

Engaging Girls in Conversations Now!

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Vimeo Website

- Link to watch missing 3 videos from presentation
 - <http://vimeopro.com/user25322707/suki-foundation-presentation>
 - (copy and paste above link into website address in Internet Browser – i.e., Internet Explorer, Chrome, or Safari)
 - **Password:** suki2015
-

The Dynamic Communication Book for Girls

- Developed by Pati King-DeBaun
 - www.creativecommunicating.com (Under **Categories** on right side of screen, click on **Dynamic and Light Tech Communication Books**. Scroll to the middle of the page, **Dynamic (Older Version) Communication CD - \$250** – Click on the drop-down menu for the **Girl** version)
 - Also set up for use in Tobii Communicator (Judy's copyrighted 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 her copyrighted eye gaze layout electronically to you
 - **Judy's email:** judy@assistivetech4all.com
-

Judy's Article from Closing the Gap

- **Title of Article:** Eye Gaze Technology for Girls with Rett Syndrome
 - Email judy.jlariviere@gmail.com
 - Put in **subject line:** Closing the Gap Eye Gaze Technology Article
-

What is Rett Syndrome?

- “Rett Syndrome (RTT) is a rare non-inherited genetic postnatal neurological disorder that almost exclusively occurs in girls, but can be rarely seen in boys”
 - Rettsyndrome.org, 2014
-

What should we expect?



What should we expect?

- So much more than making choices between two foods, toys/activities, or DVDs
- Expressing needs and wants and that something hurts
- Being able to have a conversation where a girl/woman expresses her feelings, opinions, directing another's actions, protesting, asking questions, teasing/joking/playing, sharing experiences, and repairing communication breakdowns, etc.
- With core phrases

What should we expect?

- Generating novel messages with a language-based system with core words and extensive vocabulary
- Learning to read silently with comprehension, write, and spell with access to tools and materials they can use in conjunction with best practices for literacy instruction
- Core phrases first for social interaction and engagement and ease of communication
- Core words – supported through language and literacy

Communication is Conversation!

- Open-ended – you don't know what a girl is going to choose or say!
 - We are not mind readers!
 - Not a test so no right or wrong answer – no need for a distracter or non-preferred item as a choice – that is a test!
 - Communication truly opens the world for these girls
 - A girl is never too young or a woman is never too old to start finding ways to improve their communication and engage her in conversations!
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Conversation with Girl in Clinic

Just before her 10th birthday



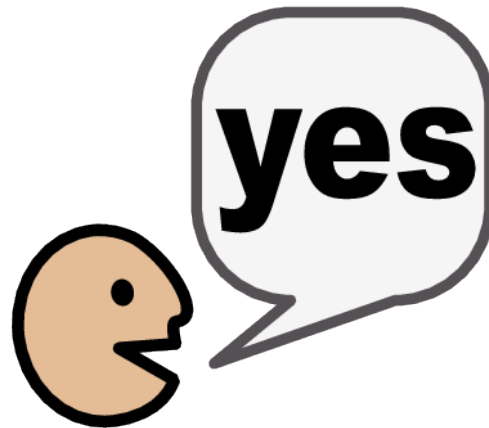
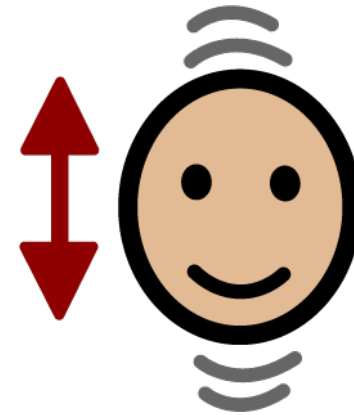
Communication is Conversation!

- Individuals with Rett Syndrome have incredible communication and learning potential – “untapped”
 - They communicate volumes through their eyes, facial expressions, and their bodies - “natural gestures” or nonverbal communication
 - Recognize and acknowledge when they are communicating
 - Children with RTT work incredibly hard to communicate so assume selections are intentional and have meaning – “presume competence”
 - Learning to communicate is not based on 100% accuracy!
-

Communication

- Includes building connections and strong emotional bonds with family members, including extended family, and friends
 - Want friendships, not just with adults, but with siblings, and same-age peers
-

Just need an observable movement for
a “yes” response/signal



Start with Partner-assisted Scanning (PAS)

- Present choices verbally and visually with a definite pause between and wait for the child to respond to indicate choice
 - Only need a “yes” response or a signal from child – lowers motor demands – focus on interaction and get more engagement
 - Allows for you to present more than one or two choices at one time; expand on what can access with hands directly
 - Incredibly useful technique for all individuals with RTT; especially at school for teaching academic concepts and active engagement in learning
-

Communication Flipbook

- Portable
- Goes in a purse, supports communication anytime, anywhere
- Use with partner-assisted scan and one of best “yes” responses
- Use Flip ‘n Talk from Mayer-Johnson (www.mayer-johnson.com)
- Communication functions – Something’s wrong/needs, things to do, opinions, questions, quick words



Not need label symbols first!

- Do not teach/test symbols individually first
 - Girls experience difficulty with learning these in isolation and out of context
 - Girls do not need to follow the typically progression from objects to photos to symbols with photos
 - Start with symbols and teach use them in a communication system in a natural and spontaneous context
- Model! Model! Model!**
- Girls are flexible and quickly learn a picture/symbol carries meaning!
-

Great for Young, beginning Communicators! AAC2Go in Go Talk Now iPad app

- Switch accessible (however, extra motor load)
- Use with partner-assisted scanning



Start > Home Talk > I want >

The image shows a sequence of screens in a language learning application:

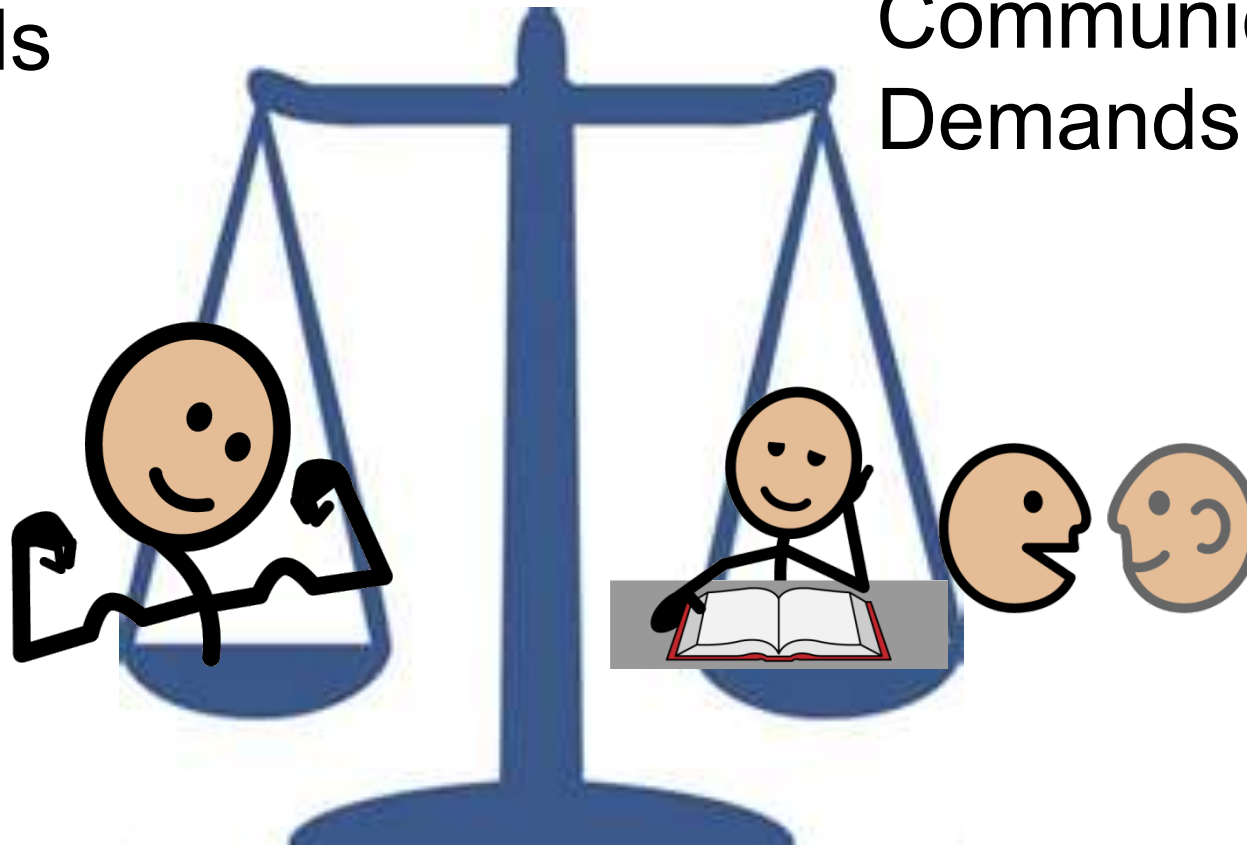
- How to ...**: A screen with a white background and a pink border.
- I want to talk.**: A screen with a white background, a pink border, and a cartoon boy with a speech bubble.
- Home Talk**: A screen with a white background, a pink border, and an illustration of a family.
- School Talk**: A screen with a white background, a pink border, and an illustration of a girl at a desk.
- My Words**: A screen with a white background, a pink border, and various word cards like 'red', 'back', 'eyes', 'fun'.
- Main Menu**: A screen with a white background and a pink border, containing several activity cards:
 - Home Talk**: A card with a family illustration and a red arrow pointing to the 'I want...' card.
 - I want...**: A card with a girl illustration and a red arrow pointing to the 'to eat' card.
 - to eat**: A card with a boy eating illustration.
 - to do something**: A card with a girl running illustration.
 - to do it**: A card with a girl illustration.
 - Go Back**: Two cards with a left arrow icon.
 - Start**: A card with a house icon.
 - Getting ready.**: A card with a girl illustration.
 - Bedtime**: A card with a girl sleeping illustration.
 - Watching TV**: A card with a family watching TV illustration.
 - Someone**: A card with a head icon.
 - a drink**: A card with a girl drinking illustration.
 - something**: A card with a hand holding a pencil illustration.

At the bottom, there are two navigation bars. The left bar has a back arrow, a home icon, and a refresh icon, with the text "Home Talk" below it. The right bar has a back arrow, a home icon, a refresh icon, the text "I Want", a person icon, a speech bubble icon, and a play button icon.

Success - It is always a balance between...

Motor
Demands

Learning and/or
Communication
Demands



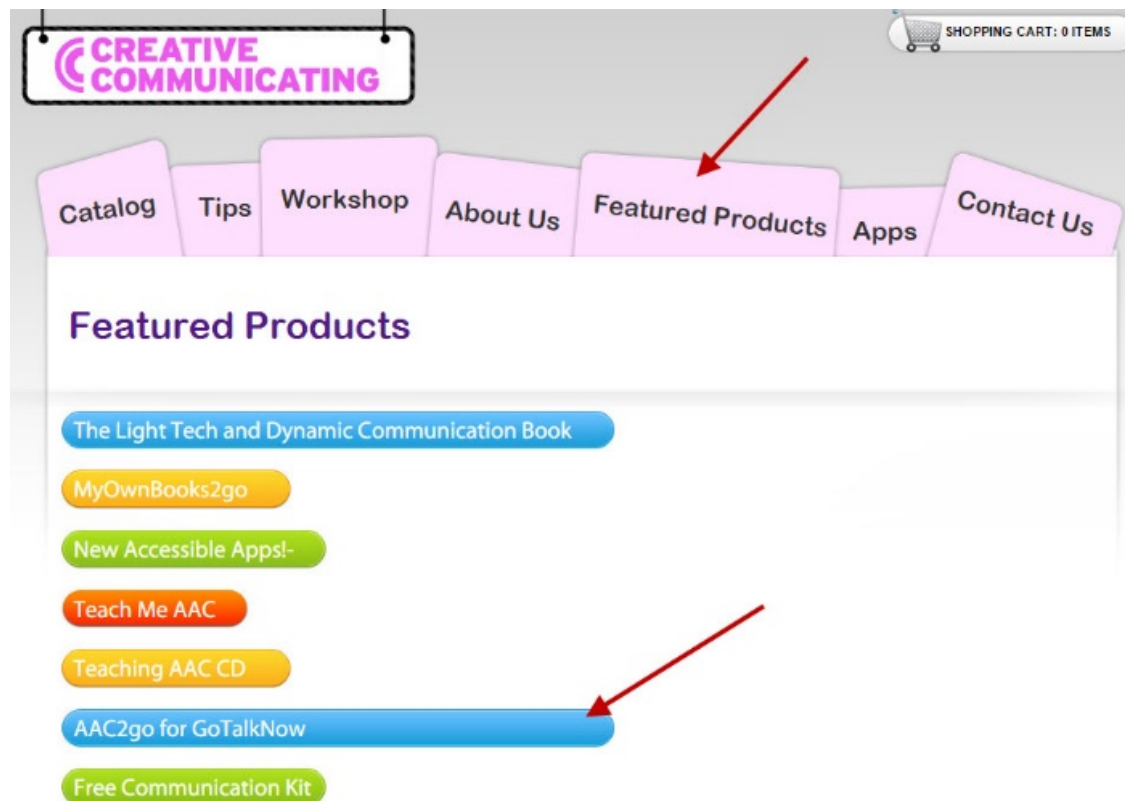
“Something’s Wrong...”

<p>Go Back</p> 		<p>Start</p> 	
<p>Go to bathroom</p> 	<p>I feel sick.</p> 	<p>Something hurts!</p> 	
<p>I'm tired.</p> 	<p>Your're mean!</p> 	<p>Leave me alone!</p> 	
	 	<p>Something's Wrong</p>  	



Communication iPad – Go Talk NOW \$79.99

- Purchase AAC2go for girls (\$50.00) from Pati King DeBaun's website – www.creativecommunicating.com



Final Stages - Teen AAC2Go for GoTalk NOW

The screenshot displays the AAC2Go software interface for GoTalk NOW. At the top, there is a search bar and two control buttons: a back arrow with a red 'X' and a trash can icon. Below these is a grid of 13 topic buttons, each with a title and an illustration:

- repairs**: Illustration of a woman with a magnifying glass.
- I want to talk**: Illustration of a woman with a speech bubble.
- Quick Talk**: Illustration of a woman laughing with the text "Ha! Ha! Ha!".
- Everyday**: Illustration of a woman eating and a man reading.
- Something is wrong!**: Illustration of a woman holding her stomach in pain.
- About something**: Illustration of a hand holding a sign that says "SOMETHING".
- About someone**: Illustration of a head with a lightbulb inside.
- I feel**: Illustration of a head with various emotion icons (happy, sad, angry, neutral).
- I want to build a sentence or spell.**: Illustration of the text "ABC" next to a list: "go", "like", "have".
- Questions**: Illustration of several question marks.
- Home Talk**: Illustration of a yellow house.
- School Talk**: Illustration of a school building.
- Activities**: Illustration of a group of people.

At the bottom of the interface is a dark green navigation bar containing three icons: a house, a circular arrow, and a person jumping. The text "Girl Start" is centered in this bar.

Extending Conversations > About Someone

I'll tell you about that person Extending Conversations

Go Back Start

What's new? I did something really fun. Have you seen any movies? I went to the movies ans saw...

I have something to show you. Tell me some more. Ask me some questions I have a question

I'll tell you what I think about that. What did you think? I'll tell you about that person Gotta go.

Extending Conversations

I'll tell you about that person Extending Conversations I'll tell you about that person

Go Back repairs pronouns Start

That person is nice. That person is smart. That person is fun! I think he is cute.

I like them. I don't like them. I think he is gorgeous! They're not nice.

They're not smart. They are a "Debbie Downer" That person is weird. Not my type.

About Someone

Access to a Voice is Empowering

- Access to light tech – paper-based system, without voice output is not enough
 - Tends to be choice-driven and does not tap into true communication abilities
 - Not support conversation – back and forth interactions; expansion of communication abilities
 - Started working with a girl where using Picture Exchange System (PECS) for two years; not the same as access to her voice in conjunction with other natural forms/modes of communication
-

Girl who has gotten “stuck” at switch access and light tech

- Used eye gaze system 3x in clinic over a period of 2 years
 - Had health issues and turnover of team members
 - Start from scratch each time
 - Not tapping into true potential
 - Using eye gaze – tired; pulled out light tech flipbook along with single message voice output – “Yes, that one”
 - Shutting down – communicating very clearly with body language and level of engagement
 - Video – Independent Access is Key
-

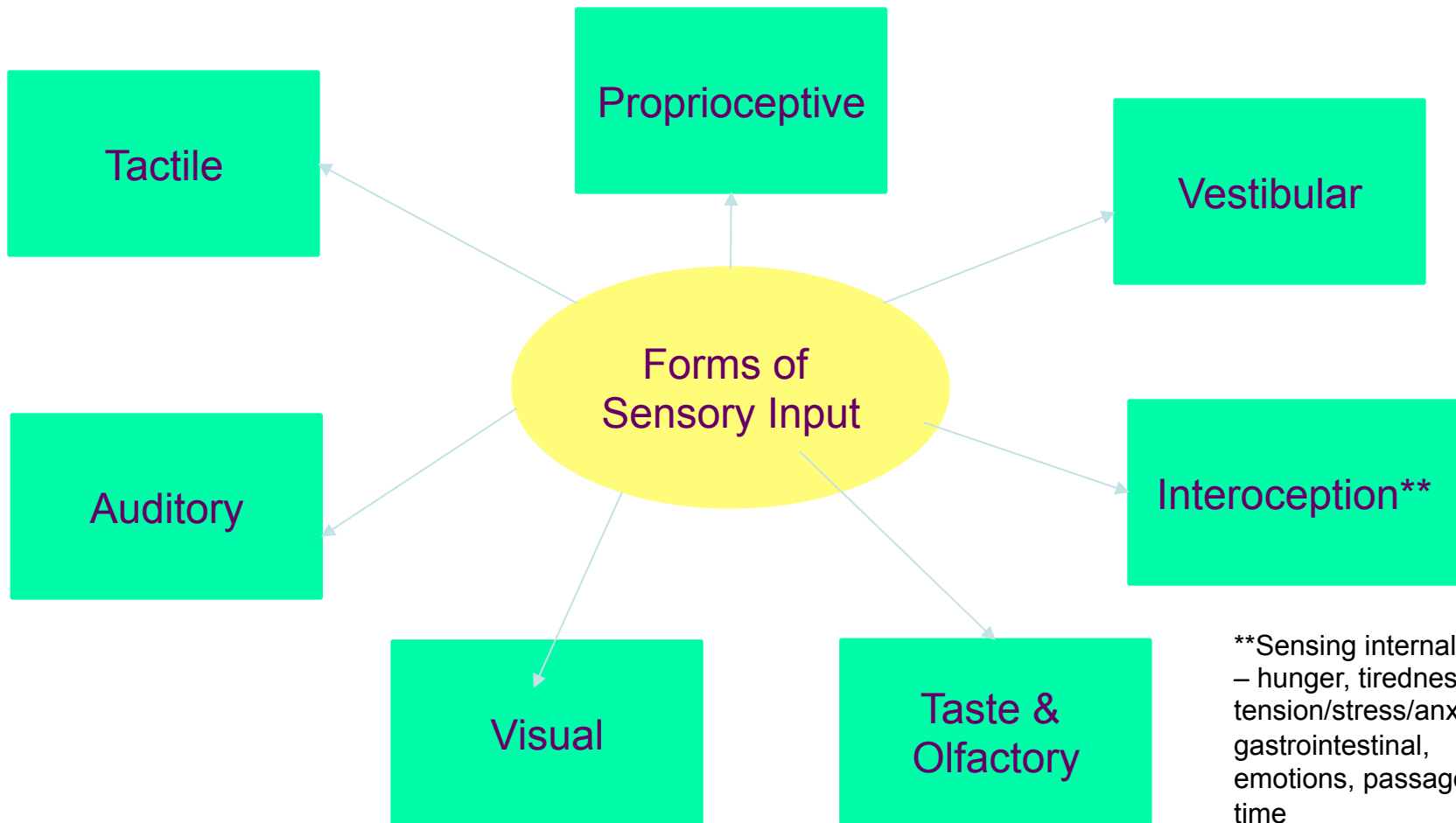
Always Communicating!!!!

- Using eyes – looking at communication partner; even how use eyes and eye brows
 - Get the “look” or “stink eye”
 - Facial expressions
 - Body movement
 - Proximity (especially for girls who walk independently)
 - Need to observe more and acknowledge what the girls use to communicate
 - Highly social and strong desire to communicate and have a conversation
-

Sensory Regulation

- Monitoring responses to sensory input – making sure they are in a good zone and “ready” to communicate and participate
 - If they are not, their observable behaviors (i.e., fussing, walking around, or closing eyes/falling asleep) may be misinterpreted as inability to do or “refusal” to work
-

Forms of Sensory Input

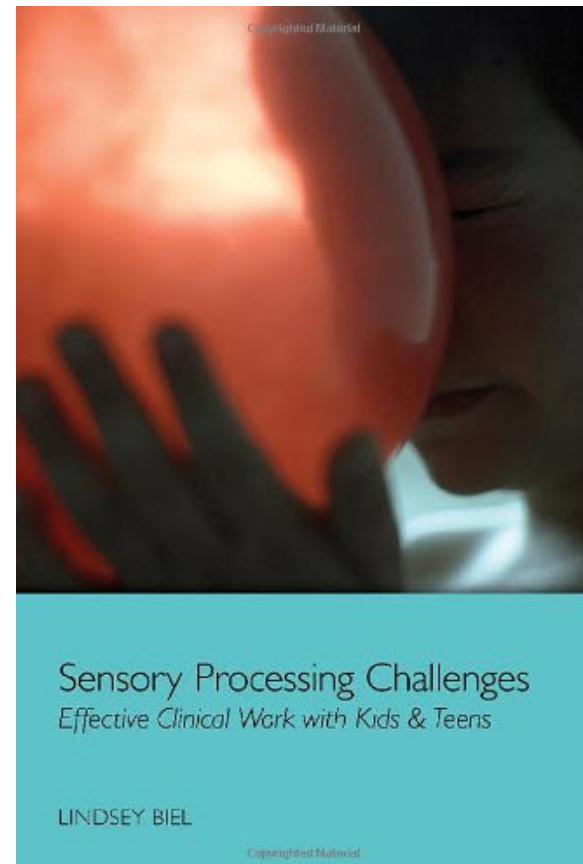


Processing of Sensory Input

- Each individual's response to various forms of sensory input is unique – avoid or seek/crave or neutral
 - Parents know what makes their child upset or happy – clues to processing of sensory input – close links to behavior
 - If possible, evaluation by an Occupational Therapist who specializes in assessing and treating Sensory Processing Disorder
 - Develop and implement a sensory diet for home and school
 - Intervention to improve how handle and respond to sensory input in various environments
-

Recommended Website & Book

- <http://sensorysmarts.com>
- Sensory Processing Challenges: Effective Clinical Work with Kids & Teens
- By Lindsey Biel, M.A., OTR/L
© 2014
- Important to understand
- Is it sensory or is it behavior?
- Kindle version available



Sensory Regulation

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

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

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Responses to Sensory Input

- Requires assistance to walk and/or stand

Levels of Sensory Regulation	Description
Level 3	Asleep or drowsy, eyes shut or agitated/crying/whining; unable to participate
Level 2	Cranky/fussy; closing eyes; not maintaining head upright position; fleeting or no eye contact
Level 1	Calm, alert and focused, head up, making eye contact and/or attention to activity at hand.

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