Using Communication Coaching to Enhance Interactions between Individuals with Rett Syndrome and their Communication Partners

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Disclosure Statement

• We have no relevant financial or nonfinancial relationship(s) within the products or services described, reviewed, evaluated or compared in this presentation.
Characteristics of Rett Syndrome (RTT)

• Occurs primarily in females
• Characterized by significant impairments in:
  – Cognition
  – Communication
  – Motor function
• Genetic cause found in 1999-
  – Over 95% of cases have a mutation in the MeCP2 gene on the X chromosome
• Most cases receive a diagnosis of Classic RTT
  – A small number have preserved speech, others have a variant form
Diagnostic Criteria for Classic RTT

*Required features*

- Early period of typical development, followed by a period of regression, followed by a stabilizing or recovery period, plus the following four main criteria:

  - Partial or complete loss of functional hand skills
  - Partial or complete loss of spoken language skills
  - Impaired apraxic gait or absence of ability to ambulate
  - Stereotypic, repetitive, nonfunctional hand movements

(Neul et al., 2010)
Communication Partners - Interpreting Meaning in Interactions

• Individuals with severe disabilities rely on communication partners for successful interaction
  • Partner uses inferences & intuition to give meaning to signals
    (Grove et al., 1999)

• Individuals with RTT are reported to use the following behaviors to signal meaning:
  • Vocalizations, head & body movements, gestures, facial expressions, eye gaze, AAC devices
    (Bartolotta et al. 2011; Hetzroni et al. 2006; Ryan et al., 2004)
Intervention with Communication Partners

- AAC Assessment and Intervention – Participation Model
  - Look at partner’s skills and knowledge
  - Play a key role in success of AAC
    (Beukelman & Mirenda, 2013)

- Partner coaching is used with many groups
  - Aphasia, fluency disorders, autism, Down syndrome
    (Kent-Walsh & Binger, 2013)

- Coaching can maximize resources
  - Clinician can coach those who spend the most time with the individual (e.g. parents, teachers, aides)
    (Bartolotta & Remshifski, 2013)
Coaching as a Tool for Improving Communication

• Can be used in conjunction with other AAC strategies and devices
  – Along with eye gaze, switches, devices, gestures, etc.

• Partner coaching can limit “device abandonment”
  – the failure to use an AAC system

• Coaching occurs in “real life” situations with “real people” and uses AAC strategies already in place
Coaching study

Hypothesis -
Coaching communication partners of persons with RTT will result in a measurable change in communicative behaviors displayed by both individuals during mealtime.

Dyads –
Individuals with RTT and their communication partners

Mealtime chosen-
- It is a regularly occurring event
- There is opportunity for repetition
- It is a rich communication opportunity
Method

Design:
Three –phase single subject design
  Phase 1: pre-coaching baseline (4 sessions)
  Phase 2: coaching intervention sessions (2 sessions)
  Phase 3: post-coaching baseline sessions (5 sessions)

Data Analysis:
  Analyzed ten consecutive minutes of each mealtime
  Coded communicative acts produced by each member of the dyad
Coding

- **Subject Bid (SB):** communication that requires a verbal or nonverbal response from partner
- **Feeder Bid (FB):** verbal or nonverbal communication from partner
- **Subject Response (SR):** communication from person with RTT
- **Feeder Response (FR):** communication from partner
- **Feeder comments not requiring a response (NRR):** comments including rhetorical questions, statements, instructions or encouragements.

(Bartolotta & Remshifski, 2013; Ryan et al., 2004)
# Subject Characteristics

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Partner</th>
<th>Communication</th>
<th>Other Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leslie</td>
<td>35</td>
<td>Mother</td>
<td>No current AAC device</td>
<td>Ambulatory; Some functional hand use (picks up food, can use spoon with support)</td>
</tr>
<tr>
<td>Michelle</td>
<td>19</td>
<td>Mother</td>
<td>No consistent use of AAC; currently trialing a tobii at school; vocalizations</td>
<td>Ambulatory; Some functional hand use (picks up food, can use spoon with support)</td>
</tr>
<tr>
<td>Taylor</td>
<td>20</td>
<td>Caregiver</td>
<td>No current AAC device; recently began trialing an iPAD; gestures hand to mouth; vocalizations</td>
<td>Ambulatory; Some functional hand use (will touch iPAD with support)</td>
</tr>
</tbody>
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Sample Coaching Strategies

• Offer choices during the meal:
  — For example, offer two different food choices or food and drink. Place choices in her line of vision and allow time for a response

• Increase delay time (by 5 seconds) between presentation of each bite or drink to allow for use of a behavior that is potentially communicative, such as:
  — Eye gaze, opening mouth, vocalizations, hand and body movements

• Respond to hand movements as if she has made a request.
  — For example, when she moves her hand to her face respond as if she is asking to eat

• Encourage responses by using more direct questions:
  — For example, ask questions during the meal: “Do you want more to drink?” “Do you want more chicken?”
Pre Coaching - Michelle
Michelle’s Coaching Strategies

1. Offer Michelle more choices during mealtime.
   Example: Place one food and one drink choice in her line of vision and wait for a response.

2. Increase wait time between presentations of food in order to allow for a behavioral response
   Example: motor movement, head turn, vocalization

3. Respond to Michelle’s hand gestures with finger extension as if she has made a request for a food choice or “more food” and then respond to that choice
Post Coaching - Michelle
Feeder Bids
Baseline → Post-Coaching

Average Frequency

Participants

Taylor

Michelle

Leslie

Baseline
Post-Coaching
Subject Responses
Baseline → Post-Coaching

Average Frequency

 Participants

Taylor  Michelle  Leslie

Baseline
Post-Coaching
Subject Bids
Baseline → Post-Coaching

Average Frequency

Participants

Taylor | Michelle | Leslie

Baseline | Post-Coaching

0 2 4 6 8 10 12 14 16 18 20
Feeder Responses
Baseline → Post-Coaching

Participants

Average Frequency

Taylor

Michelle

Leslie

Baseline

Post-Coaching
The Data Revealed….

- For two of the three dyads, there was an increase in feeder bids at post-coaching;
- For all dyads, there was an increase in the subject responses to feeder bids at post-coaching;
- We also found that as feeders recognized subject bids, their responses to those bids increased;
- Consequently, the number of bids made by subjects decreased, as their bids were more readily acknowledged by the feeder on the first attempt.
Outcomes of Coaching

- Data suggests both individuals with RTT and their communication partners change communication as an outcome of coaching:
  - Each partner makes more requests and provides more responses.
  - The behavior of other individuals (e.g. parents, siblings, teachers) changes
    - They begin to offer more opportunities for communication in other contexts (e.g. circle, work time, etc.)
Selected References


