

Research findings, information, assessments, and teaching and training materials.

Cerebra funded resources

Academic research

With funding from Cerebra from 2014 to 2020, we have published 85 research papers and over 40 abstracts in peer reviewed scientific journals and we have made over 100 presentations at research and clinical conferences in 15 countries. Our work has been published in the leading journals in our field: Nature Reviews Genetics, Lancet Psychiatry, Molecular Autism, PLoS ONE, Sleep, Frontiers in Psychiatry, Neuroscience and Biobehavioral Reviews, and the Journal of Child Psychology and Psychiatry.

Our research was cited by other researchers over 4,000 times and on an open source website (Researchgate.net) our research papers were read more than 500 times during December 2019 alone. These academic metrics demonstrate that our work informs others in the field and influences the direction of research.

The FIND website



The FIND website is our main resource for providing up to date, accredited, evidence based information and advice.

“My state/country U.S. are cutting services for the disabled and this information is going to be so helpful in keeping the services which he presently has. Thank you!”

Feedback from a parent of a child accessing the FIND website

Dr. Jane Waite (Lecturer in Psychology at Aston University) developed, maintained and oversees the website. Information on the website has been accessed in 200 countries, with approximately 30,000 new visits in the last year.

Making assessments available

Paper based psychological assessments are often expensive to purchase and cannot usually be used more than once. For example, a commonly used screening assessment for autism, such as the Social Communication Questionnaire, costs \$166 for the manual and 40 assessment forms, and 20 more forms would cost \$53. Cerebra funding has enabled us to develop eleven measures of behaviour, emotion, sociability and mood for use with children and adults with complex needs and make these available online, at no cost, with a manual that describes the use of the measures, scoring protocols, normative data and interpretation.



UNIVERSITY OF
BIRMINGHAM

Informant assessments of behaviour and affect for people with intellectual disability

by

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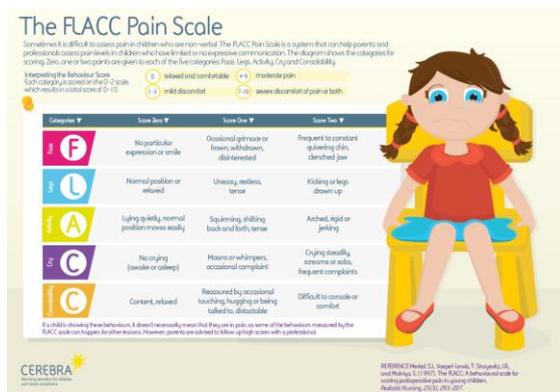
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Many of the measures have been translated into eleven languages. In the first two months that the manual and measures were made available, they were downloaded by 85 NHS Trusts and more than 150 professional bodies across 26 countries. The

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availability of the manual and measures at no cost means these assessments are equally available in low, middle and high income countries and can be accessed by any clinician, practitioner or researcher who needs them.



The FLACC pain scale graphic developed in collaboration with Cerebra is widely used in clinical practice

Feedback to parents

Every family that participated in a programme of research received a report detailing the results and further information.

I've just received the feedback on research letter in the mail. I look forward to reviewing it and wanted to let you know that we greatly appreciate the work you have done on behalf of families affected by Lowe syndrome. It is not easy to find researchers to focus on such a small syndrome and group of people.

The Cerebra guides

With Cerebra we have produced guides on sleep, pain, anxiety, self-injurious behaviour, autism in genetic syndromes, and sensory processing disorders that have been downloaded nearly

40,000 times. The sleep guide is used in the Public Health England policy document on sleep and was highly commended as an information source by the British Medical Association.



Informing and influencing policy

Our research is used to inform policies recommended by the National Institute of Clinical Excellence and Public Health England and international treatment and management guidelines for some rare syndromes.

CONSENSUS STATEMENT

OPEN
EXPERT CONSENSUS DOCUMENT
Diagnosis and management of Cornelia de Lange syndrome: first international consensus statement
Antonine D. Klimec^{1,2*}, Joanna F. Moss^{1,2*}, Angelo Solicera^{1,2*}, Anne-Marie Bisgaard^{1*}

Teaching and training materials

We have produced a training video covering challenging behaviour in collaboration with Birmingham Community Healthcare NHS Foundation Trust. The video features actors from the Department of Drama and Theatre Arts at the University of Birmingham who developed their portrayal of people with severe intellectual disability with respect and care. This gives the viewer the opportunity to see scenarios and behaviours based on real people and episodes whilst protecting the dignity of people with complex needs. The video is available at <https://tinyurl.com/vyhIndpy>