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Oral (or Poster) Presentation

Eye gaze technology as a form of augmentative and alternative communication support for individuals with Rett syndrome: experiences of families in the Netherlands.

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Background: A study was conducted into the experiences of individuals with Rett syndrome (RTT) and their families with regard to use of eye gaze technologies to support communication.

Method: An online survey relating to communication skills and support for communication was circulated to families through the Dutch Rett Syndrome Parent Association. Within the broader survey was a special focus on eye gaze technology. Completed surveys were analysed with regard to systems and software used; expert knowledge, advice and support; funding; perceived benefits and shortcomings; and measures of progress.

Results: Sixty-three families responded to the question asking whether their child had an eye gaze system, 32% (n=20) of whom were currently using or had previously trialled a system and 64% (n=43) who had never used one. The 20 individuals who had used an eye gaze system ranged in age from 6 years 3 months to 18 years 6 months. Levels of support varied. Despite frustrations with the technology, satisfaction with the systems was higher than satisfaction with the support. Almost all families noticed progress in their child's skills.

Conclusions: The findings suggest that although eye gaze technologies offer potential to individuals with RTT and their families, greater input from suppliers and knowledgeable AAC professionals is essential for individuals and families to benefit maximally.