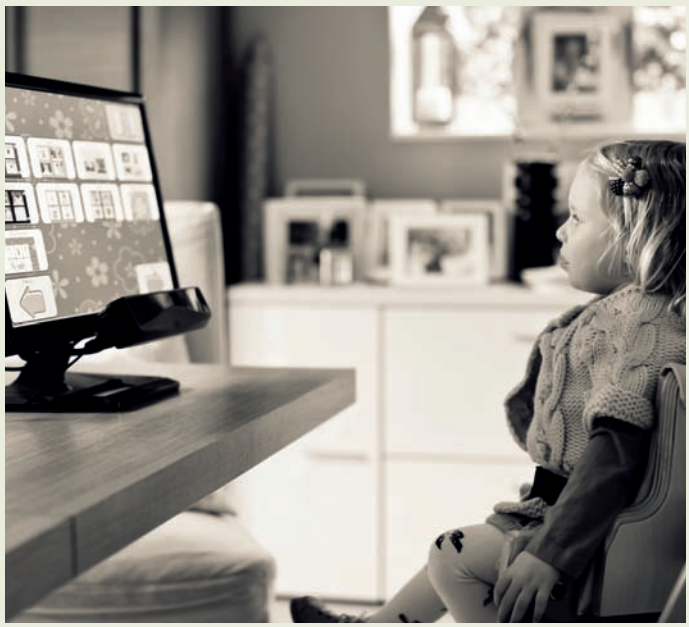
Sally-Ann Garrett

Opinion

Sally-Ann Garrett says SLTs need to be open to the potential of eye gaze and eye-tracking technology in Rett syndrome

The eyes have it: unlocking potential in Rett syndrome



Rett syndrome (RTT) is a rare genetic neurological disorder affecting approximately one in 12,000 females (NHS, 2012). However, with only 850 individuals with RTT known to the Rett Association in the UK, you may never come across a case. The presentation is variable. Some girls have early onset seizures, while others may develop 'normally' until they are around 18 months or two years of age, after which they lose functions like walking, talking and eating. Speech and language therapists have a vital role in supporting individuals' communication skills. Initial difficulties with language and/or dysphagia should result in a referral to paediatric speech and language therapy services. Older girls and women should be able to access their local learning disability team.

People with RTT have specific preference orientation towards people and a keen interest in establishing interaction (Djukic and McDermott, 2012). Their nonverbal communication, particularly using eye gaze, is effective and purposeful, but is dependent on carer interpretation and response. Apraxia, one of the most disabling aspects of the disorder, interferes with the individual's ability to carry out purposeful actions and demonstrate understanding. This can result in erroneous findings in language and psychometric testing, leading to the assumption that they are severely cognitively impaired (Baptista PM et al, 2006; Berger-Sweeney 2011).

Offering simple augmentative and alternative communication (AAC) is successful because access through eye gaze seems to bypass the apraxia (Djukic and McDermott, 2012). Although people with RTT are usually unable to use switches or keyboards a few children in the UK can now access eye-tracking technology. Companies such as Tobii, LC Technologies and Dynavox have developed eye control units, either built in to communication devices or linked to a personal computer. The most widely used designs are video-based eye trackers, which calculate the position of the pupil and the corneal reflection to identify where on a screen a person is looking.

Research carried out at the Rett Syndrome Centre in New York revealed the hidden, inner world of children who have RTT (Djukic and McDermott, 2012). This confirms observations that girls understand more than they can demonstrate. Centre Director Aleksandra Djukic says, "The eye-gaze technology is helping us to unlock the girls' minds. It brings smiles to us and to their parents, because for the first time we have proof of their mental activities. But it also imposes a huge obligation to properly advocate for these children."

In the UK, we are lagging behind in this kind of research, because the technology is expensive and information limited. Eye-gaze technology is suitable for people with RTT, and SLTs need to be open to the possibilities of what it can offer. Funding may be problematic, but the benefits of independent communication demonstrate clear personal preferences and interests. From my personal experience from UK Rett clinics there are positive results for even very young children and non-verbal adults. Many have demonstrated cause and effect, played music, and 'painted' on screen. One 42-year-old woman, who had never had access to any kind of AAC support, selected symbols to make a request for a drink for the first time in her life.

Further clinical research is needed to evaluate the suitability of eye-gaze control for children and adults with RTT so we can inform commissioners in health and education about the suitability of such equipment. We may then have a better understanding of cognitive and linguistic development in people with RTT, which will help us see their potential to communicate more fully than anyone has yet thought possible. ■

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References & resources

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Rett Syndrome Center: Visit: www.montekids.org/services/leadership/neurology/rett-syndrome