COMMUNICATION INTERVENTIONS IN RETT SYNDROME

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Goals for this session

• Describe the best evidence for assessment of communication skills in individuals with Rett syndrome (RTT)

• Describe the best evidence for design of intervention programs to improve communication in RTT

• Discuss varied intervention strategies

• List the key components of a communication coaching program for home and school
Assessment of communication

• Best practices in assessment
  • Systematic review of evidence in assessment suggests individuals with RTT are capable of intentional communication using a combination of:
    • Behavioral observations
    • Standardized assessments which allow for inclusion of nonstandard behaviors
  • Individuals with RTT use body movements, vocalizations, eye gaze, facial expressions for meaningful communication
  • Challenging to validate these behavioral observations
  • We need a standard measurement to assess individuals with these complex communication needs and behaviors

(Sigafoos et al., 2011)
Useful tools for assessment and tracking progress

- **Inventory of Potential Communicative Acts**

- **Communication Matrix**
  - [http://www.communicationmatrix.org/](http://www.communicationmatrix.org/)
• Learn from a communication partner how an individual…
  • Conveys **Social Conventions**
    • Greets others, indicates farewell, responds to his/her own name
  • Obtains **Attention to Self**
    • Gets attention, seeks comfort, requests a cuddle/tickle, shows off
  • Communicates **Rejection** and **Protests** when..
    • Routine is disrupted, asked to do something they don’t want to do, doesn’t like something, a favored toy is removed, an adult ends a favored interaction
• **Requests**…
  • An object, something to eat, more of something
• **Requests action**
  • Help with dressing, help with a game, going to the bathroom, wanting someone to come or be near
IPCA

- **Requesting information**
  - Asking for clarification, seeking information about something

- **Commenting on emotions and feelings**
  - Being happy, enjoying something, being excited, sad, bored or disinterested, finding something funny, feeling frightened or surprised, being in pain or sick, feeling angry or frustrated, being tired

- **Choice making**
  - Making a choice between objects or foods, choosing activities, choosing when to start or end activities

- **Answering**
  - Reacting when someone talks to them, responding to yes/no questions

- **Imitation of…..**
  - Speech, head nods for yes and no, shrugging shoulders, pointing, other body movements
Inventory of Potential Communicative Acts

Date: ____________________________

Name of the individual: ____________________________

Name of the informant: ____________________________

Informant's relationship with the individual:

☐ Teacher  ☐ Parent  ☐ Other ____________________________ (Specify)

How long have you known this individual? ___________ years ___________ months

Individual's date of birth: ____________________________

Diagnoses: ____________________________

Social convention
Please describe how the individual...

<table>
<thead>
<tr>
<th>Items</th>
<th>Behaviors</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Greets you/others</td>
<td></td>
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<td></td>
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<tr>
<td>2. Indicates farewell to you/others</td>
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<td></td>
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<td>3. Responds to his or her own name</td>
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<tr>
<td>4. Other</td>
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</tbody>
</table>

### Attention to self
Please describe how the individual...

<table>
<thead>
<tr>
<th>Items</th>
<th>Behaviors</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Gets your attention</td>
<td></td>
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<td></td>
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<tr>
<td>2. Seeks comfort</td>
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<tr>
<td>3. Requests a cuddle/tickle</td>
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<td>4. Shows off</td>
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<tr>
<td>5. Other</td>
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</tbody>
</table>

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<table>
<thead>
<tr>
<th>Social convention</th>
<th>Attention to self</th>
<th>Reject/protect</th>
<th>Request object</th>
</tr>
</thead>
<tbody>
<tr>
<td>greet</td>
<td>get attention</td>
<td>do</td>
<td>object</td>
</tr>
<tr>
<td>wave</td>
<td>comfort</td>
<td>dislike</td>
<td>more</td>
</tr>
<tr>
<td>name</td>
<td>coddle</td>
<td>take</td>
<td>TV or music</td>
</tr>
<tr>
<td>other</td>
<td>shoes off</td>
<td>admin</td>
<td>other</td>
</tr>
<tr>
<td>routine</td>
<td>routine</td>
<td>routine</td>
<td>object</td>
</tr>
<tr>
<td>do</td>
<td>dislike</td>
<td>routine</td>
<td>food</td>
</tr>
<tr>
<td>dislike</td>
<td>routine</td>
<td>routine</td>
<td>more</td>
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<tr>
<td>routine</td>
<td>routine</td>
<td>routine</td>
<td>object</td>
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<tr>
<td>object</td>
<td>routine</td>
<td>routine</td>
<td>food</td>
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<tr>
<td>food</td>
<td>more</td>
<td>routine</td>
<td>other</td>
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<tr>
<td>dress</td>
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<tr>
<td>Request action</td>
<td>Request info</td>
<td>Comment</td>
<td>CM</td>
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<td>----------------</td>
<td>--------------</td>
<td>---------</td>
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<tr>
<td>game</td>
<td>toilet</td>
<td>near</td>
<td>other</td>
</tr>
</tbody>
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IPCA

- Didden et al, 2010
  - IPCAs were completed on 120 individuals with RTT
  - Findings:
    - Prelinguistic behaviors that were most commonly reported were eye contact and eye gazing
    - Most recognized communication abilities:
      - Social convention – hi, bye
      - Commenting
      - Answering
      - Requesting
      - Choicemaking
Reports of communication:

- Parents reported girls with RTT can express discomfort and pleasure, and make requests and choices using a variety of modalities including:
  - Vocalizations, body movements, and eye gaze
    - (Urbanowicz et al, 2014)

- Parents and teachers interpreted behavior of individuals with RTT and identified: requesting objects, commenting, and protesting, as being clearly communicated.
  - (Julien et al., 2014)

- Recommendation: gather information from familiar adults (parents, teachers) and observe in familiar settings to get a full assessment of skill
<table>
<thead>
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<th>COMMUNICATION</th>
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</thead>
<tbody>
<tr>
<td><strong>Barriers</strong></td>
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<tr>
<td>• Unfamiliar partner</td>
</tr>
<tr>
<td>• Underestimating skills</td>
</tr>
<tr>
<td>• Inconsistent responses</td>
</tr>
<tr>
<td>• Apraxia – motor planning</td>
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<tr>
<td>• Access to appropriate services</td>
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<tr>
<td>• Medical conditions (e.g. seizures)</td>
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<tr>
<td>• Attitudes</td>
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</table>

| **Facilitators** |
| • Using multiple modalities for communication |
| • Using aided and unaided strategies together |
| • Recognizing nonstandard behaviors as communicative |
| • Optimism |
| • Motivation |
| • Consider parental perspectives |

- (Bartolotta et al., under review; Urbanowicz et al., 2014)
Best practices in intervention

• Based on the literature the following can be recommended:

  • Begin by teaching a simple requesting response

  • Ensure the targeted response is within the child’s physical capabilities – look at nonstandard behaviors

  • Consider a simple motor act rather than speech or gestures
    • Touch a switch
    • Hand movement
    • Natural gesture

  • Assess use of eye gaze – most commonly used modality
    • Offer choices
    • Develop consistency across two favored objects
    • Explore expanding set to three or more choices
Best practices in intervention

- Explore AAC strategies
  - Begin with no tech – develop some valid level of response
  - Allow for inconsistency
  - Remember to wait – consider influence of apraxia
  - Move to low tech or high tech, depending upon:
    - Interest level, Skill, Resources, Contexts
- Use the communication partner to interpret and reinforce behaviors
- Personal Communication Directory – guidebook describing communicative behaviors
  - (Wine, 2011)

- To keep in mind…
  - The evidence is limited
  - However, anecdotal evidence suggests all ages and phases of RTT can improve
    - (Bartolotta & Remshifski, 2012; Neul et al., 2010; Sigafoos et al., 2009)
Begin with requesting

- Example from the literature – Van Acker & Grant, 1995

  - Computer-based requesting system with motivating graphics and speech output

  - Taught three girls with RTT to touch a screen to request preferred food and drink items

  - Activation of screen was accompanied by a speech prompt, e.g. “Would you like some milk”

  - All subjects learned to touch the screen to request at least one food/drink item

  - All demonstrated ability to discriminate between preferred and non-preferred items

  - All demonstrated generalization to at least one setting (classroom or home) outside of treatment
Consider nonstandard behaviors
Is speech an option?

- There are reports of some individuals with RTT using speech –
  - Most are nonverbal
  - Some can vocalize or produce word approximations
  - Motor planning challenges can be significant
Strategies for AAC

- **Direct selection**
  - Can the individual touch or pick up an object or picture?
  - Can they press a switch?

- **Scanning**
  - Can they look at objects/photos/symbols held by someone else?
  - You can begin with one or two photos, then increase as ability increases
  - Partner – assisted scanning
    - Where the partner directs the individual’s attention to the items and waits for some type of response –
      - A head nod, a gesture, a vocalization, an eye blink, or something else
• PODD – Pragmatic Organization Dynamic Display Communication Books
  • Accessed using direct selection, scanning, partner-assisted scanning
  • Available from Mayer-Johnson
  • Linda Burkhart - [http://www.lburkhart.com/](http://www.lburkhart.com/)
Eye gaze

• Most commonly used modality for communication in RTT

• Eyetracking technology allows for us to:
  • Assess competencies
  • Use the eye gaze modality for communication

• Eye tracking is a reliable tool for assessment

• Individuals with RTT demonstrate similar eye gaze preferences as typical children:
  • Prefer novel, socially weighted and salient stimuli
  • Prefer faces to objects

(Djukic & McDermott, 2012; Djukic, et al., 2012)
Eye gaze technology for AAC

- Tobii C12 Communicator
- Dynavox EyeMax
- Tobii eyemobile
Eye gaze research

- Currently engaged in research to use eye gaze to assess receptive vocabulary and demonstrate effective communication
- Using tobii technology
- Assessing eye gaze technology to measure receptive vocabulary
  - using known and unknown words as reported by parents
  - Individual with RTT looks at screen that has two photos
  - tracking duration of gaze on each picture
- Using tobii pc mobile for expressive communication – using favored and unfavored objects
- Research is supported by a grant from Rettsyndrome.org
Data collection underway

- Lab at Monmouth University in West Long Branch
- Challenges
  - Calibration in the assessment phase
  - Individuals can move around and lose calibration
  - In research – you can’t coach!
- Will enroll more subjects in the coming months
- Data can be collected at the home of subjects if they can’t travel to Monmouth University
Partner Instruction: A Coaching model

- Communication partners interpret behaviors of individuals with disabilities.
- Coaching effectiveness has been demonstrated with a number of populations:
  - Aphasia, fluency disorders, social-pragmatic challenges.
- Some SLPs are using partner instruction informally with RTT:
  - (Waldin, Lindberg & Sonnander, 2014)
- Coaching is effective in terms of SLP time:
  - coach those who spend the most time with the individual with the complex communication needs.
- Can integrate any type of AAC strategy into a coaching model:
  - (Bartolotta & Remshifski, 2012)
Coaching can be done at school or at home

• Studied coaching at home with parents/caregivers and at school with teachers/therapists/aides
• Mealtime chosen because it is:
  • A regularly occurring event
  • Lots of opportunity for repetition
  • Rich communication opportunity
• Case example:
  • Girl with RTT, age 19
  • Feeder - Mother
  • Baseline – 4 sessions; Analyzed videos; Coaching sessions at home; Repeat baseline measures over 4 weeks – then 1-month follow-up
Precoaching
Coaching Strategies

1. Offer 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 her 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
Postcoaching
Outcomes of Coaching

- Data suggests both girls and their feeders change their communication as a result of coaching:
  - Girls make more requests and provide more responses
  - Feeders make more requests and provide more responses
  - Behavior of others in the classroom changes – begin to offer more opportunities for communication in other contexts (e.g. circle, work time, etc.)
Summary

- *Communication is possible!!*

- Explore **multiple** options
  - Use AAC: aided and unaided strategies
  - Hi tech – may have great possibilities
  - Always have a number of options

- Involve **parents and teachers** in assessment and treatment decisions

- **Partner training/coaching** is key to success
References


