Communication Strategies for Children who have Rett Syndrome: Partner-Assisted Communication with PODD

Adopt these Beliefs:

- Not having speech is not the same as not understanding
- Everyone Communicates
- Communication happens all the time
- Communication is NOT just an activity
- Communication Begins with Intent
- Getting from Intent to Action is What is Difficult for many children with physical disabilities
- The result of the effort, must be worth the effort
- Communication is about something we don't already know
- We can not know what another person is thinking
- Keep your expectations **open**

Current Communication Strategies and Challenges

- Children who are non-verbal are often asked direct questions with a right or wrong answer or given limited choices that don't go anywhere
- There is a need for children to initiate and carry-on a conversation - not just respond
- Currently, vocabulary flies in out of thin air and then poofs back into oblivion at the end of the activity. Activity specific vocabulary is great, but it needs to become a part of the child's larger system
- We need to be presenting vocabulary that doesn't disappear and can be built upon, instead of replaced.
- The brain builds understanding based upon patterns
- Current strategy: "20 Questions"
- Need a way to systematize "20 Questions" so the child can begin to recognize a pattern in how vocabulary is presented
- Working memory can only deal with a limited amount of information at a time - especially auditory memory
- Need to develop automaticity of operational skills, so attention can be focused on interaction and communication
- PODD Communication Books are one way to answer some of these problems

Creating a Multi-Modal Language Learning Environment

- 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
- Language is not learned by straight imitation, it is learned through broad experiences that provide multiple repetitions of concepts, vocabulary and conventions. This provides a scaffold from which children can construct language
- Input before Output - Receptive language input is necessary for developing language expression
- Analogy to Foreign Language Immersion vs drill and practice
- Children who will need to use scanning systems have very limited opportunities to observe others using similar systems to communicate
- Aided Language Stimulation (Goosens', Crain and Elder) - Multi-Modal Language Stimulation - information needs to go in before it comes back out
- Children can not be expected to know how to use something until they are given an opportunity to learn how to use it in natural contexts
- Children most effectively learn to use augmentative communication through the same methods that they learn to use verbal communication - through modeling in natural and functional contexts
- Talking to the Child with his system:
    - Validates the child's means of communication
    - Acknowledges that children learn to communicate in the way they have experienced communication
    - Gives the partner a good perspective on what the child is facing
- Modeling and a simulated immersion environment are powerful teaching tools
- Utilize communication books/boards/devices to point to or indicate communication symbols receptively throughout the day. This is important even when child may need to use a different access strategy - such as scanning or eye-gaze. *Model the child's access strategy at least some of the time.
- Drill and practice, rote learning and artificial rewards are not very effective for learning language
- Language learning requires active social and emotional engagement
- Learning in functional situations and natural contexts 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.
- Early vocabulary is first introduced receptively
- Try Song books and Song Boards to illustrate the patterns of language
- Avoid asking too many questions, use more comments and social expressions ("that's silly", "uh oh!". "we need to clean it up.")
- When asking a question, provide a concrete or multi-modal means for student to respond ("Do you want chocolate or regular milk" - showing both containers or pictures for child to select from)
- A wide variety of communicative functions need to be represented. For example:

- initiate or call attention
- greet
- accept
- reject
- protest
- request objects
- share and show objects
- request information
- name
- acknowledge
- answer
- comment on action/object
- express feelings
- assert independence
- ask questions
- share information
- relate events
- call attention to how things are related - similar and different
- talk about past and future
- negotiate and bargain
- state opinions
- tease
- threaten
- make up stories
- express manners and consideration for others

Partner-Assisted Communication

- Not a new strategy - people have been using a form of asking yes/no questions to communicate for years - This is just a new way to look at the organization of vocabulary and systematize how the '20 questions' are asked.
- A communication partner presents vocabulary items to the child in a list - either visually, auditorally, or both
- The child indicates "no" to each item until the item she wants to "say" is listed. Then, she indicates "yes". The partner then responds to the child's message. She treats this response the same as if the child spoke that message

Partner-Assisted: Which Children and Why:

- Children who face significant motor and communication challenges and can not directly access a communication display by pointing with their hand, eyes, or some type of tool
- Girls with Rett Syndrome, who's hand use can be unreliable at times (Some girls may use a direct selection some days, and partner-assisted communication other days)

- Children who have additional multiple challenges including visual and/or auditory processing challenges
- Beginning Communicators or children who don't have any effective forms of communication yet
- Struggling Device Users - still working on access, even if they have a device
- When other communication strategies are not available at the moment

"Smart Partner" vs. Technology:

- Because the partner is human as opposed to a computer, she can be "smarter" than the computer
- Communication Partners can:
    - 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
    - Focus on developing language and communication skills separately from motor skills
- Accuracy of motor skills is not as crucial for success

Strategies for Learning to Model Partner Assisted Communication - with PODD:

- The partner needs to become fluent in communicating with this system in order to be able to immerse the child in the learning of the system
- The child needs to experience an environment where their PODD system is one of the ways people communicate. People around the child will need to learn how to communicate with this system to provide these models - Create a multi-modal language learning environment
- Symbolize communicative intent
- Model communicative intent in context
- Use conversational language ("That looks like fun," "Your car is crashing", "That's big", "I'm going to throw the ball", etc.)
- Encourage others to model
- Ask the child questions - using the system
- Model a form of "Yes" / "No" as you go (Use what will be most likely to be learned by the child, and also most clearly interpreted by others)
- Model initiation
- Avoid asking too many questions, use more comments and social expressions ("that's silly", "uh oh!",, "that looks yummy.")
- When asking a question, provide a concrete or multi-modal means for student to respond ("Do you want chocolate or regular milk" - showing both containers or pictures for child to select from)
- Ask open ended questions with no right or wrong answer
- Model operational speech as well as social speech

    - Use different tone, voice and expression for self-talk and operational speech than you do for the actual social communication.
- Position yourself for best observation by the child visually and auditorally
- Model and encourage self-talk using multi-modality supports ("Hmmm…. I'm looking or what I want to say… I don't see it, I'm pointing to 'turn the page'… I'm turning the page… there it is!… I wanted to say I'm surprised!)
- State why you are turning to a particular page: "I'll tell you who" …"go to 14"… so I'll turn to page 14 which is the people page
- Watch the child for clues of active listening and self-talking along with you to guide your pace and acknowledge his/her efforts
- Model How the Child Will Need to Use the system as Often as Possible

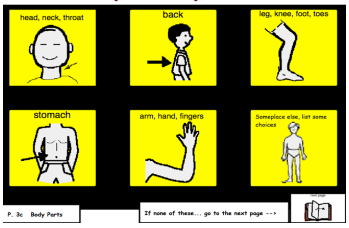
Pragmatic Organization of Vocabulary (Gayle Porter):

- One word messages can be easily misinterpreted when children are not able to add the context with gestures and intonations. Pragmatic organization establishes the pragmatic intent of the message first
- PODD books usually begin with quick words on page 1, with pragmatic intents on p. 2 - That works well for children who direct select (point to symbols on a page)
- PODD books that are used with partner-assisted scanning begin with communicative intents and a quick words link on page 1 - then quick words are on page 2 (Note: since the current version that is available commercially is for direct selectors, these pages can be swapped for the auditory/visual scanner using Boardmaker)
- Examples of Communicative Intents:
    - I want something
    - Something's wrong
    - I'll tell you what I think (or I like and I don't like)
    - It's time for something
    - Let's chat
    - I'm asking a question
    - Let's pretend
    - I have an idea
    - I'm telling you a story
- Examples of Quick Words:
    - more
    - different
    - done
    - me, mine, my turn
    - you, yours, your turn
    - someone else
    - hurry
    - uh oh!
    - help

"Something's wrong"
go to page 3

"Something Hurts"

"head, neck, throat"



- Pages are numbered for easy organization
    - Page one - intent: I'll tell you what I think - go to page 4
    - page 4 - choose item - that makes me mad!
    - Page one - intent: Something's Wrong - go to page 5
    - page 5 - choose item - I'm tired!
    - Page one - intent: Something's Wrong - go to page 5
    - page 5 - choose item - something hurts - go to page 6 (body parts)
    - page 6 - choose item - tummy
    - Note: body parts could also be reached via "what itches" or a tickle game.
- Activity specific pages are included in the PODD and may be in the main book if used frequently, or located around the environment with the activity, for less frequent activities, or when the PODD book gets too large
    - variety of vocabulary related to one activity
    - Linked from I want or It's time for / activity page. For example: read a book, would branch to an activity specific page of vocabulary frequently used when reading a book
    - Stay on this page during activity, unless child indicates something else to say
- Categories: These pages are used like a dictionary, when needed for expansion and generating novel ideas not found on other pages. Branches to categories are found throughout the PODD and are most often used once the main intent of the message has been established
- Chat, news and Story pages - personally relevant messages that can change over time
- Predictably associated vocabulary reduces the number of page turns to communicate a message in sentence format for the direct selector. For the scanner, this is abbreviated to less items and/or used as a list of "little words"
- Customize language in the system - according the the needs, environments and desires of the child - but leave the general structure or "road map" as designed
- Make use of lists to add vocabulary at any time

PODD (Pragmatic Organization Dynamic Display) Communication Books

- Created by Gayle Porter, Melbourne Australia
    - More than 15 years of development with a wide variety of access technologies, formats, and language levels
    - Comprehensive, multi-page communication books for communication "all the time"
    - Designed to be used receptively and expressively in natural daily contexts
- Commercial Product (CD set of Boardmaker templates, information files describing language level and organization for each template set, step by step directions, and an extensive application manual)
    - Direct access templates (currently available in 2 formats)
        - Australian version - A4 size paper and 'Aussie' vocabulary

        - North American version - Letter size paper and North American vocabulary
        - Order from:
            - Mayer-Johnson www.mayer-johnson.com
            - CPEC: podd@cpec.com.au
            - Spectronics: www.spectronicsinoz.com
    - Alternative access templates (not yet available)
        - eye-gaze
        - partner-assisted scanning
        - coded access
        - combination access methodologies
    - Alternative visual / auditory presentation templates (not yet available)
        - High contrast reduced visual complexity symbols
        - partner-assisted auditory scanning
        - partner-assisted auditory plus visual scanning
        - direct access to high contrast symbols.
    - Templates for Speech Generating Devices - (Future Development)

How do you model a partner-asssisted scanning PODD?

- Sometimes in the reality of the day doing the full listing model all the time will mean that the child won't get as many models of the language, so sometimes for efficiency, partial models or quick models are used. In addition, the full model can be very wordy, so some experience with the partial or quick model helps to focus the child on the targeted vocabulary on each page.
- **Full model** – This is the most clear way for the child to learn the system. And should be used as much as practical. The partner goes through every item, one by one (or group/item) beginning on page 1 and following the links until the whole message is completed.
- **Partial or direct model** – Starting on page 1, directly indicate (point, name, show) the item that you want to say. Follow that link to the the indicated page and then once again directly indicate the desired item. Continue this method until you finish communicating your message. (Note: sometimes a full model is used, once the last page of a message is reached.) ex: say/point to SOMETHING'S WRONG, turn to the something's wrong page and scan SICK (shaking my head no), TIRED (shaking my head no), SOMETHING HURTS (nodding my head YES).
- **Quick model** - say/point to the items the child would need to say YES to construct their message, e.g. SOMETHING'S WRONG, SOMETHING HURTS, TUMMY, etc.
- **No book talk** –include the branch pathway words in general conversation without actually using the book, e.g. "I'm telling you something, It's going to happen, Oh, I need a People word, the whole family, go back to categories, Places, are going to the movies, go back to categories, Days and times, tonight. Parents often memorize sections of the book after using them frequently, and then can talk to the child while cooking, driving or other activity that makes it difficult to use the book

Strategies for Learning Partner Assisted Communication - Expressive Language:

How do we know when the child is ready to use the PODD expressively?

- There are no pre-requisites for using a PODD receptively to model how this system of communication is used.
    - An initial focus on receptive input not only provides the child with essential opportunities to learn, over time, how aided symbols are used to communicate, it also provides parents and professionals with opportunities to observe the child's response to this mode of communication and discover, over time, the strategies which will enable the child to communicate more effectively
    - Experiment from time to time when using receptive language input to see if the child has something to say by giving her opportunities
- For some children receptive input and general opportunities are all that's required to stimulate spontaneous expressive communication. Some children will begin expressively using the PODD after only a few models, other children will require many months (years) of receptive input.

Partner's perspective:

- Respond to all communication as intent - build a sense of competence
- Look for subtle, nonverbal communicative intents and negations
- Assume the child has something to say
- Assume that you don't know what the child wants to say - Communication is new information, not something already known by the partner
- Communication Autonomy: Child's Message - Even if he needs help to communicate it
    - Communication of genuine messages - child's agenda - not partner's agenda
    - Need to be able to initiate message to express what is in your head
    - Not just responsive to the options provided by others

Encouraging Expression;

- Recognize when the child may have something to say. They may start to fuss, make a sound, look at you, look at their book, etc. Ask them if they have something to say and if you get some type of positive look or confirmation, begin using the book to give them an opportunity to tell you something. At this stage the child may not have a clear yes and no, but do your best to read the child's body language and assume that he is being intentional. Don't worry if the child doesn't say anything profound. Any experience using the system will be helpful. Think of babies and toddlers learning to speak for the first time. They may only use a word approximation, gesture or intonation, and we don't always know what they are trying to tell us, but we attribute meaning to their attempts and over time they get better at letting us

know what is on their minds. Remember that at this stage whatever the child says IS CORRECT and should be responded to as an interesting comment.

- While working with the child, pause periodically and provide an opportunity for the child to communicate, without requiring them to do so.
- Offer the child: "Do you have something to say", when you see a change in the child's: affect, attention, body movements, vocalizations, raising/waving arm, or looking toward communication book
- Engineer opportunities for Expression according to communicative intent
- Provide opportunities for expression after modeling. Children may be more able to use the system to say something immediately after it has been modeled.

How do I respond to the child's communication?

- After the child indicates "yes" to an item, you say that word or phrase out loud and respond to the child's message as if she had just spoken it
- Do not ask the child to re-confirm each word – but do respond appropriately to any looks/behaviors that indicate you have gotten the message wrong and give her a chance to correct herself.
- Regularly recap the message to assist everyone to remember what has been said so far. For example: Something's wrong, something hurts, etc. A good time to do this is as you are turning pages to continue the message. This is especially important when there has been a distraction or interruption during the construction of the message.
- Always ensure that you provide the opportunity for the child to add more information to their message. Ask the child if she has more to say about that, if yes, ask her if it is on this page or section, does she want to go to categories, or does she want to go back to start.
- The child will communicate ideas in key words and phrases – not typical complete English sentences. Once the child has finished his message, rephrase the meaning in a complete sentence and check for confirmation with the child. If the child says yes, respond to the message as if it was spoken by the child. If the child says, no, you can refine your guess to see if meant something close to that. Once you figure it out, you can then model how the child might use the book to tell you more about that. If you can't figure it out, ask the child if he can tell you more about it.
- Expand upon what the child says, using the system when possible. Once the child has completed their message, use the system to expand your understanding of the message. Continue your conversation using the child's system. THINK "If the child spoke that message, what would I typically say next?"
- Expand upon any efforts by the child to communicate, using vocabulary, communicative functions, and longer utterances just above what the child is able to express. This helps guide the child and provide a model for higher levels of language usage
- Have a conversation!
- Communicate respect for all her attempts to communicate

But the child doesn't have a clear YES / NO – do I need to teach one first? How will I know what they are trying to say?

- You can begin using the PODD prior to the development of a clear yes/no response.
- Discovering and/or teaching movements for expressive communication may take some time.
- Start with a smile or a look toward you for "yes" and then slowly move to a more clear form of confirmation
- There is frequently a period of exploration, where a range of different, less intelligible movements are interpreted within the context of communication, to discover possible ways for the child to indicate Yes/No and initiate communication. Do your best to read the child's body language and interpret all possibly communicative movements. Think of babies and toddlers learning to speak for the first time. They may only use a word approximation, gesture or intonation, and we don't always know what they are trying to tell us, but we attribute meaning to their attempts, provide them with feedback and suggestions and over time they learn to communicate more clearly.
- After a period of exploration it is then necessary to agree on a particular manner for the child to communicate YES and NO that is known and used by all communication partners. Initially accept less intelligible movements, gradually requiring more intelligible movements over time (shaping). Just as typically developing children learning to speak take many years to develop mature, intelligible articulation, children with complex sensory-motor challenges will need to learn, over many years, the sensory-motor control required to produce intelligible movements for communication.
    - Experiment with two voice-output devices such as Personal Talkers from Attainment Company. Hold "no" to one side of the child's head and "yes" to the other side or under her chin. Model the use on yourself, before asking the child. **NOTE**: If both sides of her head are equal in the ease of turning - place the "NO" switch on the child's left side. NEVER switch the yes and no sides, once you have established this plan
    - Gently brushing each switch against her cheek as you ask "yes" and "no" can give her a cue where the switches are. If she turns toward a switch, activate the switch, even if she doesn't push hard enough to activate it herself. This will give her the feedback that she said "yes" or "no". Later this strategy can be faded to use just your hands where the switches would be placed, and later she may just turn or nod her head herself. **NOTE:** Mounting the switches, instead of holding them, may be too difficult at first. The act of holding the switches and socially connecting to the child with your touch and facial expression helps her respond
    - Alternatively, place the "no" switch next to the child's cheek to encourage a head turn to the side and the "Yes" switch under her chin to encourage a nod for yes.

    - Some girls will do better with "no" switch by her cheek and "yes" switch out front to reach with her hand
    - Some girls may be able to reach to both switches with her hands, if held far enough apart in front of her. NOTE: if she is just using one hand, center both switches around that hand so each is easy to access.
    - Some girls may eye-gaze to yes/no pictures or talking switches
- Use of both a confirmation (yes and no) and negation can make the communication more clear. This gives the child more control and is easier for the communication partner. Confirmation alone (yes) requires the partner to be very "tuned in" to timing of items presented and subtle responses from the child, adding a "no" puts the child back in control of the pace.
- Yes and No should not be used for random questions - because the answer is hardly ever just yes or no - Always use the yes/no within the context of partner-assisted scanning of the PODD
- Some children will also benefit from sensory motor programs to develop motor control and learn specific movements for communication. (PT, OT)
- Verbally reference (say out loud) the movement you observed and the meaning you assigned to this movement. This provides the child with feedback to understand your response and may stimulate attempts to produce clearer movements. A more experienced partner stating their observations and interpretations also assists new partners to observe and appropriately interpret the child's movements.

Additional Strategies:

- Use clear language that implies it is the child who is speaking now: Did you want to say a quick word, like more, done, different?, Are you saying that you want something?, Did you want to tell me what you think?, Are you saying that something's wrong?, etc.
- At first, give All the Choices First. Then, List them Simply and Slowly. Once she is familiar with the lists in her PODD, you can just start indicating them one at a time
- Once a child is familiar with the pattern of choices, you can list groups of items to increase speed and efficiency - for example name items in each column and ask, is it in this column?
- When the child is communicating to you, you can also use speech to let them know what operational cue, you are responding to.
- Be careful not to give too many verbal prompts - give conversational feedback instead
- Use Both "High Tech" and "Light Tech" - both are important - don't choose just one or the other
- Move toward adding technology when possible to increase independence
    - May need to reduce cognitive task when adding technology
    - Balance cognitive and motor task
    - Provide fun, easy, play opportunities to practice access
    - Continue "light tech" as well as introducing "high tech"

- Focus on interaction
- Have a conversation

Tips, Hints and Tricks for Partner Learning

1. Establish the HABIT that the communication book is always with the child
First thing: If you carry the book with you and have it with the child at all times for the first week - you are doing great!

2. Always start on page 1 and follow the numbered page links. Don't get overwhelmed by the size of the book. You will only go to pages that you need by following the links, but the rest of the vocabulary is there, if you need it. Remember, children will learn to use their system in the way partners model it

3. Use the system to "talk" to the child in normal every day contexts all day long, whenever possible
- Model Initiating
- Model Self-Talk:
- Verbal Referencing - acknowledging what you see the child doing that may be used as intentional communication
- Model a Range of Communicative Functions
- Encourage Others to Model
- Model How the Child Will Need to Use the system as Often as Possible

4. Set manageable goals for yourself, Then Add More Conversation as you learn parts of the book
- Start with words on the quick word page
- Use the book to give opinions
- Use the book to say where we are going
- Use the book to ask a question

5. Practice, Practice, Practice!

6. Can't find a word? - Write it on the List!

7. It is Good to Make Mistakes:
Communication Partners May Also Get "Stuck" - Use this as a "Teachable Moment" - with Self-Talk and Repair Strategies - often the flap or side panel of a PODD has "Oops" that can be used when you get to a page and realize that you didn't want to go there.