Self-injurious behaviour in children and young people with neurodevelopmental disorders

A Cerebra funded research programme

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Clinicians in the field of autism and severe learning disability will identify the most severe self-injury, such as headbanging or face punching, as one of the most challenging and difficult behaviours they encounter. Our research in self-injury has been led jointly by Dr. Caroline Richards (Lecturer in Neurodevelopmental Disorders at the University of Birmingham) and Dr. Debbie Allen (Lecturer in Psychology at the University of Wolverhampton). Caroline has studied the prediction of future risk for self-injury, early intervention and possible causes of the most severe self-injury, and Debbie has developed and applied a comprehensive clinical assessment method for use in NHS settings for children with severe intellectual disability who are autistic.

Dr. Caroline Richards (L) and Dr. Debbie Allen (R)

In a number of studies across syndromes such as Tuberous Sclerosis Complex, fragile X, and Cornelia de Lange and in autism and intellectual disability, we have identified clear behavioural risk markers that can predict (within reasonable margins of error) who will start to show self-injury, whose self-injury will persist and whose self-injury will increase in severity. For the first time we have a set of identifiable characteristics and behaviours that will enable us to target early intervention toward those children at the highest risk for developing severe self-injury. This is critical to effective and efficient early intervention.

The work on these risk markers and the interpretation of their role in self-injury has opened new avenues for research and given new insight into causes. Impulsivity and repetitive behaviours are both predictors of severe self-injury. We think this indicates a problem with behavioural self-regulation and this may explain why some people who show the most severe self-injury seek to restrict their own movements at times. One implication of this is that traditional behavioural interventions may not be the most effective for some people.

Alongside this work on prediction and theories of cause, Dr. Debbie Allen has conducted the first clinical case series study of 30 autistic children with severe intellectual disability. The children were nonverbal or minimally verbal and so the clinical challenge was substantial. Having developed a battery of state of the art assessments of pain and sleep and then using functional analysis, observation and interview alongside health assessments by paediatricians and dentistry, Debbie has collected the most comprehensive and systematic, clinical dataset ever compiled on this very high-risk group. The result of this work will be an assessment protocol that will indicate which type of intervention should be prioritised for different patterns of assessment results.

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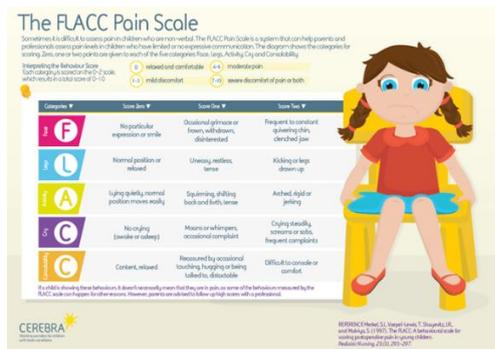
The FLACC pain scale graphic developed with Cerebra and used by Dr. Debbie Allen to study the role of pain in self-injury

These two approaches to research, the assessment of clinical groups and the statistical modelling of risk and causes of self-injury, complement each other perfectly and represent the value of research teams that involve clinicians and researchers turning research into practice.

The next steps for this programme of research are to translate the identification of reliable risk-markers into a risk-informed early intervention programme, trialled in community services. Alongside this, evaluation of the causal interactions between sleep, anxiety and self-injury is clinically warranted. Work led by the Cerebra Network for Neurodevelopmental Disorders will address these aims.

Examples of publications:

Richards, C., Davies, L. and Oliver, C. (2017). Predictors of Self-Injurious Behavior and Self-Restraint in Autism Spectrum Disorder: Towards a Hypothesis of Impaired Behavioral Control. *Journal of Autism and Developmental Disorders,* **47**, 701-713.

Richards, C., Moss, J., Nelson, L. and Oliver, C. (2016). Persistence of self-injurious behaviour in autism spectrum disorder over three years: A prospective cohort study of risk markers. *Journal of Neurodevelopmental Disorders.* **8**:21