Rett Syndrome: Avenues for Building Communication Low and High Tech

Susan Norwell M.A.
Educational Specialist
Co-Founder www.Rett-U.org
www.focusedlearningsolutions.com
Avenues for Building Communication
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- Language immersion throughout everyday experiences
  - Effect of “Pivotal Response”
  - Can’t start too soon

- Through play and interaction
  - Suggested activities to enhance communication
  - Suggested Apps to engage without stressing hand use

- Through the controlled vocabulary of Literacy-based experiences to experience and retell
  - Importance of “Dialogic Reading” for our kiddos
Language Immersion

Throughout Everyday Experiences
(We need to “speak symbol”
to build robust vocabulary)
Communication with Girls with Rett Syndrome

- Presume communication competence – even though selections may seem random or exploratory in nature there is meaning to what a girl selects

- If unsure, check in with parents about the context

- Accept motor approximations; Don’t wait for 100% accuracy before responding

- Observe, observe, observe and respond

- Join in conversation – you talk WITH them not at them.
Communication Hierarchy:
No Tobii?  No Excuse

- Two hands
- Picture symbols that include more than nouns
- Partner-Assisted-Scan
- Soft-Tech Four Square – paper or Ipad
- Tobii
- Core-word book
- Spelling
Teach Eye Gaze

- Train eye gaze early
- Respond to what they naturally do
- Read all eye gaze efforts and respond
- Often start with light tech out of necessity
- Use MEANINGFUL activities
  - Fun not just “functional”
Build Reciprocity

- Open/close circles of communication
- Keep it fun and fast as possible
- High affect and lots of humor
- Model “cool stuff” like peers are doing
- Need lots of opportunities for practice
- PREPARATION!
Need to Have an Opinion

thumbs up

thumbs down

cool

fun

scary

don't like
Soft-Tech 4-Grid

Download at: www.focusedlearningsolutions.com
To Adapt
Purchase at: www.Rett-U.org
Made out of durable plastic
Put grids strategically around house/classroom

- If we have to run to get them we won’t or we miss the “moment”
- Content specific at first is helpful
- Core Word on edges can begin the idea of combining
- You are modeling and mapping meaning onto symbols interactively
- Remember we talk to babies for one year before we expect a single word back
Take a Bath
Sono Primo by Tobii
### In The Bath

<table>
<thead>
<tr>
<th>I</th>
<th>want</th>
<th>soap / soap</th>
<th>Get me out</th>
</tr>
</thead>
<tbody>
<tr>
<td>do</td>
<td>bathtub</td>
<td>water</td>
<td>towel?</td>
</tr>
<tr>
<td>again</td>
<td>soap</td>
<td>bubbles</td>
<td>toy</td>
</tr>
<tr>
<td>all done</td>
<td>play</td>
<td>hot</td>
<td>cold</td>
</tr>
</tbody>
</table>
Get Ready for Bed
Sono Primo by Tobii
“Highest” Tech

• Tobii Eye-gaze allows for most flexibility

• Communicator flexible programming

• Language sets in Communicator Suite grow with the child

• Most independent Communication

• Allows for “tattling”, retelling, story-co-construction, talking photo albums to share
Mother’s Day Grid

www.pagesetcentral.com
Sono Flex
Snack Context
Language Immersion

Through Play and Interaction

(We need to “speak symbol” to enrich vocabulary & learn about the world)
Play to Communicate

- Create chance for pretend play
- Have girls direct you or others
- Don’t force hands
- Take what they give and build
- Follow their lead and expand
- You can play without using your hands
Play Mats
No device? – No excuse!

- Low tech – use for all
- Visually organize the play
- Ready access to symbols to communicate around play
- Let girls direct the play - not hand over hand
- Builds in comments and questions
Farm & Bathtime Playmats
Props & Symbols

- **Washcloth Prop (front)** (get, washcloth)
- **Washcloth Prop (back)**
- **Bathtub Prop (front)** (in, bathtub)
- **Bathtub Prop (back)**
Play is Foundational

- Builds ability to predict and plan
- Tells a story with beg, middle and end
- Chance to learn about the world
- Chance to express own ideas
- Lends itself to communication practice
- Repetition for an authentic purpose not kill and drill
Play “Page” Set-Up

- Need all parts of speech
  - nouns for choosing
  - verbs for directing action
  - adjectives/adverbs to describe
  - comments for fun!
  - Questions to support curiosity
  - prepositions for learning where
Functions Related to Play

- Direct others actions
- Comment on actions
- Greetings
- Negation, Affirmation, Re-occurrence
- Descriptions (size, color, speed, shape, texture)
- Time (now, later, before, after)
- Needs, requests (see what’s at the bottom 😊)
Let’s Play Tea Party
Sono Flex
Apps for Play 😊

Toca Boca

Bamba Apps
What to look for in APPS

- Easy swipe to make big things happen
- Age and interest appropriate
- Clearly organized options
- Options spread out to make PAS easier
- All kids would like to play with it
- Would entice peers to join in
What We’ve Learned

- Language immersion throughout everyday experiences
- Effect of “Pivotal Response”
- Can’t start too soon

Through play and interaction
- Suggested activities to enhance communication
- Suggested Apps to engage without stressing hand use

- Lots of errors in beginning communication for ALL kiddos not just AAC users