



UNIVERSITY OF  
BIRMINGHAM

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The Core Research Programme at  
The Cerebra Centre for Neurodevelopmental  
Disorders

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**Prepared by:**

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## Our purpose

Our aim is to identify the causes of the most pressing problems for children with neurodevelopmental disorders in order to develop effective interventions that are delivered at the right time to enable long term change.

## Our work

What's the problem? It sounds like a straightforward question but it's not. Many children with neurodevelopmental disorders experience a range of problems that impact negatively on their lives and the lives of their families. These problems change as the children grow up and include autistic like conditions, self-injury and aggression, sleep disorders, and emotional and mental health problems. Critically, the chance of having one of these problems is linked to the cause of neurodevelopmental disorders. Children with autism who cannot speak are more likely to self-injure, children with Smith-Magenis syndrome are much more likely to have problems sleeping and children with tuberous sclerosis complex are more likely to experience hyperactivity and be impulsive. Once we know the cause of a neurodevelopmental disorder we now know the chances of a specific problem occurring and this makes it possible to plan for the future and develop early intervention strategies. **At the Cerebra Centre we have identified specific problems in more than 20 neurodevelopmental disorders.**

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### Prevalence of autism spectrum disorder phenomenology in genetic disorders: a systematic review and meta-analysis

*Caroline Richards, Christopher Jones, Laura Groves, Jo Moss, Chris Oliver*

What causes these problems? By studying the problems we have identified in specific neurodevelopmental disorders, we have been able to identify specific causes. For example, we have shown that pain resulting from untreated gastro-oesophageal reflux (severe heartburn) can be a cause of self-injury, breathing problems can make sleep problems worse in Smith-Magenis and Angelman syndromes and problems with flexible thinking can lead to severe anxiety in social situations. **At the Cerebra Centre we can make specific recommendations for interventions and also promote early intervention targeting these causes.**



How can clinicians, teachers and parents identify the cause of a problem? Whenever a problem develops, careful assessment is critical to choosing the right intervention. Knowing that the chance of a problem occurring is higher in some neurodevelopmental disorders than others means that priorities for assessing causes can be tailored for individual children. However, assessment of causes is difficult when children have very severe disabilities and limited communication. New assessments and road maps for the decision making process during assessment are needed to make sure the cause of any problem is identified accurately and efficiently. This means the right treatment is more likely to be delivered quickly. **At the Cerebra Centre we have developed new assessments for children who are**

severely disabled and nonverbal to identify clinically significant low mood, pain, unusual social behaviour, impulsivity and overactivity and repetitive behaviours. We have also made significant progress on protocols for the assessment of self-injury and sleep disorders.

### The FLACC Pain Scale

Sometimes it is difficult to assess pain in children who are non-verbal. The FLACC Pain Scale is a system that helps parents and professionals assess pain levels in children who have limited or no expressive communication. The diagram shows the categories for scoring 2m, 1m or 0m responses to each of the five categories: Face, Legs, Activity, Cry and Consolability.

Interpreting the Behavioural Score  
 Each category is scored on the 0-2 scale which makes the total score 0-10.

- 0 relaxed and comfortable
- 1 mild discomfort
- 2 moderate pain
- 3 severe discomfort/pain or both

Category	Score One	Score Two	Score Three
<b>F</b> Face	No particular expression or smile	Occasional grimace or frown, withdrawn, distressed	Frequent to constant quivering chin, clenched jaw
<b>L</b> Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
<b>A</b> Activity	Lying quietly, normal position moves easily	Squirming, shifting back and forth, tense	Arching, rigid or jerking
<b>C</b> Cry	No crying (awake or asleep)	Moans or whimpers, occasional complaints	Crying steadily, screams or sobs, frequent complaints
<b>C</b> Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractible	Difficult to console or comfort

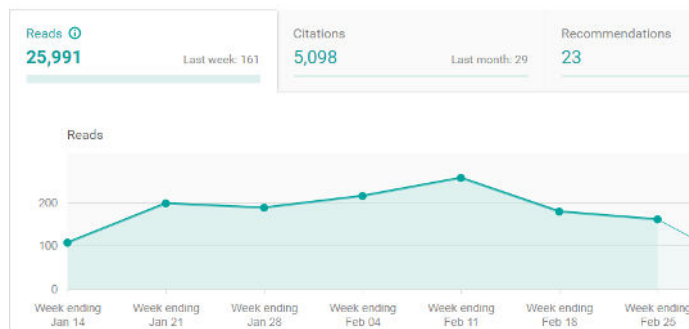
If a child is showing these behaviours, it doesn't necessarily mean that they are in pain, as some of the behaviours measured by the FLACC scale can happen for other reasons. However, parents are advised to follow up high scores with professional.

**CEREBRA**

REFERENCE: Henley, G.L., Vogel, Lewis, T., Shugrue, J.R. and Malloy, S. (1997). The FLACC: A behavior scale for scoring and assessing pain in young children. Pediatric Nursing, 11(1), 20-27.

## Our information

It is estimated that it takes between 10 and 17 years for a research finding to be implemented in practice. That is too long. We do publish the results of our research in scientific journals so that they are subject to peer review and made available to other researchers and clinicians. However, we also provide information based on our latest research at parent and practitioner meetings, the FIND website (<http://www.findresources.co.uk/>), presentations at professional and scientific conferences and websites such as Researchgate. **At the Cerebra Centre we deliver about one presentation a week at meetings, our research papers are read 150 times a week on Researchgate and elsewhere, 200 parents very year receive an individualised report on their child and around 14,000 people have visited our website.**



## Our team

At the heart of the Cerebra Centre are the people who do the work. At any one time we will have between 30 and 40 people working in the Centre. Some are Postdoctoral Research Fellows who completed their PhD in the Centre and have gone on to win their own grants to fund further research and support further PhD candidates. This generational progression has been critical to the success of the Centre. Other people who work in the Centre are Undergraduate, Masters and Clinical Doctoral students on placement. The core team supervise the work of these students who make a significant contribution whilst being trained in research methods. **At the Cerebra Centre we have trained more than 50 Doctoral students and 30 Masters students. Last year, Postdoctoral Research Fellows associated with the Centre were awarded close to £500,000 in grant funding in addition to funds provided by Cerebra.**



## Our future

The Cerebra Centre is now well established with an international reputation, the largest database of rare genetic disorders in the world, a team with clinical and research training, support from parent groups, effective dissemination, demonstrable impact, a strategy for future development and a clear purpose. The task now is to convert our past and future findings into effective assessment and intervention delivered at the right time in the right way. **At the Cerebra Centre we will continue to develop innovative, accurate and efficient assessments to identify the causes of the problems experienced by children with neurodevelopmental disorders and develop new interventions that can be delivered at the right time to enable long term change.**

