Rett Syndrome:

Tots to Ladies
Communication and Learning

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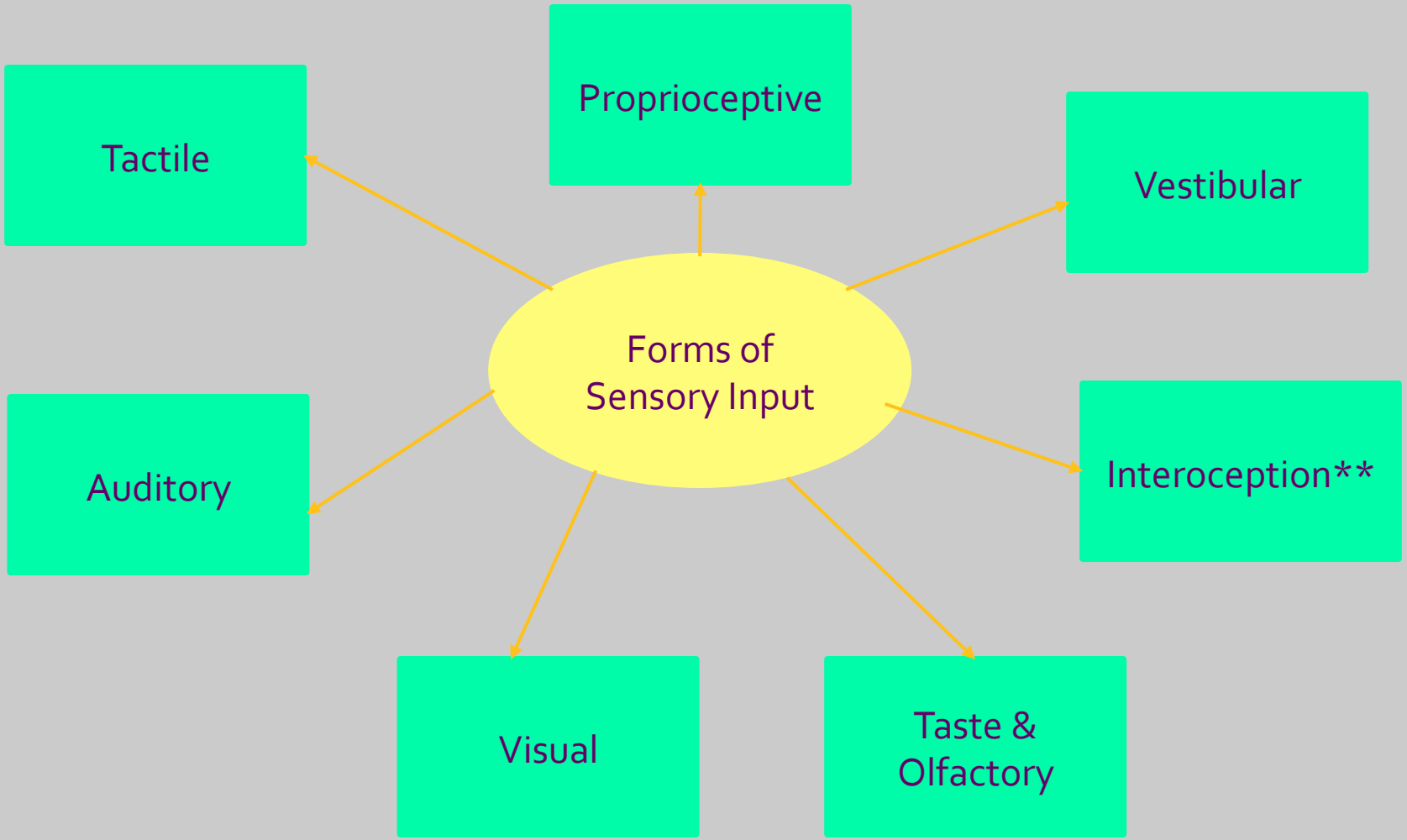
Communication

- Express oneself; open-ended
- Not a test or only choice making
- Includes building connections and strong emotional bonds with family members, including extended family, and friends
- Want friendships, not just with adults, but same-age peers and siblings
- This is possible through use of a communication device in combination with other natural modes of communication

Unique Characteristics

- Extreme motor planning difficulties – apraxia
- Difficulty with completing motor acts upon command or organizing body to give a response; does not mean a girl does not understand or cannot do - apraxia
  - (Video 1-Apraxia; 3 year old girl during eye gaze trial; first time using Tobii with Judy's eye gaze trial layout)
- Highly motivated, self-initiated motor acts or give quick response – indication of true ability
  - (Video 2-No Apraxia; 8 year old girl during eye gaze trial; not used Judy's page set after months of not using them)

Forms of Sensory Input



Responses to Sensory Input

- **Requires assistance to walk/stand**

Levels of Sensory Regulation	Description
Level 3	Asleep or drowsy, eyes shut
Level 2	Fidgeting; not establishing eye contact, decreased attention
Level 1	Alert and focused, making eye contact or attention to activity at hand.

Responses to Sensory Input

- **Walks independently**

Levels of Sensory Regulation	Description
Level 3	Distressed, agitated, refusal/ resistance to participate
Level 2	Difficulty remaining seated; walking around aimlessly,
Level 1	Calm, attentive, interested and ready for engagement

Sensory Regulation Chart

OVER STIMULATED **Sensory Overload**	**Level 3**	Needs strong sensory input from sensory diet to "calm down," overwhelmed May also shut down; fall asleep
OVER RESPONSIVE	**Level 2**	Needs sensory break to help return to Level 1; snack or drink; music or change of activity
FUNCTIONAL STATE OF AROUSAL	**Level 1**	Ready to communicate and learn
UNDER RESPONSIVE	**Level 2**	Needs break involving movement/change of position; snack or music
UNDER STIMULATED	**Level 3**	Shutdown; falling asleep; needs strong sensory input to "rev up" system

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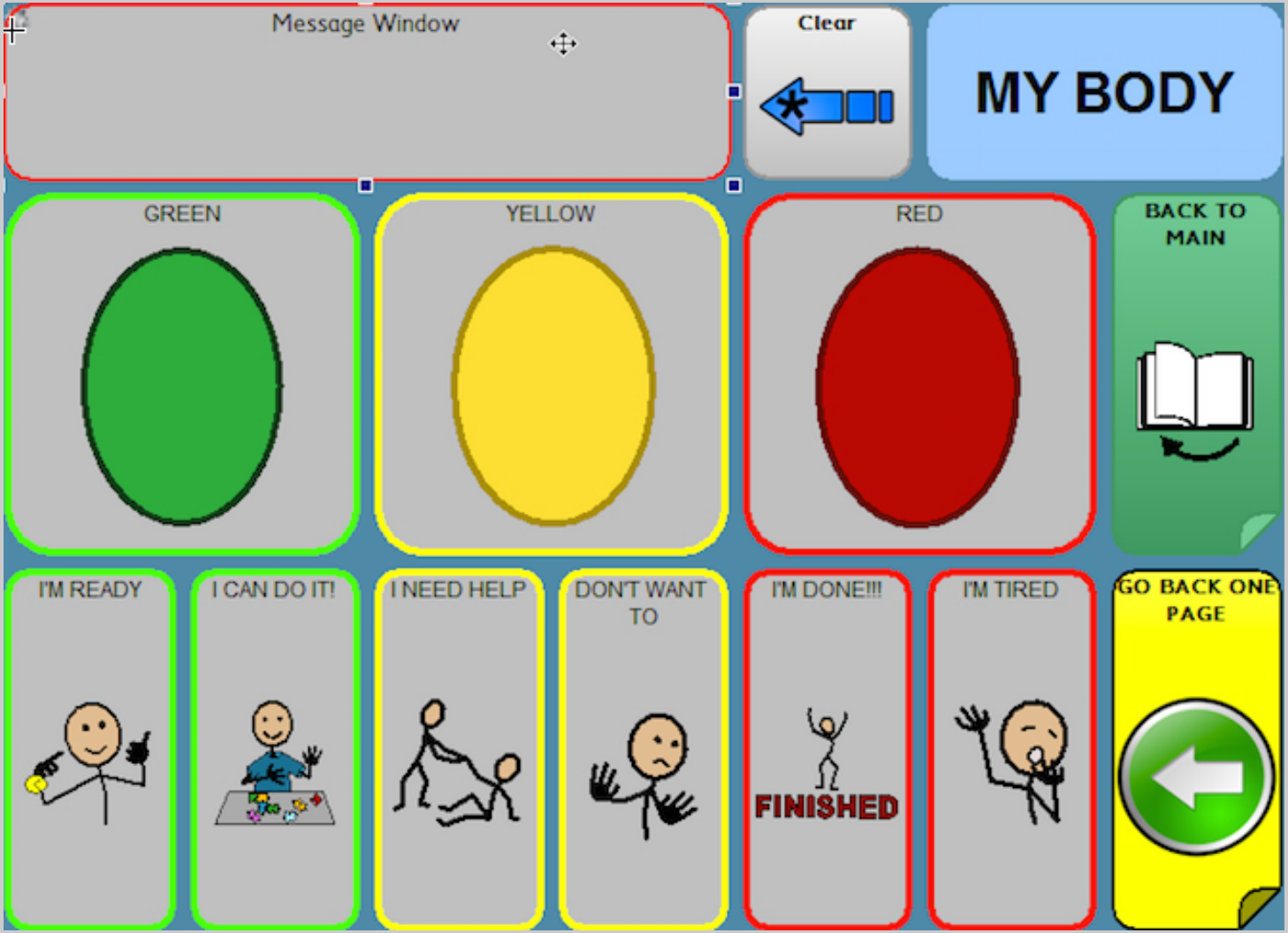
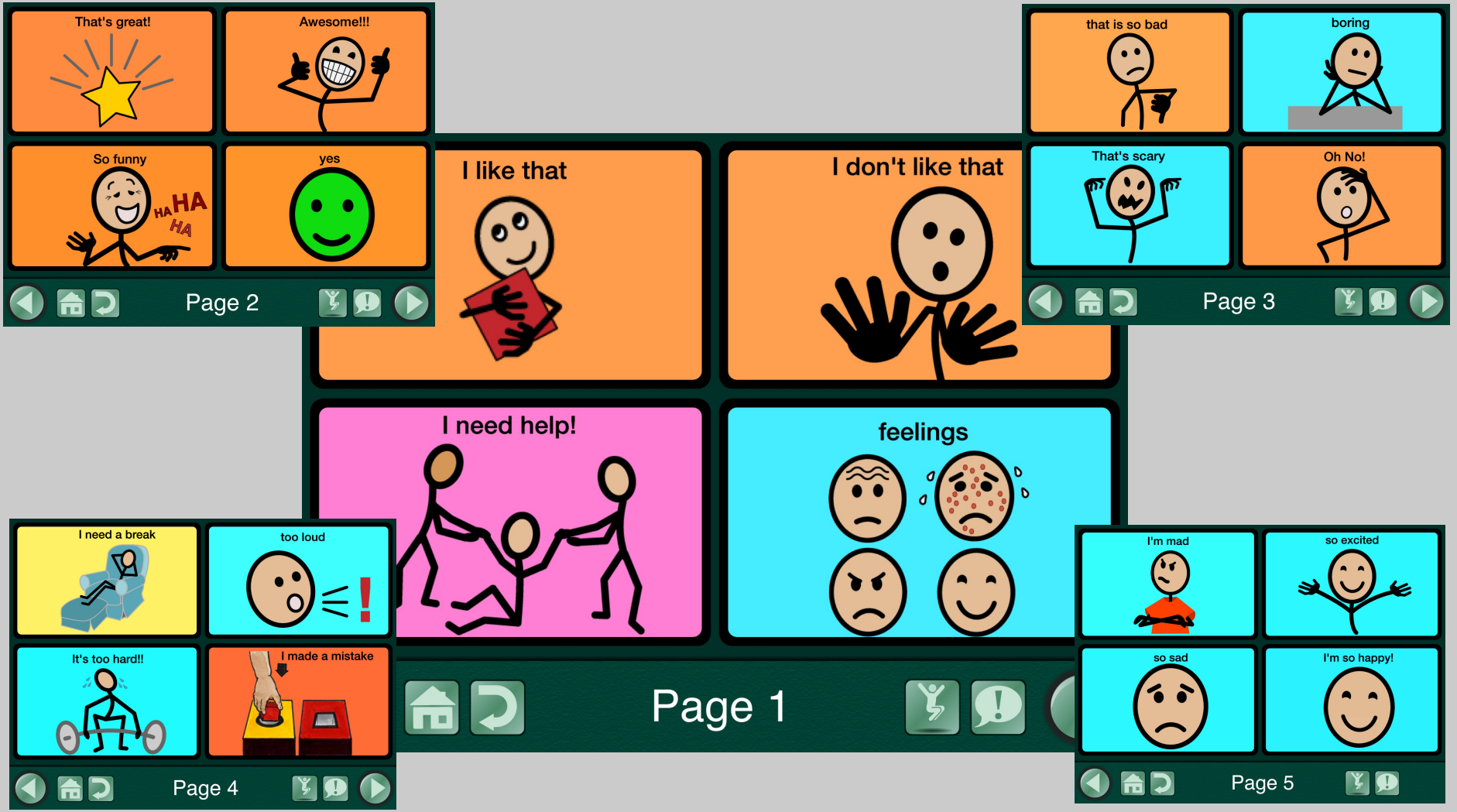
Communicating Sensory Level



Be a Meaning Maker

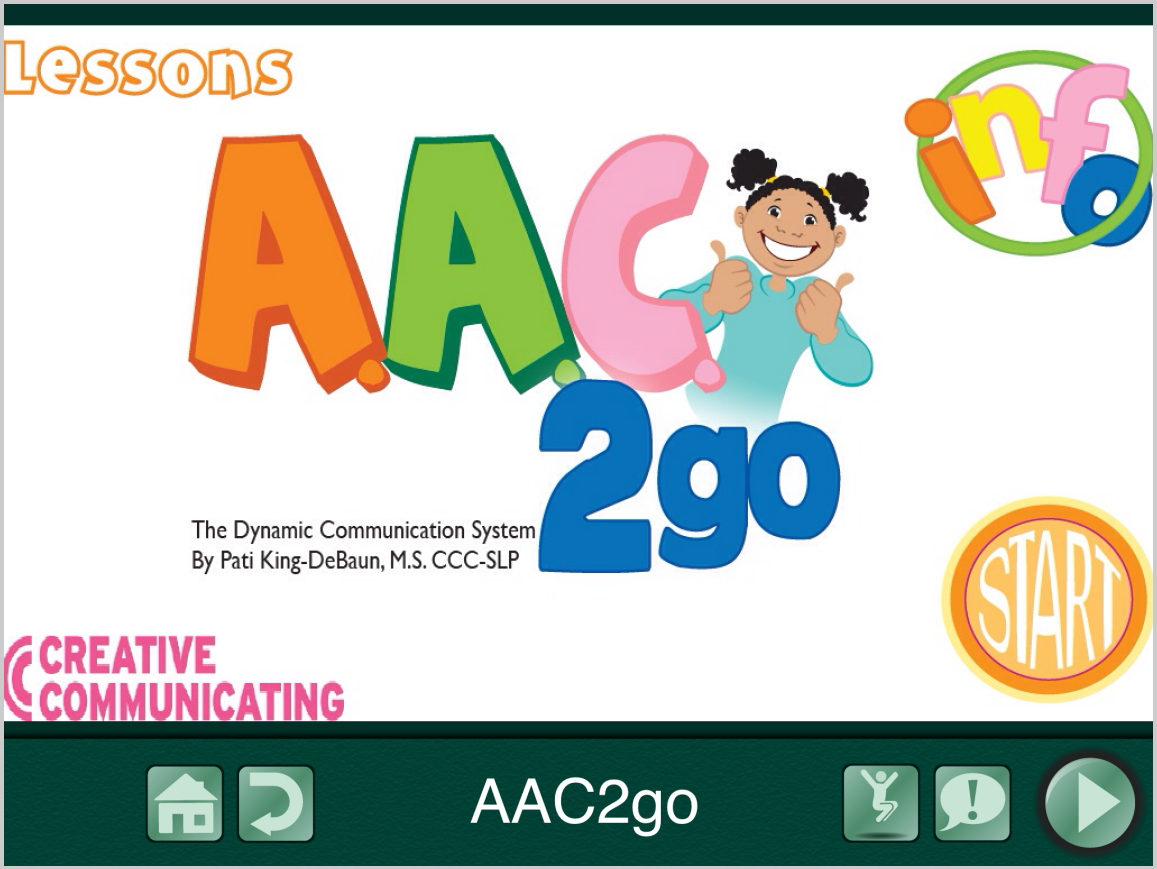
- Attach meaning to each action
- Give names to their feelings
- Credit for all forms of communication
- Assume competency
- Be their voice – but be cool!

4 Grid in GoTalk Now



Great for Beginning Communicators! AAC2Go in Go Talk Now Plus iPad app

- Switch accessible
- Can also use with partner-assisted scanning



Start > Home Talk > I want >

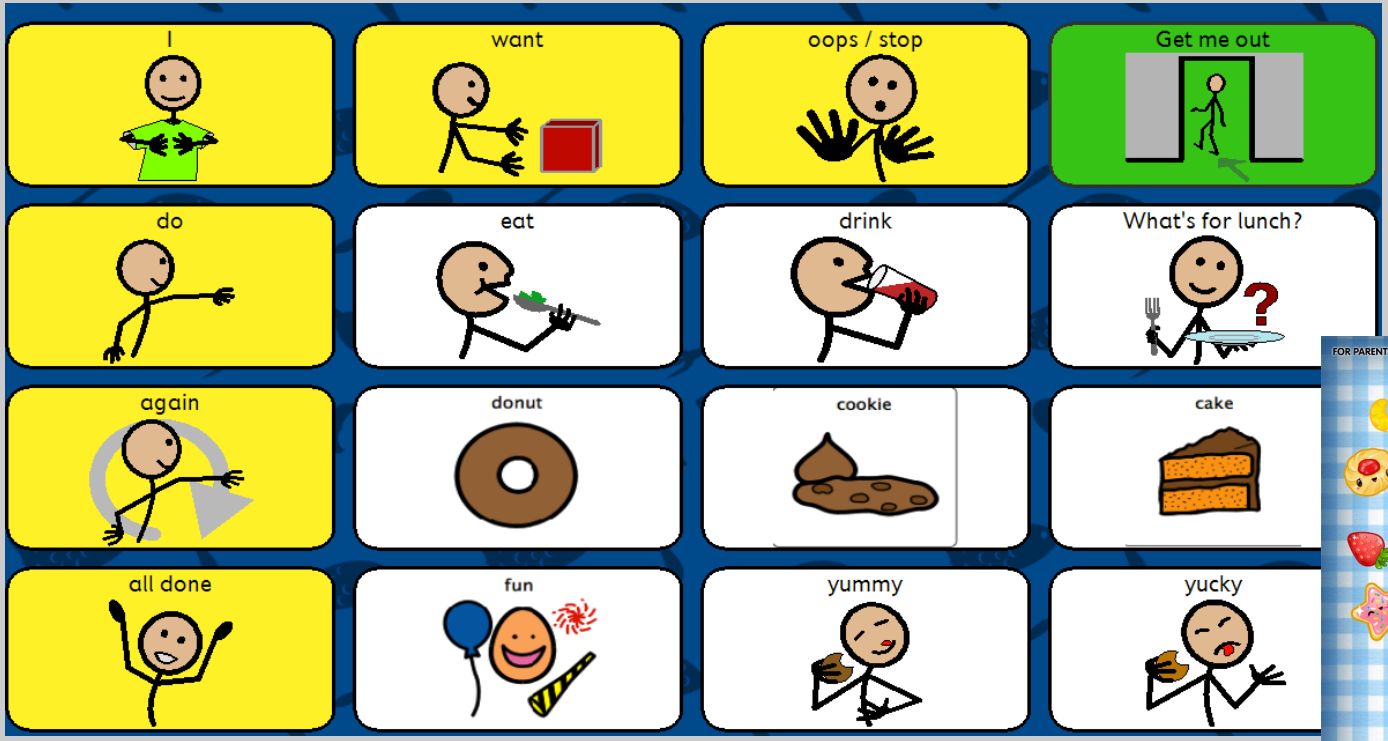
Build Reciprocity

- 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!

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

Let's Play Tea Party



Communication

- Separate is not equal
- Needs to be viewed within the context of typical language development (mama)
- The developmental process has lots of errors
- Let's give them something to talk about

  (AKA – don't be boring!!) (adult eye-gaze)

Ultimate Communication Goal

- Being able to say what you want to say, when you want to say it, and how you want to say it
- To accomplish this goal, a girl needs independent and easy access to a dynamic display (multiple page) communication device so she can navigate between pages – eye gaze technology.

"It's in their eyes" Eye Gaze/Eye Tracking System

- Eye gaze technology taps directly into individuals with RTT incredible use of their eyes for communication
- Their eyes function as their index finger for pointing and gives them the ability to directly select what they want to say
- One of the easiest means of access to technology – so learn quickly
- Provided…we have given them access to the "just right" setup

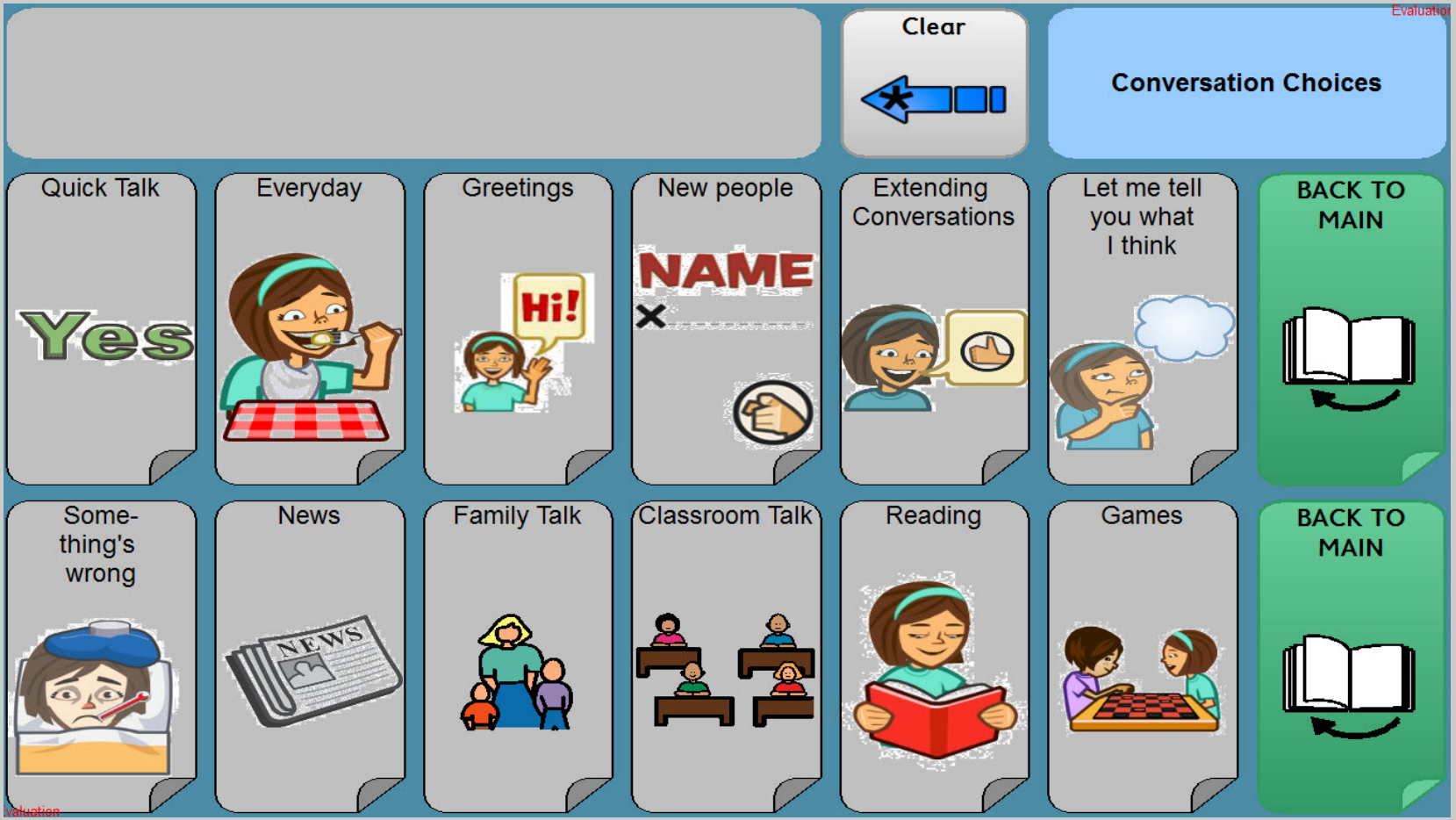
We have an Eye Gaze System Now what???

- **More** vs. less
  - **Core phrase-based system** to support success with low motor demands, increased communication
  - Need **consistent structure and organization** of system
- **Don't reinvent the wheel!!!**

Judy’s Eye Gaze page layout

- Starting page

Main Conversation page



The Dynamic Communication Book

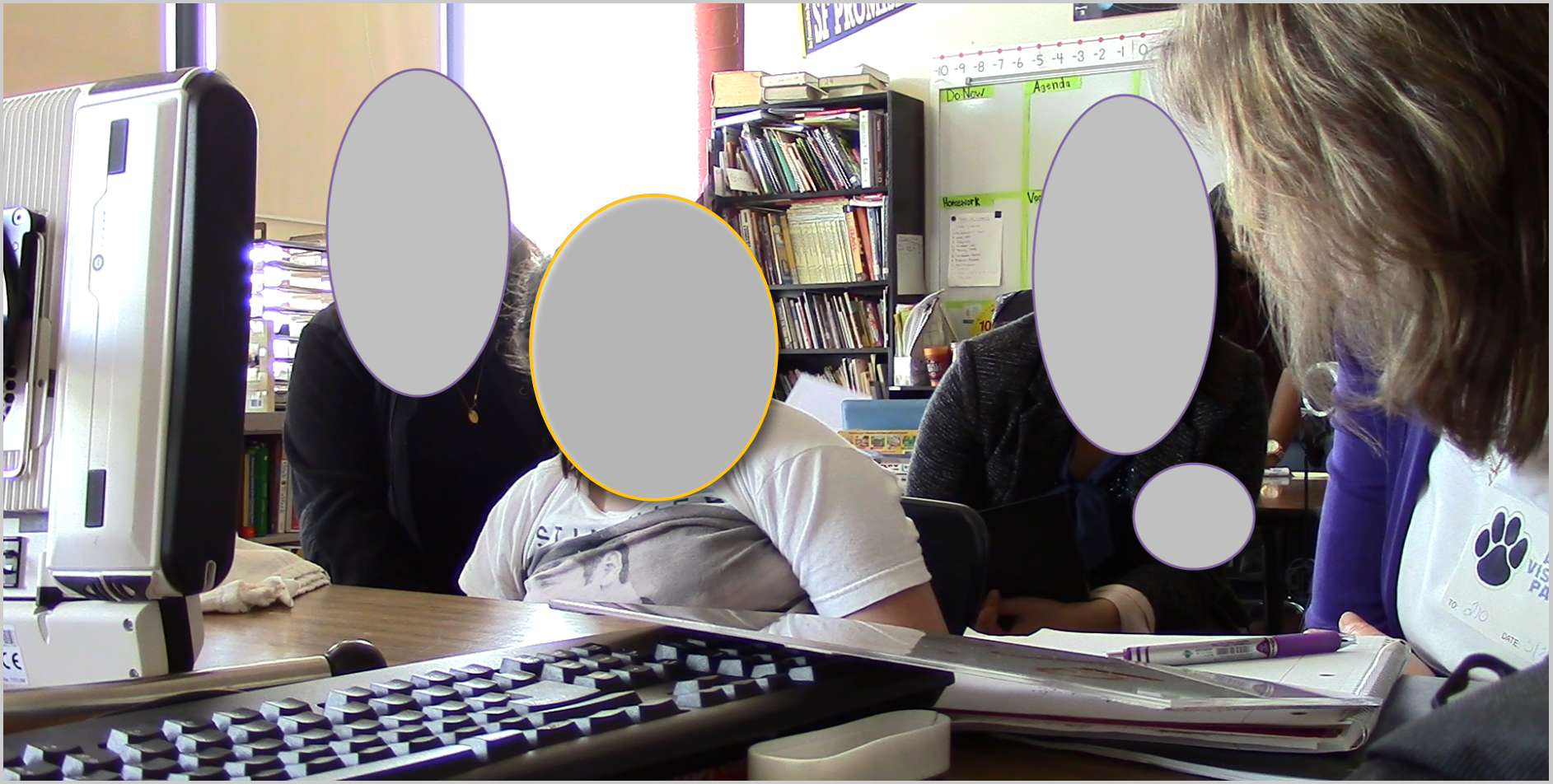
- Results seen across multiple girls and teens using this (multiple case studies):
  - The phrases have allowed girls to **initiate conversations, ask questions, and make comments** – beyond needs and choice making
  - The girls are highly motivated, interested, and **engaged** in the interaction using the phrases in this book.

The Dynamic Communication Book

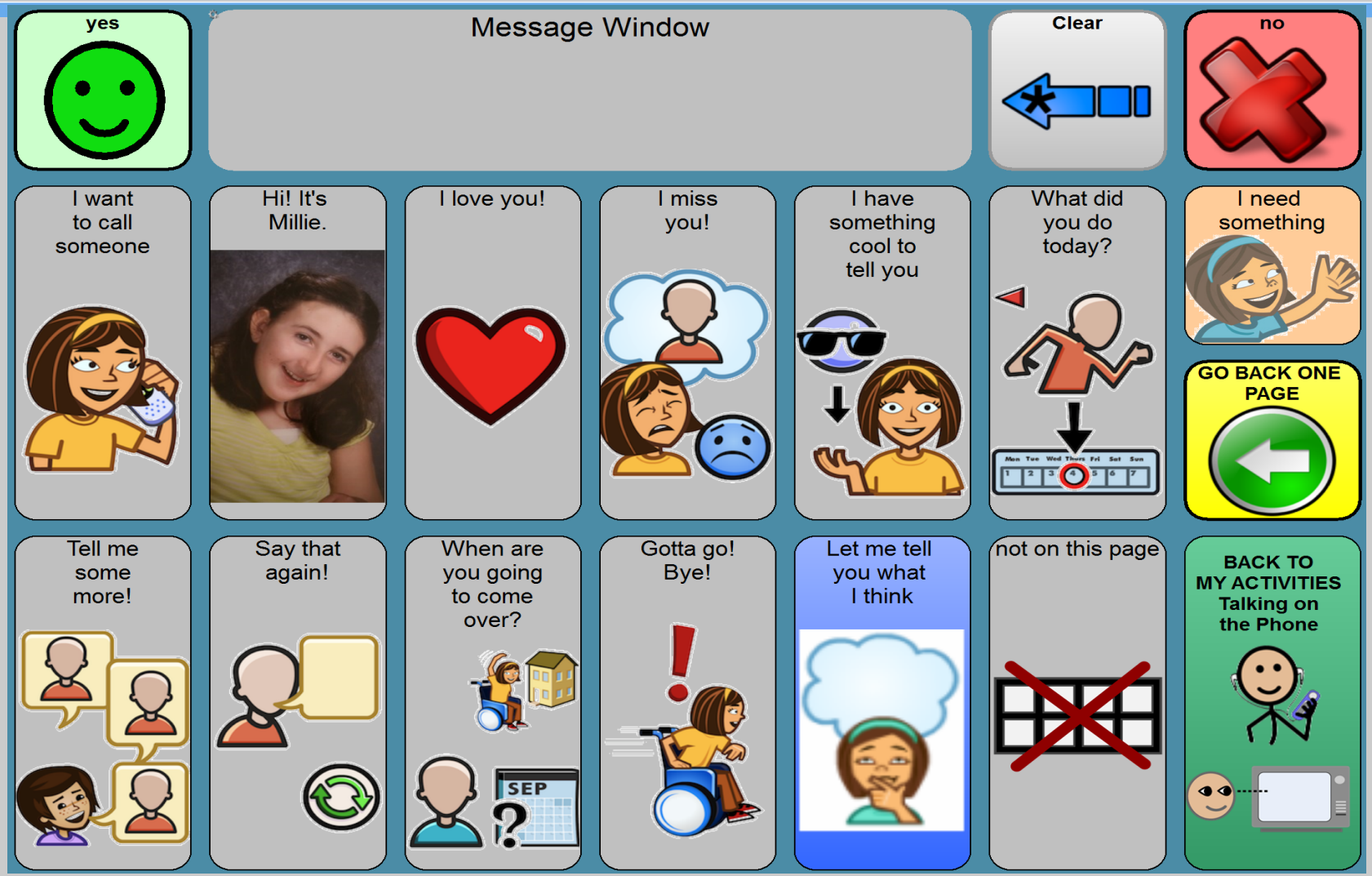
- Girls are **independently navigating** to different pages to communicate what they want to say, when they want to say it.

- The girls are more of an **equal partner** in the conversation when using phrases – reciprocal communication!

Phone Conversation



Telephone Page- Customized



Supporting Conversations with Eye Gaze Technology

- Acknowledge motor approximations
- Asking questions with only one answer doesn't work; even asking directed questions doesn't always work – why? Apraxia….especially with technology!
- Don't expect independent navigation to a specific page in response to a question – WHY? – Apraxia!
- If ask what he/she thinks about something – take to the comments page
- Keep it **natural!**

Tobii EyeMobile or PCEye Go with Laptop

- Gives access to more affordable eye gaze technology for communication – independent access
- Use with Tobii Communicator for communication

Tobii PC Eye Go ($1,995.00)

Tobii EyeMobile

Tobii EyeMobile

Tobii Bluetooth Speaker

- Works well for some
- Have to try before buy
- Smaller screen so need to assess for access
- Works with Windows Pro 8 tablets
- www.tobiiati.com

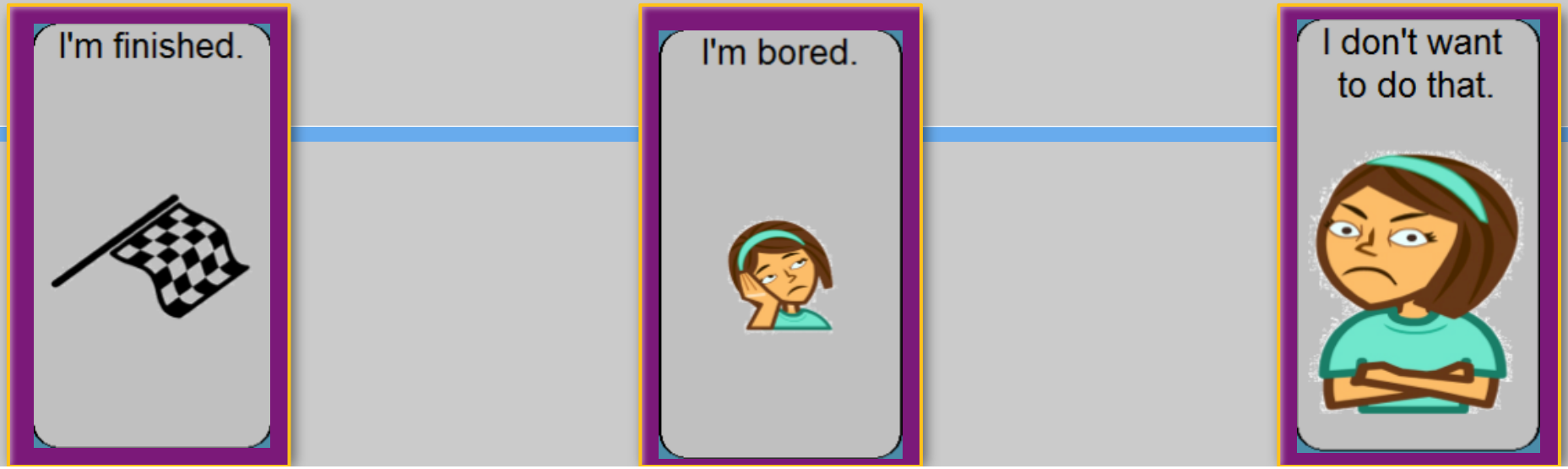
What we've learned:

- If you put academics on the communication device and make it about "right & wrong" they will stop using it
- Beginning communicators (and even more seasoned ones) cannot just get to an answer on their device due to apraxia
- Reduce the motor while increasing the cognitive demands
- Lots of errors in beginning communication for ALL kiddos not just AAC users

Communication Partner Basics

- Girls require a knowledgeable communication partner
  - Someone who can read their intent
  - Someone you can read their "best yes"
  - Someone who knows their device and can model language (have I talked about modeling enough??)
  - Someone who is not just asking questions
  - Someone who can chat and interact
  - Someone who can anticipate dysregulation and replace with communication
  - Someone who understands communication is a learning process that includes errors
  - Someone who is fun, flexible and supportive

Without access to appropriate communication, life is reduced to answering yes/no questions.



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The Dynamic Communication Book for Girls

- Developed by Pati King-DeBaun
- www.creativecommunicating.com (click on Catalog, then click Visit our NEW Shopping Cart, then Dynamic Communication Book - Girl)
- Over 100 Communication Pages set up in BoardMaker Plus with SpeakingDynamicallyPro
- Also set up for use in Tobii Communicator (Judy's eye gaze layout with 2 rows x 7 columns – easier motor plan); email Judy picture of what Pati sends you or copy of invoice and Judy will send content
  in my eye gaze layout electronically to you
- $250 US

Teach Me AAC-CLL – Conversations, Language, and Literacy:

- Specifically designed for students with Rett Syndrome
- Watch Pati's & Judy's websites for details

www.creativecommunicating.com (Pati's)

www.assistivetech4all.com (Judy's)

Avilable August 2014

FURTHER TRAINING