

Apraxia and Communication in Rett Syndrome

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What is Apraxia?

Apraxia is the inability to reliably connect thought to action

Driving Analogy



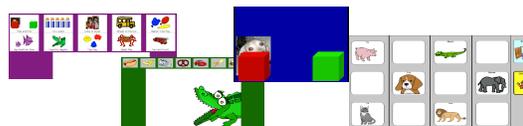
Apraxia in Rett Syndrome

- Neurological connections are formed, but not as many
- Compare to using the back roads instead of the main highway
- Getting from intent to action takes **more time!**

Apraxia Increases with Demand

- The harder the child tries, the harder it is for her to perform on demand
- May need to move away before moving toward what she intends

Provide Opportunities for Exploratory Play on the Computer



Fun activities that the child can open, play, and close - using switches or eye-gaze with no timing and no right or wrong answers

• **Apraxia Also Affects Movements that Control Speech**

• **Apraxia 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**

Neurological Stereotypies

• **Neurologically caused - child does not intend to make these movements**

• **Varies with day, stress, anxiety, pain, fatigue and other unexplained reasons**

• **Masks intelligence**

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

• **Wait for a response beyond the stereotypy with patient anticipation**

• **Splinting**

• **Music**

• **Intention/Interest**

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

Expectant, Quiet Wait Time is Critical!

Utilize Strategic Feedback Instead of Prompting

Respond to what she does instead of telling her what to do

Strategic Feedback and a little Assistance when Stuck

• **Move the child a little bit to get movement started**

• **Separate her hands**

• **Only help once child shows intent**

• **Allow child to complete movement on her own**

• **Share the joy with the child when she is able to do something on her own**

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

Very Sensitive to Non-Verbal Communications and Attitude of Others

- Very tuned into what you are thinking and will reflect hidden emotions
- Will often have certain people that they work well with - people they can rely on to wait and respect them

Motivated by Connection with Others:

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

Child must see a purpose or reason for doing something -
Why am I doing this?

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

Therefore, they may get labeled as “pre-intentional” or “low functioning” and not provided with an appropriate learning environment with Augmentative and Alternative Communication Supports

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

Where Do You Start?

- Look for, and respond to, any **subtle** communicative signals the child uses

Language is multi-modal Any Attempts at Communication are Accepted as Valid

Work Towards Clearer and More Reliable Signals

- Move towards more independence over time
- Support the child's Intent

Attentive Wait Time

- Wait with playful attention
- Don't keep "re-booting" the system by asking the same thing over and over

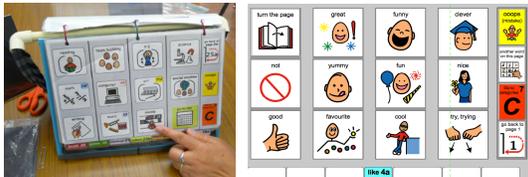
Attentive Wait Time

- 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

Try Different Body Parts for Access

- head
- cheeks
- shoulders
- nose
- etc.

Present Visual Language Receptively Systematically and Predictably



- PDD Communication books
- Gayle Porter (Melbourne Australia)
- Child is in control of speed and navigation through the book

Keep Your Expectations OPEN!

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