

Eye Gaze Technology for Girls with Rett Syndrome: From Trials to Conversations

ABSTRACT

Eye gaze technology represents the best means of access to an AAC device for many girls and women with Rett Syndrome (RTT) as it builds on their natural use of their eyes to socially engage and connect with others. However, this technology is not always being used to unlock the girls' hidden communication and learning potential. Girls are having the opportunity to participate in trials using AAC devices with eye gaze technology, but these may not be successful due to the page layout or criteria for their performance. Even when girls gain access to an eye gaze system, they are often provided with access to limited vocabulary sets until they demonstrate mastery. It is important for educators and clinicians to implement page layouts and strategies that have been found to be effective in supporting girls in moving beyond choice making and requesting by engaging girls with RTT in conversations.

BACKGROUND

Eye gaze technology is "opening up the world" of communication and literacy learning for individuals with Rett Syndrome (RTT).^{*} Eye gaze technology gives girls and women with RTT easy and independent access to their "voice" by capitalizing on their eye movements that they naturally use to socially engage and connect with people. Essentially, their eyes represent their index fingers for pointing; eye gaze



Image 1: Photo of a 3-year-old girl sitting on her Dad's lap during her session with Judy Lariviere at Katie's Clinic for Rett Syndrome & Related Disorders at UCSF Benioff Children's Hospital Oakland. She is using the Tobii I-12 with Judy's eye gaze trial page set in Tobii Communicator.

technology gives the girls a direct means of access to a dynamic display Augmentative and Alternative Communication (AAC) device, which enables them to independently navigate across pages to express what they want to say, when they want to say it and how they want to communicate what is on their minds and in their hearts. Given the high cost of eye gaze technology for an AAC device, it has often been viewed as the "cadillac" of access methods.

As a result, eye gaze technology has only been considered after a girl or woman has demonstrated limited progress or lack of success with hand or switch use. However, at this point in time, there is no other access method that most girls and women with RTT can learn as quickly and effortlessly as eye gaze technology. This significant progress has been demonstrated in over 250 initial eye gaze trials during which girls and women with RTT, ranging from 2

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conferences nationally and internationally about her work with children and adults with RTT. In addition, she is a full-time Professor as an Assistive Technology Specialist in the Disability Resource Center at Skyline College in San Bruno, CA. Currently, Judy is working in collaboration with Pati King-DeBaun in developing an online AAC interactive curriculum called "Teach Me AAC - Conversation, Language & Literacy (CLL) for Rett Syndrome," which will be available soon. Judy also has developed customized eye gaze trial page sets for girls and women with Rett Syndrome, as well as Eye Gaze Video Players and Eye Gaze Music Players for children, as well as teens and adults in Tobii Communicator. These are available through www.assistivetech4all.com.

WHAT IS RETT SYNDROME?

Rett syndrome is “a rare genetic postnatal neurological disorder that occurs almost exclusively in girls, but can be rarely seen in boys” (<http://www.rettsyndrome.org/about-rett-syndrome>; Accessed October 12, 2014). Rett Syndrome results from a mutation in the MECP2 gene on the X chromosome; given there are over 200 mutations of the MECP2 gene, individuals with Rett Syndrome present with a diverse range of abilities. Apraxia and severe physical challenges affect their ability to speak, walk, eat and, in many cases, use their hands. Cognitive assessment in children with Rett syndrome is extremely difficult; recent eye tracking research and detailed descriptive accounts of what girls and women are expressing spontaneously using an Augmentative and Alternative Communication (AAC) device with eye gaze technology are providing insight into their true communication and learning potential.

to 40 years of age, have learned how to use my customized eye gaze trial page set. The layout of my customized eye gaze trial page set is designed to build on their natural patterns of eye movement horizontally across a page and then either up or down. Given this eye gaze trial page is set up in Tobii Communicator, it works on all Tobii Eye Gaze systems.**

I have also used this same page set with girls and women with RTT using Tobii’s PCEye Go on a Windows-supported tablet as Tobii EyeMobile (as shown in Image 2) or on a laptop computer. The PCEye Go represents a significantly less expensive eye gaze system that plugs directly into a USB port on a Windows-supported tablet,

including the Surface Pro 3, or on a laptop computer running the Windows operating system. The PCEye Go provides a more affordable eye gaze option for school districts and families to use with computer-based technology they may already have to enable girls and women with RTT to have independent access to their “voice,” which often stays locked within using other methods of access.

Over the past five years, ever since eye gaze technology was introduced as a means of access to portable, battery-operated AAC devices, an increasing number of girls and women with Rett Syndrome have had the opportunity to trial and use eye gaze technology to support their communication. Use of eye tracking technology has capitalized on the girls’ and women’s natural use of their eyes for communication. As a result, girls have quickly learned how to use their eyes to make intentional and appropriate selections. I have used my customized eye gaze trial page sets that build on a girl’s natural and spontaneous use of horizontal eye movements with over 250 women and children with RTT through my private practice and Katie’s Clinic for Rett Syndrome & Related Disorders at UCSF Benioff Children’s Hospital Oakland. Typically, they are communicating using eye gaze technology within the first 20 minutes of being introduced. In the many years that I have worked with individuals with Rett Syndrome, assessing and implementing a wide variety of access methods, including hand use for direct selection and two-switch access for step scanning, eye gaze technology by far represents the quickest and easiest access method for most girls and women with Rett Syndrome to learn. They naturally use their eyes to communi-

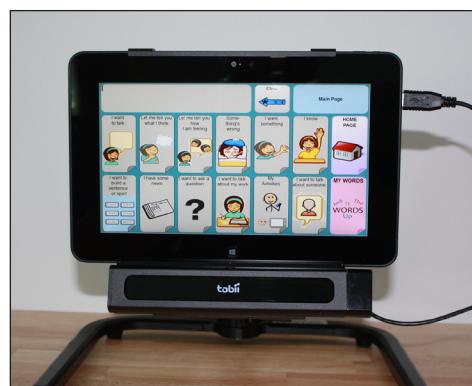


Image 2: Tobii EyeMobile with Main Page from Pati King-DeBaun’s Dynamic Communication Book for Girls

cate. When girls are capable of touching or make selections with their hands, observation reveals that they lead with their eyes first and then their hands follow. In addition, out of the 150+ girls and women with whom I have worked through Katie’s Clinic for Rett Syndrome & Related Disorders, I have only seen one or two girls effectively use their hands to directly access a communication-based app on an iPad. If girls are using their hands, often their communication skills are limited by their motor abilities rather than by what they are capable of expressing. Through the use of eye gaze technology, girls and women with RTT are making dramatic changes in their expressive communication.

CONSIDERATIONS FOR SUCCESS

There are several special factors that are important to take into account when working with girls with RTT in order to support their success in their communication and literacy learning experiences.

Apraxia represents one of the most significant challenges that individuals with RTT experience. Rettsyndrome.org defines apraxia as “difficulty with the usually automatic planning done by the brain to execute voluntary movements.” (<http://www.rettsyndrome.org/for-families/glossary>, accessed on 10/19/2014). Another way to view apraxia is the difficulty with completing motor acts, particularly in response to a command or request; it affects the ability to organize one’s body in order to give an observable response or complete a motor act. Apraxia does not mean a girl with RTT cannot understand or do; it interferes with her response to a request to do something, especially when this is out of context of a natural

*Given this author has only used eye gaze technology with girls and women with Rett Syndrome (RTT) and has not yet had the opportunity to conduct eye gaze trials with boys with RTT or MECP2-related disorders, this article will focus on its use and application to girls and women with RTT.

**Given the recent release of NuVoiceTM 2.0 software for Prentke Romich Company’s (PRC) Accent 1200 with NuEyeTM Tracking System, I will now be able to program the same page layout with the shape and layout of buttons on a page that supports the natural eye gaze movements of girls and women with RTT. As a result, this same page layout and eye gaze trial page sets will be available for girls and women very soon.

situation. Apraxia affects all motor movements, including those of their eyes. A girl's absence of a response or a delayed response to a request, particularly when it is out of context of a natural situation, is often misinterpreted as her inability to understand what is being asked of her or that she has not yet learned the concept and needs additional repetition; a girl's apraxia often accounts for these misinterpretations.

It is important to recognize that when a girl spontaneously initiates a movement, based on motivation or a strong emotion, typically the effects of apraxia are reduced. For example, during extended eye gaze trials, when girls are using a loaner AAC device with eye gaze accessory at school and at home, teachers and therapists always comment that the girls "can always find their music page," even when they need to navigate through several pages to access it. One example of this is a 10-year-old girl who had completed an extended trial with a Tobii C12 with CEye Module using my Eye Gaze Trial Page set and there were delays in submission of the funding due to changes in the family's insurance. Eight months later, when she had a trial session with a Tobii I-12 using the same page set, she immediately made the following selections: "Goodbye," to go to this page where she selected "Goodbye" and "Gotta go" and then looked at me to clearly communicate what she was thinking. When her teacher walked over to her and responded, "I don't think so," the girl immediately selected "Something's Wrong," and on this page selected, "I need a break," and then on the "Break" page, selected the button, "I want to listen to music" and then selected her favorite music video on this page. It is important to note that this represented an indirect path to get to her music page, but she remembered this from her eye gaze trial eight months earlier. Girls with RTT are always highly motivated by their favorite music and/or videos. Most often, a second favorite is books.

A strategy for working around a girl's apraxia is to provide "gentle" guidance or just talk with her naturally, rather than giving direct commands telling her what she needs to do and then wait quietly, observing any response the girl gives, regardless of how subtle it may be. Acknowledge a girl's response and give meaning to it. For example, when reading a book, the statement, "Oh, I see a beautiful butterfly with purple wings" will be much

Always acknowledge and give meaning to any and all communication attempts

more effective than "Look at the butterfly" or "Find the butterfly." Another approach is to acknowledge when you see a girl looking at something by saying, "I see you looking at the butterfly," and then make a comment about it, such as "It has beautiful purple wings." Quite often, as soon as you acknowledge what the girl is looking at, you will also see her smile in response to your statement or spontaneously look to you in agreement. This same approach can be used when a girl is using an eye gaze system and you are reading a book with her. You can model the use of comments, core words or descriptive words on her eye gaze device while you are talking about a book you are reading to her. Then wait and observe her response, which may be using her natural gestures or selections on her eye gaze system.

Sensory regulation represents another important consideration when working with girls with RTT. A girl's difficulty in modulating sensory input can result in her being overly responsive or under responsive to different forms of sensory input. The various forms of sensory input that an individual processes include visual, auditory, tactile, proprioceptive or sense of body in space without vision, vestibular or sense of movement, as well as taste and smell (Biel, 2014; Biel & Peske, 2009). One form of sensory input that is rarely talked about, but plays a major role in a girl's attention and engagement in any activity is interoception (Taylor, 2006). This refers to the perception of hunger, thirst, gastrointestinal functioning, level of fatigue based on quantity and quality of sleep and stress or anxiety. Additional information about sensory processing challenges can be found at <http://sensorysmarts.com/index.html>.

Given a girl's level of sensory regulation influences her ability to communicate, learn and demonstrate "what she knows" through a motor response, I developed charts that describe a girl's level of sensory regulation to use as guidelines for deter-

Responses to Sensory Input	
• Requires assistance to walk/stand	
Levels of Sensory Regulation	Description
Level 3	Asleep or drowsy, eyes closed to reduce one form of sensory input
Level 2	Fidgeting; not establishing eye contact, eyes starting to close; decreased attention
Level 1	Alert and focused, making eye contact with communication partner and/or attention to activity.

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Image 3: Lariviere's Responses to Sensory Input Chart outlining observations across various levels of sensory regulation for a girl who requires assistance to walk or stand.

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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Image 4: Lariviere's Responses to Sensory Input Chart outlining observations across various levels of sensory regulation for a girl who walks independently and can stand up from a sitting position independently.

mining when a girl is ready to communicate, participate and learn. These charts have been used in classroom and therapy settings to assist educators, clinicians and parents in identifying a girl's level of sensory regulation. The charts resemble a rocket ship getting ready to blast off, so girls are "ready" when their responses to sensory input are at Level 1.

Separate charts were developed for girls who require assistance to walk or stand as shown in Image 3 and for those girls who walk independently (see Image 4) as these two groups of individuals with RTT often have different sensory profiles and responses to sensory input.

It is important for educators, clinicians, parents and other communication partners to continually observe for signs that indicate when a girl's sensory system is moving out of a regulated state, i.e. from a "green" Level 1 to a "yellow" Level 2 as shown in Image 5. Once these indicators are recognized, it is important to give her some form of sensory break to get her back into Level 1 before continuing with

the lesson or therapy session. If the signs are missed or a girl in a classroom setting is not given a snack or something to drink until the scheduled "snack" or "lunch time," then the girl's sensory system will typically move into a "red" Level 3 of sensory regulation. As a result, a girl may fall asleep or just close her eyes to cut out the sensory input.

Access is the key to unlocking the true communication potential of individuals with Rett Syndrome.

TRIALS WITH EYE GAZE SYSTEMS

Even though more girls and women are having the opportunity to participate in trials using AAC devices with eye gaze technology, these may not be successful due to the page layout or criteria for their performance. In addition, all AAC devices with eye gaze technology are NOT the same. When looking at eye gaze systems, it is essential to take into account the girl's positioning and natural movement patterns in relation to the size of the eye gaze system's track box. The track box is an invisible area in front of the eye tracking cameras located in the eye gaze accessory within which a girl's eyes, head and body can move while her eyes continue to be tracked. The dimensions of the track box are unique to each eye gaze system and are expressed in terms of height for vertical movements, width for lateral movements and depth for forward and backward movements. The track box dimensions are expressed in terms of the optimal distance that a user's eyes must be positioned from the eye gaze accessory and typically range between 24 and 27 inches. It is essential to match the eye gaze system to the girl's spontaneous and natural eye gaze patterns, head and upper body movements, as well as positioning in sitting or standing. A bigger screen is not always better. A girl's range of natural eye movements may be smaller and may not require the use of a larger screen.

Just because a girl is an independent walker does not mean she cannot use an eye gaze system for communication. In this author's experience, many girls walk up to an eye gaze system that is positioned on a table in a commonly used room at home (i.e., living room, kitchen, etc.) that they can access independently. In these situations, the eye gaze system is positioned at the correct height and distance from their eyes so they can stand and make their selections to initiate interactions.

Over the past five years, many eye gaze systems have become commercially available for portable, dedicated AAC devices and, more recently, for Windows-based tablets, laptops and desktop computers with external monitors. Although this article will focus on a few systems that have been used by this author and found to work consistently for the most number of girls and women with RTT, there are other systems out there. Even though these systems will not be discussed in this article that is not to say that these eye gaze systems will not work for them. It is incredibly important that for any eye gaze system that is being considered for a communication system, eye gaze trials need to be conducted with it. Equally important is to try at least two different eye gaze

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/drink; change of activity
UNDER STIMULATED	Level 3	Shutdown; falling asleep; needs strong sensory input to "rev up" system

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Image 5: Lariviere's Sensory Regulation Chart provides an integrated color-coded version of the various levels of sensory regulation based on how a girl is processing sensory input in her environment. This chart includes a description of some of the strategies that can be used to support a girl in returning to a Level 1 of Sensory Regulation when she is ready to communicate and learn.

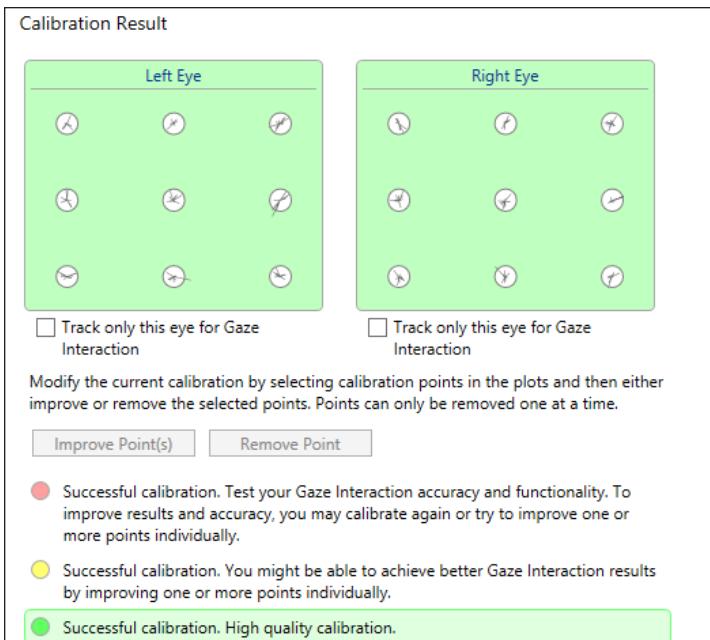


Image 6: Screenshot of a Calibration Result with a Successful 9-point Calibration on a Tobii I-12. The markings in the center of the circles indicate that the individual fixed and held his/her gaze on the presented visual stimulus during the calibration process.

systems with an individual with RTT so that a comparison can be made based on ease of access.

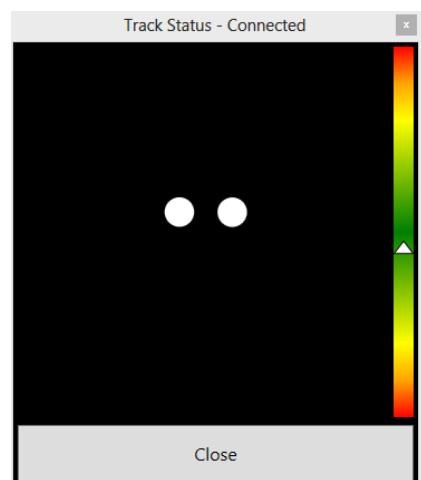
In order for a girl with RTT to be successful in any task or activity, it is important to balance the motor demands with the learning and/or communication demands. When conducting eye gaze trials, this represents a new access method for a girl that has increased motor demands. Although this is not standard practice when using eye gaze technology, I do not have a girl calibrate the eye gaze system during her first eye gaze trial session(s).

Guiding principle: For girls to be successful, the motor demands need to be balanced with the learning and/or communication demands.

Having a girl maintain her gaze on a series of five buttons in a specified order, even when a highly motivating photo or video is used, taps directly into her apraxia. Rather than having the girl use a poor calibration or tire her eyes very quickly during the calibration process, I have one of her parents complete a 9-point calibration of the eye gaze system, given their eyes represent a close genetic match to their daughter's eyes. This way, the girl uses a high quality calibration as shown in Image 6. After a girl's parent calibrates the system, then I position the eye gaze system by finding the girl's eyes in the Track Status window. I reposition the device so that her eyes are displayed in the middle of the Track Status Window and the indicator (i.e., white arrow) is in the green section to indicate that the device is the proper distance from the eye gaze system for optimal tracking of the girl's eyes as shown in Image 7.

Essentially, girls need to perform two motor actions when using an eye gaze system. They need to visually scan across the screen to find the button they want to select and then they need to maintain their visual attention/fixation or dwell on the button for a predetermined time in order to select it. Therefore, it is important to lower the communication and learning demands. When applying this principle to initial eye gaze trials, I often program in photos of family members and the girl/woman in my eye gaze trial page sets and take the girl to this page first. Research with girls with RTT supports that they naturally look at people and focus on their face and eyes rather than at objects (Djukic & McDermott, 2012; Djukic, McDermott, Mavrommatis, & Martins, 2012). Having a photo page with family members helps a girl to start using this technology right away as she naturally will look at her Mom, Dad and other people or pets in her family. I use this as an opportunity for the girl to introduce me to her family members, as well as herself. In addition, I program highly motivating content by integrating the girl's favorite music videos as motivators, along with less familiar ones so that I can see if she is being successful with the access method by selecting her favorites. Girls are always able to find and select their favorite video. This approach also helps to minimize the effects of apraxia during the eye gaze trial given the girls have a strong emotional connection to their family and their favorite music video that they can recognize by a screenshot of the character from the TV show (e.g., Dora or Doc McStuffin) or movie (e.g., Elsa from the movie, Frozen) or song artist (s) (i.e., One Direction or Taylor Swift for older girls). During the eye gaze trial, I also model how to stop a video or start it again when it finishes and how to select a button on the page that takes her back to a music selection page where she can choose a different video. After she has selected a video two or three times, I navigate to the "comments" page for her and verbally name the choices for her while pointing to each button. I always make sure to point to the top portions of the buttons from above so that I don't block the eye gaze accessory, which is typically positioned at the bottom of the device. In the majority of cases, a girl will select the comment

Image 7: Screenshot of Track Status Window on Tobii I-12 showing that the eye gaze system is connected. The two white circles show the position of the girl's eyes in relation to the eye gaze accessory or cameras. The white arrow in the middle green portion of the vertical bar on the right side of the Track Status Window indicates that the device is positioned at a suitable distance from the girl's eyes.



that corresponds to her repetitive selection of a particular video.

When using eye gaze technology with girls, I typically set the dwell between 500 and 600 milliseconds, but will adjust it to a shorter or longer dwell time so that it correspond to a girl's natural length of visual attention or fixation on a button. The length of dwell does not represent a motor skill that needs to be improved or incorporated into an IEP goal. In all of the eye gaze trials I have completed with girls and women with RTT over the years, I have never set the dwell to one second or longer. This length of dwell is too long for a girl to physically maintain her visual focus and attention on a desired button before it is selected. I consistently use the red clock as the form of visual feedback that girls and their communication partners receive. Using the clock as visual feedback enables the girl's team to see when she is partially dwelling on a button but not looking at it long enough to select it. This provides valuable information about the length of the dwell and whether its length is matched to the girl's natural length of gaze or fixation. In addition, the clock also provides information about the girl's natural gaze pattern and if she is experiencing difficulty in accessing the outer buttons on a page, as shown by partial circles, while she looks at the buttons but never maintains her gaze for a sufficient length of time to select the button(s).

In May 2014, Tobii ATI released Tobii Gaze Viewer, a tool that records where a girl is looking across pages over time, up to a 30-minute session. Tobii Gaze Viewer also records the audio during this process. Images and videos of heat maps and gaze plots can be created that show exactly where a girl is looking on the screen at any point in time and her gaze patterns when she is looking at various buttons across the pages in Tobii Communicator. I now use Tobii Gaze Viewer during a girl's eye gaze trial to document a girl's natural eye gaze patterns. It also documents evidence of a girl's selections throughout the eye gaze trial that can be later analyzed for data to support the funding process. Even though Tobii Gaze Viewer represents a useful tool for documenting results during eye gaze trials, I also recommend videotaping the session(s) as this allows for observations relating to how a girl uses her natural gestures or unaided communication in conjunction with the selections she makes when using an eye gaze system. These forms of communication reinforce that her selections are intentional and have meaning.

Whenever you use an eye gaze system with a girl, it is important for the interactions to be natural and meaningful. It is not "target practice," so asking a girl to "Look at this..." or "Find a specific

picture" taps directly into her apraxia and does not reflect a girl's true potential or ability to use an eye gaze system. Given eye gaze represents a new means of access to her "voice," there will be errors or mishits in her selections. However, typically a girl will indicate in some way when she selects a button that she did not want. One example of this relates to an eye gaze trial with a 29-year old woman with RTT at Katie's Clinic for Rett Syndrome & Related Disorders. She had a previous one-month trial with the DynaVox EyeMax with the assistance of a Speech Language Pathologist in her community. Based on her difficulties in calibrating and using this eye gaze system, it was determined that she could not use eye gaze technology. Prior to her clinic appointment, her father provided me with some titles of songs she listened to on a regular basis. These music selections consisted primarily of songs by Patsy Cline. I included a few of these music videos in my eye gaze trial page set that was set up in Tobii Communicator for use on a Tobii eye gaze system. I also included some music video clips from American Idol when Scotty McCreery, Lauren Alaina and James Durbin competed. Although this young woman initially selected familiar Patsy Cline songs, she then started to explore other options and frequently selected songs by James Durbin. At one point during the trial, she was observed to select a song artist, after which she immediately navigated back to the music choices page. While she was trying to select a button on the far right of the screen to get to music videos with James Durbin, she accidentally selected the button to the left of this and again navigated immediately back to the music options page where she successfully selected James Durbin and then selected the music video, "Will you love me tomorrow?," which was positioned to the left of midline. As soon as the video started, she vocalized her pleasure with playing the music video she wanted to watch. Prior to this time, she had been quiet and completely focused on the eye gaze system while making multiple selections to navigate to the page with music videos of when James Durbin competed on American Idol.

There are some adjustments that I have frequently made during initial eye gaze trial sessions and extended ones to further reduce the motor demands associated with using eye gaze technology and, thereby, improve a girl's ease of access to support her communication. When I observe that one of the girl's eyes moves inward, a condition known as esotropia, or deviates outward in exotropia (<http://en.wikipedia.org/wiki/Esotropia>, accessed October 17, 2014), I change the settings so that the eye gaze system only tracks the girl's eye that does not display this condition. Given this adjustment may limit or narrow the range of eye movements a girl can track across the screen, I reduce the size of the window in Tobii Communicator and position it in the location of the device's screen that corresponds to her natural eye gaze patterns as shown in Image 8.

Tobii Communicator has a feature called Page Set Properties that can be accessed through its File Menu to allow for these adjustments for improving a girl's ease of access using the eye gaze system (Please see Image 9). Even though part of the device's or computer's desktop is displayed outside Tobii Communicator, the girl's selections continue to be restricted to the buttons displayed on a page within Tobii Communicator.

When a girl's team, including her parents, identify which eye gaze system is best suited for her based on the eye gaze trial sessions and extended trials, ease of access should drive this decision first.



Image 8: Screenshot of Run View of Tobii Communicator with the height and width of the pageset set to 80 percent relative to the screen size and positioned in the top left corner of the screen.

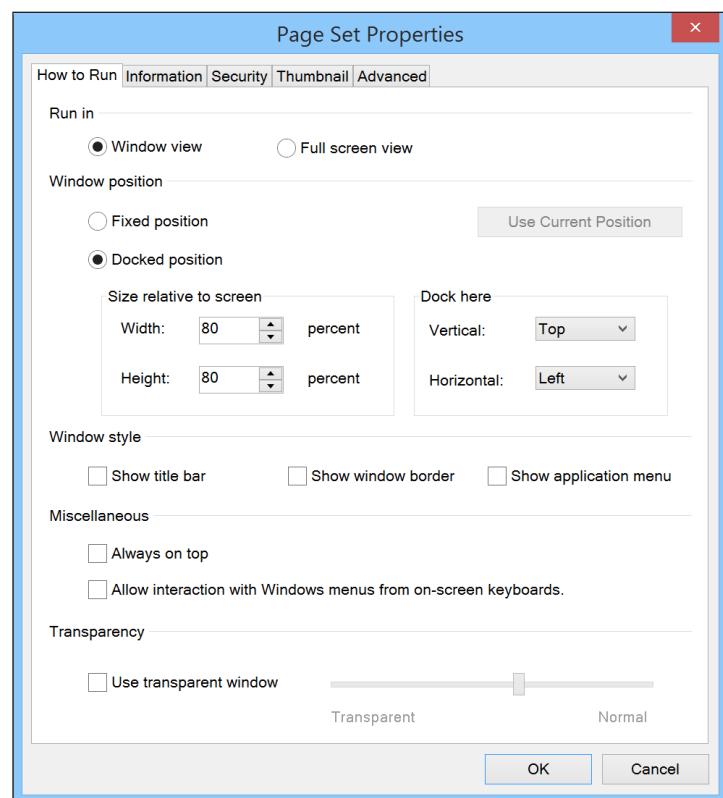


Image 9: Screenshot of Page Set Properties feature in Tobii Communicator showing settings for reduced Window/Run View with 80 percent width and height and the docked position of the top left corner of the screen.

Some of the factors to take into account during this evaluation process include the ease with which a girl has selected buttons in all areas of the screen across different pages and on different days when her responses to sensory input have been determined to be at a level 1, so she was focused and engaged and how the eye gaze system "tracked" her eyes when the position of her eyes changed (i.e., with head movements, moving her head and trunk forward or backward in a chair, walking up to eye gaze system from different angles, etc.). If a girl's access was the same across the two eye gaze

systems trialed with her, then other considerations, such as the language system or familiarity with programming a specific AAC device, can assist in determining the “just right” device for the girl. Then the application for funding process begins for that device.

I could write an entire article on conducting eye gaze trials, as there is so much to take into account and adjustments that can be made to support a girl’s ease of access based on observations of what a girl is selecting or not selecting. I am in the process of developing an online course through Rett University that will provide detailed information about setting up and conducting eye gaze trials with various eye gaze systems, calibration, positioning, what to include in a report when applying for funding for a speech generating device with eye gaze accessory through insurance or state funding, comparisons between dedicated AAC devices with eye gaze accessory as compared to tablets with a USB eye gaze system, various mounting options, IEP goals, the role of software applications to teach cause-and-effect, tracking, etc. for windows control through eye gaze technology. I will also outline and demonstrate in detail the steps involved in setting up an AAC device with eye gaze technology when it first arrives and strategies for engaging girls in conversations. This online course will be available through Rett University <http://www.rett-u.org/>.

FUNDING HAS BEEN APPROVED FOR AN EYE GAZE SYSTEM. NOW WHAT?

At this point in time, there is no need to reinvent the wheel when programming vocabulary on an eye gaze system incorporating Tobii Communicator for a girl or woman with RTT. It is important to think of “more rather than less” in terms of the number of buttons on a page and the number of pages a girl can learn to use. Even when girls gain access to an eye gaze system, they are often provided with access to limited vocabulary sets, primarily based on making choices and expression of wants and needs, until they demonstrate mastery. In some cases, I have seen pages with only two very large buttons on a page, representing only two choices. Many years ago, when I was first consulting with Pati King-DeBaun at Standing Tall in New York City, she had just developed her Dynamic Communication Book to use with the students with complex communication needs in this setting (King-DeBaun, 2012). Pati developed the Dynamic Communication Book as a communication system that incorporates vocabulary to support conversation, literacy and language. At that time, the Dynamic Communication Book was in printed form and set up in Mayer Johnson’s Speaking Dynamically Pro in a traditional rows and columns format, as shown in Image 10. At that time, Pati gave permission for me to program the Dynamic Communication Book for Girls in Tobii Communicator in the copyrighted eye gaze layout that I had designed specifically for girls and women with RTT based on their natural eye gaze patterns (Please see Images 11 and 12). Pati’s Dynamic Communication Book incorporates core phrases, vocabulary words organized by categories, context-based pages for various activities, including shopping, watching TV and, talking on the phone, sentence starters for present and past tense, and an alphabet. When girls, teens and young women have used the Dynamic Communication Book for Girls on Tobii eye gaze devices, they have made dramatic progress in their communication skills over a relatively short period of time. The core phrases have enabled girls to naturally and spontaneously initiate and participate in conversations with their communication partner by making comments, asking questions, describing

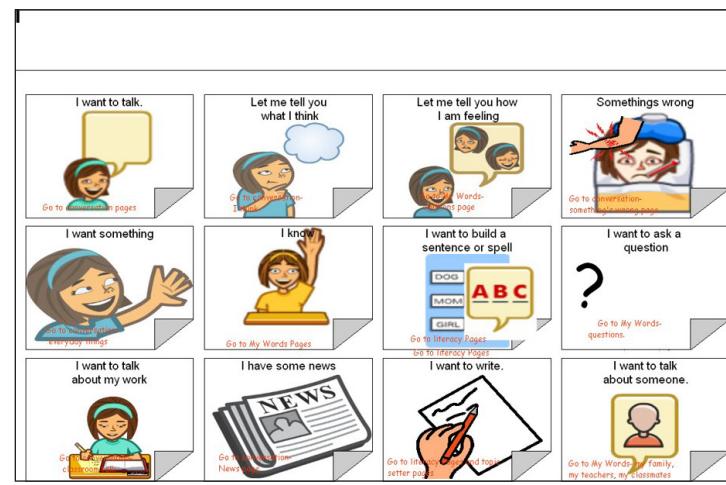


Image 10: Screenshot of the start page in the Dynamic Communication Book for Girls developed by Pati King-DeBaun. This page is displayed in Mayer Johnson’s Speaking Dynamically Pro.

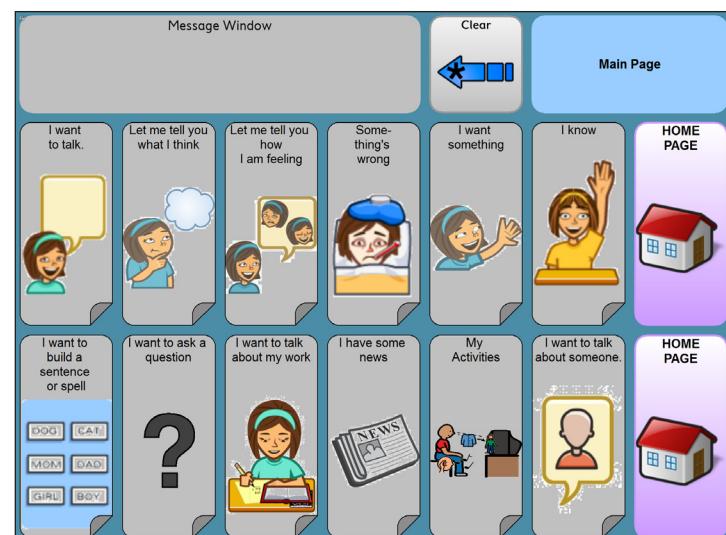


Image 11. Screenshot of the start page in the Dynamic Communication Book for Girls developed by Pati King-DeBaun. This page is displayed in Tobii Communicator.



Image 12. Screenshot of the Conversation page in the Dynamic Communication Book for Girls developed by Pati King-DeBaun, in Lariviere’s eye gaze layout. This page is displayed in Tobii Communicator.

events and directing another's actions. They have become more of an equal partner in conversations when using core phrases. The girls are highly motivated, interested and engaged in social interactions when using the Dynamic Communication Book, so their true communication potential is being seen at home and at school. These reported findings with girls with RTT reflect those found in research that supports use of core phrases for increasing other AAC users' spontaneous interactions and engagement with communication partners (Erickson, 2007). As a result, girls and women with RTT need access to phrases so they can spontaneously initiate and participate in conversations with their peers and communication partners. These phrases are also needed on devices that primarily have core words as their language systems.

Girls also benefit from having activity-specific or context-based pages so they can direct another's actions, express their opinions through comments and ask questions during play-based activities and to support their active engagement at home school and in the community. Some of the activities in The Dynamic Communication Book include playing house with a doll, dress-up, cooking and shopping (as shown in Image 13). I have customized a version of The Dynamic Communication Book for girls who are around 9 years old and up that incorporate age-respectful comments, and additional activities, such as getting dressed, talking about movies (as shown in Images 14 and 15), music and fashion.

SCRAPBOOK OF LIFE EXPERIENCES

Given we all like to share stories and pictures about our life experiences, as evidenced through the extensive use of social media, it is equally important for girls with RTT to have access to pictures on their device so that they can talk about their life experiences as well. This form of scrapbook can be set up in many ways on a girl's eye gaze system. I typically have a separate page set for "News" that is integrated into the girl's home page and linked into The Dynamic Communication book's "News" page so that she can access this from different locations. When parents share photos with me about major events in a girl's life, such as birthday celebrations, vacations, holidays, events at school, etc., I link these to a button on her topic-based news page (as shown in Image 16) and then have it automatically open to a page displaying the larger version of the picture. I integrate "hot spots" on these pages so that the girl can talk about the photo by naturally looking at different parts of it. Given a girl's natural tendency to look at photos of herself and other people in the photo, I program the hot spots so they disappear after she looks at and selects a hot spot, as shown in Image 17. This avoids repeated selections of the same hot spot over and over again. When a girl navigates or receives assistance in navigating away from this photo page, the hot spots on the photo become active again so she can talk about the photo again when she returns to this page. I have used the scrapbook on a girl's eye gaze device to support writing for a purpose that can be integrated into a girl's picture selection for a topic and then writing about the picture in the form of a label or caption or a sentence talking about her experience. I use the core words and sentence starters in the Dynamic Communication Book to support a girl in her beginning writing experiences in conjunction with partner-assisted scanning to an alphabet flipbook for invented spelling of words.

Having these scrapbook pages integrated into a girl's communication system allows for modeling of and/or a girl's spontaneous



Image 13. Screenshot of the Activities page in the Dynamic Communication Book for Girls developed by Pati King-DeBaun, in Lariviere's eye gaze layout. This page is displayed in Tobii Communicator.

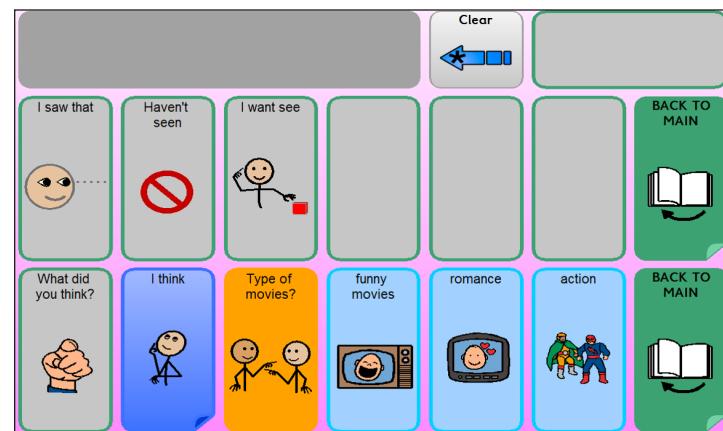


Image 14. Screenshot of the Movies page developed by Judy Lariviere in the Dynamic Communication Book for Girls developed by Pati King-DeBaun, in Lariviere's eye gaze layout. This page is displayed in Tobii Communicator.

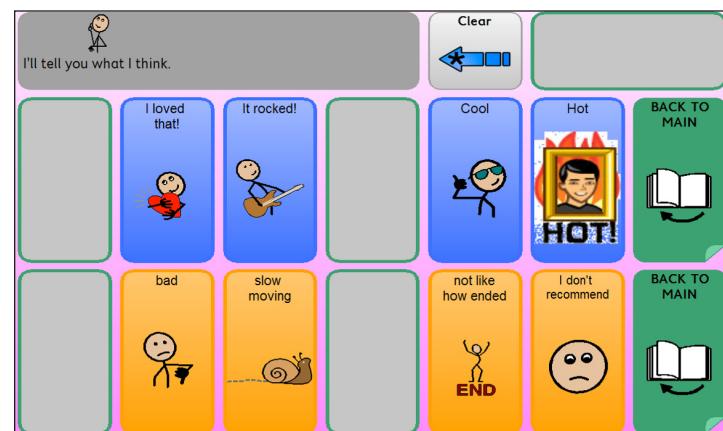


Image 15. Screenshot of the Movies Comment page developed by Judy Lariviere in the Dynamic Communication Book for Girls developed by Pati King-DeBaun, in Lariviere's eye gaze layout. This page is displayed in Tobii Communicator.

expression of text-to-self connections that demonstrates reading comprehension or her understanding of a topic being taught in an inclusive educational setting. An example of this relates to a teenager who was taking a 10th grade biology class with her

peers in September. The teacher put up a picture of a butterfly on his computer that was projected on the white board in the classroom. As soon as she saw this butterfly, she immediately navigated through multiple pages on her Tobii C-12 with CEye Module until she accessed her scrapbook with the news page that related to her experiences during a class trip to the Natural Museum of Science in May of that same year where she visited a butterfly emporium. While she was in the butterfly emporium, a butterfly landed on her wheelchair and head and on one of the paraprofessional's phone (Please see Image 18). There were pictures of these events included in her scrapbook pages. In this situation, she spontaneously demonstrated a connection between the topic of butterflies and her own life experiences.

ACCESS TO A LANGUAGE SYSTEM

Girls also need access to a language-based system with core words and vocabulary for generating language. All eye gaze systems have these, such as Unity for Prentke Romich Company's Accent 1200 with NuEyeTM Tracking System and NuVoiceTM 2.0, SonoFlex, Picture Word Power, LiterAACy for the Tobii I-series or Tobii EyeMobile. Having independent access to a language system that is integrated into their communication device allows them to generate novel messages that may not otherwise be programmed in their device. I have several stories about how girls have spontaneously initiated communication and navigated to different pages within a language system to create a message ranging between 1 and 4 words "in the moment" that is completely relevant to the context of the situation. For example, a teenager was sitting in her wheelchair and was pushed into her Math class by her paraprofessional. Her Tobii was positioned on her wheelchair mount and turned on so she had access to her voice. A group of Math teachers at her school had shaved their heads as a fund raiser for "Locks for Love." As soon as this teenager saw her Math teacher, she immediately navigated to Picture WordPowerTM from her conversation page set and navigated to places and selected "barber" and looked at her teacher. A 10-year old girl was very excited about a music recital in which she was participating with her class for the school. She wore a dress to school. As soon as she sat down at her desk, she immediately navigated to Picture WordPowerTM and combined symbols and words to create the following message: "I am pretty. I want to sing." Without having access to a language system with extensive single word vocabulary and having use of the words modeled to them throughout the day in natural contexts and at home and school, these girls would not have been able to communicate what was on their minds. Typically, these girls demonstrate the best use of their language systems when they are in a natural context that is emotionally charged for them as this helps them to minimize the influence of their apraxia on their selections, using their eyes.

Presuming competence allows you to truly see what girls are communicating and learning! Their selections have meaning! If unsure, share the information with their parents for insight.

Girls also use their communication systems to share information or an account of something that happened in their life with their communication partners. It is important for communication partners to always presume

Image 18. Screenshot of a Scrapbook or News page about a teenager's class trip to the Museum of Natural Science developed by Judy Lariviere. This page is displayed in Tobii Communicator.

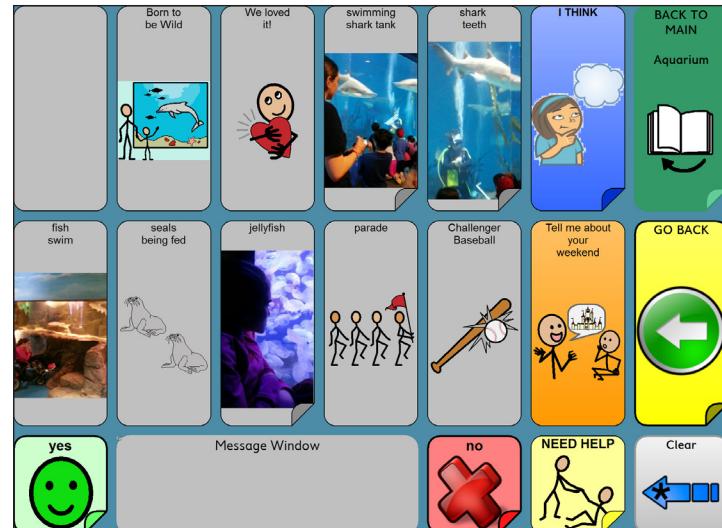


Image 16. Screenshot of a News page about a teen's trip to the aquarium developed by Judy Lariviere. This page is displayed in Tobii Communicator.

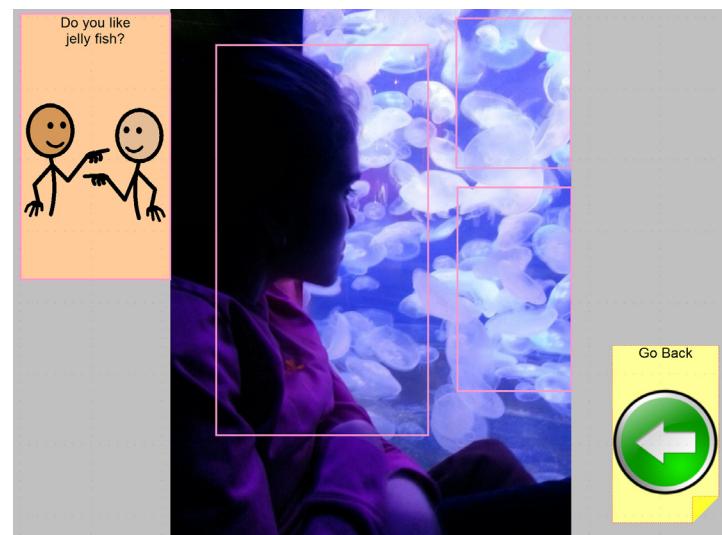
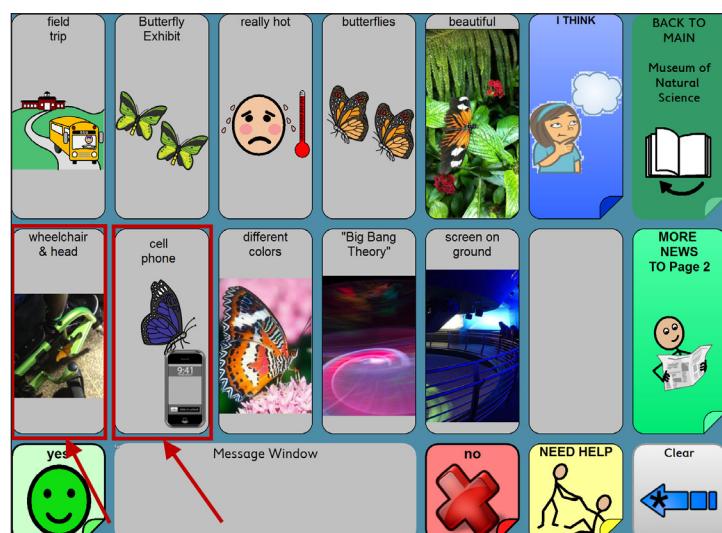


Image 17. Screenshot of a Photo page with "hot spots" related to a teen's trip to the aquarium developed by Judy Lariviere. This page is displayed in Tobii Communicator.



competence when working with girls with eye gaze systems. Even though something they say may seem out of context, their selections always have meaning, even if it is not relevant to the immediate situation. For example, one day a teenage girl was dropped off by her mom at school. Usually she rode the bus, but they were running late that morning. As soon as this teenager got into her wheelchair with her Tobii turned on, she immediately navigated to her Picture WordPowerTM and went to the "People" page and selected "brother" and automatically returned to the Main page. She then selected "Toys and Games" and repeatedly selected "Lego." Her teacher and paraprofessional acknowledged what she said by saying, "I know Matthew likes his Lego." At the end of the day when the teenager's mom was picking her up from school, her paraprofessional told her mom that she was selecting "Matthew and Lego" on her Tobii in the morning. Her Mom then told the story about what happened on the way to school. Her younger brother dropped his Lego creation, which fell apart, and some of the pieces went under this girl's automatic seat that lifts her in and out of the van. As a result, her brother had a "meltdown" about his Lego and her mom worried that the Lego pieces were going to break the motor on her seat. It turned out to be quite the morning drive to school! The teenager was sharing this experience with her teacher and paraprofessional using her Tobii and it was completely accurate and in context of the drama that had taken place that morning. Amazing and incredible communication moments happen with girls and women who are using eye gaze technology when you least expect them.

It is very important for a girl to have access to her eye gaze system across as many natural settings as possible. This represents her "voice" and there should not be restrictions on when she can use her voice to communicate. Quite often this translates into having two different mounting systems to support her access across multiple settings. For example, for girls who can walk independently, a rolling floor stand can be used at home with another one or a table mount for use at school. Girls who need assistance to stand and walk often need a table stand so they can get up closer to tables and a wheelchair mount so they have access to their "voice" in the community, especially when they are shopping at the mall. Girls also need

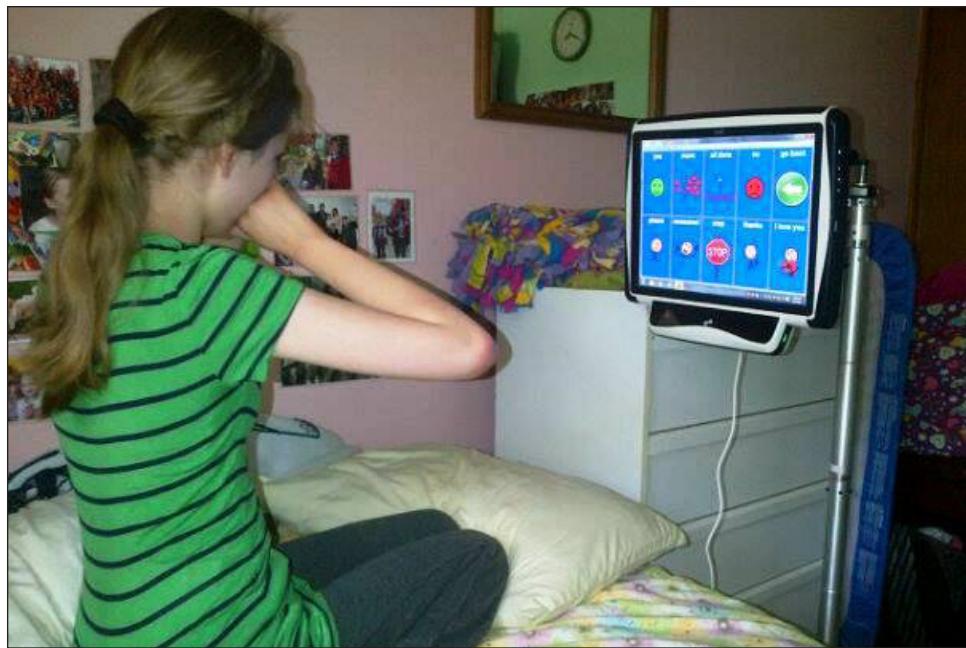


Image 19: Photo of 15-year-old teenage girl sitting on her bed and exploring the vocabulary and pages that are programmed into her Tobii C15 with CEye Module. The device is supported on an Ideas Rolling Floor Stand.

time to explore the vocabulary and pages that are on their device without demands or expectations. Often these opportunities can take place at home in natural settings, as shown in Image 19.

When girls and women are given independent and easy access to their "voice" with eye gaze technology, their personalities shine through. They engage in conversations and show us what they know and what they have learned. The possibilities are endless!

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RESOURCES

The Dynamic Communication Book
www.creativecommunicating.com

Email Judy (judy@assistivetech4all.com) a photo or screenshot of the receipt/confirmation Creative Communicating sends you and Judy will send content in her copyrighted eye gaze layout designed for individuals with Rett Syndrome to you electronically

Eye Gaze Trial Page Set in Tobii Communicator (for Individuals with Rett Syndrome) www.assistivetech4all.com

Eye Gaze Video Player for Children and Eye Gaze Video Player for Teens in Tobii Communicator www.assistivetech4all.com

Eye Gaze Music Player for Children and Eye Gaze Music Player Teens in Tobii Communicator www.assistivetech4all.com

From Eye Gaze Trials to Device – online course through Rett University <http://www.rett-u.org/>

Ideas Rolling Floor Stand [http://ideasfil.com/](http://ideasfil.com)

Picture WordPowerTM www.inmaninnovations.com

Accent 1200 with NuEyeTM Tracking System and NuVoiceTM 2.0 www.prentrom.com

Tobii I-series, Tobii EyeMobile, Tobii Gaze Viewer www.tobiiai.com