

Enhancing Communication: Improving Access and Regulating Sensory Input



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My Background



- First girl with Rett Syndrome (RTT) – 14 years ago – challenges with access – two switch step scanning
- For the past 11 years, been consulting with girls, families, and teams throughout the United States through my private practice
- Communication Specialist at Katie's Clinic for Rett Syndrome at Children's Hospital & Research Center, Oakland in December 2008 – serving over 130 girls
- As young as 2 ½ years old and up to 30 years old



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My Goals



- Show you what girls are communicating using eye gaze technology – so much more than what people have known or expected these girls to do
- Importance of engaging girls in conversation – moving beyond choice making and giving them a means to interact socially
- What you can do now to expand what your daughter or a girl with whom you work is able to communicate using light tech means, apps on iPhone or iPad, and other technology
- Tomorrow – more about eye gaze technology and literacy!

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Communication



- Open-ended – you don't know what she is going to say!
- 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!
- Girls work incredibly hard to communicate so assume selections are intentional and have meaning – “presume competence”
- Includes a range of functions beyond choice making
- Do not need to teach individual symbols before using them; No “find the,” “look at the” – testing and if doing it with technology – becomes target practice

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Enhancing Communication for Girls with Rett Syndrome (RTT)

1. Processing of sensory input – get a girl ready to communicate and learn; difficulties with processing of sensory input can be misinterpreted as inability to do or understand – affects attention and focus and ability to engage
2. Take into account a girl's apraxia when communicating, especially when using technology; one of biggest challenges; very social so talk with them



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Enhancing Communication for Girls with Rett Syndrome (RTT)

3. Supporting ease of access to technology (light tech and high tech)
 - Not working for 100% accuracy
 - It's communication, not a test!
 - Repetition with variety
 - Girls have untapped communication and learning potential
 - See dramatic results quickly!
 - Be flexible



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Processing of Sensory Input - Various Forms

- Tactile
- Proprioceptive – sense of body parts in space without vision
- Vestibular – how the body handles movement
- Auditory
- Visual
- Taste and smell
- Interoception – sensing internal status – hunger, tiredness, tension, bowel and bladder, feelings, passage of time



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Processing of Sensory Input

- Each girl's response to various forms of sensory input is unique – avoid or seek/crave or neutral
- 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



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Some signs that a girl's sensory system is "out of regulation"

- Always on the move – walking aimlessly around a classroom
- Only able to sit for short periods of time during therapy or school
- Screams or becomes agitated on the playground or during assemblies
- Falls asleep or "zones out" at school on a consistent basis
- Closes eyes when outside in the sun or at school
- Inconsistent in responses at school but reports of more advanced communication skills at home or during private therapy sessions
- Note: when have gas/constipation, "out of regulation"

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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.

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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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Sensory Regulation Chart

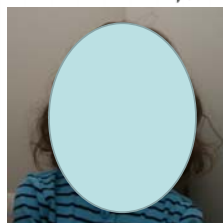
© Lariviere, 2009

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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3-year old girl

- First time using Tobii C12 with CEye Module; 16 ½ minutes into eye gaze trial
- Independently navigated to "Something's wrong" said "tired;" had a short break; starting up again after break
- Repeatedly selecting the same button and using other modes of communication – strategy
- Often girls will tell us what they need to help them stay "regulated"



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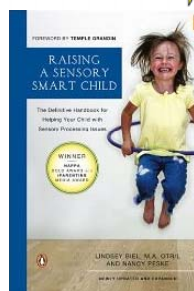
Video of girl during Tobii eye gaze trial

- Selecting "I'm tired" and looking to communication partners
- Observe communication intent with selections on Tobii in conjunction with other modes of communication (i.e., looking to communication partner)
- Very quick in using eye gaze layout on the eye gaze pages designed by Judy Lariviere; based on natural eye movements and used successfully in eye gaze trials with well over 100 girls and women with Rett Syndrome

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Recommended Reading

- Raising a Sensory Smart Child: The Definitive Handbook for Helping your Child with Sensory Processing Issues
- By Lindsey Biel, M.A., OTR/L and Nancy Peske
- 2009 edition



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Apraxia

- Interferes with a girl's response to a request to do something upon command, especially out of context
- Affects a girl's motor movements, including their eyes, when using technology
- Does not mean a girl does not understand what you ask her to do; just means that the message from her brain to a part of her body gets scrambled; longer response times
- When a girl initiates a movement based on motivation, apraxia fades away
- [Apraxia with eye gaze](#)
- [Initiated navigation – no evidence of apraxia](#)



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Access

- Determine access first
- Must represent an easy motor plan; build on natural spontaneous movements and gestures
- Avoid holding back communication development while hand use or other motor skills improve
- Common limiting factor – exclusive use of a girl's hands with limited progress; hand use varies day to day
- Ultimately, all girls need an independent means of access to a dynamic display communication device so that they can independently navigate to different pages on their own



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All girls have a natural “yes” response

- Need to observe to find out what it is; subtle
- In clinic, do you want to listen to music?
 - Wait and look for response – in most cases the girl will smile or smile and look at me; in some cases, eye brow raise, vocalize or slight head nod
- Build on natural “yes” response; acknowledge it to shape it and increase its frequency, consistency, and ease with which a girl uses it
- Absence of “yes” response can be a no
- Integrate it into partner-assisted scanning with light tech communication pages or iPad



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Partner-assisted Scanning

- Present choices verbally and visually with a definite pause between and wait for the girl to respond to indicate choice
- Only need a “yes” response – 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
- Helps when having a tough motor day or motor time when hands not work as well to make choices – typically can give a “yes” response on those days
- Easier than using eye gaze frame with choices

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Partner-Assisted Scanning

- Video showing girl using partner-assisted scanning with Judy
- Judy verbally names each item while presenting it visually on Flip ‘n Talk (related to what girl thinks about using her eyes to make selections on communication device with eye gaze) and waits for the girl's response
- In the video, you see the girl (teenager) indicating a “yes” response by looking at Judy and looking away for her “no” response

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Partner-Assisted Scanning – Light Tech version

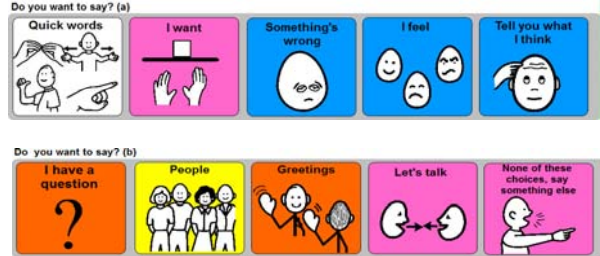
- Flip 'n Talk Book – www.mayerjohnson.com
- \$29.00 US



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Best Yes for Expanding Communication

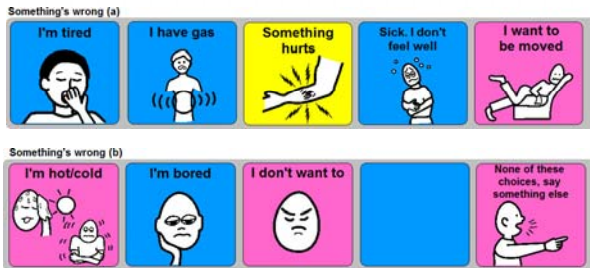
- Pragmatically Organized – Main Pages



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Best Yes for Expanding Communication

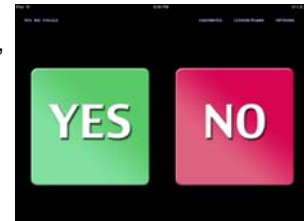
- “Something's wrong” page



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Answers: Yes No

- iPhone, iPod Touch, iPad
- \$3.99



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Answers: Yes No Favorites



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Answers: Yes No Happy Mad



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Answers: Yes No Happy Mad



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iPad - TouchChat HD - \$149.99

- Easily customized for access for direct touch or communication partner selects based on "yes" response
- Does not include scanning
- Supported communication – girl needs assistance accessing it
- SilverKite (branch of Saltillo)
- iShare; Windows Desktop Editor



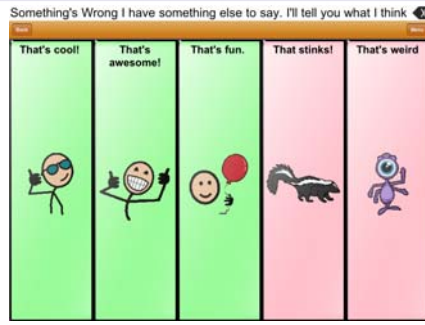
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Fully Customizable – Very Easy



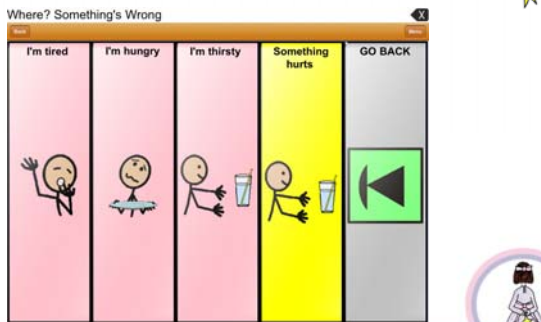
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I think – one selection and automatic return



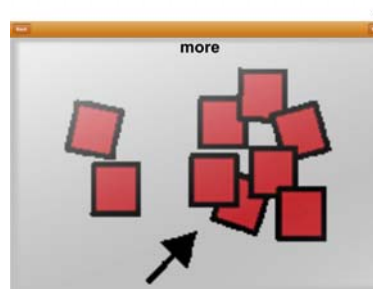
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Something's Wrong - Control Navigation



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Present one symbol at a time in TouchChat HD and swipe to the next



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Video Example using iPad for social interaction

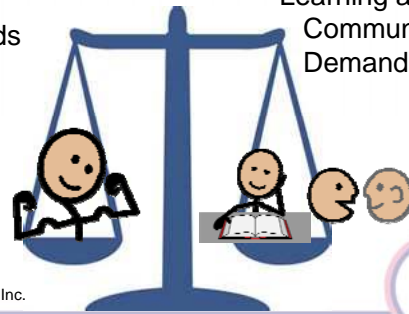
- See girl sitting on floor in clinic session using iPad with Judy
- Judy is engaging girl in social interaction – greeting
- Typically this girl uses her hands to access iPad but she is experiencing some difficulties with this during her afternoon clinic appointment – she is tired
- Instead the girl is using her eyes to respond to what Judy is asking and even in response to Judy activating the iPad to share a voice output message
- Once observers leave, girl reaches out to touch the iPad to select “gotta go” as she wanted to be finished for the afternoon; “motivation” helps to override a girl’s motor apraxia

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Success = a balance between...

Motor Demands

Learning and/or Communication Demands



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Optical Head Pointing

- Provides access to more options/choices than through hand use and ability to navigate between pages
- Gives girls a “voice” which increases engagement and motivation significantly over paper-based symbol systems

TrackerPro



HeadMouse Extreme



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Optical Head Pointing

- Motor pattern transfers to eye gaze technology when reflective dot placed between eyebrows just above bridge of nose
- Use communication-based software with built-in dwell feature – Tobii Communicator or BoardMaker Plus

SmartNav 4



CameraMouse



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Optical Head Mouse Options

- Madentec's TrackerPro
 - <http://www.ablenetinc.com/>
- Origin Instruments HeadMouse Extreme
 - <http://www.orin.com/>
- One week evaluation/test drive
- SmartNav4
 - <http://www.naturalpoint.com/smartnav/products/compare.html>
- Camera Mouse 2011 (uses webcam)
 - <http://cameramouse.org/>



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Teaching Use of Optical Head Pointer

- SoftTouch's Teaching Access Ability – mouse movements
- Teach girls in Clinic in under 30 minutes
- Quick at learning head movements
- Reinforce with Reader Rabbit Toddler (responds to mouse movements)



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Video of 3 year old girl learning to use Optical Head Pointer

- Video of very young girl using TrackerPro with Mouse activity in SoftTouch's Teaching Accessibility CD
- The video shows the girl learning to move the object to the left side of the screen using her head movement and in the second video from the bottom to the top (up movements)
- In some cases, the girl is initiating doing these movements without prompting – evidence of learning how to use head movements to move the mouse pointer on the computer

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BoardMaker Plus; Tobii Communicator - Video of 3 year old girl

- Video of the same girl using TrackerPro with Judy's eye gaze page set in BoardMaker Plus (also works in Tobii Communicator) using built-in dwell feature of these programs
- Dwell (how long girl must maintain mouse pointer depicted by a thick red box around button before the button is selected) is set to around 500 ms or 0.5 seconds, can be lower initially
- In video, the girl is tired as she has been very focused and working hard while learning how to use optical head pointer

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BoardMaker Plus; Tobii Communicator - Video of 3 year old girl Cont'd

- She selects "I need a break" on the Something's Wrong page in Judy's eye gaze layout and then on the "break" page selects "I'm thirsty" and "I need to go for a walk."
- She also hovers over "I'm all done" a couple of times but this button is not selected; Judy acknowledges this motor approximation by saying "I saw you were trying to tell me that you're all done."
The girl responds by looking at me to affirm and giving the sign for "all done"

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Judy's Eye Gaze Trial Page Sets – Design is Copyrighted

- Preschool and elementary school age versions for Tobii Communicator will be available June 18, 2012 (DynaVox version available after that)
- Middle school and high school version for Tobii Communicator will be available at the same time. (DynaVox version available after that)
- Can also be used with optical head pointers (i.e., TrackerPro)
- Check website <http://jlariviere.com> for details beginning in June 2012
- Cost: \$75.00 US



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Conclusion

"There is something that is much more scarce, something far finer, something rarer than ability. It is the ability to recognize ability."

Albert Hubbard



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Website for Handouts

<http://orsa2012.jlariviere.com>



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