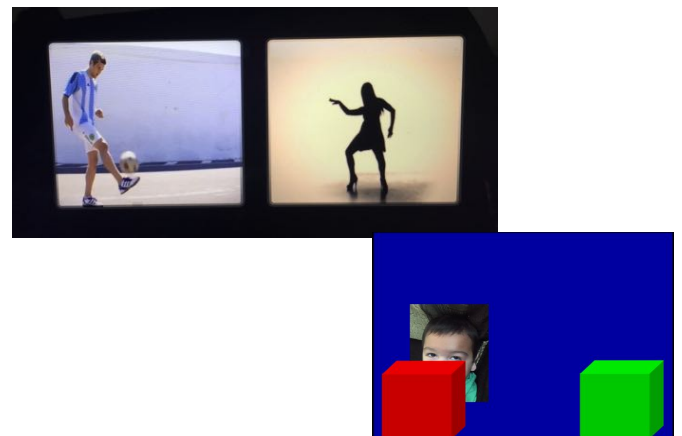
136

Personally Relevant (topics, photos, videos)



137

Large Targets



138

Limited Number of Targets

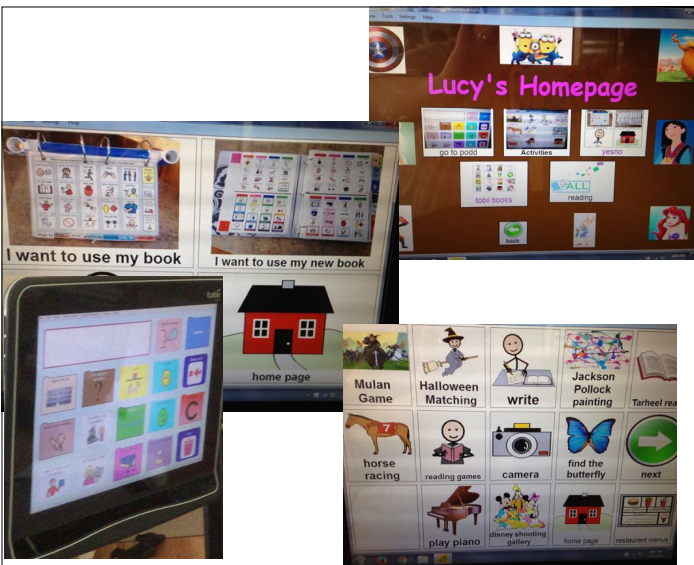


139

Control to Choose, Change and Stop

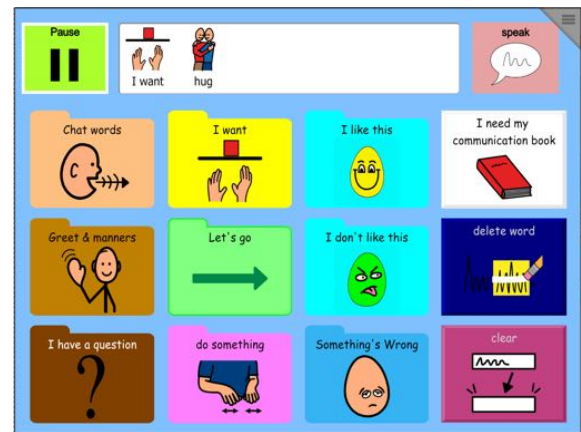


140



141

Simple Powerful Pageset



142

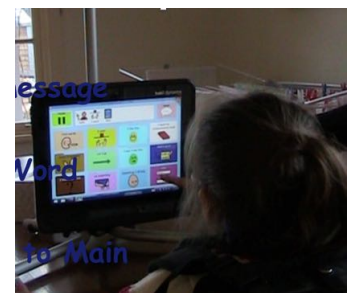
Pause Button to use during Modeling
 (should be on every screen if individual can not easily pause the camera in another manner)



143

Self-Talk Operational Commands as you model

- Speak message
- Pause
- Delete Word
- Clear
- Go back to Main



144

Need a way to ask for her "talker" in her book and a way to ask for book from her talker

Individual develops strategic competencies to choose the best modality for the situation

145

Problems with Testing and Assessment

146

Testing Provides None of the Needed Components that Facilitate Use of Automaticity

147

Testing Provides None of the Needed Components that Facilitate Use of Automaticity

- Intent
- Purpose
- Variation

148

Teaching vs. Testing

- Imagine driving someplace in another town where you have gone for years



149

Teaching vs. Testing

- Now imagine taking a test on the directions to get there:



- How many cross streets before your second left?
- Name of all the streets
- What is on all four corners of your 4th right hand turn

150

Teaching vs. Testing

- Being able to do something in context is different than taking a test about it



151

Teaching vs. Testing

- Children Learn by Doing
- Emphasize Experience - Not Drills



152

Focus on Instruction and Experience vs Testing

153

Dynamic Assessment

- Assess within natural contexts
- Integrated within the day
- Collect data over time, instead of sitting down in one session

154

Direct Questions Increase Difficulty of Moving with Intention

Make Statements Instead:
I wonder where the _____ is
I'm looking for _____

155

5 to 1 Rule of thumb in Natural Contexts:

- 5 inputs: teaching, commenting, explaining, demonstrating, modeling (may need to be 5 or 6 to 1 at first)
- 1 integrated test question related to that teaching (stated indirectly if possible)
- Repeat (data collected over time not in one sitting)

156

Plan and Look for Teachable Moments

- Follow the child's interests
 - Relate information to the child's life experiences
- Child needs to understand:
 - Why am I doing this?**

157

"Electronic" eye-pointing and switch access

- Remember: You can not use an access strategy to test a child, until that access strategy has become automatic

158

Language Samples

- Collect language samples in natural contexts
- Sample instead of writing down everything
- Note partners communication before and after
- Note cued, responded to a question or initiated
- Note communicative function

159

Language Sample

Language Sample Form

Student: _____ p. _____
 *For each series of communicative turns, start with writing **date, time and context** on one line and then start recording the conversation on the next line. Use one line for each new communicative turn

Who	Message		

160

Code: Plain text = Speech

Interpretations / gestures = Enclosed in parenthesis

Aided Language use (Light Tech, such as PODD) = underlined, *SGD (Speech Generating Device)

Capital letters = Sign Language

Italics or Cursive = list of choices and concrete items according to a context (used for children who scan)

// = phrase or word represented by one symbol or one activation in aided systems

" " = speech- word approximations from student

161

Language Sample Form - Partner Assisted Scanning

Student: Allie p. 1
 *For each series of communicative turns, start with writing **date, time and context** on one line and then recording the conversation on the next line. Use one line for each new communicative turn

Who	Message		
B / 23 /09	2:30 - Eating blueberries		
Allie	(reaches for PODD communication book)		
Linda	Do you have something to say?		
Allie	(Yes) / Quick Word / Uh oh		
Linda	Uh oh, you ate them all. Do you have more to say?		
Allie	(Yes) / more		
Linda	Oh, you want some more blueberries		
Linda	Back to start / I think is / great - Those blueberries are great		
Linda	More to say / Favorite - Those blueberries are your favorite		

162

Quick Language Sample

Student Name:

Date child initiated	To whom	How	Message that the child communicated	Context
6/7/11	Kate	Looked at book	Want / bathroom	Math - independent
6/7/11	Kate	vocalized	Think / silly	Group - children's funny sentences
6/7/11	Sue	Seemed upset	stop	Reading - worksheet
6/7/11	Kate	Touched book	Something's wrong / sick / tummy / go / home	lunch
6/7/11	Mary	Looked at book	goodbye	End of day

initiation and function only LS sample

163

The Juggling Act and Working Memory



164

Juggling Sensory, Motor, Language and Cognitive skills



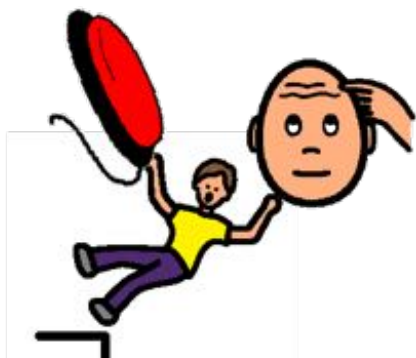
165

Girls with Rett Syndrome May Have Lost or Never Reached a Level of Automaticity with Motor Skills

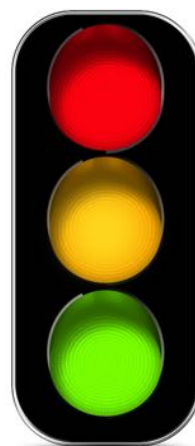
May Require a Great Deal of Cognitive Effort to Move

166

Balance Cognitive and Motor Difficulty



167



Hard

motor

Easy

language
cognitive

168

Eye-Gaze May be an Easier Motor Skill When Learning a New Cognitive or Language Skill

169

Juggling Explains Inconsistency of Performance



170

- Need to take successes and move on, as opposed to requiring repetition of the task over a given number of trials
- Provide opportunities for repetition/ practice within natural contexts with variation and natural motivation

171

Parallel Programming



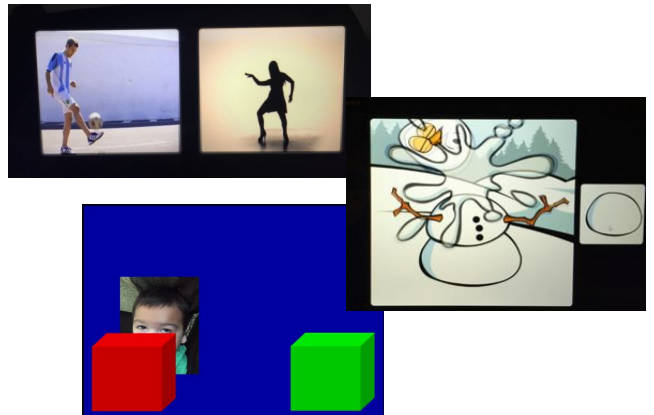
172

"Non-Electronic" Communication Book for Learning Language



173

Play to Develop Eye-Gaze Motor Skills

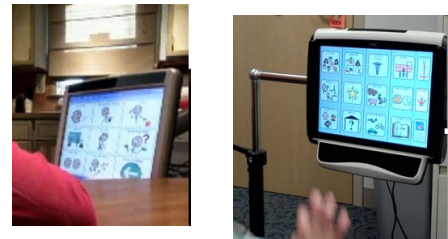


174

Switch Play to Develop Motor Skills

175

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



176

Tips for Literacy and Academic Learning

177

Separate Academics from Communication

AAC is how we talk about work - not the work



178

Produce a product as a result of the child's efforts

- We often we make the child work until they fatigue or the time runs out, instead of them feeling like they completed something
- When using manipulatives, also make sure there is a product (note, photo, etc.)

179

Modify the amount and specific components of work required

- Teacher determines what is most important for each activity
- Focus on quality learning instead of quantity

Name _____ Date _____

Subtraction

9	-	4	=	<input type="checkbox"/>
7	-	5	=	<input type="checkbox"/>
8	-	7	=	<input type="checkbox"/>
9	-	2	=	<input type="checkbox"/>
6	-	5	=	<input type="checkbox"/>
8	-	1	=	<input type="checkbox"/>

180

Modify the amount and specific components of work required

- Teacher determines what is most important for each activity
- Focus on quality learning instead of quantity

Name _____ Date _____

Subtraction

9 - 4 =

7 - 5 =

8 - 7 =

9 - 2 =

6 - 5 =

8 - 1 =

181

Immersion in Language and Literacy

- Best practices in teaching aided-language involves immersion in aided-language learning environment - based upon how typical kids learn to speak
- Best practices in teaching literacy involves immersion in a literacy rich environment, in conjunction with a robust literacy program - based upon how typical kids learn to read

182

Literacy Four Blocks

(Patricia Cunningham)

- Working with Words (phonics, letter names and sounds)
- Shared Reading or Guided Reading (comprehension)
- Self-Selected Reading
- Writing



Karen Erickson and David Koppenhaver

Center for Literacy and Disability Studies


https://www.med.unc.edu/ahs/clsds

Jane Farrall Consulting www.janefarrall.com
Sally Clendon

183

Changing the amount of time allowed to complete work

- May need to break up assignments into shorter time periods across multiple days
- Writing a simple story may take a week or two



Writing With Alternative Pencils
Center for Literacy and Disability Studies UNC

184

Writing: Write for a purpose and an audience

- Sample purposes: email, text, cards, invitations, shopping list, sign, letters, story, journal, Facebook post, etc.
- Remnant books for setting topics
- Robust AAC system to talk about writing
- Share writing with others

185

Forms of Writing (Always have a purpose)

- Scribbling / Writing with the Alphabet
- Co-planning Errorless Writing
- Predictable Charts and Sentence Starters for group writing
- Writing with AAC - Robust Language System
- Combination of AAC and alphabet at child's discretion

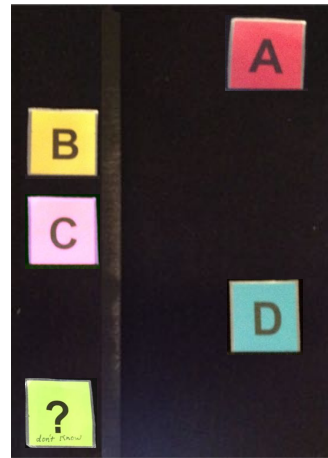
186

Modeling Writing

- Model writing for multiple purposes throughout the day
- Use child's alternative pencil
- Use child's AAC system
- Don't worry about using full sentences for a child who is at a younger expressive language. Model slightly above the level they produce
- Use Self-Talk and Verbal Referencing

187

When Testing Comprehension



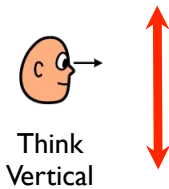
Only infrequently and integrated with teaching

A, B, C, D
Not Sure

go back and re-read, compare best options...

188

Position of child in relationship to position of materials



Think Vertical

May need to move materials into view as child sits and stands

189

Adapt on the fly Post-it Notes and Two White Boards



190

Dollar Store Picture Frames for quick eye-gaze

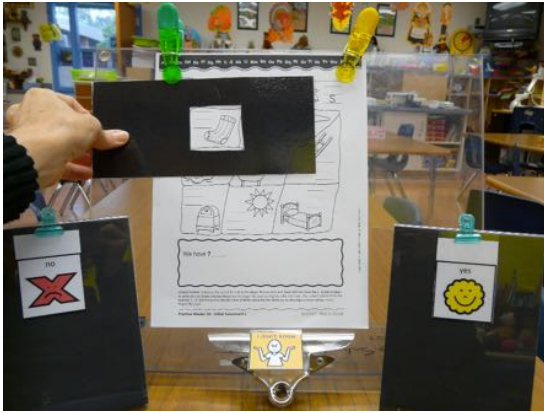


191

Help the child focus attention on the important relevant components of a task

192

Window to Direct Visual Focus



193

Window to Direct Visual Focus



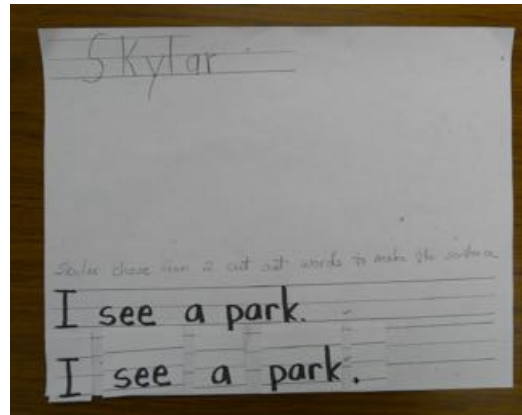
194

Window to Direct Visual Focus



195

Cut Words Apart to Build Sentence



196

Math: Working with manipulatives that the child may not be able to directly interact with

Counting Manipulatives



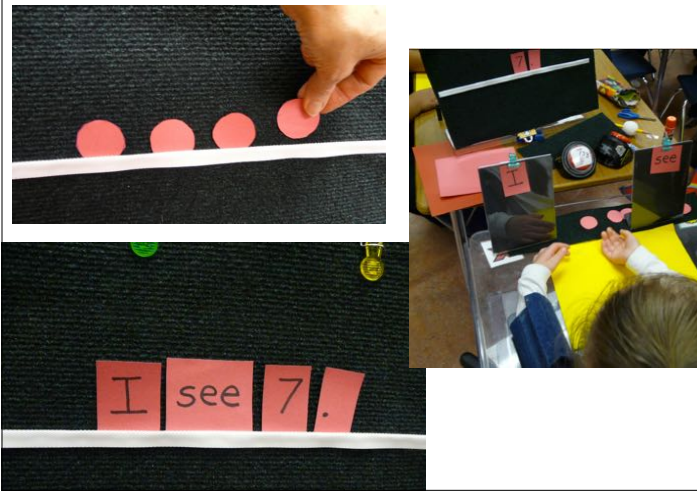
"That's it"

"1, 2, 3, etc., I don't know"

197

198

Carpet Square and Velcro



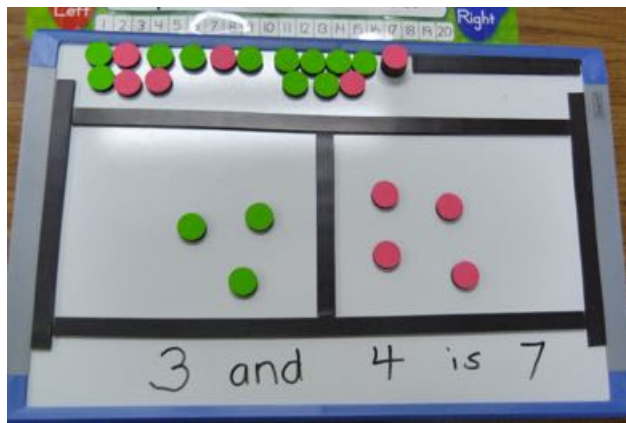
199

Counting Manipulatives



200

Number Sentence / Part Part Map



201

Adopt these Beliefs:

- Everyone Communicates
- Communication Begins with Intent
- Getting from Intent to Action is What is Difficult
- The Effort Must be Worth it!

202

Model Language with AAC Systems:

- Use AAC to talk about what matters to the child and what they might want to say
- Within a wide range of natural contexts
- For a full range of communicative purposes
- By a range of communication partners
 - Teachers, Therapists, Paraprofessionals,
 - Family members
 - Peers

203

Modeling AAC for Cognitive Motivation

- Keep implied pressure low
- Make an effort to get to know the individual and use AAC to talk about her interests
- Model things she might want to say



204

Modeling AAC for Cognitive Motivation

- Linguistically map your modeling based upon the child's behavior, state of regulation, interest and attention
- Describe, explain, and wonder with AAC

205

Modeling AAC for Autonomous Motivation

- Reduce or limit the use of questions
- Pause often
- Model ideas of what the user might want to say in a given situation, instead of modeling what they should say

206

Modeling AAC for Autonomous Motivation

- Model language without expecting a specific response back from the child at that time (no 'mand' modeling)
- Use patient encouraging wait time

207

Modeling AAC for Social Motivation

- Research shows that language is learned most effectively through interactive discourse (model conversation)
- Start a conversation using the individual's AAC systems
- Always say something with AAC in response when an individual uses AAC to say something - even when babbling

208

Modeling AAC for Social Motivation

- Use AAC to talk to others around the child
- Model with the intent to connect to the individual, not teach him something
- Respond to any communicative attempts from the child as intentional and interesting - respond to and expand upon what the individual might have meant

209

Modeling AAC for Social Motivation

- Use what you model to build a relationship and communicate your interest and enjoyment in interacting with the individual
- Use mutually appreciated humor and teasing

210

"It's such a beautiful gift to model AAC -- whatever system. It's so respectful. It's such a sign of love we can give to our children. When we keep this in mind -- the overwhelming task of trying to help a non verbal child find their voice slowly begins to feel less like a task and more like a gift."



**Karen Owens
WeSpeakPODD**

211

Assume Potential!

212

Allow way more time!

Pause, wait, pause some more

213

Keep Your Expectations OPEN!

214

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215