

Multi-Modal Communication Strategies for Children Who have Rett Syndrome

Linda J. Burkhart

Adopt these Beliefs:

- Everyone Communicates
- Communication Begins with Intent
- Getting from Intent to Action is What is Difficult for Girls with Rett Syndrome
- The result of the effort, must be worth the effort

Apraxia

- Girls with Rett Syndrome's most profound disability is Apraxia or Dyspraxia
- Apraxia is the inability to carry out a cognitive intent - The child intends to move a particular way, but the neurological signal doesn't reliably get to the right muscles to move them consistently
- Some motor skills remain intact - but only when triggered with an automatic event that doesn't require forethought or cortical intent. This can be confusing and may be interpreted by others as stubbornness, because it seems that the child can perform a task some of the time. However, the harder the child tries, the harder it is for her to perform it on demand.
- Sometimes the child seems to need to move away before moving toward what she intends. If you don't wait for the child to finish the intent, it may appear that she is rejecting or responding incorrectly, when in reality she hasn't finished her movement yet
- Delayed processing from intent to movement is typical for these girls
- Apraxia also affects muscles that control speech
- Apraxia affects other communication skills - including ability to use some non-verbal social signals and sustained eye contact
- May make it difficult to maintain eye gaze and move eyes between a desired object and a person who might be able to retrieve the object
- Waiting for a response with patient anticipation is critical to success. The child learns which people will likely take the time to wait for her, so she can decide if it is worth her effort
- Sometimes talking the girl through the motor movements and /or modeling them can be helpful.

Neurological Stereopathies

- Hand wringing
- Mouthing
- Neurologically caused - child does not intend to make these movements
- Child may have to "fight" these movements to move with intent
- Inconsistency is the norm
- Varies day to day
- Varies with stress, anxiety, pain, fatigue and many other unexplained reasons
- Masks intelligence
- May be interpreted by others as severe retardation
- Music may reduce stereopathies for some girls
- Splinting non-dominant elbow may lessen and improve function of other hand
- Splinting both arms may work better for some girls
- Even though using hands looks more "normal" and seems to work some of the time, the child may be able to move a different body part more reliably to indicate intent for communication purposes or switch activation
- On some days and at certain times, being able to break out of the stereopathy to use hands may be very difficult and may be frustrating for the child and other options should be provided
- Waiting for a response beyond the stereopathy with patient anticipation is critical to success. The child learns which people will likely take the time to wait for her, so she can decide if it is worth her effort to comply or initiate

The Juggling Act

- Working Memory can only deal with a limited amount of information at a time
- Cognitive attention is needed to focus on anything that is not automatic
- Girls with Rett Syndrome may not have reached, or may have lost, automaticity with many skills, especially those with a motor response, and thus need to focus attention on each component to be successful
- To be able to communicate effectively, many individual components must be coordinated. For example:
 - **Sensory-motor demands:** motivation, strength, motor planning, endurance, motor automaticity, auditory filtering, reaction time, visual discrimination, visual scanning/memory, visual tracking
 - **Cognitive demands:** motivation, cause/effect, initiating, discriminating purpose and function, developing cognitive schemas, making active choices, trial and error, problem solving, memory

- **Language components:** motivation, processing of language in activity, pragmatics, processing of questions, auditory filtering, processing of symbol set, syntax/grammar, attention to task, memory
- Juggling means that the child may only have some of the 'balls in the air' at any given time, and having all the 'balls in the air' will be rare. **This explains why performance is so inconsistent and can not always be predictably repeated**
- 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 without pressure. Use variation and natural motivation
- Recognize the difference between Testing and Teaching
 - Children learn by doing
 - Emphasize Experience - not drills

Parallel Programming:

- Coordinating all components of a task on an automatic level is extremely challenging for children with Rett Syndrome
- Child can become easily frustrated
- If we wait for everything to develop in a coordinated fashion, we will be waiting forever
- We don't want to hold the child back in one area because of deficits or difficulties in other areas
- We need to be careful not to get stuck trying to 'prove' mastery
- The answer to this problem is to work on individual components in parallel.
- Use functional and natural contexts to give the child opportunities to develop skills, where only one component is cognitively challenging her at a time. For ex: motor, cognitive, language, etc.
- Child needs to experience success with at least one component at a time - engineer activities so this is possible
- The task should not be so difficult that the child doesn't experience some sense of success, nor too boring as to not be worth the effort
- Provide a variety of these types of activities throughout the day - to challenge the child in all areas of development, but mainly just one at a time.
- Plan as a team to make sure individual skills are moving in a coordinated direction and will eventually be able to be integrated into meaningful tasks
- Help the child make associations see the relationships between skills that she is developing
- Model component skills as well as integrated skills, so the child can see how things will eventually work together

Parallel Components for Communication: Language Skills and Motor Access

Strategies for Developing Motor Access skills:

Reduce Motor Demands

- Utilize multiple modalities
 - Eye-gaze, reaching, direct switch access, step scanning, touch points, subtle non-verbal communication, head stick/pointer, voice and intonation
 - Be flexible to use whatever system seems to work best in that situation at that time
 - Model use of all the systems throughout the day
- Revisit strategies, such as eye-gaze periodically, even if it wasn't effective in the past. Girls abilities can grow and change throughout life
 - PVC pipe eye-gaze stand
 - baseball card album page with center cut out
 - flashlight cueing
 - talking picture frames for auditory feedback on eye-gaze frame
 - model eye-gaze as you communicate to the child - looking at child, then item, then back to child
- Try a light pointer (laser pointers are not safe for other children in the room, as they are dangerous if accidentally pointed into their eyes. A focusing flashlight may be all that is available, until some vendor decides to produce a safe laser that will work on any surface. Vendors in the past, have produced safe light pointers, so second-hand ones may be available.)

Minimize Random Activations

- Increase distance between selections so it becomes difficult to accidentally activate both switches with one movement or reach
- Use different movements / body parts for different responses or for different switches
- Have child move to selection in his environment, if they are mobile
- Wait for child to focus on selection before moving it within reach

- Ask for confirmation (ie a smile) when using eye point strategies if you are not sure what the child looked at, but always accept child's subtle attempts if you understand them
- Successively eliminate choices. (verses in a song, building parts)

Allow the child to withdraw and center and then continue at her own pace.

- Kids learn in short spurts and then need time to process information
- Children sometimes need to re-center themselves neurologically by taking a break, staring, rocking, etc. They usually know what works best for them
- Allow the child to take these breaks and then entice them back
- Go with distractions, identify them, and then entice the child back
- Provide the child with a means to communicate about sensory needs, fears, and distractions

Provide Low Stress Play Activities with Motor Access Strategies (based on Stepping Stones to Switch Access - Burkhart 2004)

- Begin with cause and effect but quickly move on to **cause and effect in multiple locations for multiple purposes**
 - Adapted battery toys with a purpose
 - Environmental control with purpose and context (blender, fan, music)
 - Co-Planned Sequenced Social Scripts - Step type devices to record a series of messages or parts of a song
 - Switch activated music and computer songs and stories
- Move to **two switches two functions** as quickly as possible
 - Increase motivation by increasing cognitive engagement and control
 - Two switches trial and error
 - Two switches positionally related to function (Left Right Switch Activities)
 - Two switches social turn talking
 - Two switches / two functions
 - Appropriate pragmatic use of function for each switch
 - Examples: Light Tech:
 - One adapted battery toy and one voice-output device (single message or step by step) For example: One switch moving pig toward blocks. One switch to ask "build up more blocks".
 - Rotating sectioned plate activities and voice-output device (single message or step by step) Items are placed in a section of the plate and the rotation is controlled with a short delay timer that rotates the plate part way around. An pointer or arrow is suspended above the plate and points to the section directly

beneath it. The item is selected by the voice-output put switch
"That's the one I want"

- Adapted game spinner switch and voice output
- One Step by Step to list choices, one to say "That's it"
- Two voice-output devices with different functions
- Examples: High Tech
 - One switch computer activity, one switch related toy or voice-output device
 - IntelliPics Studio - two switches two functions from overlay
 - PowerPoint, IntelliPics Studio, HyperStudio, BuildAbility or other computer story with one switch, and the other switch can be a voice-output device for repeated line, sound effect, or to comment about the story.
- Model access by taking turns with the child, using switches yourself in the same way the child would use them
- Move to **Errorless Two Switch Step Scanning** - access where there is no timing of motor movements involved, and where any answer is correct
- Provide concrete activities to **Teach Two Switch Step Scanning**, if the child doesn't cognitively understand the process (One switch moves something repeatedly and the second switch does something only when item has moved to destination)
- Utilize and model partner-assisted listing/scanning strategies for communication in parallel, to help establish the cognitive pattern of 'no, no, no, yes' or 'move, move, move, get'
- Provide play activities to reach a **Target item with Two Switch Step Scanning**, by leaving only one item to target in an array of blanks. (Do this while still providing play errorless activities as well)
- Provide fun choice making activities with step scanning that have correct or more correct answers to **increase accuracy of selection**

Strategies for Developing Language skills:

Input Before Output

- Children most effectively learn to use augmentative communication through the same methods that they learn to use verbal communication - through immersion in natural and functional contexts.
 - Drill and practice, rote learning is not very effective
 - Learning in functional situations facilitates generalization

- Anything that has some intrinsic motivation for the child is more likely to be practiced in different settings and used by the child.
- Aided Language Stimulation (goossens', Crain, and Elder)
 - Use multi-modality aided language stimulation to model appropriate use of language
 - Utilize same access strategy as the child will use (switches, eye gaze, etc.)
 - Modeling and a simulated immersion environment are powerful
 - Compare to a foreign language immersion environment
 - Theme based learning provides multiple experiences with a concentrated set of vocabulary and concepts without being monotonous.
 - Talk to the child using the communication system, all day long in all types of activities and situations

The Use of Active Learning is much more effective than Passive Learning

- Problem of learned helplessness
- Student's interest and ability to learn will be increased with active participation
- Everyone has a basic need for control in their lives within the context of general societal controls
- Children need a balance of familiar repeated information and new or different interesting information.
- A feeling of "I can do this," "I want to try it myself," or "I know how to do it!" goes a lot farther than hand over hand participation or passive compliance
- Use a prompt hierarchy of least to most - start with waiting with anticipation and move to indirect prompts and modeling by taking a turn if the child does not initiate
- If the child sees a reason or purpose to participate, he/she will be much more likely to be actively involved. Provide a purpose in a manner that makes sense to the child.
- The challenge is to find some method or adaptation for the student to have active participation and a feeling of control and choice in every activity.
- The child develops a sense of self by initiating, making decisions and directing action

Follow the child's direction or lead: empowering the child and giving her the control

- Child directed activities keep the child's interest and receptivity high

- Don't get into a battle of wills (example of snack - teacher directed: show me cookie vs. what do you want? or just providing the opportunity to request and comment)
- Set up scenarios that encourage initiation. (phone play, bubbles, balloons, interactive songs)

Provide Simple Choices

- Create and provide multiple opportunities for choices throughout the day and represent these choices visually
- Provide choices that matter to the child and are easy to discriminate
- Provide choices with multiple modes: two hands, objects, pictures, eye gaze, light pointer, talking switches, environmentally placed talking switches, head activated talking switches, touch points, etc.
- Try requesting actions on objects instead of just requesting the object - actions are more fun and many of the girls are not able to do much with a static object

Provide child with natural multiple opportunities by responding with small amounts of what was requested or actions of short duration.

- Offer small bites at snack
- Try actions on toys. ("make it go some more")
- Communicate multiple times within the activity instead of just choosing the activity

Keep questions and extraneous language to a minimum

- This may feel unnatural.
- Put verbal patter in your head and a look of expectation and interest on your face - wait for a response.
- Avoid using What is this? and random yes/no questions
- Use natural prompts, facial expressions, look of interest, attend to another child (doll or puppet), feigned disinterest, or pauses to encourage initiation

Respond with Natural Consequences:

- Respond to all attempts to communicate regardless of form (voice, gesture, picture symbol, eye gaze, etc.)
- Respond with natural communicative response (provide item requested, "oh you want some popcorn - here you go")
- Avoid artificial rewards for talking such as unrelated treats or "good talking"

Partner-Assisted Listing (Scanning)

- **Vocabulary is presented in an organized format / multipage communication book**
 - Items are listed and/or shown one at a time in a predictable sequence
 - Child indicates 'yes' or 'no' for each choice
 - Always start on the first page and follow the logical marked branches (for example: "I'll tell you what I think" - go to page 4: opinions or "Something's wrong" - go to page 3: things that might be wrong)
- **"Smart Partner" vs. Technology:**
 - Read subtle nonverbal cues and adjust the interaction as needed
 - Interpret movement - recognize intent and ignore associated reactions
 - Alter timing according to the child's reaction
 - Accuracy of motor skills is not as crucial for success
 - Focus on developing language and communication skills separately from motor skills
- **Pragmatic Organization of Vocabulary (Gayle Porter):**
 - Begin with communicative intents and quick words on page 1
 - Examples of Communicative Intents: I want, Something's wrong, I'll tell you what I think, It's time for, I have a question, etc.
- **Strategies for Teaching Partner Assisted Communication:**
 - Input comes before output - Receptive Language first
 - Input should be the same form as the child will later use for output
 - Aided Language Stimulation
 - Ask Questions - using the system
 - Symbolize communicative intent
 - Model communicative intent in context
 - Encourage others to model
 - Look for subtle, nonverbal communicative intents and negations
 - Start with the child's way to confirm - for example a smile
 - Use of both a confirmation and negation can make the communication more clear
 - Model a form of "Yes" / "No" as you go
 - Try 2 voice-output switches for "Yes" / "No" (always keep 'yes' on the same side or at the same location opposite from 'no'. For example: either side of child's cheeks)
 - Move toward adding technology when possible, increase independence
 - May need to reduce cognitive task when adding technology
 - Balance cognitive and motor task
 - Model initiation

- Assume the child has something to say
- Respond to all communication as intent - build a sense of competence
- Engineer opportunities for Expression according to communicative intent

Co-Planned Sequenced Social Scripts (Caroline Musselwhite and Linda Burkhart)

- Reduce the motor requirement for accessing a device - while providing opportunities to practice using a single switch within the context of social interaction
- Sequential message device for a series of communicative turns
- Great way to develop pragmatic skills of turn taking and conversational flow
- Create and co-plan the script with the child - giving her choices of what to record throughout the script (Its helpful to write the script with the child first and then record it on the device with the child watching.)
- Begin with attention getters
- Use a variety of communicative functions: humor, teasing, transfer of information, asking questions, commenting, turn transfer (Guess what?, Do you want to know where I went?, I'll give you a hint..., what do you think?)
- Allow the child to initiate, don't say "press your switch" Approach the child with a look of interest on your face and wait. You can try a natural verbal prompt if necessary such as "So, what's up?" or "How's it going?"