

## Ready or Not?

### Facebook: Rett Syndrome and Speech and Language Therapy - A document to be shared

Sally-Ann Garrett, SLT, UK

The question, “*How do we know when a person with Rett Syndrome is ready for an eye gaze unit?*” seems to be on the minds of many people at the moment, people such as parents, clinicians, teachers, researchers, and fund holders. I frequently read that a parent has been told that a girl or woman with Rett syndrome is “not ready” to use eye gaze technology or does not need eye gaze. I wondered why this statement was being made or how such a decision was concluded, so I asked the parents for information and asked questions about the girls’ abilities, to try to find out why the decision maker had come to the conclusion that the girl was not ready.

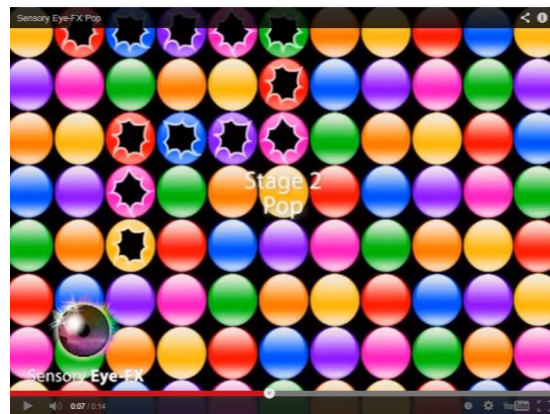
Sometimes the decision seems to have been made because the girl is able to walk, and the decision maker believes that eye gaze technology is only for people with grossly impaired motor functioning. Sometimes the girl has been using switches and has not shown that she can use the switch functionally; her lack of interest in switches was seen as lack of interest in communicating. Sometimes it was because she has not yet had the chance to try out the eye gaze technology, and no one believes she will be capable! Given these varied reasons and possible criteria for deciding the eligibility for eye gaze, I thought it might be helpful to provide guidance for assessment using the principles of the Tobii Learning Curve, and access to “Sensory EyeFX” and “Look to Learn” software. (All of this information is available on the internet, so there is no reason for people not to know about this technology. The links in this document are live when seen on a screen and can be accessed directly.)

First, there is no age limit (upper or lower), nor ability limitation - quite simply if the girl with Rett syndrome has eyes that are trackable, then the process of learning to use eye gaze can start with blank screen engagement. In the recent study we carried out (Minto and Garrett, 2013) we found that 98% of the girls and women assessed were trackable. The process we used in the study incorporated the steps outlined below.

Using the **learning curve** as a framework for assessment, the first screens and activities that are offered can be termed “sensory”, and work on the principle that if the girl or woman moves her eyes while the eye gaze unit is set up in front of her (it does not need to be her calibration) then something will happen on screen, for example a trail of stars will follow the path of the cursor, or items on the screen will move out of the way. The two pictures over the page show screen shots from Sensory Guru software called *Sensory EyeFX* which has been specifically designed for this purpose. Quite often when the girl sees the effect, she will look at the supporting adult – her referential gaze shows us she has realised something happened! The important next step is now possible – the adult can **comment** on her performance. Tell her – “You made the stars!”, and add more information, e.g. “that’s pretty”, or “You popped the bubbles!”

This is not just a fun activity - object displacement activities introduce some of the methods of eye gaze control, such as dwell function, and targeting, helping the girl to learn that what she does has an effect on the computer screen.

Other activities in these earlier stages support skills such as zoned focussing, active exploration, and controlled targeting.



Studies carried out in New York, at the Montefiore Institute in 2012 showed the girls preference for looking at people (Djukic, A. et Al), and it is easy to set up content for the assessment using pictures of people. For example if the child likes Justin Fletcher, Mr Tumble, The Doodle Bops, Westlife, Carrie & David's Popshop, Justin's House, or Something Special, pictures for her assessment session can be downloaded and added to the device for assessment and teaching. Some of the pages on the internet have interactive games and these could be tried with eye gaze control, for example:

<http://www.bbc.co.uk/cbeebies/justins-house/games/justins-house-racegame/>

<http://zui.com/webpages/free-online-doodlebops-games>

A single composite picture can easily be set up on the Tobii unit to fill the screen, selecting content from what the girl or woman is interested in, providing further opportunities for **commentary**. Now, when she looks at the screen, the cursor is visible, and, by watching the visible cursor, the adult can see what the girl or woman is looking at, making it simple to comment appropriately about what she is looking at.



Suggesting commenting about what is happening on the screen matches advice that is given to parents of children with language delay, where commentary and indirect techniques are used to talk to the child about their play and activities, so that the parent matches language input to the child's activity. The techniques include **self-talk, parallel talk, description, repetition, expansion, and expansion plus**. Speech and Language Therapists will be very familiar with these indirect techniques, and will also know that, initially, direct techniques, such as **questioning** and **imitation requesting** should be avoided, but other direct techniques such as **reinforcing** should be used. One of the best ways to encourage children to communicate is to respond to their communication attempts. Reinforcement encourages behaviour to continue, this responding to the child's communication encourages them to do it more. If a baby babbles you should babble and chat back to them. If a child tries to tell you something, take the time to try to figure it out. Be sure to always acknowledge their communication attempts and provide time for communication with them.

The pictures could be put into four cells so that there is more varied content. Many children (in UK) like Mr Tumble, and pictures about him, carrying out various actions to describe, can be found on the Internet.



When this set of pictures is shown on the screen, the cursor movement will show you that she is looking around at the items in the pictures; the person supporting her should tell her what they see her looking at. The adult could say for example, “Oh, Mr Tumble has a rabbit; I like rabbits. Or, Mr Tumble is waving/singing; Mr Tumble has a teddy and a doll”, or just “Mr Tumble”, “Doll”, “Rabbit”.

You can check to see if the girl or woman looks at the items when you say a sentence with the word in it – the cursor will show where the girl or young woman is looking. The directions given to her are important. Not “Show me the\_\_” or “Where is the \_\_\_\_”, but indirect commentary: “I bet the **rabbit** is soft”; “I like it when he **sings!**”; “**Cuddles** are fun”. Only when you have talked to her about what is in the pictures, should you test her! (I will repeat: “**Tell** then test”).

The eye gaze activities are NOT about output, but provide great opportunities for learning and language input, which must come first - you put nothing in, you get nothing out, so talking to the girl or woman about what she is doing is essential.

The content or items displayed on the screen are under the control of the person doing the assessment. Nothing happens on the PC or Tobii device unless the adult selects what software to use, what video to watch, what games or music to play. The content has to be meaningful to the child or adult, so preparation time is needed for setting up pages ahead of any assessment session.

**Here is another idea, using books that the person likes, for example, Room on the Broom,** (hope you know this one), there are lots of resources that can be downloaded for this book <http://roomonthebroom.com/activities/>

One is a pdf, called “Can you find”. I borrowed this view and made a page set in Tobii Communicator for this picture. As before, when the picture is shown on the screen, the child will likely look around at the items in the picture, and the person supporting her will tell her what they see her looking at as the cursor moves across the screen. As above, to start with, only when you have talked to her about what is in the picture, should you test her! The adult should say for example, “Oh I see the castle/ the birds/the cat/the sheep, and check to see if the child looks at the named items – the cursor will show where the child is looking. The directions given to the child are important. Not “Show me the\_\_”. or “Where is the \_\_\_\_”, but indirect commentary: “Oh, the witch is on the broom”; “Her hat might blow away!”; “That’s a funny owl in the tree”.

With Tobii Communicator, the page can be made into a single interactive screen. Individual elements on the page can be made into “buttons” so that when the girl looks at an item, the “button” can be made to say the word e.g. (bird, bow, dragonfly, squirrel, dog, cat, and owl) or to play a sound. This becomes an activity she can also do on her own, to explore what happens on the screen.

A single pictures page can be linked to other pages: it was easy to make a page set for the “Can you find” game, with one page for the castle, a next page for the birds, another for the

sheep, dragonflies, and finally the witch's bows. The activation of the page sequences needs adult support, but a button can be added for "next page".



I think you can see that the idea of a fixed criteria of readiness to use eye gaze technology is an artificial concept especially for a girl who has had limited access to technology so far in her life. How can she have learned to use the computer if she has never had the chance? The next steps that could lead the girl to be able to use the device to communicate will flow from skills such as accessing vocabulary and turning the page, skills that can be learned though the previous activities.

Susan Norwell, an Educationalist in the USA, with a huge experience of Rett Syndrome, wrote

*"If we waited until a typical baby was "ready" to talk to communicate with us it would be called neglect. I have found that if the girls can activate the device and engage around communication with intent, they are ready to be taught how to communicate with the device.*

*Eye gaze is life changing for many girls (with Rett syndrome) as it gives them independent access but it also provides a platform for teaching language. I work with a little girl who got her Tobii at 2 years of age. What she has learned between 2 and 4 years of age is amazing!!!! She would have lost all that learning, would not be combining 3/4 words to communicate, telling stories, making connections and much more if the powers that be had waited until she was "ready."*

*Find someone who believes in her, set it up for success and video the whole thing. My bet is she is ready now!"*

The next part of this article has been downloaded from the Tobii website, and modified slightly for this paper document. The Tobii website also has stories about girls with Rett syndrome (see link:

<http://www.tobii.com/en/assistive-technology/global/search/?search=rett>

When assessment using the Learning Curve shows what level the girl is capable of, then the links to the relevant software show how to extend those skills. There are several reasons as to why eyegaze access is suitable for early learners beyond simply providing a new range of experiences. It can be a vital window into a new world of communication and computer access. It can be a way for learners to show us what they already know and their current level of understanding. It has the potential to enable learners to access their environment in new ways and help to develop them in their learning.

Eye gaze technology can:

- provide evidence relating to learners' existing abilities
- support access to new learning experiences
- become a valuable communication method

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### **Tobii Learning Curve**

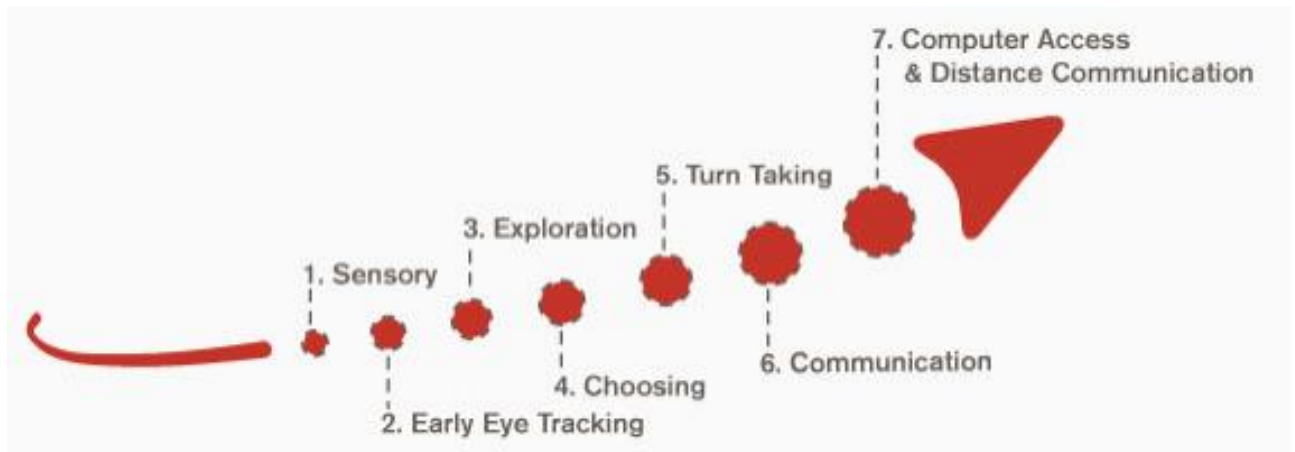
The Tobii Eye Gaze Learning Curve is a clear pathway to success with Eye Control and Gaze Interaction. It is broken up into easy to understand components that lay out different possible steps for the use of Eye Control by users with different levels of physical and cognitive ability, and has been trialled with more than 150 girls with Rett Syndrome in UK.

Each level provides development possibilities within itself, and even if a level is reached that can't be expanded upon for an individual, the concepts used will allow for a fun and enriching learning experience, using Eye Control with software such as Look to Learn.

Until recently, Eye Control and Gaze Interaction within Assistive Technology have been reserved for those who have a proven understanding of Cause and Effect and who are demonstrating that they are ready for an Alternative and Augmentative Communication (AAC) device that they will be able to use with their eyes and Eye Control, usually together with one or another type and level of AAC Vocabulary.

Reaching the level of success with Eye Control and the level of cognitive ability needed to achieve a successful assessment (and thus, in many cases, the professional recommendation needed to purchase, fund and use an Eye Controlled device) can be difficult. Eye Control, Gaze Interaction and their different methods for use are skills like any other. At Tobii, we believe that they should be taught in constructive and structured ways in order to assist individuals in learning the practical and cognitive skills needed to reach the level of ability required to communicate with AAC vocabularies using Eye Controlled devices, and even to open individuals up into the world of literate, long distance communication.

The Tobii Eye Gaze Learning Curve is a step by step, component based, teaching-and-learning pathway for Eye Control and Gaze Interaction. It incorporates teaching and learning techniques, software and suggestions for care givers, teachers and professionals assisting users from their earliest experiences and engagements with a screen, through to high level literate access and use.



## 1. Sensory



The Sensory component of the Tobii Eye Gaze Learning Curve is all about establishing screen engagement. It encompasses a user's very first experiences in front of a computer screen. Here we are trying to encourage the user to understand that when they look at the screen, something happens, that they caused something to happen; and as much as possible, something fun, exciting or engaging.

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### Links, pages and apps appropriate for the sensory learning curve component & eye gaze interaction

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- [target and touch patterns](#)
- [target and touch music](#)
- [early mouse movements](#)
- [hidden grid](#)
- [jackson pollock](#)

## 2. Early Eye Tracking



The Early Eye Tracking component focuses on the care giver looking for an appropriate response in the user.

If we have a user engaging with the screen with Sensory applications in the Sensory environment we can now start watching the cursor or selection area move around. By using games and applications with a visible cursor, or those that leave a visual cue as to where the user is looking, we can see if a user is responding and reacting appropriately. Gather a user's favourite photos, videos and images or use the available games and look at them and talk about them together.

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**Links, pages and apps appropriate for the early eye tracking learning curve component & eye gaze interaction**

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- [aunt maggies recipe](#)
- [counting songs](#)
- [growing with timocco](#)
- [tim focus](#)
- [poisson rouge](#)
- [busy things](#)
- [choose it maker](#)
- [choose and tell nursery rhymes](#)
- [choose and tell legends](#)
- [target and touch music](#)
- [tag galaxy](#)
- [clicker 6 - oxford reading tree exercises](#)

### **3. Exploration**



This is possibly the most critical component of the Eye Gaze Learning Curve. Exploration is about the user getting to know their computer, applications and Eye Control. This is time spent alone or with the assistance of a care giver learning to manipulate the screen; playing, splatting, smudging, revealing, painting, drawing, making music. There may even be some



minimal “quick dwell” selecting and basic, no-fail, targeting here, but above all exploring and engaging, and having fun doing it.

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**Links, pages and apps appropriate for the exploration learning curve component & eye gaze interaction**

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- [pagesetcentral](#)
- [tobii sono primo](#)
- [target and touch patterns](#)
- [target and touch music](#)
- [early mouse movements](#)
- [hidden grid](#)
- [jackson pollock](#)
- [aunt maggies recipe](#)
- [counting songs](#)
- [growing with timocco](#)
- [tim focus](#)
- [mouse skills](#)
- [poisson rouge](#)
- [busy things](#)
- [choose it maker](#)
- [clicker paint](#)
- [revelation natural art](#)
- [eagleeyes - aliens and paint](#)
- [myzone](#)

#### **4 and 5 - Choosing & Turn Taking**



Components 4 and 5, Choosing and Turn Taking are critical steps that need to be learned before we get into the world of AAC communication. They are, in fact the first steps that show if AAC vocabulary use is even a possibility for a user.

Here the first real attempts at active targeting are introduced using Eye Control. It is important that at this stage there are no negative consequences if the choice is wrong. We like to call this “No-Fail” targeting. Use online resources, flash based games, games applications and simple, large button Page Sets and games from [Page Set Central](#) and Tobii’s own [Sono Primo](#) software. These are truly extensions of Exploration but here, engaging and exploring with help from assistants and care givers.

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## Links, pages and apps appropriate for the choosing & turn taking learning curve components & eye gaze interaction





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- [pagesetcentral](#)
- [tobii sono primo](#)
- [target and touch patterns](#)
- [target and touch music](#)
- [aunt maggies recipe](#)
- [growing with timocco](#)
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- [eagleeyes - aliens and paint](#)
- [smarty pants](#)
- [choose and tell nursery rhymes](#)
- [choose and tell legends](#)
- [myzone](#)
- [duplo website](#)
- [tag galaxy](#)
- [clicker 6 - oxford reading tree exercises](#)

### 6. Communication



The Communication component is all about Communication and AAC Vocabularies. This has been, and will continue to be, a main focus area for Tobii Assistive Technology. Tobii has already put in a lot of time, effort and research to create a comprehensive map of different available software Content, “Page Set Apps”, based on [Tobii Communicator](#) for the many different levels of cognitive ability and literacy. Ranging from the situation based visual scenes, hybrid scenes and simple vocabulary grids of [Sono Primo](#) (and games based on these different situations) through to the flat layout, symbol based communications charts from the similar contexts and vocabulary categories of [Sono Flex](#) to the more complex symbol-based vocabulary structures of [Sono Lexis](#); from there, going on to the early stages of literacy with the alphabetically based, quick access to words, Page Sets of [LiterAACy](#) and moving finally to the [Sono Key](#) and [Sono Scribe](#) applications for those with full literacy and a need for consistent written and spoken communication that we will pick up in Component 7.

<p><b><u>Tobii sono primo</u></b></p>  <p>Sono Primo is a powerful modular system of situation and grid-based Page Sets enabling users to communicate on their own terms. The Sono Primo vocabulary can be used with both Tobii Communicator and Tobii SymbolMate/S32.</p>	<p><b><u>Tobii sono flex</u></b></p>  <p>A symbol-based vocabulary for Tobii Communicator, laying out a growth path towards the persistent use of a communication aid for preliterate AAC users.</p>
<p><b><u>Tobii sono lexis</u></b></p>  <p>A personal symbol-based vocabulary, enabling advanced communication without literacy skills, using individual sentences built word by word.</p>	<p><b><u>Tobii LiterAACy</u></b></p>  <p>LiterAACy is a very efficient Symbol Vocabulary that fosters reading and writing. Making use of the partial reading competency of preliterate communicators, it integrates the learning paths of acquiring literacy and mastering AAC vocabulary.</p>

## 7. Computer Access & Distance Communication

The focus of the Computer Access & Distance Communication component of the Learning Curve is on full computer access for literary users with functional disabilities or the need for Rehabilitation through Eye Control and Gaze Interaction.

It is not yet known to what level girls and women with Rett Syndrome can progress, as very few have been given the opportunity. Ready or Not? They are ready if they are given the chance!

### References

- Djukic, A., Valicenti McDermott, M. (2012a) Social Preferences in Rett Syndrome, *Pediatric Neurology*, 46 (4), 240-242.
- Djukic, A., Valicenti McDermott, M., Mavrommatis, K. & Martins, C. L. (2012b) Rett Syndrome: Basic Features of Visual Processing- A Pilot Study of Eye Tracking, *Pediatric Neurology*, 47 (1), 25-29.