

Get Involved - Research Projects

Communication in Angelman syndrome

We are looking for parents of children with Angelman syndrome to take part in a study looking at communication, based at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham.

What is the aim of the research?

This study aims to gain further understanding about the receptive (what they can understand) and expressive (what they can say) communication skills of individuals with Angelman syndrome. This will allow us to develop our understanding of the specific communication profile in Angelman syndrome and allow us to develop and inform effective intervention.

What will the research involve?

The study consists of two parts, which are completed separately.

Part 1 is an online questionnaire that will be exploring the vocabulary that your child/person you care for understands and produces alongside any gestures they may use. We will also ask for background demographic information at the start of the survey. This part of the study will take approximately 45 minutes to complete.

The second part of the study is a telephone interview (arranged at a time of your convenience) where we would like to discuss your child's/person you care for's adaptive behaviour, such as their communication, daily living skills, socialisation and motor skills. This part of the study will take no longer than 45 minutes.

How do I get more information or get involved?

To be eligible to take part in this study, your child must be under 16 years of age, have English as their first language and have a non-deletion subtype of Angelman syndrome.

To receive a copy of a detailed project information sheet, please contact either Effie Pearson on email: exp137@student.bham.ac.uk

or on Tel: 0121 414 2855 or email Dr Mary Heald on: mxo988@bham.ac.uk.



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