The Cerebra Network for Neurodevelopmental Disorders

Annual Report 2021-2022
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
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*
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.
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 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 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.
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.
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:

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.
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 CIASP-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 CIASP-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.
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.
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.
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 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 Covertor, 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
Sukhmani 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 Wisdom (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 Dilaweza 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)
Research funding

New grants awarded and started since September 2021:


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.


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.


Grants started prior to September 2021:


Publications

Peer Reviewed Articles Published since 2021:


**Peer Reviewed Articles Currently In Press:**


**Journal Articles Currently Under Peer Review:**


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*. 


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

Journal Articles Currently in Preparation:


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

Current Research Activity
Ongoing pre-registered research studies:


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


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.*


6. Crawford, H., Mental health in rare genetic syndromes. *Birmingham and Solihull Mental Health Foundation Trust Academic Meeting, June 2022*


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

**Peer reviewed national and international conference presentations**


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.*


Public engagement activities

Network related talks and presentations


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


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


**Parent/Carer articles/guides**


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

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:


Book chapters:


Academic / Professional Engagement Activities

Annual Lectures, Plenary, Opening and Keynote Addresses


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


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.


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.


11. Moss J. Autistic traits and mental health in females with the FX-p. Fragile X syndrome research workshop. June 2021


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.


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


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

Public engagement activities

Network related talks and presentations


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


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


Parent/Carer articles/guides


2. Be-Well checklist, 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


Media Engagement


3. https://redirect.vuelio.co.uk/broadcast?data=RFI0di9BbUEwQUVQRmJzY041Nk12MDFpTE15YTd3NE[...]Q2V1UVVZGFndjldGttYY0R2R1J2dnREaGw1&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)