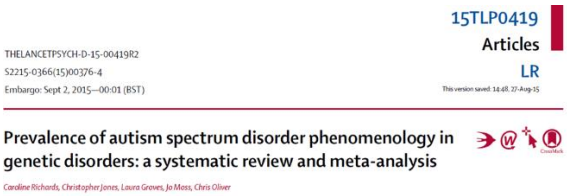
Atypical autism in children and young people with neurodevelopmental disorders

A Cerebra funded research programme

The James Lind Alliance identified access to a diagnosis of autism as a high priority for parents. For many families that access has improved significantly but for children with complex needs it is still a challenge to have a child assessed for autism or to be given a diagnosis. This is often because the characteristics of autism in some children are unusual or atypical and so not easily recognised. Also when a child has a named syndrome, for example fragile X syndrome, it is difficult to know whether differences in social behaviour are related to autism or caused by something else that is a feature of the syndrome, such as social anxiety.

Dr. Hayley Crawford (L) and Dr. Jo Moss (R) led the Atypical Autism research programme

Dr. Jo Moss (Lecturer in Developmental Psychology at the University of Surrey) and Dr. Hayley Crawford (Assistant Professor at University of Warwick Medical School) have led a programme of work in this area to better describe and understand autism in children with the most complex needs. The aim of the research has been to level the playing field and ensure that all children and their families have the same access to diagnosis and specialist services.



Our work in this area has generated the most comprehensive study of the prevalence of autism in different genetic conditions conducted to date. This study was published in the Lancet Psychiatry in 2015 and has become the seminal paper in this area and the standard work for researchers to consult. The information brought together for the first time in this paper demonstrates very clearly that assessment and diagnosis of autism should be considered, even though a child or young person has a rare genetic syndrome.

Using eye tracking to learn more about how people process social situations

A major barrier to assessing some social aspects of autism is that it is often necessary for children to follow quite complicated instructions during assessments. Dr. Jo Moss and Dr. Hayley Crawford were amongst the first researchers to overcome this problem by using state of the art eye tracking techniques with children and young people with Cornelia de Lange, Rubinstein-Taybi and fragile X syndromes. The studies involved the children watching a screen whilst a sensitive camera recorded their eye movements and showed which

parts of the images they were looking at. They found that children with fragile X did not look at people's eyes but this was not related to any autistic characteristics. Children with Cornelia de Lange syndrome tended to be very slow to look at some social information, particularly when it was presented in a more direct way. These findings are important as they help to differentiate between unusual social behaviours that are not related to autism and those that are in children who are usually excluded from commonly used diagnostic assessments.

A second theme in this research has been the changes in characteristics of autism as children get older. This is well understood in the majority of autistic children with characteristics appearing in the early years. Cerebra funded PhD students Lisa Cochran and Laura Groves showed that this is not always the case and that in Cornelia de Lange syndrome the characteristics emerge much later and become stronger in teenage years. This finding has led to a specific recommendation in the International Treatment and Management guidelines for this syndrome that a diagnosis of autism should be considered throughout childhood and into young adulthood.

Hayley Crawford's work on fragile X syndrome also showed that autism in this syndrome was related to ADHD characteristics as children grew older. This is a novel observation and suggests a common mechanism might underpin both of autism and ADHD in this syndrome. This is useful information for predicting future needs.

Our work in this area has clearly shown that autism can and should be assessed in children and young adults with the most complex needs and rare syndromes. The challenges being confronted now by Dr. Jo Moss and Dr. Hayley Crawford as part of the Cerebra Network for Neurodevelopmental Disorders are to develop assessment methods that ensure sensitive and accurate diagnosis and make the access to diagnosis widely available as a part of standard clinical services.

Examples of publications:

Crawford, H., Moss, J., Oliver, C. and Riby, D. (2017). Differential effects of anxiety and autism on social scene scanning in males with fragile X syndrome. *Journal of Neurodevelopmental Disorders, 9:9.*

Mulder, P. A., Huisman, S., Landlust, A. A., Moss, J., SMC1A Consortium, Piening, S. C., Hennekam, R. and van Balkom, I. D. C. (2019). Development, behaviour and autism in individuals with SMC1A variants. *Journal of Child Psychology and Psychiatry*, **60**, 305-313.