

Teaching movements for communication for individuals who have 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.



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.

- Afferent kinesthetic (sensory)
- Efferent kinesthetic dyspraxia (motor)



Dyspraxia and 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!**



Inability to move increases with demand

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



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
- Often confused with sensory processing or cognitive challenges



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 / Rhythm
- Intention / Interest



Breathing and alerting abnormalities affect ability to move as intended

- Difficulties with autonomic nervous system controlled by the brain stem
- Breathing dysrhythmias
- Weak parasympathetic (automatic calming) response
- May get too much or too little oxygen and/or carbon dioxide due to breathing
- Fatigue



Additional challenges with Autonomic Nervous system

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



Teaching movements for communication - initiation

- **Need to learn movements to intelligibly indicate initiations of communication**
- **These movements may include:**
 - lifting up an arm (wearing a wrist band)
 - looking towards a wrist band
 - vocalising
 - reach and touch (to step-by-step communicator)
 - looking to partner then looking to book
- **Partners need training in observing movements**
- **Easier for the child to move when they have their own message and are motivated to communicate**

Teaching movements for communication

- selecting messages (non-electronic)

- **Eye pointing**

- use of directed gaze to objects in environment to indicate preferences or requests

- **Partner-assisted visual scanning**

- partners provide scanning by showing/pointing to the names of items
- child responds to each scan by indicating yes/no
- teaching two movements enables a child to control the rhythm and timing of the scan
- head movements to accept/reject can be more universally understood by communication partners

Teaching movements for communication

- selection of message
(electronic)

Switch access/eye gaze

- Start with play
- Build access skills over time
- Avoid high cognitive load when learning access
- Can not use for testing until access is automatic

Fleur

Physical strategies which enable a stable position in her trunk and upper limbs for communication

- Lateral supports on her supported seating
- Ankle weights to assist with feet flat (disassociation and weight-bearing)
- Knee strap to reduce external rotation
- Second skin boned arm gators/arm wraps
 - also supports healthy development of Fleur's hips
- When using Tobii (electronic) - grasp bar and wrist cuffs (assist with disassociation and stability).

Learning to intend head movements in group using Rhythmical Intention

Learning to initiate communication

- Fleur's movements for initiation can be subtle and variable
- Introduced a step-by-step communicator with 'I have something to say' to help partners recognise her initiations
- Fleur will now vocalise and look to her communication book to initiate communication

Self regulation

Fleur's ability to self regulate has improved with:

- maturity
- increased strength and endurance
- socialisation at Kinder
- increased use of language to express herself; complain, protest and share opinions appropriately
- consistent partner use of operational procedures in PODD communication book

Questions???

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