

Get Involved - Research Projects

Supporting individuals with Williams Syndrome to manage difficult emotional experiences

Experiencing difficult or unhelpful emotions is one of the major difficulties faced by individuals with Williams Syndrome. Specifically, it is approximated that as many as 40-50% of individuals experience feelings of worry or anxiety. This prevalence is remarkably high and unsurprisingly, this can have a significant impact on a person's quality of life.



Researchers at the Cerebra Centre for Neurodevelopmental Disorders (CCND) believe it is essential to focus on issues which are of real concern to individuals and families and to find ways to improve quality of life. This has been the motivating force for the development of a new research project, headed by Professor Chris Oliver and Professor Patricia Howlin, to explore emotional difficulties and anxiety in Williams Syndrome.

For further information please continue reading below or watch the following video:

This research is made up of three stages. The first stage involves a telephone interview with families in order to learn more about emotional difficulties that are of concern. This will be followed by an online survey which will take around 30-45 minutes to complete and will ask about a range of different issues including emotional and behavioural difficulties, health, quality of life and sensory processing. This final stage will involve a face to face clinical assessment.

Families can choose to take part in one stage or all of the stages. An individualised feedback report will be provided to all participants.

Why is this research important?

Giving people a voice: It is essential to give people with learning disabilities the opportunity to contribute to research that directly affects them and to help with the increased understanding of their syndrome. Therefore, this research aims to carry out interviews with individuals who have Williams Syndrome, as well as their parents and carers.

A step towards intervention: It is important to have a rounded perspective and understanding of the profile and nature of these difficulties before tailored and specific strategies to reduce them are developed. With the

information collected during this research study, the next step will be to develop effective interventions and ways to reduce difficult or unhelpful emotions experienced by people with Williams Syndrome.

Development of resources: We will utilise this research to create an online resource about Williams Syndrome. This will be designed to be accessible for families and will be shared through this website.

Further information

The more families who take part, the more likely the results will be meaningful and helpful to other families in the future. If you think you may be interested in taking part or if you would like some further information please contact Rachel Royston at rxr180@bham.ac.uk or 0121 414 2855.

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