The mental health of children and young people with neurodevelopmental disorders

A Cerebra funded research programme

Not so long ago it was thought that people with the most severe intellectual disability and complex needs did not experience the most common mental health problems such as anxiety and depression. This meant there were no assessments available and so the problems could not be identified even if they were there. In our research we have focussed on anxiety as we believe it to be common but neglected. The challenges have been to accurately assess and describe anxiety in people who cannot self-report, to find out what type of anxiety problems people experience and to uncover what might be the causes of these problems. This research has been led by Dr. Jane Waite (Lecturer in Psychology at Aston University) and Dr. Hayley Crawford (Assistant Professor at University of Warwick Medical School).

Dr. Jane Waite (L) and Dr. Hayley Crawford (R)

Anxiety is thought to be a very common feature of Williams syndrome becoming more disabling in the teenage years and into young adulthood. PhD student Rachel Royston and Jane Waite used a wide range of methods to understand the experience of anxiety in people with Williams syndrome. They conducted the first large scale review of the prevalence of anxiety in people with intellectual disability to be able to make comparisons and Rachel's systematic analysis of the studies on Williams syndrome showed that anxiety was much more common in this group.

Rachel's next studies used psychophysiological assessments such as heart rate and the amount of sweat produced in the palm of the hands, clinical interviews, observation and cognitive assessments to show that there were two main types of anxiety experienced by people with Williams syndrome: specific phobias and generalised anxiety. The highlight of this work was that sensory sensitivity (particularly sensitivity to loud noises or 'hyperacusis') was associated with phobias but the generalised anxiety was related to finding uncertainty about the future unusually difficult. Rachel and Jane also showed that the characteristics that were associated with anxiety in Williams syndrome were different from those associated with anxiety in Prader-Willi and fragile X syndromes.

Studying anxiety in children with fragile X syndrome

Other work by Hayley Crawford and Jane Waite has shown that different types of anxiety problems are more common in different syndromes. Phobias and social anxiety are both common in fragile X syndrome whist generalised anxiety and separation anxiety are more common in Cornelia de Lange syndrome. Also, anxiety in Cornelia de Lange syndrome is particularly strong in social situations where the person has to initiate conversation.

This work shows clearly that people with complex needs can have different profiles of anxiety and that these can be assessed and identified if we use the right tools. Crucially once the type of anxiety is identified we do not need to develop new interventions, instead we can apply well known and effective interventions. Dr. Jane Waite is now leading a programme of research into interventions for phobias experienced by autistic children with severe intellectual disability.

The Cerebra Centre for Neurodevelopmental Disorders

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Working wonders for children with brain conditions

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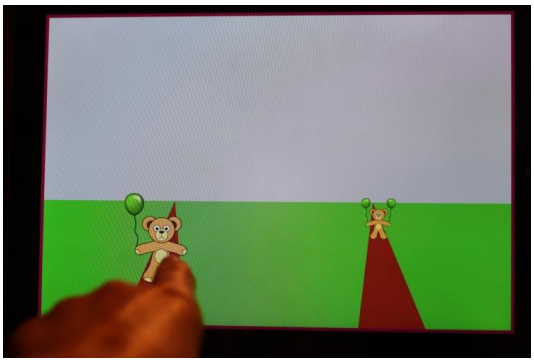
The research team attended a Lowe syndrome meeting in the USA to give out information and collect data

In a second line of research we have focussed on temper outbursts. These are not traditionally thought of as mental health problems but the problem of controlling extreme emotions is a good fit. In early studies we showed that people with Prader-Willi syndrome felt intense remorse after temper outbursts that are characteristic of the syndrome and that temper outbursts were triggered by changes to routine. This work led Dr. Kate Woodock and PhD student Leah Bull to study what made routines more rigid and whether warning children of an unexpected change to routine would help reduce outbursts. Kate Woodcock has now developed a programme of promising research in this area in her own lab. We also collaborated on the first successful trial of vagal nerve stimulation for the treatment of temper outbursts in Prader-Willi syndrome. Work that was conducted at the University of Cambridge by Prof. Tony Holland and colleagues.

We have also studied temper outbursts in Smith-Magenis and Lowe syndromes. Jane Waite, Hayley Crawford and Lucy Wilde's innovative work on Lowe's syndrome used a computer game played by the children to see if they could wait for a bigger prize or if they would choose a quicker but smaller prize. Remarkably, the children who found it too hard to wait for the big prize were those children who had more outbursts during the day. This is an important finding as it shows a basic cognitive or emotional difference in the children that is additional to their intellectual disability. This means that their experience of waiting for things in day to day life is fundamentally different from that for other children. It is harder for these children, they are not just impatient.



A computer game assesses whether children find it harder to wait for bigger rewards

In both the areas of anxiety and temper outbursts the work we have conducted is being rapidly translated into interventions. Low mood is also a priority as Cerebra PhD student Jess Penhallow showed that low mood is the strongest predictor of quality of life 12 years later. Dr. Jane Waite and Dr. Hayley Crawford are now leading a programme of work on mental health problems in children and young adults in the newly formed Cerebra Network. The work is important as we have produced evidence that anxiety can be a central and pervasive problem that can underlie other problems such as sleep disorders, self-injury and selective mutism. Tackling the core problem of anxiety can lead to benefits in many areas and is a priority for future work.

Examples of publications:

Royston, R., Waite, J., Howlin, P. and Oliver, C**.** (2017). Anxiety disorders in Williams Syndrome contrasted with intellectual disability and the general population: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders.* **47**, 3765–3777.

Cressey, H., Oliver, C., Crawford, H**.** and Waite, J. (2019). Temper outbursts in Lowe syndrome: Characteristics, sequence, environmental context and comparison to Prader-Willi syndrome. *Journal of Applied Research in Intellectual Disability Research*, **31,** 1216-1227.