CEREBRA
Working wonders for children with brain conditions

The Cerebra Network for Neurodevelopmental Disorders

The Cerebra Network for Neurodevelopmental Disorders

Annual Report 2021-2022

UNIVERSITY OF BIRMINGHAM
WARWICK THE UNIVERSITY OF WARWICK
Aston University BIRMINGHAM UK
UNIVERSITY OF SURREY

Executive Summary

The Cerebra Network for Neurodevelopmental Disorders was established in September 2020 and is a unique collaborative research network that truly integrates knowledge, expertise and resources across four leading institutions to deliver greater insight into children with rare and complex syndromes. The aim of the Cerebra Network is to improve the evidence that underpins better assessment and support which in turn leads to improved outcomes for children with complex needs and their families.

This year has seen the Cerebra Network **grow and thrive**. The Network is now supported by 20 members of staff including; four Network Directors and a team of lecturers, post-doctoral researchers, research assistants and research therapists. In 2021-2022 this core team has supervised, supported and trained over 75 students. Our productivity this year is evidenced by the wide-ranging research and impact activities and achievements of the staff, students and volunteers who comprise the Network (See Appendix A for a detailed list of achievements and outputs in 2021-2022).

Since September 2021 we have:

- Provided research support and training to 18 Doctoral students, 10 Masters students, 7 Clinical Psychologists in training, 34 Undergraduate dissertation students and 16 Undergraduate placement students.
- Published 15 original scientific articles in peer reviewed journals, with a further 14 articles currently under review and a further 19 articles currently in preparation.
- Delivered 44 oral presentations to academics, parents, carers and professionals.
- Led 8 Patient Participant Involvement activities.
- Been awarded 13 research grants which will be supported by the infrastructure of the Network. This enables us to expand the scope of research and impact activities delivered by the Cerebra Network.
- Delivered research-led teaching across 10 undergraduate and postgraduate Psychology modules.

Our successes over the last year and cumulative achievements since the Cerebra Network was established in 2020 demonstrate the way in which the **unique structure** of the Network continues to support the delivery of high impact from its work and funding. This **pioneering approach**, alongside the breadth and quality of our research, places the Cerebra Network for Neurodevelopmental Disorders at the **forefront of research** into children with rare and complex conditions in the UK.

Dr Hayley Crawford,
University of Warwick

Dr Jo Moss,
University of Surrey

Dr Caroline Richards,
University of Birmingham

Dr Jane Waite,
Aston University

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Report Highlights

Our Cerebra funded PhD students are now in their second and third years of study and have been sharing findings at national and international conferences

Spotlight on PhD Students, p5

We launched the BEOND survey which will explore outcomes in more than 30 rare genetic syndrome groups

Developing an infrastructure for research and impact, p9

Two of our Network Directors received promotions to Senior Lecturer roles

Success Stories, p4

Dr Jo Moss was invited to present at the Royal Society of Medicine

Knowledge Exchange, p12

The LADDERS intervention from our Aston team was well received by CAMHS professionals

Impact, p11

The Be-Well Checklist was launched to parents, caregivers and professionals, with positive initial feedback and ongoing plans to continue developing and refining the measure in the coming years

The Highlights of 2022, p13

Growing capacity and the next generation of research leaders

A primary focus of the Cerebra Network is to grow capacity and train the **next generation of research leaders and clinicians**. This commitment to training promotes longevity of our transformative research into the future and ensures that those providing services to people with rare and complex needs and their families have a solid grounding in this research.

Through the unique structure of the Cerebra Network, we can train significantly more future research leaders and clinicians than if we were working in silos. During the first year of funding, each Network Lead has grown capacity at their institution and these new researchers have become fully embedded into the Cerebra Network. Our collaborative approach ensures that new researchers **benefit from the expertise** across the Cerebra Network through joint supervision and shared training opportunities.

Masters/undergraduate research and placement students

In the academic year 2021-22 the Cerebra Network provided research support and training to 3 Masters students, supported 15 undergraduate research projects, and offered professional placements to a further 9 undergraduate students. This is far higher than any individual approach could offer. This year we host a further 14 students at the undergraduate and Masters level. These training opportunities often provide an introduction to research into rare and complex needs and place students in a strong position to obtain funding to conduct further study.

Five Cerebra Network undergraduate placement students secured paid research assistant posts following the successful completion of their placements (four at University of Birmingham, one at University of Surrey) and another two placement students (University of Surrey) conducted their final year research projects in the Cerebra Network. This highlights the strong motivation for students who experience research in this area to continue to expand their expertise.

Doctoral students

September 2022 saw two new PhD students start their projects within the network, they join our ten existing PhD students and three further students joining us to complete their research projects for their Doctorate in Clinical Psychology. Each PhD student is funded for three years full-time to conduct ground-breaking research into children with rare and complex needs and their families. Many of these students are co-supervised by one or more Network Leads which demonstrates our unique approach to integrate knowledge, expertise and resources across institutions and, ultimately, results in research that adopts a more holistic view of children with rare and complex needs and their families. PhD students play an integral role in the Cerebra Network and, as a result, students engage in activities that strengthen their position to obtain competitive post-doctoral research posts. This year, one of the PhD students contributed to winning pilot funding at a Naturalistic Experimentation Workshop at Birkbeck University

Success stories

Dr Jo Moss

We are delighted to report that two Cerebra Network leads have been promoted to Senior Lecturer (**Dr Jo Moss** and **Dr Hayley Crawford**). Each of the four leads now hold established positions as Senior Lecturer/Associate Professor within their institutions, influencing the research agenda from the ground up.

Dr Hayley Crawford

Dr Georgie Agar

Dr Georgie Agar and **Dr Hayley Trower** have secured competitive lectureships. Dr Georgie Agar worked as a post-doctoral researcher in the Cerebra Network following her Cerebra-funded PhD and is now a full-time lecturer at Aston University. Dr Hayley Trower works as a Research Fellow in the Cerebra Network (University of Warwick) and has recently secured a part-time lecturing position at the University of Wales Trinity Saint David (UWTSD) alongside this. Both Georgie and Hayley are now in strong positions to lead research into children with rare and complex needs and their families, using the knowledge and skills acquired through their time in the Cerebra Network to continue a collaborative approach to research and capacity-building.

Dr Hayley Trower

Dr Catherine Laverty successfully completed her PhD (University of Birmingham) and has already made a huge impact on the Birmingham team as a post-doctoral researcher. Since her graduation Dr Catherine Laverty has been leading on the Sleep-Impulsivity-Behaviour (SIB) study exploring the role of sleep and impulsivity in self-injury in autistic children with an intellectual disability. In addition to this she has been supervising one of our Clinical Psychology Trainees on a continuation of her own PhD research investigating social outcomes in children born mid-late preterm. We are very excited to see Dr Catherine Laverty join the BEOND study in April 2023. Although Dr Catherine Laverty's original PhD was not funded by Cerebra, she offers an excellent example of how the breadth of work that is supported by the Network is able to build expertise, recruiting and retaining exceptional researchers in our teams.

Dr Catherine Laverty

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Spotlight on: PhD students

We continue to be inspired by the creativity and dedication of our three Cerebra funded PhD students. Now in their second and third years of study we asked Lauren, Rory, and Jess for an update on their research:

Lauren Jenner, University of Surrey

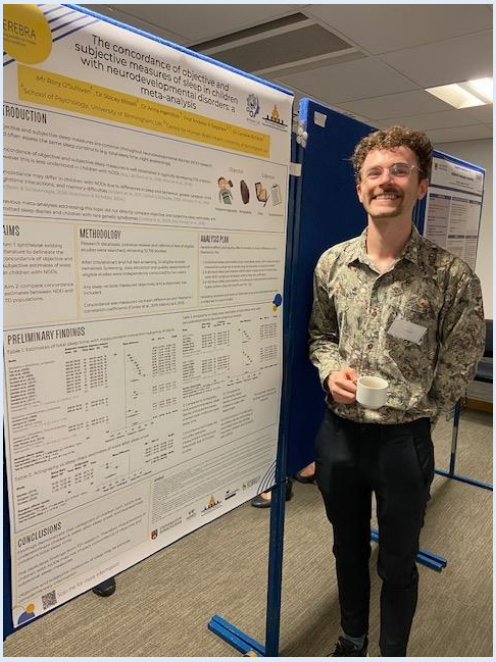
I am currently in the third year of my PhD, funded by Cerebra. My research is on social abilities and autism characteristics in Prader-Willi syndrome (PWS), Down syndrome (DS) and non-syndromic autism (AUT). From October 2021 – January 2023, a total of 87 children (DS = 34, PWS = 32, AUT = 21) have participated from across the UK. Data collection has involved various online and in-person tasks. These include assessments of children's verbal and non-verbal abilities, alongside measures of social abilities. Using eye-tracking technology, I have been able to record how children process and understand social information. I have also recorded play-based social interactions between children and their parents. Questionnaires and interviews were also completed by parents, to better understand children's day-to-day behaviour.

Preliminary analyses indicate divergent profiles of social abilities (e.g., gaze-following, imitation, mentalising) across children with PWS, DS and AUT. By using parent-informant measures alongside behavioural data from parent-child social interactions, these profiles will be explored across contexts and in relation to autism characteristics.

In addition, my studies have enabled me to work on a literature review on the heterogeneity of autism characteristics in genetic syndromes. I have also conducted a systematic review and meta-analysis on the use of eye-tracking technology in people with intellectual disability, which I presented at the Neurodevelopmental Disorders Annual Seminar 2022 in Edinburgh. Last year, I also attended the 11th International Prader-Willi Syndrome Conference in Limerick. Following this experience, I was invited to become a member of the IPWSO Mental Health Network. In April 2023, I will be presenting findings on 'Overimitation: Insights from Down syndrome, Prader-Willi syndrome, and autism' at the 55th Annual Gatlinburg Conference in Kansas City. I am incredibly grateful for these opportunities to network, collaborate and share my research.

Rory O'Sullivan, University of Birmingham

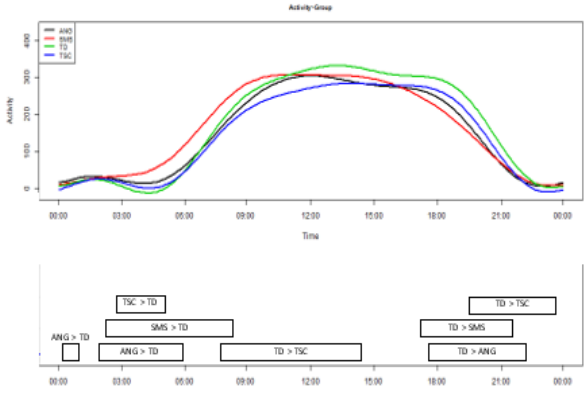
I am now in the second year of my Cerebra funded PhD and my PhD projects have progressed well over the last year. I have reviewed and meta-analysed previous studies exploring the concordance of objective and subjective measures of sleep in children with neurodevelopmental disorders. I look forward to sharing the findings through upcoming talks and journal publications.



I am currently conducting a secondary analysis of actigraphy data obtained through previous Cerebra funding, to describe patterns of physical activity in children with rare genetic syndromes and see how this compares against caregiver-reported overactivity. Some initial findings from this work are presented below. I am also obtaining ethical approval for a sleep study that will use objective techniques to explore how sleep and impulsivity are associated in children with rare genetic syndromes.

Since January 2022, I have presented my work at the Neurodevelopmental Disorder Annual Seminar 2022 in Edinburgh, and been invited to present my work at the 55th Gatlinburg Conference in Kansas City. I have also enjoying meeting families at the SMS Bright Futures 2022 Conference, where I chaired several talks and shared current Cerebra funded research projects. In the near future I will also be leading a sleep workshop with clinical assistants in the NHS, discussing the underpinnings of poor sleep and relevant interventions for children with neurodevelopmental disorders.

Take a look at some of Rory's work below:



Results of secondary analysis of actigraphy data: Functional linear model and permutation F-test for 24-hour activity profiles of children with Angelman syndrome (ANG), Smith-Magenis syndrome (SMS), tuberous sclerosis complex (TSC) and TD children

The upper panel presents the mean 24-hour activity levels of children with Angelman syndrome (AS), Smith-Magenis syndrome (SMS), tuberous sclerosis complex (TSC) and typically-developing (TD) children. The y-axis represents the intensity of physical activity, the x-axis represents the hours within a 24-hour cycle.

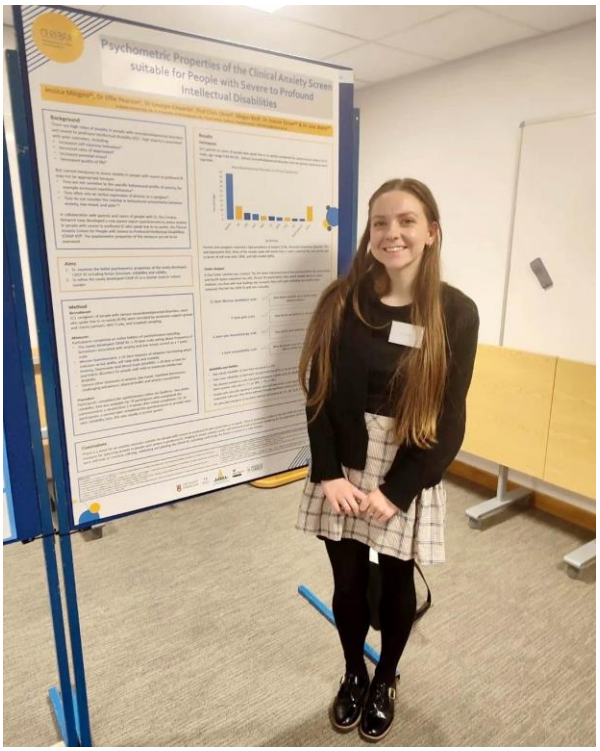
The lower panel presents the times at which activity in one group is significantly greater than another group. Note that in the early morning hours, activity levels are significantly higher in the syndrome groups compared to the TD group. In contrast, activity levels are higher in the TD group than the TSC group throughout the late morning and early afternoon, and higher compared to all syndromes during evening hours.

Jess Mingins, Aston University

My PhD is focused on mental health in rare genetic syndromes associated with intellectual disability. Primarily, my focus is on assessment of anxiety and factors associated with anxiety in Fragile X Syndrome and Cornelia de Lange Syndrome. I applied for this project after completing an integrated Masters degree at the University of Birmingham in Psychology and Psychological Practice. During my final year, most of my time was spent working on a meta-analysis summarising research on how intellectual disability may be linked to anxiety in autistic children. One of the key findings of the report was that anxiety measures for children with intellectual disabilities were extremely limited, and I became interested in learning more about how we can recognise anxiety sooner in children with intellectual disabilities.

The first year of my PhD saw me completing secondary data analysis to refine a questionnaire for anxiety, the ClASP-ID, and assess its reliability and validity in a large group of people with intellectual disability. The results have been exciting, as the new measure shows good reliability and validity. Last year I also had the opportunity to attend a wide variety of training courses, which have been incredibly valuable to both my project and my professional development. This has included training on the gold-standard assessment of autism characteristics, the ADOS-II. I have also received training on a parent report interview of anxiety and training on how to use CardioWorkshop, a software which allows assessment of heart rate. Attending conferences and seminars has allowed me to showcase my work through oral and poster presentations, both online and in person. I especially enjoyed attending the Neurodevelopmental Disorders Annual Seminar in Edinburgh last June.

I'm now in the second year of my PhD and have submitted applications for ethical approval which will allow me to visit families of people with Fragile X Syndrome and Cornelia de Lange Syndrome. On these visits I will conduct direct assessments of anxiety, autism characteristics, sensory sensitivities and assess heart rate. Families will also complete sleep diaries and a range of questionnaires to assess characteristics related to anxiety. This means that I can assess the reliability and validity of the ClASP-ID in Fragile X syndrome and Cornelia de Lange syndrome specifically. I will also look at the relationships between anxiety, sleep and behaviours that challenge in Fragile X syndrome and Cornelia de Lange syndrome. I look forward to the next stages of the project, and especially to working with families in the near future.



As well as the impressive work of our Cerebra funded PhD students, our teams host a number of students whose PhDs are supported by other funders. They add significant value to the work of the Network, capitalizing on the Network infrastructure and increasing the breadth and depth of our activities. Here's what some of them had to say about working as part of the Cerebra Network:

Katherine Marlow: **Understanding self-restraint shown by autistic children and/or those with an intellectual disability.**
A highlight of my PhD was travelling to Edinburgh for my first in-person conference at the Neurodevelopmental Disorders Annual Seminar. I enjoyed finally meeting other PhD students across the Network face-to-face, a luxury that was previously impossible due to Covid-19!

Naomi Williams: An Evaluation of the Competency, Suitability and Effectiveness of Child and Adolescent Mental Health Services Across England: Autism, Intellectual Disability and Clinical Practice
Being linked to the Cerebra Network through my supervisor has helped to expand my knowledge in this area, see where the study fits alongside other research being conducted at the same time and also connect with other PhD students, during the coffee mornings.

Kayla Smith: Assessing the social behavioural profile of people with fragile X syndrome
As a PhD student in the Cerebra Network, it is encouraging to be a part of a team dedicated to improving the lives of people with rare and complex syndromes and their families. While my research may be focused on mental health and wellbeing, being part of the Cerebra Network helps me to understand how my research may impact health outcomes more broadly or how other health outcomes, such as pain and sleep, may impact mental wellbeing.

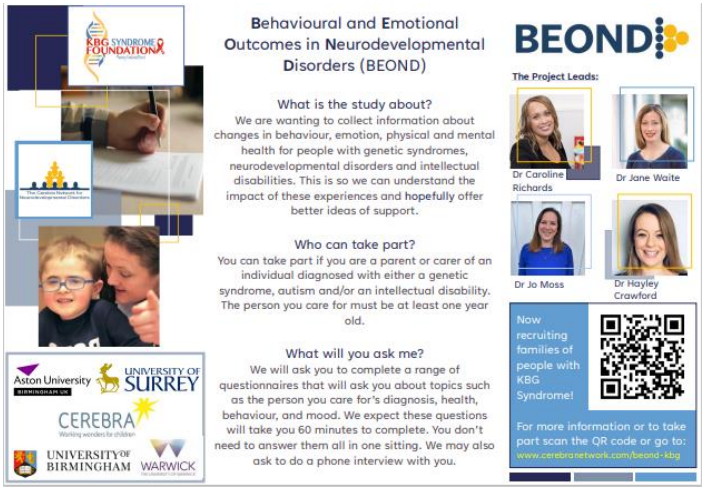
Courtney Greenhill: Mental health in individuals with Rubinstein-Taybi Syndrome (RTS).
I will be collaborating with Cerebra Network on the BEOND project to collect questionnaire data on behaviour, well-being, emotion, cognition and health in children and adults with RTS. Being a part of BEOND allows me to gain a better insight into the development of RTS across the lifespan due to the longitudinal nature of the project, which will support me to meet the aims of my PhD.

Nicky Thomas: Parents mental and physical wellbeing whilst caring for a child with an intellectual disability
Working with a passionate and unique group of researchers across four leading institutions has been extremely enjoyable and an invaluable learning curve for me as I continue to develop my own research skills. It has allowed me the opportunity to gain knowledge and guidance from experts in the area of neurodevelopmental disorders, working collaboratively to support the BEOND study, as well as meeting parents, families and professionals at Cerebra Network events. The research network has given me greater insight into children with rare and complex syndromes and I feel very fortunate to be part of such a pioneering team.

Bethany Jones: Examining the relationship between anxiety and autistic-like characteristics in Cornelia de Lange Syndrome (CdLS)
Part of my research will be in collaboration with members of the Cerebra Network for Neurodevelopmental disorders where we are launching the BEOND survey study. I am thankful for the opportunity to be part of the amazing work that is happening within the Cerebra Network and work alongside a supportive and passionate team of researchers.

Andrea Thomas: Defining the behavioural phenotype of CHARGE syndrome
Being a part of the Cerebra Network has been incredibly valuable for my research. I've drawn on the knowledge and expertise of other researchers within the network to inform my own research and improve my methods. Additionally, the networking opportunities provided by the Cerebra Network have allowed me to collaborate with researchers from other institutions and expand the scope of my project.

Developing an infrastructure for research integration and impact



November 2022 saw the launch of the **BEOND study** (Behavioural and Emotional Outcomes in Neurodevelopmental Disorders). This study is the first to operate simultaneously across all four network sites, with each team contributing to design, recruitment, data collection, and eventually to analysis and publication. BEOND operates primarily as an online survey, collecting information across a range of topics including behaviour, physical and mental health, sleep, access to support, wellbeing, and social development. In addition to following up many participants from the historical 'Cross Syndromes Survey' run by the Cerebra Centre, the BEOND study will be introducing a number of new syndrome groups – with intentions to recruit from **33 unique syndrome groups**.

BEOND has been an ambitious undertaking and it has taken a lot of time and care to establish the correct infrastructure to ensure this study meets all the needs of researchers across the Network, and the families that we are here to support. In taking the time to get the correct processes in place for BEOND we have laid the foundations to make future collaboration and data sharing across network sites much easier. In particular, we now have a Data Sharing Agreement in place which covers the breadth of work conducted across the network, saving the delay of seeking a new agreement for each new Network study, as well as finding new tools and processes for facilitating collaboration.

Built into BEOND is the update of our **legacy participant database**. The legacy participant database was built by the Cerebra Centre as a way of keeping in touch with families who were keen to participate in future research. The database includes hundreds of families across 20+ syndrome groups but until now this database has been located solely at the University of Birmingham. Through the BEOND study these families will be approached and re-consented to be part of a new **Cerebra Network Participant Database**. So far we have seen great uptake of the participant database from individuals accessing the BEOND survey and we are confident that this will become an incredibly important resource for the Network moving forward.

The BEOND survey is recruiting now and will remain open until November 2023, with the first round of follow-ups starting at the end of 2024.

Dr Kelly Wade
Network Coordinator

Public Involvement and Engagement

Conducting meaningful research that aligns with the values and priorities of families is a core value of the Cerebra Network. This year we have extended our approach to Patient and Public Involvement (PPI) through a series of **eight innovative and interactive activities** (see Appendix A for full titles). These activities have been designed to capture needs that cut across groups as well as the individual needs of people with specific syndromes, and their families. We have also engaged with professional stakeholders in Education when developing a novel **Online Teacher Training Resources** to ensure that the resources are meet the needs of the community and have attended NIHR Stakeholder events to shape the direction of research into youth mental health. Finally, for the first time, we have piloted new methodological approaches to train experts by experience so they can contribute as co-researchers. These co-researchers have supported the analysis of interview data and the drafting papers for publication. This pilot activity has been a huge success and we intend to continue to expand our repertoire of participatory approaches.

Impact

We aim to place as much emphasis on ensuring real-world impact of our research as on the research activities themselves. This year we have received additional funding from the University of Surrey, ESRC IAA fund to translate our research into a Teaching Training Module (See '*The Highlights of 2022*' for more details). We also received funding from Aston University to develop *Key Skills Recap Videos* for parents who have taken part in our LADDERS intervention, which focuses on reducing anxiety in autistic children with severe intellectual disability. We are currently building on this work by adapting the LADDERS intervention for

Key Skills Recap Videos

Five videos for families were developed by Effie Pearson (Cerebra Postdoctoral Researcher) and Jessica Hughes (Co-funded by Cerebra). These Key Skills Recap Videos support parents to retain the skills obtained, and progress made, during the LADDERS intervention. An example of the impact of the LADDERS intervention was recently provided by a psychiatrist from a local NHS CAMHS service, who contacted us after two people who she was supporting had accessed the intervention (provided below).

"Both with this and another case, the end of the intervention from Aston overlapped with involvement from the CAMHS ID team in Nottinghamshire. This appeared to be valuable, allowing parents to consolidate their learning and maintain their confidence, even though support from Aston had ended. In both cases significant improvements had occurred and parental confidence was maintained.

The intervention from Aston has been so impressive, that our team wish to adopt the Ladders approach to utilise with some of our families. We felt it was particularly important to note the points made by [child's name]'s mum regarding confidence building, hand holding, setting expectations, working as an equal partner. It was particularly significant to note that this was a 16-20 week intervention (relatively short-term in terms of the NHS) and weekly appointments lasted 30 minutes. This would therefore seem to be eminently practical in terms of our team working."

Feedback from NHS CAMHS service

Further Inform Neurogenetic Disorders (FIND)

Our key dissemination platform, FIND, continues to maintain a steady number of visitors (approx. 4,000 per month). Our audience is global, with 74.5% of users being outside of the UK. Over 120 NHS professionals remain registered through the site for updates.

Knowledge Exchange

2022 has seen a continuation of our engagement with clinical and academic partners. Our Network Directors have been invited to present to a number of clinical groups including the **Royal Society of Medicine**, the **Council for Disabled Children**, **Birmingham and Solihull Mental Health Foundation Trust**, and **Evelina London Children's Hospital**.

In addition to invited talks, researchers across the network continue to present their work at research conferences at both a national and international level. We are proud to say that knowledge from the research of the Cerebra Network helps to inform students on a number of undergraduate and post graduate courses, including Psychology, Medicine, and Clinical Psychology – with staff at all four network sites involved in the design and delivery of specialist teaching on intellectual disabilities.

The Warwick Team hosted Oxford Professor Gaia Scerif to run a workshop on Bayesian statistics for our network researchers. This event was appreciated by all who attended and we have further plans for similar events in the coming year.

Building our connections with syndrome support groups

We continue our commitment to the syndrome support groups that have supported our research for many years. We have continued to present our findings regularly at syndrome support group conferences and events, delivering talks at **20 events** in the reporting period. Talks have covered a wide range of topics including sleep, anxiety, challenging behaviour, changes with age and parent well-being.

The launch of the BEOND study has been supported by syndrome support groups both in the UK and in America and Australia. The reputation of our research has prompted approach from several new syndrome groups who we began working with for the first time in 2022 – **Wolf-Hischhorn Syndrome Trust**, **Jansen de Vries Syndrome Foundation**, and **Coffin Sirris Syndrome**.

The Highlights of 2022

The Checklist Project

We were delighted to partner with Cerebra to launch the Be-Well Checklist in June 2021. The Be-Well Checklist is an accessible summary of factors that are important to assess when considering behaviour and wellbeing in children with severe learning disability and complex needs. The Be-Well Checklist has been extremely well received by both parents/carers of children with rare and complex needs and healthcare professionals. We have received feedback that parents have used it to structure their conversations with Clinical Psychologists during their consultation appointments and that it has led to identification of areas for future monitoring.

The Be-Well Checklist was led by Professor Chris Oliver with collaboration from the Cerebra Network and other researchers - it was developed by a team of researchers based on over 20 years of research and clinical experience with children with moderate-profound intellectual disability. With funding from Great Ormond Street Hospital Charity, the Checklist Project commenced in October 2021. The aim of the Checklist Project is to use co-production methods to further develop the Be-Well Checklist, ensuring that parents/carers and clinicians have input into the development alongside researchers. During 2021-2022 we convened a Checklist Development Group consisting of two parents of children with moderate-profound intellectual disability, a Clinical Psychologist, two paediatricians, and four academics. The Checklist Development Group met monthly for eight months to collaboratively develop the Be-Well Checklist. Following this, two focus groups were held with parents of children with intellectual disability and one focus group was held with healthcare professionals to obtain feedback on the revised Be-Well Checklist. We are delighted that the new version of the Checklist, co-produced with parents, academics and healthcare professionals, is complete and ready to be trialled in routine paediatrician appointments within Birmingham Community Healthcare NHS Foundation Trust throughout 2023.

Online Teacher Training Resource

This year we have been working on an exciting new development for our impact portfolio. Supported by funding from the ESRC and Centre for Educational Neuroscience, we have been developing an online bespoke training resource for education practitioners which will raise awareness and understanding of the complex needs of children with genetic syndromes in educational practice.
We have worked closely with teachers, educational psychologists, parents and carers to identify key training needs and to ensure that the resource is useful and accessible for education practitioners with a wide range of experience, roles and responsibilities. In 2021-2022 we held focus groups with teachers, parents and carers prior to the content development phase of the project and have consulted with education practitioners to hear their feedback on the resource content, features and layout. We are looking forward to launching the resource in early 2023!

Summary and Future Directions

Overall, this has been another highly successful year for the Cerebra Network as we have grown and expanded. We are thrilled to have launched BEOND which will be a world-leading study of children with rare genetic syndromes. We have also developed our Open Science strategy to ensure that our research process and outcomes are **transparent and replicable.** We are particularly proud this year of the successes of our postdocs and students who continue to embody our person-centred values while being committed to research excellence. Next year, as well as continuing to progress our research projects within the themes of mental health, autism and sleep, we will see the **deepening of connections** with our PPI group in line with our goals for inclusive research. We look forward to updating Cerebra as the work progresses.

Appendix A

Cerebra Network for Neurodevelopmental Disorders
Research and Impact Activities
September 2021 - Current

Network Co-Directors: Dr Hayley Crawford, Dr Jo Moss, Dr Caroline Richards, Dr Jane Waite

Cerebra Network Team

Current team members

University of Birmingham

Dr Caroline Richards	Network Director
Dr Kelly Wade	Network Coordinator
Dr Stacey Bissell	Lecturer
Dr Laura Groves	Post Doctoral Researcher
Dr Catherine Laverty	Post Doctoral Researcher
Denise Bain	Research Therapist
Miriam Shabetai	Research Assistant

University of Surrey

Dr Joanna Moss	Network Director
Dr Katherine Ellis	Post Doctoral Researcher
Dr Caitlin Murray	Post Doctoral Researcher
Lucy Heap	Research Assistant
Shelley Wilson	Research Assistant
Gillian Hughes	Research Assistant

University of Warwick

Dr Hayley Crawford	Network Director
Dr Hayley Trower	Post Doctoral Researcher

Aston University

Dr Jane Waite	Network Director
Dr Effie Pearson	Post Doctoral Researcher
Dr Jo Tarver	Lecturer
Jessica Hughes	Research Assistant
Ruth Roberts	Research Assistant

Previous team members

2020-22 Natali Bozhilova, Post Doctoral Researcher (University of Surrey)
2020-22 Georgie Agar, Post Doctoral Researcher (University of Birmingham)
2021-22 Arianna Paricos, Research Assistant (Aston University

Cerebra Network Supported Students

PhD Student Supervision
PhD students currently supervised by Cerebra Network members

Supervised / co-supervised by Dr Jane Waite:
Courtney Greenhill (RTS-UK match funded PhD)
Karin Madericova (funded by Aston University)
Lucinda Thomas (funded by Nutricia)
Lauren Shelley (funded by Baily-Thomas Doctoral Fellowship)
Jessica Mingins (Cerebra Network match funded PhD)

Supervised / co-supervised by Dr Jo Moss:
Lauren Jenner (Cerebra Network match funded PhD)
Beth Jones (funded by University of Surrey and Cornelia de Lange syndrome Foundation UK & Ireland)
Gloria Yoshikova (funded by University of Surrey and Williams Syndrome Foundation).

Supervised / co-supervised by Dr Caroline Richards:
Katherine Marlow (funded by Baily-Thomas Doctoral Fellowship)
Lucy Licence (funded by the ESRC DTP)
Rory O'Sullivan (Cerebra Network match funded PhD)
Victoria Newell (funded by ESRC)
Connor Keating (funded by MRC)
Andrea Thomas (funded by Birmingham Hospital Charity)

Supervised / co-supervised by Dr Hayley Crawford:
Nicky Thomas (funded by NIHR ARC-West Midlands & Warwick Medical School)
Kayla Smith (funded by Chancellor's International Scholarship, University of Warwick)
Mirabel Pelton (funded by Coventry University)
Naomi Williams (funded by Midlands Mental Health and Neuroscience PhD Programme for Healthcare Professionals).

Supervision of Clinical Psychology trainees

ClinPsyD thesis projects currently supervised by Cerebra Network members:
Gabrielle Leen, *Cognitive and behaviour profiles in BBS* (supervised by J. Moss)
Ellie Armitage, *Mental health in rare syndromes* (supervised by J. Waite)
Alice Watkins, *Dravet syndrome* (supervised by C. Richards)
Victoria Turner, *Sleep interventions in Smith-Magenis Syndrome* (supervised by C. Richards)
Christina Griva, *ADHD in Sturge Weber syndrome* (supervised by J. Moss)
Emma Coverton, *Social understanding in children born mid-late preterm* (supervised by C. Richards)
Amy Millington, *Cognitive profiles and executive function in FASD* (co-supervised by J. Moss).

Graduated ClinPsyD students (2020-current):
Claire Wright, *Self-injury in autism*
Natalie Hallett, *Sleep in rare syndromes*
Elizabeth Hawkins, *Self-harm in autism and the wider family*

Supervision of students at Masters level

Masters students currently supervised by Cerebra Network members:
Danielle Till (University of Birmingham) MSci Psychological Practice
David Harris (University of Warwick) Masters of Medical Education
Louise Fletcher (University of Surrey) Psychology MSc programme
Shamoon Gondal (University of Aston) MSc programme
William Corbett (University of Aston) MSc programme
Joyce Imiegha (University of Aston) MSc programme
Henrietta Pfeifer (Aston University) Msc programme

Graduated Masters students (2020-current):
2021-22 Emily Warren (University of Birmingham) MSci Psychological Practice
2021-22 Atalia Welch (University of Surrey) Psychology MSc programme
2021-22 Madiha Majid (University of Warwick) Masters in Public Health

Undergraduate students

Undergraduate research projects currently supervised by Cerebra Network members:
Lucy Deeprose (University of Surrey) BSc Psychology
Rachel Howard (University of Surrey) BSc Psychology
Shona Harrisson (University of Surrey) BSc Psychology
Meenusha Baskaran (University of Surrey) BSc Psychology
Libby Corke (University of Warwick) MBChB
Will Fleet (University of Warwick) MBChB
Hannah Doran (University of Warwick) MBChB
Robyn Spibey (University of Warwick) MBChB
Laura Whitter (University of Warwick) MBChB
Emma Cogswell (University of Warwick) MBChB
Rose O'Grady (University of Warwick) MBChB
Amber Bassi (Aston University) BSc Psychology
Wabida Begum (Aston University) BSc Psychology
Sukhmuni Jagpal (Aston University) BSc Psychology
Isma Mahmood (Aston University) BSc Psychology
Paige Mattison-Weekes (Aston University) BSc Psychology
Karenjot Multani (Aston University) BSc Psychology
Mienaatchi Ravichanthiran (Aston University) BSc Psychology
Satara Williams (Aston University) BSc Psychology

Completed undergraduate research projects:
2021-22 Tabitha Mclachlan (University of Surrey) BSc Psychology
2021-22 Penny Currey (University of Surrey) BSc Psychology
2021-22 Remsha Hanif (University of Warwick) MBChB
2021-22 Tim Morris (University of Warwick) MBChB
2021-22 Lydia Cartwright (University of Warwick) MBChB
2021-22 Isobel Roberts Rajoo (University of Warwick) MBChB
2021-22 Adejah Wisdon (Aston University) BSc Psychology
2021-22 Provvidenza Singh (Aston University) BSc Psychology
2021-22 Abrafi Kyei (Aston University) BSc Psychology
2021-22 Isabella Johnson (Aston University) BSc Psychology
2021-22 Nafeesa Sultana (Aston University) BSc Psychology
2021-22 Omobolanle Balogun (Aston University) BSc Psychology
2021-22 Dilawez Ramsan (Aston University) BSc Psychology
2021-22 Hadeeqa Chowdry (Aston University) BSc Psychology
2021-22 Roshni Patel (Aston University) BSc Psychology

Undergraduate students currently on placement in Cerebra Network teams:
Aamina Khan (University of Birmingham)
Najma Hassan (University of Birmingham)
Abby McCourt (University of Surrey)
Freya Morris (University of Surrey)
Zach Chan (University of Surrey)
Holly Snellgrove (University of Surrey)
Emma Dolly-Acquah (Aston University)

Completed undergraduate placements
2021-22 Poonam Virdee (Aston University)
2021-22 Courtney Greenhill (Aston University)
2021-22 Kiranjot Kaur (University of Birmingham)
2021-22 Rachel Martlew (University of Birmingham)
2021-22 Elizabeth Berry (University of Birmingham)
2021-22 Lucy Phillips (University of Birmingham)
2021-22 Lucy Deeprose (University of Surrey)
2021-22 Rachel Howard (University of Surrey)
2021-22 Alkistis Papadopoulos (University of Surrey)

Cerebra Network Research Activities

Research funding

New grants awarded and started since September 2021:

1. The Safety, Acceptability, Feasibility and Efficacy of Bed Enclosure Designs in children with intellectual disability (The SAFE BED study). Agar, G. (Co-PI), **Richards, C. (Co-PI),** Bissell, S., Joseph, D., Hill, C. & Oliver, C. Baily Thomas Charitable Fund (£90,715). January 2023 – December 2025.

2. Objective Actigraphy Study in Sleep of Children with Intellectual Disability and their Siblings (OASIS-IDS): Direct assessment of sleep in children with intellectual disability, complex health needs and their siblings. Bissell, S. (Co-PI), **Richards, C. (Co-PI),** Agar, G., Hastings, R., de Vries, P., Bagshaw, A. & Hill, C. Baily Thomas Charitable Fund (£88,247). October 2022 – September 2024.

3. Increasing the adoption assessment measures and interventions strategies for anxiety in autistic people who speak few or no words. Pearson, E., & Waite, J. *Aston Joint Research Fund* (£1990). November 2022.

4. Extending parent and clinician resources for anxiety in autistic children with severe to profound intellectual disability. Hughes, J & Pearson, E (Joint PIs). *Aston University Research Impact Fund* (£6874). 7 months, January 2022.

5. Mental health and well-being in people with Rubinstein-Taybi syndrome. Match-funded PhD studentship. Waite, J. (Primary Supervisor)**.** *Jointly funded by RTS UK & Aston University* (£73,330).

6. Improving evidence-based practice in schools for children with rare genetic syndromes associated with intellectual disability through online bespoke training for special education practitioners. Moss (PI), Farran E (CI), Gilligan-Lee (CI), Ellis K (CI), Crawford H (CI), Richards C (CI), Waite J (CI) and Wilby L (CI). *ESRC Impact Acceleration Account* (£22,996) AND *Centre for Educational Neuroscience* (£5,000). 12 months, January 2022.

7. Autistic traits and mental health in women with the Fragile X premutation: A multi-level study of behavioural, cognitive and genetic profiles. Moss, J (PI) *Academy of Medical Sciences Springboard Award,* £99,989.00. 24 months. September 2021.

8. Farran E (PI), Moss (CI), Dongol B (CI). EPSRC Doctoral Training Partnership PhD Studentship. The use of information technology and traditional methods to understand the impact of motor impairment on cognitive development in neurodevelopmental conditions. *EPSRC DTP* (£80,770) and *Williams Syndrome Foundation* (£10,000).

9. Moss (PI)**,** Ellis K, Bozhilova N, Farran E, Mukherjee R. Autism and related characteristics in individuals with Fetal Alcohol Spectrum Disorders. *FHMS Faculty Research Support Fund* (£10,000). 9 months, June 2022.

10. Anxiety in individuals with Cornelia de Lange syndrome: behavioural indicators and co-occurrence with autism symptomatology. Moss, J & Askew C. PhD studentship University of Surrey Doctoral College Studentship Award in partnership with the CdLS Foundation UK & Ireland. £64,000. 36 months. October 2021.

11. Crawford, H (PI), Roberts, J. (2022-2023). Disentangling anxiety and autism in fragile X syndrome. *University of Warwick International Partnership Fund,* £4,426

12. Crawford, H (PI), Richards, C., Waite, J., Moss, J., Wade, K. (2022). Maximising impact in rare genetic syndrome research. *University of Warwick ESRC Impact Acceleration Account, £2,700*

13. Autism and anxiety in fragile X syndrome. Fully funded PhD studentship. Crawford, H. (PI), Waite, J (Co-I). University of Warwick Chancellor's International Studentship awarded to Kayla Smith. £110,170. October 2021.

Grants started prior to September 2021:

1. Assessing the feasibility of the i-RISC preventive intervention programme for individuals at clinical-high risk for challenging behaviour. Richards, C. (PI), Groves, L. (PI) et al., Baily Thomas Charitable Fund (£90,853). July 2020 – June 2022.

2. Understanding the Social World through Overhearing in Autistic Children with Intellectual Disabilities. Elsherif, M. (PI), Surtees, A. (PI), Richards, C. (Co-I) & Van Zoest, W. Baily Thomas Charitable Fund (£96,803). Jan 2022 – Dec 2024.

3. Understanding how sleep is impacted by neurological and neurodevelopmental conditions using personalised brain networks from EEG data. Junges, L. (PI), Bagshaw, A., Richards, C. (Co-I), Seri, S., Terry, J., Winsor, A. Waterloo Foundation (59,281). Sept 2021 – August 2023.

4. Road to recovery: Understanding the impact of COVID and recovery phases on children and young people with Intellectual Disabilities and their families. Gillespie-Smith, K., (PI), Richards, C., (Co-I), Goodall, McConachie, Ballantyne, Van Herwegen, J., Outhwaite, Gallagher-Mitchell, Crawford, H., Moss, J. ESRC. £227,925. Sept 2021 – Sept 2022.

5. Mapping and Evaluating Services for Children with Learning Disabilities and Behaviours that Challenge (MELD). Hastings, R (PI), Langdon, P., Gilespie, D., Petrou, S., Bradshaw, J., Gore, N., Liew, A., Lovell, M., North, S., Richards, C. (Co-I), Seers, K. & Shurlock, J. NIHR. (£895,266, £9,769 awarded as Co-I time). November 2020 – February 2024.

6. Covid-19 impact on mental health and wellbeing in families of children with rare genetic and neurodevelopmental syndromes: CoIN Study**.** Tye, C., (PI) Scerif, G., Baker, T., Baker, K. & Richards, C (CI). Baily Thomas Charitable Fund (£68,000). June 2020 – June 2022.

7. Remote assessment of executive function in pre-schoolers with intellectual impairment: a pilot study of tuberous sclerosis complex. Tye, C., Jones, E., Bolton, P., Charman, T., Hendry, A., Mason, L., Loth, E., Bissell, S., Richards, C. (CI). Baily Thomas Charitable Fund. (£90,000). April 2020 – April 2022.

8. Characterising separation anxiety in individuals with moderate to profound intellectual disability. Pearson E, Waite J, Moss J, Oliver C and Clayton-Smith. Baily Thomas Charitable Fund, £63,220.00. 15 months. Jan 2022 - March 2023

9. Developing a parent-led anxiety intervention for minimally verbal autistic children. Autistica Future Leaders Award. £98,000. Waite, J (PI). November, End date Sept 2022

10. Personal characteristics, mental health and well-being in Bardet-Biedl syndrome. Waite, J. (PI). Baily Thomas Charitable Fund. £75,969.60. End date Sept 2022

11. Towards improved assessment of mental health difficulties in people with an Autism Spectrum Disorder. Waite, J., (Joint PI) *et al*. Autistica. £166,000.End date Sept 2022

12. Anxiety in children with severe to profound intellectual disabilities. Waite, J. (PI), Liew, A., Oliver, C., Crawford, H., Ruddick, L. Birmingham Children's Hospital Research Foundation, £41,000. End Date March 2022.

13. The behavioural and cognitive characteristics of autism spectrum disorder in genetic syndromes. Moss J, White S, Hamilton, A & Oliver C. The Baily Thomas Charitable Fund, £89,279. 24 months. September 2018. Extended to March 2022

14. Licence, L., Cooke, J., & Richards, C. Understanding Self-Harm in Autitsic Young People. ESRC DTP Studentship, £85, 000, 48 months. (October 2018, Extended to the end of 2022).

15. Sleep-Impulsivity-Behaviour (SIB) Study: examining pathways to self-harm in children with autism and intellectual disability. Richards, C. (PI) *et al.,* Medical Research Council/Medical Research Foundation (£725,708). October 2019 – September 2022.

16. A clinical checklist of causes of poor behavioural outcomes in children with moderate-profound intellectual disability and complex needs. Crawford, H., Bull, L., Gray, K., Liew, A., Oliver, C & Sloneem, J. (awarded March 2021). *Great Ormond Street Hospital Charity and Sparks Charity, £110,067*

17. Behaviours that challenge in SATB2-associated syndrome. Fully funded PhD studentship. Waite, J., Crawford, H, Richards, C. Tarver, J (Supervisors). Baily Thomas Charitable Fund. £79,011, June 2020.

18. Parent behaviour and well-being and its relationship with anxiety in individuals with autism and intellectual disability. Tarver & Waite. Baily Thomas Charity Trust. £31,606. Awarded July 2019.

19. Person and environmental characteristics associated with anxiety in minimally verbal individuals with autism. Fully funded PhD studentship. Waite, J. (PI). Baily Thomas Charitable Fund. £77,595. June 2018.

Publications

Peer Reviewed Articles Published since 2021:

1. Groves L, Moss J, Oliver C. Royston R, Waite J, Crawford H. (2022) Divergent presentation of anxiety in high-risk groups within the intellectual disability population. *Journal of Neurodevelopmental Disorders, 14*, 54.

2. Awan, N., Pearson, E., Shelley, L., Greenhill, C., Tarver, J., & Waite, J**.** (2022). The behavioral phenotype of Rubinstein–Taybi syndrome: A scoping review of the literature. *American Journal of Medical Genetics Part A*, *188*(9), 2536-2554.

3. Oliver C, Ellis K, Agar G, Bissell S, Cheuk Yin Chung J, Crawford H, Pearson E, Wade K, Waite J, Allen D, Deeprose L, Edwards G, Jenner L, Kearney B, Shelley L, Smith K, Trower H, Adams D, Daniel L, Groves L, Heald M, Moss J, Richards C, Royston R, Tarver J, Welham A, Wilde L, Woodcock K (2022).Distress and challenging behavior in people with profound or severe intellectual disability and complex needs: Assessment of causes and evaluation of intervention outcomes. *International Review of Research in Developmental Disabilities, 62*, 109-189.

4. Bissell, S., Oliver, C., Moss, J., Waite, J., Crawford, H., Richards, C., et al (2022). The behavioural phenotype of SATB2-associated syndrome: a within-group and cross-syndrome analysis. *Journal of Neurodevelopmental Disorders,* 14, 1-21

5. Perry V, Ellis K, Moss J, Beck SR, Singla G, Crawford H, Waite J, Richards C and Oliver C. (2022). Executive function, repetitive behaviour and restricted interests in neurodevelopmental. *Research in Developmental Disabilities,* 122.

6. Edwards, G., Tarver, J., Shelley, L., Bird, M., Hughes, J., Crawford, H., & Waite, J. (2022). Utilising Interview Methodology to Inform the Development of New Clinical Assessment Tools for Anxiety in Autistic Individuals Who Speak Few or no Words. *Journal of Autism and Developmental Disorders*, 1-21.

7. Edwards, G., Jones, C., Pearson, E., Royston, R., Oliver, C., Tarver, J., ... & Waite, J. (2022). Prevalence of anxiety symptomatology and diagnosis in syndromic intellectual disability: a systematic review and meta-analysis. *Neuroscience & Biobehavioral Reviews*, 104719.

8. Waite, J., Beck, S. R., Powis, L., & Oliver, C. (2022). The executive function account of repetitive behavior: Evidence from Rubinstein-Taybi syndrome. *American Journal on Intellectual and Developmental Disabilities*, *128*(1), 49-65.

9. Thomas, A. T., Waite, J., Williams, C. A., Kirk, J., Oliver, C., & Richards, C. (2022). Phenotypic characteristics and variability in CHARGE syndrome: a PRISMA compliant systematic review and meta-analysis. *Journal of neurodevelopmental disorders*, *14*(1), 1-20.

10. Agar, G., Oliver, C., and Richards, C. (2022). 'Direct Assessment of Overnight Parent-Child Proximity in Children With Behavioural Insomnia: Extending Models of Operant and Classical Conditioning'. *Behavioural Sleep Medicine*. Pp. 1-19.

11. Agar, G., Bissell, S., Wilde, L., Over, N., Williams, C., Richards, C., and Oliver, C. (2022). 'Caregivers' Experience of Sleep Management in Smith–Magenis Syndrome: A Mixed-Methods Study'. *Orphanet Journal of Rare Diseases, 17* (1), pp. 1-15.

12. Ezell, J., Hogan, A., Will, E. A., Smith, K., and Roberts, J. (2022). 'Cardiac startle response and clinical outcomes in preschool children with fragile X syndrome and autism spectrum disorder'. *Frontiers in Psychiatry, 12*.

13. Bozhilova N, Welham A, Adams D, Bissell S, Bruining H, Crawford H,' Eden K, Nelson L, Oliver C, Powis L, Richards C, Waite J, Watson P, Rhys H, Wilde L, Woodcock K, Moss J. (2023) Profiles of autism characteristics in thirteen genetic syndromes: a machine learning approach. *Molecular Autism.*

14. Laverty C, Oliver C, Agar G, Sinclair L**,** Moss J, Richards C. (2023). The 10-year trajectory of aggressive behaviours in autistic individuals. *Journal of Intellectual Disability Research.*

Peer Reviewed Articles Currently In Press:

1. Crawford , H. (in press). Social anxiety in neurodevelopmental disorders: the case of fragile X syndrome. *American Journal on Intellectual and Developmental Disabilities.*

Journal Articles Currently Under Peer Review:

1. Jenner, L., Howard, R., Richards, C. and Moss, J. (in review). Heterogeneity of autism in genetic syndromes: key considerations for assessment and support. *Current Developmental Disorders Reports.*

2. Thomas, N., Atherton, H., Dale, J., Smith, K. and Crawford, H. (in review). General practice experiences for parents of children with intellectual disability: Systematic review. *British Journal of General Practice.*

3. Laverty, C., Surtees, A., Sutherland, D, and Richards, C. (in review). 'A Qualitative Interview with Mothers of Moderately or Late Preterm Infants; Where are the care gaps?' *Early Human Development.*

4. Marlow, K., Agar, G., Jones, C., Devine, R. and Richards, C. (in review). 'The prevalence and correlates of self-restraint in individuals with autism and/or intellectual disability: a systematic review and meta-analysis'. *Review Journal of Autism and Developmental Disorders.*

5. Martin, J., Robertson, K., Richards, C., Scerif, G., Baker, K. and Tye, C. (in review). 'Experiences of parents of children with rare neurogenetic conditions during the COVID-19 pandemic: an interpretative phenomenological analysis'. *BMC Psychology*

6. Groves, L., Davies, G., Oliver, C., Allen, D., Bamford, C.,…and Richards, C. (in review). 'The development and validation of models of risk for behaviours that challenge in children with developmental disabilities: a novel machine learning approach'. *Digital Medicine*.

7. Groves, L., Jones, C., Liew, A. and Richards, C. (in review). 'Non-pharmacological and pharmacological interventions for the reduction or prevention of behaviours that challenge in people with intellectual disabilities: a meta-analysis of randomised control trials'. *Lancet Psychiatry*.

8. Shelley, L., Waite, J., Tarver, J., Oliver, C., Crawford, H., Richards, C. and Bissell, S. (in review). 'Behaviour that challenges in SATB2-associated syndrome: correlates of self-injury, aggression and property destruction'. *Journal of Autism and Developmental Disorders*.

9. Newell, V., Cassidy, S., Richards, C., Phillips, L., Townsend, E. and Jones, C. (in review). 'A Systematic Review and Meta-Analysis of Suicidality in Autistic and Possibly Autistic People without Co-occurring Intellectual Disability

10. Pelton, M., The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: a theory-driven network analysis

11. Hogan, A. L., Smith, K., Mian, N. D., Black, C., Hunt, E., Knott, C., Moser, C., Smith, J., Caravella, K., E., Hills, K., Fairchild, A., Carter, A. S., and Roberts J. E. (in review). 'Utility of the Modified Anxiety Dimensional Observation Scale (M-Anx-DOS) in autistic preschoolers.'

12. Will, E. A., Wickstrom, J., Smith, K., Thrum, A., and Roberts, J. E. (in review). 'Motor trajectories and communication outcomes in a genetic model of ASD: Early development in fragile X with and without ASD.'

13. Lacombe, D. et al. Diagnosis and Management in Rubinstein-Taybi Syndrome: First International Consensus Statement

Journal Articles Currently in Preparation:

1. Ellis K., White, S., Dziwisz M., Webster B., Argarwal P, Griva C., Jones B., Mclchlan T and Moss, J. Visual attention patterns during gaze following in neurogenetic syndromes: Cornelia de Lange and fragile X syndromes.

2. Welham, A. et al., (in preparation). Identifying Autism Symptomatology in Genetic Syndromes; A comparison of the Social Communication Questionnaire and the Autism Diagnostic Observation Schedule.

3. Jenner, L., Welham, A., Farran, E., Howard, R., Sahni, R., Jones, C. & Moss, J. (in preparation). The use of eye-tracking technology as a tool to evaluate social cognition among people with an intellectual disability: a systematic review and meta-analysis

4. Jenner, L., Ellis, K., Farran, E. & Moss, J. (in preparation). Overimitation: insights from Prader-Willi syndrome, Down syndrome, and autism.

5. Jenner, L., Ellis, K., Farran, E. & Moss, J. (in preparation). Use of directional gaze cues in Prader-Willi syndrome, Down syndrome, and autism.

6. Jenner, L., Ellis, K., Farran, E. & Moss, J.(in preparation). Implicit and explicit false-belief reasoning in Prader-Willi syndrome, Down syndrome, and autism.

7. Jenner, L., Farran, E. & Moss, J.(in preparation). Profiles of social cognition and autism characteristics in Prader-Willi syndrome and Down syndrome.

8. Trower, H., Bamford, C., Moss, J., Crawford, H., Jones, C., Corke, L., Flett, W., and Williams, N. (in preparation). A meta-analytic study of risk markers for self-injurious behaviour, aggression, and destruction in individuals with intellectual disabilities. Retrieved from https://doi.org/10.17605/OSF.IO/TVUPW

9. Wade, K., Trower, H., Crawford, H. (in preparation). Physical health problems in neurogenetic syndromes: A cross syndrome analysis.

10. Perry, V., Smith, K., Groves, L., Moss, J., Oliver, C., Knight, E., Patterson, T., Rodgers, J., Waite, J., and Crawford, H. The relationship between anxiety and intolerance of uncertainty in Cornelia de Lange and fragile X syndrome.

11. Crawford, H, Roberts, J., Groves, L., Bradley, L., Smith, K., Hogan, A., Renshaw, D., Waite, J., and Oliver, C. Behavioural and physiological indicators of anxiety reflect shared and distinct profiles across individuals with neurogenetic syndromes.

12. Edwards, G., Tarver, J., & Waite, J. Identifying correlates of anxiety in children and adults with moderate-profound intellectual disability: A questionnaire study

13. Hughes, J., Roberts, R., Warters-Louth, C., Zhang, B., Southward, E., Shaw, R., Waite, J. and Pearson, E. (in preparation). "It wasn't the strategies on their own". Exploring caregivers' experiences of accessing services in the development of interventions for autistic people with intellectual disability.

14. Roberts, R., Shelley, L., Kutsch, A., Crawford, H.,Oliver, C., Waite., J. Brief Report- The function behaviour that challenges in Lowe syndrome

15. Mingins, J., Tarver, J., Pearson, E., Edwards, G., Oliver, C., Bird, M., Crawford, H., Shelley, L., Waite, J. The development of the Clinical Anxiety Screen for People with Severe to Profound intellectual disability.

16. Yuill, N., Marshall, J., Elphick, C., Waite, J., Davies, A., et al. Behaviour in Wiedemann-Steiner syndrome: An interview study.

17. Elphick, C., Marshall, J., Waite, J., Davies, A., & Yuill, N., et al, The diagnostic experiences of parents of children Wiedemann-Steiner syndrome.

18. Griffiths-King, D., Delivett, C., Peet, A., Waite, J. & Novak, J. Systematic Review of the value of MRI in predicting Future Cognitive Morbidity in Survivors of Paediatric Brain Tumours.

19. Pakau, R. et al. Diagnosis and Management in Williams Syndrome: First International Consensus Statement

Current Research Activity

Ongoing pre-registered research studies:

1. Laverty, C., Surtees, A., & Richards, C. (2019, October 18). The Impact of Prematurity on Social Understanding.
Retrieved from https://osf.io/8e3wy

2. Laverty, C., Surtees, A., Sutherland, D., & Richards, C. (2020, November 11). An Online Questionnaire For Parents & Caregivers of Infants Born Preterm. Retrieved from https://osf.io/cr7jx

3. Laverty, C., Surtees, A., & Richards, C. (2021, February 10). A Qualitative Interview For Parents & Caregivers of Infants Born Moderately to Late Preterm. Retrieved from https://osf.io/69csz

4. Laverty C., Surtees, A., O'Sullivan, R., Sutherland, D., Jones, C., Richards, C. Prevalence and profile of autism spectrum disorder in individuals born preterm: a meta-analysis. PROSPERO 2019 CRD42019125412. Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019125412

5. Agar, G., Brown, C. N., Bagshaw, A., Devine, R. T., Symons, F., & Richards, C. (2020, January 27). Sleep-Impulsivity-Behaviour Project. Retrieved from https://osf.io/k5qpx

6. Agar, G., Brown, C. N., Bagshaw, A., Devine, R. T., Symons, F., Richards, C., & Skubera, M. (2021, January 4). Sleep-Impulsivity-Behaviour - Study 2. Retrieved from https://osf.io/v9chj

7. Thomas, A., Waite, J., Oliver, C., & Richards, C. (2021, June 12). Sleep, Pain and Behaviour in CHARGE Syndrome. Retrieved from https://osf.io/xzmr4

8. Thomas, A., Waite, J., Oliver, C., & Richards, C. (2021, June 11). CHARGE syndrome: Insight from an investigation of behavioural and adaptive functioning. Retrieved from https://osf.io/qbkps

9. Marlow, K., Richards, C. & Devine, R. T. Prevalence and correlates of self-restraint in individuals with intellectual disability and/or autism: a systematic review and meta-analysis. PROSPERO 2020 CRD42020223972 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020223972

10. Jenner, L., Farran, E. & Moss, J., (2021, March 23). Eye-tracking as a measure of social cognition for individuals with an intellectual disability: a systematic review. Retrieved from https://osf.io/b65za

11. Licence, L,. Cooke, J., & Richards, C (2021, March 30). The Prevalence and Profile of Self-Harm in Autistic People without Intellectual Disability: A Systematic Review and Meta-Analysis. PROSPERO 2021 CRD42021193943. Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021193943

12. Licence, L,. Cooke, J., & Richards, C (2021, January 18). The Prevalence, Profile and Risk-markers of Self-Harm in Autitsic Young People. Retrieved from: https://osf.io/9m6yq

13. Richards, C., Crawford, H., Moss, J., Waite, J., & Wade, K. A. (2021, October 6). BEOND: Behavioural and Emotional Outcomes in individuals with Neurodevelopmental Disorders. Retrieved from: https://osf.io/n89x7

14. Wade, K., Berry, E., Brown, C. & Richards, C. Observational assessments of pain in children and their associations with self-report: a meta analysis. PROSPERO 2022 CRD42022314338 Retrieved from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42022314338

15. O'Sullivan, R., Bissell, S., Hamilton, A., Bagshaw, A., & Richards., C. (2022, January 31). Concordance of objective and subjective measures of sleep in children with neurodevelopmental

disorders: a systematic review and meta-analysis. PROSPERO CRD42022307499. Retrieved from: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=307499

16. O'Sullivan, R., Bissell, S., Spiller, J., Agar, G., Bagshaw, A., & Richards., C. (2022, August 30). Exploring objective measures of overactivity in children with rare genetic syndromes: a pilot study. Retrieved from: https://doi.org/10.17605/OSF.IO/NP36K

17. O'Sullivan, R., Bissell, S., Thompson, P., Bagshaw, A., & Richards., C. (2022, October 15). Sleep in rare genetic syndromes: a large-scale cross-syndrome survey. Retrieved from: https://doi.org/10.17605/OSF.IO/5TZV7

18. Trower, H. and Crawford, H. (2022, June 5). A clinical checklist of causes of poor behavioural outcomes in children with moderate-profound intellectual disability and complex needs. Retrieved from: https://osf.io/ctekw/?view_only=fa0d242daebd47bc914f8c7a9b6c529f

19. Trower, H., Bamford, C., Moss, J., Crawford, H., Jones, C., Corke, L., Flett, W., and Williams, N. (2023). A meta-analytic study of risk markers for self-injurious behaviour, aggression, and destruction in individuals with intellectual disabilities. Retrieved from

20. Smith, K., Waite, J., Roberts, J. and Crawford, H. C. Factors associated with anxiety in fragile X syndrome: A systematic review. PROSPERO 2022 CRD42022379328 Retrieved from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42022379328

21. Shelley, L., Tarver, J., Bissell, S., Richards, C., Crawford., and Waite, J. (2022). Cognitive Difference, Anxiety and Behaviours that Challenge in SATB2-associated Syndrome. Retrieved from: https://osf.io/vne92

22. Shelley, L., Tarver, J., Crawford, H., Richards, C., and Waite, J. Measures to assess challenging behaviour in intellectual disability: A systematic review and meta-analysis of psychometric properties. PROSPERO 2021 CRD42021239042 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021239042

23. Pearson, E., Roberts, R., Waite, J., Moss, J., and Oliver, C. Characterising separation anxiety in individuals with moderate to profound intellectual disability. Retrieved from: https://osf.io/2rncq https://osf.io/9dfp8

Academic/professional engagement activities

Academic Teaching Sep 2021-22

1. ClinPsyD course (University of Birmingham) *'Functional Analysis in Learning Disabilities'* two day long teaching sessions delivered by K. Wade
2. ClinPsyD course (University of Birmingham) *'Genetic Syndromes and Behavioural Phenotypes'* lecture delivered by K. Wade
3. MB ChB Medicine course (University of Warwick) '*Intellectual Disabilities'* 30 hours of teaching delivered by H. Crawford
4. Health and Medical Sciences BSc (University of Warwick) 'Mental Health in Intellectual Disability' lecture delivered by H. Crawford
5. Health and Medical Sciences BSc (University of Warwick) 'Intellectual Disability' technology-enhanced learning session delivered by H. Crawford
6. Health and Medical Sciences BSc (University of Warwick) 'Behaviours that Challenge' technology-enhanced learning session delivered by H. Crawford
7. Undergraduate Psychology (University of Surrey) *'Neurodevelopmental Disorders'* final year module led and delivered by J. Moss
8. Undergraduate Psychology (University of Surrey) *'Developmental Psychology'* first and second year. A range of module lectures and seminars delivered by J. Moss
9. Undergraduate Psychology (University of Surrey) '*General Psychology'* final year module: 'Myths of Autism' lecture delivered by J. Moss.
10. Undergraduate Psychology (Aston University) '*Clinical Psychology of Intellectual Disability*' final year module led and delivered by J. Waite

International and National Invited Presentations (Academic\Professional)

1. Moss J. Post-diagnostic research in intellectual disability of known genetic origin – understanding behavioural phenotypes, *Royal Society of Medicine, Genetics of Intellectual Disability, June 2022.*
2. Moss J. Females with FXS and the FXp, *Fragile X research workshop, Oxford University. June 2022.*
3. Moss J. Understanding atypical patterns of autism in individuals with genetic syndromes associated with intellectual disability. *CEDAR, University of Warwick. February 2022.*
4. Crawford, H., Liew, A., Campbell, N. Increasing the uptake of annual health checks in children and young people with learning disability. *Council for Disabled Children National Event, February 2022.*
5. Crawford, H. Developing a clinical checklist of causes of behaviours that challenge for people with severe-profound intellectual disability*. Applied Research Collaboration-West Midlands Scientific Advisory Group, University of Birmingham, June 2022.*
6. Crawford, H., Mental health in rare genetic syndromes. *Birmingham and Solihull Mental Health Foundation Trust Academic Meeting, June 2022*

7. Crawford, H., Smith, K. Anxiety in FXS. *Fragile X research workshop, Oxford University. June 2022.*

8. Crawford, H., Identification of anxiety in people with intellectual disability: what does anxiety look like?. *CEDAR seminar, University of Warwick, June 2022*

9. Crawford, H., and Trower, H. The Checklist Project: A clinical checklist for identifying the causes of behaviours that challenge in children with a moderate-profound intellectual disability. *University of Surrey Academic Meeting. May 2022.*

10. Crawford, H., Trower, H., and Oliver, C. The Checklist Project: A clinical checklist for identifying the causes of behaviours that challenge in children with a moderate-profound intellectual disability. *Evelina London Children's Hospital Academic Meeting. October 2022.*

11. Waite, J. Panel discussion/Q&As. Wiedemann Steiner Syndrome Conference - USA. October, 2022

Peer reviewed national and international conference presentations

1. Bissell, S. UK research update on Tuberous Sclerosis Complex (TSC): An exploration of TSC-Associated Neuropsychiatric Disorders (TAND). 7th NDAS Conference, Edinburgh, UK, June 2022.

2. Bozhilova, N et al. Autism-Related Phenotypes in Genetic Syndromes: A Machine Learning Approach. *Neurodevelopmental Disorder Seminar Series, Edinburgh, June 2022*

3. Bozhilova, N et al. Profiles of autism characteristics in genetic syndromes. *Autistica Conference, July 2022*

4. Bozhilova et al. Autism-related phenotypes in genetic syndromes. *Society for the Study of Behavioural Phenotypes Annual Conference*, *Virtual Symposium September 2021.*

5. Cartwright, L., Oliver, C., Crawford, H. Fragile X syndrome: A longitudinal analysis of genetic modifiers and behavioural trajectories over three years. *Neurodevelopmental Disorders Annual Seminar*

6. Jenner, L., Farran, E. & Moss, J. An open research approach to investigating how eye-tracking technology has been used as a tool to evaluate social cognition in intellectual disability. *The Inaugural Annual Open Research Lecture, April 2022.*

7. Jenner, L., Welham, A., Farran, E., Howard, R., Sahni, R., Jones, C. & Moss, J. The use of eye-tracking technology as a tool to evaluate social cognition among people with an intellectual disability: a systematic review and meta-analysis. *Neurodevelopmental Disorders Annual Seminar, June 2022.*

8. *Jones, B., Askew C, Ellis, K and Moss, J.* Anxiety and autism in Cornelia de Lange Syndrome - Overview of PhD. *Naturalistic Experimentation Workshop, Birkbeck University, September 2022.*

9. Perry, V., Smith, K., Groves, L., Crawford, H. Intolerance of uncertainty mediates the relationship between autism spectrum disorder and anxiety in Cornelia de Lange syndrome. *10th Biennial Scientific Virtual Symposium on Cornelia de Lange Syndrome, Cohesin and Related Genes, June 2022.*

10. Perry, V., Smith, K., Groves, L., Crawford, H. The relationship between anxiety and intolerance of uncertainty in Cornelia de Lange and fragile X syndrome. *Neurodevelopmental Disorders Annual Seminar, Edinburgh, Scotland, June 2022.*

11. Trower, H. The Checklist Project: Co-developing a clinical behaviour checklist for children with intellectual disability. *British Association for Community Child Health Conference. September, 2022.*

12. Thomas N., Atherton, H., Dale, J and Crawford, H Understanding the experiences of parents of children with disabilities interactions with general practice: A systematic review. Society for Academic Primary Care. July, 2022.

13. Thomas N., Atherton, H., Dale, J and Crawford, H. General practice and its role in supporting the mental and physical health of parents who care for children with intellectual disability. University of Warwick symposium. June, 2022.

14. Shelley, L., Tarver, J., Crawford, H., Richards, C., & Waite, J. An examination of the caregiver-reported profile and function of behaviour directed towards others (aggressive behaviour) in children and adults with SATB2-Associated syndrome. *24th Society for the Study of Behavioural Phenotypes International Research Symposium, Oslo, Norway, September 2022*.

15. Shelley, L., Crawford, J., Richards, C., Tarver, J., and Waite, J. The profile of aggressive behaviour in children and adults with SATB2-associated syndrome: Use of an exploratory caregiver interview. *Neurodevelopmental Disorders Annual Seminar, Edinburgh, Scotland, June 2022.*

16. Mingins, J., Pearson, E., Edwards, G., Oliver, C., Bird, M., Tarver, J. & Waite, J. Psychometric properties of the Clinical Anxiety screen suitable for people with Severe to Profound Intellectual Disabilities. *Neurodevelopmental Disorders Annual Seminar, Edinburgh, Scotland, June 2022.*

17. Mingins, J., Pearson, E., Edwards, G., Oliver, C., Tarver, J. & Waite, J. The development of an anxiety assessment measure for autistic individuals who speak few or no words. *Autistica Virtual Research Festival, July 2022.*

18. Mingins, J., Waite, J., Crawford, H. & Tarver, J. Triggers and correlates of anxiety in Cornelia de Lange syndrome. *10th biennial Virtual CdLS Foundation Symposium on CdLS and Cohesin and Related Genes, June 2022.*

19. Hughes, J., Pearson, E., Tarver, J., Edwards, E., Bird, M., Greenhill, C. & Waite, J. A parent-led intervention to reduce anxiety in autistic children with a severe to profound intellectual disability: current data from the LADDERS pilot feasibility trial. *Neurodevelopmental Disorders Annual Seminar, Edinburgh, Scotland, June 2022.*

Public engagement activities

Network related talks and presentations

1. Panel member for the Be-Well Checklist Launch Event. January 2022. Cerebra (JM, HC, CR, JW).

International and National Invited Presentations
(Professional and Syndrome Support Organisation Conferences)

1. Moss J. Fragile X premutation associated conditions: an overview. FXS conference, Birmingham September 2022

2. Moss J. Understanding autism in fragile X syndrome. FXS conference, Birmingham, September 2022

3. Moss J. Changes with age in CdLS. CdLS Foundation UK and Ireland conference, October 2022

4. Moss J. Understanding autism in Cornelia de Lange syndrome. CdLS national conference. April 2022.

5. Moss J. Beyond genetics: the lived experience of women with the fragile X premutation. International Women's Day symposium, School of Psychology, University of Surrey. March 2022

6. Crawford, H., Smith, K. Anxiety in fragile X syndrome. Fragile X Society Family Conference, June 2022

7. Crawford, H., Stanfield, A., Johnson, K. The development of integrated guidance for fragile X syndrome. Fragile X Society Conference, September 2022

8. Crawford, H., and Trower, H. The Checklist Project: A clinical checklist for identifying the causes of behaviours that challenge in children with a moderate-profound intellectual disability. The CdLS Foundation UK and Ireland Conference. April 2022.

9. Waite., J. Making sense of behaviours that challenge in Rubinstein-Taybi syndrome. Spanish RTS Syndrome Support Group, March 2022

10. Waite, J., Cornelia de Lange Syndrome: Anxiety Workshop. Cornelia de Lange Syndrome Foundation UK and Ireland Conference, April 2022.

11. Waite, J., Anxiety in Smith Magenis Syndrome. Smith Magenis Foundation UK Conference, May 2022

12. Waite., J. Research into behaviour, cognition and emotion in Angelman syndrome: Future Directions. Angelman Syndrome UK Conference. June 2022.

13. Waite, J. Making Sense of Behaviours that Challenge. Wiedemann Steiner Syndrome Family Conference. June 2022.

14. Waite, J. Research into behaviour, cognition and emotion in Rubinstein-Taybi syndrome: Past, present and future. Rubinstein-Taybi Syndrome UK Conference, June 2022.

15. Waite, J., Parent Well-Being Workshop. Cornelia de Lange Syndrome Foundation UK and Ireland Conference, October 2022.

16. Shelley, L. Behaviours that challenge in SATB2-associated syndrome: A research update. SATB2 Gene Trust UK national conference, July 2022.

17. Pearson, E. and Hughes, J. Making sense of behaviour: Workshop. RTS-UK Family Conference. June 2022.

18. Richards, C. & Agar, G. Sleep in Smith Magenis Syndrome. SMS Foundation, Sweden. September 2022.

19. Richards, C. Sleep, pain and challenging behaviour. Southampton Sleep Training Conference, Online, September, 2022.

20. Richards, C. Self-injurious behaviour in children with intellectual disability: from research to practice. Paediatric Mental Health Association, UK, January, 2022.

Parent/Carer articles/guides

1. Buell, S., Bissell, S., Bradshaw, J., Chadwick, D., & Allen, D. (2022). Communication with children with severe or profound intellectual disabilities: A guide for parents. *Cerebra*.

2. Waite, J (2022) Review and update to 'Anxiety: A Parent Guide'. *Cerebra*.

3. Wade, K (2022) Review and update to 'Pain: A Parent Guide'. *Cerebra*.

Professional and Academic committee positions

Editorial Review Board for American Journal on Intellectual and Developmental Disabilities (Crawford, Richards)

Editorial Review Board for JIDR (Waite)

Editorial Review Board for Research and Practice for Persons with Severe Disabilities (Waite)

Editorial Review Board for Research and Practice for Persons with Severe Disabilities (Crawford)

Specialist Advisor to the Fragile X Society (Crawford)

Associate Member of the UK Scientific & Clinical Advisory Team, Cornelia de Lange Foundation (Crawford, Waite, Richards, Ellis)

Co-Chair of the UK Scientific & Clinical Advisory Team, Cornelia de Lange Foundation (Moss)

Member of International Scientific Advisory Council, Cornelia de Lange World (Crawford, Moss, Waite, Richards)

Kleefstra Syndrome Consensus Guidelines International Consortium (Stacey Bissell and Jane Waite)

Rubinstein Taybi Syndrome Consensus Guidelines International Consortium (Waite)

Williams Syndrome Consensus Guidelines International Consortium (Waite)

Research Lead (Eat/Sleep cluster) and co-Lead (Overactive/Impulsive cluster) for the TAND Consortium (tandconsortium.org) - TSC (Stacey Bissell)

Midlands Sleep Group (midlandssleep.org) (Stacey Bissell and Caroline Richards)

Affiliate member of the Smith-Magenis syndrome Foundation UK Scientific and Clinical Advisory Group (Stacey Bissell and Georgie Agar)

Editorial Board: Journal of Intellectual Disability Research (Moss)

Editorial Board: Journal of Applied Research in Intellectual Disabilities (Moss)

NIHR Mental Health TRC Workstream Member (Richards)

NHS England Transforming care autism pathway committee (Richards)

Smith Magenis syndrome Foundation UK Scientific Advisory Committee Co-Chair (Richards)

Charles Sharland Award, Autistica Steering Group (Richards)

IASSIDD Autism Spectrum Disorder Special Interest Group Secretary, (Richards)

Executive Committee Member, Society for the Study of Behavioural Phenotypes (SSBP), 2015-current. (Waite)

Surrey Clinical and Research Network Co-Lead (Moss)

Assistant Deputy Director of Midlands Mental Health and Neuroscience PhD Programme for Healthcare Professionals (Crawford)

Scientific Advisory Group Member: 'What Works Centre SEND Service Improvement' funded by Department for Education (Crawford)

Prizes and bursaries

1. Runner-up award for research in underserved areas, mental health incubator award, mental health research awarded to Dr Hayley Crawford
2. Les and Robbie Fountain Student Bursary awarded to Lauren Shelley in September 2022: 24th Society for the Study of Behavioural Phenotypes International Research Symposium, Oslo, Norway.
3. Friends of IPWSO Travel Fellowship for the 11th IPWSO Conference in Limerick, Ireland. Awarded to Lauren Jenner in March 2022.

PPI activities:

1. NIHR ARC-WM Stakeholder events - one for public contributors/service users and one for service providers to shape future research on research into youth mental health (theme dedicated to neurodevelopmental disorders led by Crawford)
2. Angelman UK Family Conference - PPI Focus Group (led by Pearson and Smith)
3. Fragile X UK Family Conference - PPI Focus Group (led by Thomas and Smith)
4. Cornelia de Lange Syndrome Family Conference - PPI Focus Group (led by Trower and Wade)
5. FASD PPI Focus Group (Led by Lucy Heap)
6. Cornelia de Lange Syndrome anxiety project PPI Focus Group (led by Beth Jones)
7. Education practitioners PPI focus groups (led by Shelley Wilson)
8. LADDERS Intervention Development Interviews - 2 x PPI groups to co-analyse interview data (led by Hughes and Roberts)

Appendix B

Cerebra Network for Neurodevelopmental Disorders
Research and Impact Activities
Prior to September 2021

Publications

Peer Reviewed Journal Articles:

1. Sloneem, J, Moss, J, Powell, S, Hawkins, C, Fosi, T, Richardson, H & Aylett, S. (2021). The prevalence and profile of autism in Sturge-Weber Syndrome. *Journal of Autism and Developmental Disorders*.

2. Marlborough, M., Welham, A., Jones, C., Reckless, S., & Moss, J. (2021). Autism spectrum disorder in females with fragile X syndrome: a systematic review and meta-analysis of prevalence. Journal of neurodevelopmental disorders, 13(1), 28.

3. Ellis, K., Moss, J., Stefanidou, C., Oliver, C., & Apperly, I. (2021). The development of early social cognitive skills in neurogenetic syndromes associated with autism: Cornelia de Lange, fragile X and Rubinstein-Taybi syndromes. *Orphanet Journal of Rare Diseases*, 16(1): 488.

4. Laverty, C,. Surtees, A., O'Sullivan, R., Sutherland, D., Jones, C., Richards, C. (2021) The prevalence and profile of autism spectrum disorder in individuals born preterm: a systematic review and meta-analysis. Journal of Neurodevelopmental Disorders

5. Pearson, E., Nielsen, E., Kita, S., Groves, L., Nelson, L., Moss, J. & Oliver, C. (2021). Low speech rate but high gesture rate during conversational interaction in people with Cornelia de Lange syndrome. Journal of Intellectual Disability Research.

6. Groves L, Oliver C & Moss, J. (2021). Behaviour across the lifespan in Cornelia de Lange syndrome. Current Opinion in Psychiatry, 34, 112–117.

7. White S, Gerber D, Hernandez RDS, Efiannayi A, Chowdhury I, Partington H and Moss J. (2021). Autistic traits and mental health in females with the fragile X premutation: maternal status vs. genetic risk. The British Journal of Psychiatry, 218(1), 28-34. https://doi:10.1192/bjp.2020.231

8. Eaton, C., Tarver, J., Shirazi, A., Pearson, E., Walker, L., Bird, M., Oliver, C. & Waite, J (2021). A systematic review of the behaviours associated with depression in people with severe-profound intellectual disability. *Journal of Intellectual Disability Research*

9. Mingins, J., Tarver, J., Waite, J., Jones, C., Surtees, A (2021). Anxiety and Intellectual Functioning in Autistic Children: A Systematic Review and Meta-analysis. *Autism.*

10. Agar, G., Brown, C., Coulborn, S., Oliver, C. & Richards, C. (2021). Sleep disorders in rare genetic syndromes: a meta-analysis of prevalence and profile. *Molecular Autism*

11. Tarver, J., Pearson, E., Edwards G., Shirazi, A., Potter, L., Malhi, P. & Waite, J. (2020). Anxiety in autistic individuals who speak few or no words: A qualitative study of parental experience and anxiety management. *Autism.*

12. Laverty, C., Oliver, C., Moss, J., Nelson, L., & Richards, C. (2020). Persistence and predictors of self-injurious behaviour in autism: a ten-year prospective cohort study. *Molecular Autism*.

13. Agar, G., Oliver, C., Trickett, J., Licence, L., & Richards, C. (2020). Sleep disorders in children with Angelman and Smith-Magenis syndromes: The assessment of potential causes of disrupted settling and night time waking. *Research in Developmental Disabilities*.

14. Oliver, C., Adams, D., Allen, D., Crawford, H., Heald, M., Moss, J., Richards, C., Waite, J., Welham, A., Wilde, L & Woodcock, K. (2020). The behaviour and wellbeing of children and adults with severe intellectual disability and complex needs: the Be-Well checklist for carers and professionals. *Paediatrics and Child Health*, 30(12), 416-424.

15. Crawford, H., Abbeduto, L., Hall, S., Hardiman, R., Hessl, D., Roberts, J. E., Scerif, G., Stanfield, A. C., Turk, J. & Oliver, C. (2020). Fragile X syndrome: an overview of cause, characteristics, assessment and management. *Paediatrics and Child Health*, 30(11), 400-403

16. Crawford, H., Scerif, G., Wilde, L., Beggs, A., Stockton, J., Sandhu, P., Shelley, L., Oliver, C. & McCleery, J. P. (2020). Genetic modifiers in rare disorders: The case of fragile X syndrome. *European Journal of Human Genetics*.

17. Ellis, K., Lewington, P., Powis, L., Oliver, C., Waite, J., Heald, M., Apperly, I. & Crawford, H. (2020). Scaling of early social cognitive skills in typically developing infants and children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 50, 3988-4000.

18. Pelton, M., Crawford, H., Robertson, A., Rodgers, J., Baron-Cohen, S. & Cassidy, S. (2020). A measurement invariance analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in autistic and non-autistic adults. *Autism in Adulthood*, 2(3), 193-203.

19. Pelton, M., Crawford, H., Robertson, A., Rodgers, J., Baron-Cohen, S. & Cassidy, S. (2020). Understanding and reducing suicide risk in autistic adults: comparing the Interpersonal Theory of Suicide in autistic and non-autistic samples. *Journal of Autism and Developmental Disorders,* 50, 3620-3637.

20. Crawford, H., Moss, J., Groves, L., Dowlen, R., Nelson, L., Reid, D. & Oliver, C. (2020). A behavioural assessment of social anxiety and social motivation in fragile X, Cornelia de Lange and Rubinstein-Taybi syndromes. *Journal of Autism and Developmental Disorders,* 50(1), 127-144

21. Winsor, A., Richards, C., Bissell, S., Seri, S., Liew, A., & Bagshaw, A. (2020). Sleep disruption in children and adolescents with epilepsy: A systematic review and meta-analysis. *Sleep Medicine Reviews,* 101416.

22. Ellis K, Oliver C, Stefanidou C, Apperly I & Moss J (2020). An Observational Study of Social Interaction Skills and Behaviors in Cornelia de Lange, Fragile X and Rubinstein-Taybi Syndromes. *Journal of Autism and Developmental Disorders*.

23. Royston R, Oliver C, Howlin P, Dosse A, Armitage P, Moss J, Waite (2020). The Profiles and Correlates of Psychopathology in Adolescents and Adults with Williams, Fragile X and Prader–Willi Syndromes. *Journal of Autism and Developmental Disorders.*

24. Steenfeldt-Kristensen, C., Jones, C. A., & Richards, C. (2020). The prevalence of self-injurious behaviour in autism: A meta-analytic study. *Journal of Autism and Developmental Disorders*, *50*(11), 3857-3873.

Book chapters:

1. Bissell, S., Liew, A., Richards, C. & Surtees, A. D. R. (2021). Sleep Problems and Developmental Delay. In D. Gozal & L. Gozal (Eds.), Paediatric Sleep Medicine (pp. 667-680). Springer Nature: Switzerland.

Academic / Professional Engagement Activities

Annual Lectures, Plenary, Opening and Keynote Addresses

1. Moss J. Autism in Down syndrome: prevalence, profile and clinical implications. Down Syndrome Research and Education Forum. March 2021.
2. Richards, C. Self-injurious behaviour in children with intellectual disability: from research to practice. Keynote at Child and Adolescent Intellectual Disability Psychiatry Network Annual Conference, UK, June, 2021.

International and National Invited Presentations (Academic\Professional)

1. Waite, J. Mental health in Bardet-Biedl syndrome. Webinar, May 2021
2. Waite., J & Tarver, J. 'Research into assessments and interventions for autistic individuals who speak few or no words, Webinar, April 2021
3. Richards, C. Managing Behaviours in SATB2-associated syndrome. SATB2 Gene Foundation. Webinar: USA, November 2020.
4. Richards, C. & Agar, G. Sleep and behaviour in Smith Magenis Syndrome. Smith Magenis Syndrome, Sweden. Gothenburg, June 2020. (Conference Cancelled, Covid-19).
5. Waite, J. Challenging behavior and mental health in SATB2 associated syndrome. Department of Psychology, University of Malaga, June 2020. CANCELLED due to COVID-19 and to be rescheduled.
6. Richards, C. & Moss, J. Behavioural phenotypes and applied behaviour analysis of challenging behaviour. Applied Behaviour Analysis Programme, Cremona, Spain. May, 2020. (Conference Cancelled, Covid-19)
7. Bissell, S. Sleep and neurodevelopmental disorders in clinical practice: Sleep in children with tuberous sclerosis complex. Virtual online event, NHS Southampton Children's Sleep Disorder Service Training, November 2021.
8. Richards, C. Bissell, S., & Agar, G. Sleep matters - children with neurodevelopmental conditions. Virtual online event, the Association for Child and Adolescent Mental Health, June 2021.
9. Agar, G. & Bissell, S. (2021). Sleep and behaviour in genetic syndromes. Virtual online event, Cerebra Network Launch Event, June 2021.
10. Bissell, S., Richards, C., & Hill, C. The importance of sleep in children with tuberous sclerosis complex (https://www.facebook.com/watch/?v=621155225946030). Virtual webinar, Tuberous Sclerosis Association, June 2021.
11. Moss J. Autistic traits and mental health in females with the FX-p. Fragile X syndrome research workshop. June 2021
12. Moss J. Autistic traits and mental health in females with the fragile X premutation: maternal status vs. genetic risk. University of Surrey, DevELOP group Seminar Series. November 2020

13. Moss J. Neurodevelopmental disorder research at the University of Surrey. Surrey Research and Clinical Network for Neurodevelopmental Disorders Workshop. May 2020.

14. Jenner, L. An introduction to understanding autism in genetic syndromes. University of Surrey, Psychology PhD Conference. December 2020.

15. Jenner, L. Identifying social-cognitive mechanisms that underlie autism in genetic syndromes. University of Surrey, Cognition Genes & Developmental Variability (CoGDeV) lab meeting. February 2021.

16. Richards, C., Agar, G. & Bissell, S. Sleep in children with neurodevelopmental conditions. The Association for Child and Adolescent Mental Health West Midlands, UK, June 2021.

17. Richards, C. Sleep in neurogenetic conditions. University College London, March 2021.

18. Richards, C. Sleep, measurement complexity and neurodevelopmental conditions. Institute for Mental Health, University of Birmingham, March 2021.

19. Richards, C. Sleep, measurement complexity and neurodevelopmental conditions. University of Cambridge, November 2020.

20. Ellis, K. Online research with children with and without an intellectual disability. Be Online Conference June 2021

21. Ellis K. Understanding social difficulties in boys with FXS. Virtual fragile X syndrome research meet-up. June 2021

Peer reviewed national and international conference presentations

1. Vanclooster, S., Bissell, S., van Eeghen, A., Chambers, N., De Waele, L., … & de Vries, P.J. Understanding the landscape of Tuberous Sclerosis Complex (TSC)-Associated Neuropsychiatric Disorders (TAND) research: A comprehensive scoping review. *21st Congress of the South African Association for Child and Adolescent Psychiatry and Allied Professions. Virtual online event (Cape Town host), July 2021.*

2. Vanclooster, S., Bissell, S., van Eeghen, A., Chambers, N., De Waele, L., … & de Vries, P.J. Knowledge gaps in Tuberous Sclerosis Complex (TSC)-Associated Neuropsychiatric Disorders (TAND) research: A scoping review. *6th IASSIDD Europe Congress. Virtual online event (Amsterdam host), July 2021.*

3. Vanclooster, S., Bissell, S., van Eeghen, A., Chambers, N., De Waele, L., … & de Vries, P.J. The research landscape of Tuberous Sclerosis Complex-Associated Neuropsychiatric Disorders (TAND): A comprehensive scoping review. *International TSC Research Conference. Virtual online event (London host), June 2021.*

4. Bissell, S., Bagshaw, A., de Vries, P.J., Hill, C., Oliver, C., Wilde, L.V., & Richards, C. Exploring Sleep in Neurodevelopmental disorders through Online and Remote Evaluation (e-SNORE): Pilot and feasibility study in tuberous sclerosis complex. *International TSC Research Conference. Virtual online event (London host), June 2021.*

5. Bissell, S., Oliver, C., Moss, J., Heald, M., Waite, J., Crawford, H., … & Richards, C. The behavioural phenotype of SATB2-associated syndrome (SAS): A cross-syndrome comparison with Angelman syndrome (AS) and autism. *54th Annual Gatlinburg Conference. Virtual online event (Kansas host), April 2021.*

6. Laverty, C., Oliver, C., Moss, J., Nelson, L., & Richards, C. (2020). Persistence and predictors of self-injurious behaviour in autism: a ten-year prospective cohort study. Autistica remote research festival, August 2020

7. Laverty, C., Oliver, C., Moss, J., Sinclair-Burton, L., Agar, G., Nelson, L., & Richards, C. Problem behaviours in autism: a longitudinal prospective cohort study over ten years. 54th Annual Gatlinburg Conference (2021).

8. Edwards, G., Tarver, J., Potter, P., Malhi, P., Oliver, C., & Waite, J. (2020). Correlates of anxiety in autistic individuals with moderate-profound intellectual disability or those who speak few or no words. Autistica Research Festival, 2020.

9. Agar, G., Oliver, C., Trickett, J. & Richards, C. The developmental trajectory of sleep on children with Smith-Magenis syndrome compared to typically developing peers. *Presented at 6th International Pediatric Sleep Association Congress, Online, February 2021*

10. Agar, G., Oliver, C. & Richards, C. Overnight parent-child proximity in relation to poor sleep in children with Angelman and Smith-Magenis syndromes. *Presented at 54th Gatlinburg Conference, Online, April 2021.*

11. Bozhilova, N., Oliver, C., Richards, C., Wait, J., Powis, L., Crawford, H., Bissell, S., Wilde, L., Welham, A., Nelson, L., Woodcock, K., Pearson E., Adams., D., Eden, K., Bruining, H., Moss, J. (2021). Autism-related phenotypes in genetic syndromes : a machine-learning study. SSBP Conference 2021.

12. Crawford, H., Beggs, A., Karakatsani, K., McCleery, J., Moss, J., Sandhu, P., Scerif, G., Shelley, L., Singla, G., Stinton, C., Stockton, J., Oliver C. & Wilde L. Self-injurious behaviour in males with fragile X syndrome: genetic modifiers and persistence over time. 54thAnnual Gatlinburg Conference, 2021

13. Thomas, A., Williams, C., Kirk, J., Oliver, C. & Richards, C. Identifying Barriers to a Better Quality of Life for People with CHARGE Syndrome: A Systematic Review and Meta Analysis. *Presented at The International CHARGE Syndrome Virtual Symposium, Online, July 2021*

14. Thomas, A., Williams, C., Kirk, J., Oliver, C. & Richards, C. Barriers to Quality of Life for People with CHARGE Syndrome: A Systematic Review and Meta Analysis. *Presented at IASSIDD, Online, July 2021*

15. Moss J, Dziwisz M, Ellis K, Agarwal P and White S. Gaze following in Fragile-X Syndrome. 54thAnnual Gatlinburg Conference, April 2021

16. Ellis, K., Dziwisz, M., Webster, B., Hamilton, A., White, S., & Moss, J. Overimitation in Cornelia de Lange and fragile X syndromes. 54thAnnual Gatlinburg Conference, April 2021

Public engagement activities

Network related talks and presentations

1. Bozhilova, N., & Moss, J. (2021). Autism-related phenotypes in genetic syndromes : a machine-learning study*. Cerebra Network Launch Event .* June 2021

2. Agar, G & Bissell, S. (2021). Sleep and behaviour in genetic syndromes. *Cerebra Network Launch Event.* June 2021

3. Moss J. Autism in genetic syndromes: challenges and future directions. Cerebra Network launch event: June 2021

4. Waite J & Crawford, H. Mental health in genetic syndromes. Cerebra Network launch event: June 2021

5. Jenner, L. (2021). Thinking styles in autism and genetic syndromes. *Cerebra Network Launch Event.* June 2021

6. Wade, K. (2021) Questions from us to you; Patient and public involvement in the Cerebra Network. *Cerebra Network Launch Event.* June 2021.

7. Ellis, K. (2021). Assessing social cognition in genetic syndromes associated with intellectual disability. *Cerebra Network Launch Event*. June 2021

8. PWSA-UK magazine. Parent's report on their child's experience of taking part in research at University of Surrey. April, 2022.

9. Jenner, L. (2022). Why open research is important for understanding how eye-tracking technology can be used as a tool to evaluate social cognition in intellectual disability. *Developmental Psychology Forum* (Issue 95), 7-9. British Psychological Society.

International and National Invited Presentations (Professional and Syndrome Support Organisation Conferences)

1. Moss, Crawford, Waite, Groves, Oliver. Presentation and panel discussion/Q&As. Cornelia de Lange syndrome Foundation conference. May 2021, October 2021

2. Tarver & Waite. Invited presentation at the All-Island ID CAMHS Network Meeting. *Research into assessments and interventions for anxiety for autistic individuals who speak few or no words.* Panel discussions/Q&As. April 2021.
   Crawford. Presentation and panel discussion/Q&A. Fragile X Society family support group annual conference. October 2020, September 2021

3. Moss, Crawford, Waite, Groves, Oliver. Presentation and panel discussion/Q&As. Cornelia de Lange syndrome Foundation conference. October 2020.

4. Bissell, S., Richards, C., & Hill, C. The importance of sleep in children with tuberous sclerosis complex (https://www.facebook.com/watch/?v=621155225946030). *Virtual webinar, Tuberous Sclerosis Association, June 2021.*

5. Jenner, L., Online Down Syndrome Research Forum 2021 (https://blogs.surrey.ac.uk/cogdev/2021/03/18/online-down-syndrome-research-forum-2021/). Blog post, CoGDeV lab. March 2021.

6. Ellis, K., & Dziwisz, M. Jan 2020 (https://thegoodthebadandtheugly.co.uk/dr-kat-ellis-research-on-autism-fragile-x-syndrome-and-cornelia-de-lange-syndrome/) Podcast interview.

7. Ellis, Scerif, Moss, Crawford & Stanfield. Co-production with individuals with FXS and their families. Virtual fragile X researcher meet-up. June 2021.

8. Thomas, A & Oliver, C. (November 2021) Behaviours and CHARGE Syndrome: Clinical and Research Perspectives. CHARGE Family Support Group Webinar.

Parent/Carer articles/guides

1. Sutherland, D., Agar, G & Richards, C. (2021). Weighted blankets for sleep difficulties in children with neurodevelopmental conditions: A Parent Guide. *Cerebra*.

2. Be-Well checklist, Cerebra.

3. Buell, S., Bradshaw, J., Bissell, S., Bradshaw, J., Chadwick, D., & Allen, D. (in press). Communication with children with severe or profound intellectual disabilities: A guide for parents. *Cerebra.*

Prizes and bursaries

1. Christian Guilleminault New Investigator Award awarded to Dr Georgie Agar by the International Pediatric Sleep Association and World Sleep Society in February 2021.

2. Early career researcher award for conference registration awarded by Noema Pharma: International Tuberous Sclerosis Complex Research Conference, virtual online event (London host) 2021. Stacey Bissell

Assessment Training Materials

1. Bissell, S., McCleery, J., O'Sullivan, R., Laverty, C., Stewart, A., & Oliver, C. (2020). PECS Critical Communication Skills Assessment training video. *University of Birmingham, Birmingham, UK.*

Media Engagement

1. https://thephoenixnewspaper.com/rare-and-complex-syndromes-in-children-to-be-investigated-by-new-research-network

2. https://www.westwaleschronicle.co.uk/blog/2021/06/18/rare-and-complex-syndromes-in-children-to-be-investigated-by-new-research-network/

3. https://redirect.vuelio.co.uk/broadcast?data=RFI0di9BbUEwQUVQRmJzY041Nk12MDFpTE15YTd3NE[…]Q2V1UVZVZGFndjlwdGtYY0R2R1J2dnREaGw1&c=UniversityofWarwick

4. Word on Neurodevelopmental Disorders in Children - Word on Health

5. Word On Health (Podcast) (buzzsprout.com)

PPI activities:

1. NIHR ARC-WM Stakeholder events - one for public contributors/service users and one for service providers to shape future research on research into youth mental health (theme dedicated to neurodevelopmental disorders led by Crawford)