CEREBRA

Working wonders for children with brain conditions

FINAL PROGRESS REPORT FORM

CONTENTS

1. GENERAL INFORMATION

PROJECT TITLE
Cerebra Network for Neurodevelopmental Disorders
PRINCIPAL INVESTIGATOR (S)
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ORGANISATION
University of Birmingham; University of Surrey; Aston University; University of Warwick
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22nd November 2024
REPORT PERIOD
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2. BACKGROUND INFORMATION

Provide an introduction that reviews the context and rationale for your research.

The Cerebra Network for Neurodevelopmental Disorders was established in September 2020 and transitioned from the Cerebra Centre at the University of Birmingham, which was founded in 2008 by Prof Chris Oliver with the support of Cerebra. Led by alumni of the Cerebra Centre, the team is now 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 neurodevelopmental conditions. 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 multiple, complex or rare conditions (MCRc) and their families. The Network comprises research hubs located at each university, which focus on key themes that are central to achieving the Network aim, including research into sleep, atypical autism and mental health, whilst also continuing pre-existing research on self-injurious behaviour and pain in these populations.

Cerebra's funding has provided critical infrastructure for the Cerebra Network, underpinning all of the research led by the four Network sites. However, for brevity and clarity in this Annual Report, we have only reported on research and outcomes where the staff, students or studentship holders undertaking the research were directly funded by Cerebra and/or where the reported research meets the explicit aim and objectives of the original proposal.

3. PROGRAMME SUMMARY

ORIGINAL AIMS AND OBJECTIVES (AS GIVEN IN YOUR APPLICATION)

Aim:

The central aim of the Cerebra Network for Neurodevelopmental Disorders is to identify and reduce the contribution of mental health difficulties, poor sleep, autism characteristics and pain and discomfort to negative outcomes in children with MCRc due to intellectual disability associated with rare genetic syndromes and/or autism.

This aim is addressed through four *Shared Objectives*. Through the interconnected Network, each shared objective is achieved by collaborative research within and across research sites. The shared objectives are:

1. We will improve *identification* of mental health problems, sleep disorders, characteristics of autism and symptoms of pain and discomfort through the development of novel tools and assessment paradigms.

2. We will *model* the unique and shared contributions of biological, cognitive and psychological mechanisms that cause and drive poor clinical outcomes in these groups.

3. We will develop and pilot timely, precise *interventions* to improve mental health, sleep and behavioural outcomes derived from improved identification tools and accurate models of cause and mechanism.

4. We will partner with Cerebra to *translate* knowledge into practice, capitalising on our expertise in multi-media dissemination, collaboration with stakeholders and intersections with policy makers.

HAVE YOUR AIMS AND OBJECTIVES CHANGED? IF SO, EXPLAIN IN WHAT WAY AND WHY

The aims and objectives have not changed from the original grant application.

SUMMARY OF OUTCOMES

Provide a detailed summary of your findings. Please make it clear whether the programme delivered against all of its objectives as set out in your application. If not, please explain what will be missing, and why.

From 2020 to 2024, we have established the Cerebra Network as a world-leading research Network, pioneering novel psychological research approaches to improve outcomes for children with MCRc. In this time we have grown and thrived, delivering on our aspiration to build capacity by training the next generation of researchers and clinicians in our field. The team has expanded, and at the end of our funded period the Network was supported by 25 members of staff including four Network Directors and a team of lecturers, post-doctoral researchers, research assistants and research therapists. This core team has supervised, supported and trained over 148 students in four years. Our productivity is evidenced by the wide-ranging research and impact activities and achievements of the staff, students and volunteers who comprise the Network. Since September 2020 we have:

- Provided research mentorship and trained **148** students across all levels of education, including **25** Doctoral students, **16** Masters students, **16** Clinical Psychologists in training, **57** Undergraduate dissertation students and **34** Undergraduate placement students.
- Published **67** original scientific articles in peer reviewed journals, with **4** articles currently under review and a further **42** in preparation. We have also contributed to **3** book chapters. These publications advance understanding, drive innovation and ensure our findings are applied in practice.
- Delivered **221** dissemination presentations to share our findings including: **71** presentations and posters at national and international conferences, **60** invited talks to academic and professional audiences, **90** presentations at public engagement events including **4** high

impact events designed specifically to drive change.

- Led **17** Patient and Participant Involvement activities, ensuring our work reflects the needs and voices of families and participants.
- Secured **24** new research grants and continued support for 10 ongoing projects. The infrastructure funding provided by Cerebra was pivotal in ensuring the smooth running of all our initiatives and will continue to be central to sustaining and expanding the Network's impact moving forward.
- Developed free resources and teacher training programs through a co-production grant, including mental health resources and the Be-Well Checklist, now implemented in two Special Schools
- Incorporated our research into teaching, delivering research-led content in **10** undergraduate and postgraduate Psychology modules.
- Recognised with **13** awards and prizes for the achievements of our Network members.
- Held **39** key professional and academic committee roles, enhancing our influence in the field.

Over the last four years, we have accelerated research in the field of MCRc that addresses the poor and iniquitous outcomes experienced by children and their families with rare and complex disorders. Here, we summarise how we have directly addressed each of our ambitious Shared Objectives through collaborative research within and across research sites. Given the depth and breadth of our work, we have selected core examples to illustrate this as opposed to documenting all of the ways in which we have addressed the objectives.

Shared Objective 1:

We have improved *identification* of mental health problems, sleep disorders, and symptoms of autism and pain and discomfort through the development of novel tools and assessment paradigms. To achieve this, we launched our flagship cross-site study, BEOND (Behavioural and Emotional Outcomes in Neurodevelopmental Disorders), in which we collected detailed data to profile the phenotype of children and adults with MCRc. Over 1000 families took part in BEOND across 48 neurogenetic syndromes owing to our strong partnerships with families and syndrome support groups. We have utilised novel, objective research methodologies including actigraphy, eye-tracking, behavioural paradigms, and physiological analysis to describe sleep disorder, autism characteristics, anxiety and clinically relevant behaviour in children with MCRc (Agar, Oliver, Spiller & Richards, 2023; Agar, Oliver & Richards, 2022; Crawford et al., 2023; O'Sullivan et al., 2024; Shelley et al., 2023; Mingins et al., 2024; Mingins et al., in prep, Greenhill et al., in prep; Ellis, White, Dziwisz, Argal & Moss, 2024; Jenner & Moss, In prep). We have complemented this approach with complex statistical and meta-analytic approaches to describe the prevalence and profile of sleep disorder, autism characteristics, and mental health, and to inform measurement of sleep and behaviour (Agar et al., 2021; Bozhilova et al., 2023; Edwards et al., 2022a; O'Sullivan, Bissell, Hamilton, Bagshaw & Richards, 2023; Shelley et al., 2024; Mingins et al., 2024, Mingins et al., in prep, Jenner, Farran, Welham, Jones & Moss, 2023). We have employed questionnaires, interviews, and focus groups to enhance the development of our measures, refine our understanding of family experience, and strengthen our descriptions of mental health problems, sleep disorders, behaviour and characteristics of autism and pain and discomfort in children with MCRc (Groves et al., 2022; Edwards et al., 2022b; Laverty et al., 2023; Hughes et al., 2023; Mingins et al., 2024; Mingins et al., in prep).

Shared Objective 2:

We have *modelled* the unique and shared contributions of biological, cognitive and psychological mechanisms that cause and drive poor clinical outcomes in this group. The data we collected through BEOND supports well-powered complex statistical modelling of the interactions between mental health, sleep, autism and behaviour. Combining our understanding from this rich data with

systematic and meta-analytic approaches, novel paradigms, and genetic and physiological analysis, we have: a) developed mechanistic models of anxiety in MCRc, including its association with autism (Crawford, 2023; Smith et al., in prep; Perry et al., under review, Mingins et al., in prep; Greenhill et al., in prep, Jones et al., in prep), b) extrapolated predictors of and pathways to behaviours that challenge (Laverty et al., 2023; Trower et al., in prep; Shelley et al, 2023), c) identified common variation in single nucleotide polymorphisms that are associated with clinically-relevant behaviours (Crawford et al., 2021; Cartwright et al., under review), d) modelled the contribution of cognitive characteristics to the presence and severity of self-injurious behaviour (Laverty et al., in prep), e) delineated contributory pathways to poor sleep across syndromes (O'Sullivan et al., in prep) alongside evaluating the contribution of sleep parameters to daytime functioning and cognition (O'Sullivan et al., in prep), resulting in more comprehensive models of sleep disorder (Bissell et al., 2021) and f) evaluated the social-cognitive mechanisms associated with the presence of autism characteristics in genetic syndrome groups and their predictive value (Jenner et al., in prep). We have also harnessed our unique position as a Network to develop international collaborations which have afforded the opportunity to share data with global partners, further enhancing the validity of our models on an international scale.

Shared Objective 3:

Derived from our improved identification tools and accurate models of cause and mechanism, we have developed and piloted timely, precise *interventions* to improve mental health and behavioural outcomes in children with MCRc. Our work outlined above highlighted a clinical imperative for tailored, syndrome-sensitive interventions in MCRc. We have utilised co-production methods to adapt our LADDERS anxiety intervention manual for individuals with MCRc (Hughes et al., 2023; Mingins et al., in prep; Pearson et al., in prep), ensuring that those delivering the interventions place emphasis on factors associated with anxiety in specific rare genetic syndromes e.g. pain, sensory processing difference and intolerance of uncertainty.

Through meta-analytic techniques we have provided comprehensive evaluation of the efficacy of existing interventions for behaviours that challenge (Groves et al., 2023), highlighting the significant need for proactive, risk-informed early intervention. We have developed a novel, machine learning based algorithm that provides quick, efficient and rigorous screening of risk markers for behaviours that challenge in young children (Groves et al., in prep). We have paired this with a newly developed proactive psychoeducation intervention for behaviours that challenge (iKNOW intervention), and demonstrated that the risk algorithm and iKNOW intervention are feasible to deliver in an NHS Trust (Walters et al., in prep).

Finally, we have undertaken pilot studies evaluating parent-led sleep interventions in autistic children with intellectual disability and syndrome sensitive daytime napping intervention for children with rare genetic syndromes. The feasibility and acceptability of these interventions has informed our planned next steps in sleep interventions. We have also worked closely with the *Cerebra Sleep Service* as they developed their CAPSAC and CIPSAC sleep courses, providing evidence-based advice on evaluation and monitoring for these research-informed programmes.

Shared Objective 4:

We have delivered on our final shared objective, to partner with Cerebra to translate knowledge into practice, capitalising on our expertise in multi-media dissemination, collaboration with stakeholders and intersections with policy makers. We have developed a wide range of tangible outputs for children with MCRc, their families, and the professionals supporting them. With Cerebra we have developed and delivered a new factsheet on Weighted Blankets which provides evidence-based information for families accessing the weighted blanket lending library. We have produced guides for parents on Communication and launched the Be Well checklist. Most recently we have delivered a new guide on self-injury, alongside an infographic and set of social media videos to increase the reach of our evidence-based outputs for families.

Co-production with families and professionals has been at the forefront of our outputs. Specifically, we have worked with teachers to develop and launch an online training resource to support education practitioners working with children with MCRc. Since its launch, nearly 500 people have registered to use the resource from across seventeen different countries. We have also convened a Checklist Development group made up of parent carers, academics and clinicians, and conducted iterative consultation to revise the Be-Well Checklist. We have piloted the use of the checklist in NHS paediatric clinical services. To ensure our research is translated into practice in a timely manner, we have hosted a number of educational events within the NHS to raise awareness of our bespoke interventions and novel research findings.

Building on our collaboration with Cerebra, we secured additional funding from Aston University and the University of Birmingham ESRC Impact Fund to support the redevelopment of the Further Inform Neurogenetic Disorders (FIND) website (www.findresources.co.uk). The platform, which currently reaches over 1,000 professionals in the MCRc field, has undergone a complete infrastructure rebuild. As part of the planned relaunch, we have updated content on five core syndromes, which have undergone rigorous peer review. The updated content is being uploaded and further refined with valuable input from both parents and professionals prior to the launch of the content to ensure its relevance and accessibility.

KEY FINDINGS

Please outline key findings that highlight the significance of this research and its implications for the health outcomes and wellbeing of children living with brain conditions.

Here we have reported on key findings that have been published in peer-reviewed academic journals during the reporting period, as well as those that are currently under review or in preparation. Key findings are organised against each of the Network's four core themes. A full list of outputs, including manuscripts currently in preparation are listed on page 15.

Key findings from research in the following themes:

Autism

Through a novel machine learning approach, we evidenced the extensive heterogeneity of autism characteristics across thirteen different genetic syndromes using a single autism screening tool (Bozhilova et al., 2023). These findings, alongside other key findings from Cerebra funded work, informed an invited review which highlighted the clinical implications of this heterogeneity (Jenner et al., 2023). A meta-analysis of existing literature demonstrated the utility of eye tracking methods as a valid tool for evaluating correlates of autistic characteristics in people with intellectual disability (Jenner et al., 2024). Having evidenced the utility of these methods, we used novel eye tracking paradigms and tasks with low verbal demands to evaluate social-cognitive abilities in children and young people with DS, PWS, CdLS and FXS. Our research highlighted subtle but critical differences in gaze following and mentalizing abilities in these populations, and variability regarding the extent to which performance on tasks measuring these core social-cognitive abilities predicted autistic characteristics in these populations (e.g. Ellis et al., 2024; Ellis et al., in prep, Jenner, unpublished thesis 2024, Jenner et al., in prep). This work has also demonstrated the advantages of novel eye tracking methodology over traditional table-top tasks of social-cognitive abilities for use in people with MCRc, providing a more accurate assessment of these skills that is less reliant on verbal abilities and therefore much more accessible to intellectual disability populations. Through direct observations of parent-child interactions, we identified different profiles of performance on a range of behavioural and cognitive related measures within groups of children and young people with PWS and DS, highlighting the variable way in which these different constructs cluster together within and between syndrome groups (Jenner, unpublished thesis, 2024, Jenner et al., in prep).

Mental health

Through conducting a novel behavioural paradigm we identified physical avoidance of feared stimuli and proximity seeking to a familiar adult are prominent behavioural indicators of anxiety in fragile X and Cornelia de Lange syndromes. These groups also display heightened pervasive physiological arousal via salivary cortisol (Crawford et al., 2023). Identifying behavioural and physiological indicators of anxiety is of utmost importance in populations who are unable to self-report their internal states. Additionally we conducted clinical interviews and revealed high levels of DSM-5 anxiety symptomatology with 91.8% and 100% of individuals with Cornelia de Lange and fragile X syndromes, respectively, displaying symptomatology for a minimum of one anxiety disorder (Groves et al., 2022).

We developed the Clinical Anxiety Scale for People with Intellectual Disabilities (ClASP-ID), refining its factor structure further through exploratory factor analysis and establishing its utility across childhood and adulthood, as well as for individuals with and without an autism diagnosis (Mingins et al., 2024). Subsequently, we confirmed the scale's factor structure using confirmatory factor analysis in a large cohort of participants with moderate to severe intellectual disability, and demonstrated its stability across various genetic syndromes, including fragile X, Cornelia de Lange, and Angelman syndromes (Mingins et al., in prep). To further enhance the measure's clinical utility, we collaborated with experts by experience to refine the administration guidelines for both the

ClASP-ID and a related anxiety intervention for specific rare syndrome groups (Mingins et al., in prep). These updates were informed further by feedback from clinicians applying the intervention in practice, ensuring appropriate adaptations. Applying the ClASP-ID across diverse groups highlighted high-risk populations for anxiety, including groups such as those with Wiedemann-Steiner syndrome, where anxiety had not previously been recognised at such elevated levels. We subsequently used the measure to map pathways to anxiety in specific syndromes, identifying key characteristics such as impulsivity and sensory processing difficulties in Rubinstein-Taybi syndrome (Greenhill et al., in prep).

Behaviour

We analysed single nucleotide polymorphisms, selected a priori, to better understand genetic risk for the variability of clinical behaviours observed in fragile X syndrome. We identified that the AA COMT genotype, linked to dopamine neurotransmission, was associated with greater interest and pleasure in the environment, and with reduced risk for property destruction, stereotyped behaviour and compulsive behaviour in males with fragile X syndrome (Crawford et al., 2021). However, it was also associated with a steeper decline in repetitive and stereotyped behaviours over time (Cartwright et al., under review).

We described behavioural correlates and risk markers for behaviours that challenge in rare syndromes (SATB2, Shelley et al. 2024; CHARGE, Thomas et al., 2022) and autism (Laverty et al., 2023; Laverty et al., 2020). Together, these data add to our growing understanding that rare genetic syndromes, severity of intellectual disability, overactivity, impulsivity, health problems and autism characteristics all increase the likelihood, severity and persistence of aggression, self-injury and destruction of property. We also conducted a rigorous meta-analysis of existing psychological and pharmacological interventions for behaviours that challenge (Groves et al., 2023), which revealed small effect sizes for any interventions and highlighted the absence of efficacy data on proactive, early intervention. To address these limitations, we have pioneered a novel intervention package employing a risk-informed approach to screen young children for correlates of behaviours that challenge and to offer a new preventative psychoeducation intervention to parents of children who score as 'high risk.. We used a data driven approach applying machine learning techniques to analyse brief, efficient screening data on known risk markers in a large (N>900) sample of children with developmental delay (Groves et al., in prep). Our algorithm demonstrated fair to good recall and precision with 83.5% of children correctly predicted as 'at risk' of behaviours that challenge Predictions of persistence and incidence of behaviour over 12 months was also good (83.5% and 83.3%, respectively). We have collected preliminary feasibility and acceptability data on the risk screening algorithm and novel psychoeducation intervention ('iKNOW intervention') in the NHS. Our data suggest reasonable acceptability and feasibility with ~40% of screened parents taking part in the intervention.

Sleep

Over the last four years, we have continued to examine measurement properties of sleep tools and pioneered novel objective sleep and behaviour measurement to increase precision in sleep science for children with MCRc. In a systematic review and meta-analysis of 31 studies, we demonstrated that the concordance between subjective (e.g., sleep diaries, questionnaires, interviews) and objective (e.g., actigraphy, polysomnography) sleep measurement in neurodevelopmental conditions is similar to that observed in typically developing children (O'Sullivan et al., 2023). Specifically we highlighted smaller mean differences and larger correlations indicative of greater concordance for parameters associated with sleep scheduling compared to parameters associated with sleep duration and night awakenings. These findings support the combination of subjective and objective sleep assessment tools to delineate sleep rigorously in MCRc. We have pioneered a novel application of actigraphy data, to estimate overactivity as well as sleep in children with MCRc, providing a robust objective measure of hyperactivity that can now be routinely collected alongside

sleep data (O'Sullivan et al., 2024).

Through our collaborative Network study, BEOND, we have collected subjective sleep data for 238 children with MCRc and showed that sleep difficulties were heightened across all syndromes when compared to typically developing peers (O'Sullivan et al., in prep). Through structural equation modelling we demonstrated that sleep difficulties were positively associated with mental health difficulties, ADHD-related characteristics, autism-related characteristics, epilepsy severity, verbal ability, severity of physical health conditions and SES. Crucially, these results demonstrate that sleep difficulties are relevant to a variety of children's daytime outcomes, even after controlling for other predictors. We have employed an objective actigraphy approach to describe sleep in autistic children with ID (Mooney, unpublished thesis), children with CHARGE syndrome (Thomas, unpublished thesis) and children with CdLS, TSC, SMS and FXS (O'Sullivan et al., in prep). Finally, we have advanced understanding of the bidirectional associations between sleep and cognition, using a repeated measures design and objective sleep and play based cognition tasks in children with MCRc. Analyses of temporal directionality support bidirectional associations between sleep difficulties and overactivity, with a stronger influence of sleep on overactivity than vice versa (O'Sullivan et al., in prep). Together, these results provide psychometrically rigorous assessment tools and validated intervention targets to support evaluation of sleep interventions for MCRc.

IMPACT STATEMENT

How will the outcomes contribute to the current scientific field, health/social policy and/or the provision of health services? To what degree are these findings being translated into tangible and actionable steps? Who will benefit?

Cerebra Network Grant Impact Statement: Four-Year Summary

Over the last four years, the Cerebra Network has significantly advanced scientific knowledge, international treatment standards, and practical interventions for use in health services for children with MCRc. By collaborating with families, clinicians, educators, and charities, we have translated research findings into accessible resources and protocols that directly enhance service provision, enrich training for professionals, and ultimately improve quality of life for families and children.

Scientific Contributions

Our research has contributed substantial insights into anxiety, self-injury, and broader behavioural needs within specific genetic syndromes. This work has not only expanded the scientific field, as evidenced by the Network's substantial publication record, but has also spurred new methodologies for assessing and intervening in these complex conditions. For example, our studies on anxiety in rare syndromes have led to new assessments for identifying and measuring anxiety in populations where traditional assessments fall short, supporting targeted intervention.

Direct Impacts on Clinical Practice

As a result of our work, new assessments and interventions tailored for individuals with complex needs have been adopted within NHS Trusts. Feedback from across multiple NHS Trusts confirms that these resources address a critical gap in care by offering practical, structured interventions that are adaptable to varied clinical settings.

> *"It is critical for the clinical services and networks concerned with the health of children with neurodevelopmental disabilities, which I work in, to be informed by robust research evidence - I have observed members of the Cerebra Network make important contributions through meaningful collaborations with clinicians, as well as delivering highly accessible presentations and publications. I am always impressed by the intellectually curious and enthusiastic approach Network researchers adopt, as they apply modern research methods sensitively with the vulnerable children and families I work with."* Dr Ashley Liew, Consultant

Paediatric Neuropsychiatrist, Evelina Hospital.

Guidelines and Treatment Standards

Our collaborations with charities and involvement in consensus guidelines for genetic syndromes are shaping national and international policy. Our scientific contributions have supported the development of international clinical consensus guidelines for conditions like fragile X syndrome (Johnson et al., 2024; Herring et al., 2024) and Rubinstein-Taybi syndrome (Lacombe et al., 2024), and we have been invited to develop guidelines for further syndromes, including Williams, Wiedemann Steiner, and SATB2-associated syndromes, as well as update existing guidelines such as the Cornelia de Lange syndrome consensus statement previously published in Nature Reviews Genetics (Kline et al., 2018). These guidelines translate research into actionable recommendations, providing a valuable resource for healthcare services and policymakers, helping to shape specialised support frameworks for children with MCRc:

> *"Exciting to hear that the consensus guidelines have been published! This is a super resource, set out in topic based sections that will be so helpful for families to share with healthcare professionals."*

Upskilling of healthcare and education professionals

Through presentations, workshops, consultation clinics, and specialised training sessions, the Cerebra Network has empowered healthcare professionals with the tools and knowledge needed to integrate cutting-edge research into everyday practice. Notably, over the course of the grant, we have delivered outcomes from work over 200 times via workshops and events attended by professionals and academics, reaching multidisciplinary professionals globally. Our tailored workshops on anxiety, sleep, autism in intellectual disability —delivered in collaboration with NHS Trusts equip clinicians to handle complex cases that might otherwise go unsupported. Professionals also gain access to online resources arising from our work, such as the Teacher Training Resources, www.findteacherresources.co.uk, which has engagement from educators worldwide.

> *"After fully exploring the online resource, I could see the huge benefits it would bring to both teachers and pupils…..I am incredibly excited about the potential for this resource and can see how it could provide education staff with the tools and knowledge they require to more appropriately manage the needs of pupils with genetic conditions like my daughter. "*

Broad Beneficiaries

The outcomes of this grant benefit a wide range of stakeholders. Families gain access to evidence-based, individualised consultations, individualised feedback reports about their children and user-friendly resources such as the Cerebra Guides and Be-Well Checklist. We have delivered 90 public/parent engagement events and activities over the four year period, including 16 talks/workshops in the last 12 months alone at syndrome support groups. Clinically active members of the Network are also integrated into services for people with specific rare syndromes (e.g. Angelman Syndrome at the Manchester Rare Disease Centre and the Bardet-Biedl Clinic at the Queen Elizabeth Hospital, Birmingham), ensuring a bridge between research and practice. Finally, research collaborators across disciplines have sparked multidisciplinary approaches that further amplify the impact. We have adopted this approach by working with parents, academics and clinicians to co-design a revised version of the Be-Well Checklist to be used in paediatric services.

> *"We have worked with the Cerebra Network since its inception in 2020 and the relationship has proved to be extremely fruitful. Their specific research into the various behaviours that affect people with CdLS has been invaluable to our families in treating and managing very serious conditions arising from this very rare syndrome. Such work has also been of immense value to other syndrome groups where common traits arise"* David Axtell Chairman of the CdLS Foundation UK and Ireland and CdLS international Federation.

Training the next generation of researchers

A critical component of the Cerebra Network's impact has been its commitment to developing future leaders in the field of intellectual disability research. Over the past four years, the Cerebra Network has provided the infrastructure for the training and mentorship to 25 PhD candidates, 16 clinical psychology trainees, who work within healthcare settings, 16 master's students, 34 placement students and 57 undergraduates many of whom have chosen to advance their careers within the intellectual disability research field. This investment in early-career researchers not only strengthens the pipeline of expertise in neurodevelopmental conditions but also ensures that our research, insights, and methodologies are carried forward and applied across a variety of healthcare and academic settings. Many of these trainees are likely to mentor future students themselves, creating a ***ripple effect*** that will amplify our impact in the years ahead.

> *"Thanks for everything this year, it feels so weird to be leaving and whilst I am excited about the next chapter I am genuinely sad to be leaving this team. This is by the far the most friendly, welcoming, and team-oriented group I have ever worked with and it has also been very empowering to be surrounded by passionate, smart, and dedicated women." - Masters student going on to further training in Clinical Psychology*

A Sustainable Future

With continued support, the Cerebra Network remains committed to fostering sustainable improvements in health service provision, treatment guidelines, and research quality for those with rare conditions. The Network's ongoing partnerships will continue to drive innovation, bridge research-practice gaps, and deliver long-lasting, meaningful support for children with neurodevelopmental conditions and their families.

This impact statement was informed by public contributor David Axtell, Chairman of the CdLS Foundation UK and Ireland and the CdLS International Federation. David provided invaluable feedback on the readability and relevance of the information, ensuring that it was both accessible and informative. Although outside the scope of the current four years of funding, David emphasised the importance of highlighting the Cornelia de Lange Clinical Consensus Statement, authored by Network leads and published in Nature Reviews Genetics in 2018. Since its publication, it has been cited 377 times during the course of the current Cerebra Network Grant. David remarked, "It includes so much work from you all over the years and is in the process of being updated." This consensus statement, along with others drafted by the Network, has been crucial in ensuring timely, effective, and sensitive support for those affected by MCRc, as well as ensuring consistent best practice guidance across the world.

4. PLAIN ENGLISH SUMMARY

Please also provide a summary of the outcomes in lay/simple language (avoiding scientific jargon where possible) including an impact statement.

In 2020, we established the Cerebra Network for Neurodevelopmental Disorders (Cerebra Network), which is a team of researchers across four different universities. Over the last four years our Network has grown and thrived, supporting 25 members of staff and 148 students across a wide range of training levels. Across the Network, each of the four institutions has led on extensive work into autism, sleep, and mental health with a shared focus on behaviour, which we know from our previous research and continued PPI activities are key priorities for families and areas where there is highest need for improved assessment and intervention. We also know that behavioural and mental health characteristics occur in combination rather than on their own. For example, someone who is experiencing anxiety may also experience sleep disturbances which can impact on behaviour. Therefore, considering all aspects of a child's presentation is crucial to improving support.

Working together across the Cerebra Network, we have been uniquely placed to be able to address a number of key challenges in this field and to improve the evidence that underpins assessment and intervention. Specifically, our research has demonstrated that inadequate identification of autism, sleep problems, and mental health conditions presents a barrier to clinical diagnosis and access to relevant services. We have developed tools to improve identification and overcome these barriers. We have also further developed models that indicate precise mechanisms that give rise to clinical presentations of autism, sleep disorders, and mental health conditions. This work has provided the foundations for the development and piloting of interventions such as the LADDERS anxiety intervention for people with genetic syndromes.

Over the last four years, the Cerebra Network has published 67 original scientific articles and 3 book chapters, delivered 72 presentations at national and international conferences, 60 invited talks at academic and professional events and 90 talks at public engagement events. Over 1000 families took part in the BEOND (Behavioural and Emotional Outcomes in Neurodevelopmental Disorders) study, where the majority of families also agreed to be contacted for follow-up in the future.

We are proud to have delivered 90 presentations and workshops at family support group conferences and events. The Cerebra Network have also hosted several events which were open to the wider community to share findings and research with clinicians, teachers, researchers and other professionals. These included topics directly linked to the Cerebra Network's objectives, such as anxiety in rare genetic syndromes, self-injury in children with intellectual disability and supporting children with genetic syndromes in education. We have also worked closely with NHS services throughout our funding period, for example, with Network members at Aston developing and delivering a series of training workshops on anxiety in severe intellectual disability, and Network leads hosting consultation clinics for families of children with rare syndromes. Those participating in our research receive personalised feedback reports, with more than 1189 feedback reports distributed over the last four years.

Throughout the funded period we have demonstrated our commitment to improving long-term outcomes for people with genetic syndromes associated with intellectual disability and/or autism. We have done this by ensuring that our research is conducted with input from key stakeholders and through efficient translation of our research findings, where knowledge is applied and integrated into practice in order to directly support the people we work with.

All of the work that we have carried out to date has been informed by parents, carers and people with a range of neurodevelopmental conditions. We have set up a Cerebra Network Patient and Public Involvement (PPI) group, conducted focus groups with parents, carers and professionals and worked with family support groups. Through these activities we have identified key research priorities and gathered feedback on research methodology and feedback report processes. We have also collaborated with experts by experience on individual research projects through which we have had the opportunity to obtain feedback on project design and study materials. Where possible, we have also worked closely with experts by experience on aspects of data analysis and write up of publications.

We are grateful for the opportunities that this funding from Cerebra has provided and we will continue to share our key findings with families, carers, clinicians, stakeholders, professionals and the wider community so that we are all able to work together to better understand and address the challenges faced by individuals with intellectual disability and their families.

This section was informed by a public contributor.

5. PUBLIC INVOLVEMENT

Complete this section outlining patient and public involvement in this research. If there is no involvement, please explain why. Please, also comment on how have the research findings been made available/accessible to lay audiences?

Please involve patient or public contributors in completing this and other sections of the progress report.

All work conducted by the Cerebra Network to date has been informed by parents, carers and people with a range of neurodevelopmental conditions. Over the last four years we have established a core group of families who form our Cerebra Network Patient and Public Involvement (PPI) group through which we have gathered feedback on research methodology and feedback report processes. Most recently the Cerebra Network PPI group has informed the design, content and interpretation of our BEOND study feedback reports to ensure that the feedback we provided was as meaningful and accessible to families as possible. In addition to working with our core Cerebra Network PPI group, we have developed PPI groups for specific projects to provide an avenue for public contributors to input throughout the life of a research project. For example, Jessica Mingins (Cerebra PhD student) used this method to gather insights from clinicians on the relevance of our newly developed anxiety assessment for Cornelia de Lange and fragile X syndromes, and Nicky Thomas utilised this method for her PhD work on understanding the role of GPs in improving health and wellbeing in parent carers of children with intellectual disability, enabling parent carers and clinicians to contribute to the development of study materials. Where appropriate, we have also included experts by experience in all stages of research, including the analysis of data (e.g.https://pubmed.ncbi.nlm.nih.gov/37712611/) and development of resources including the revision of the Be-Well Checklist (Trower et al., in prep) and the development of the teacher training resource: https://www.findteacherresources.co.uk/.

Alongside our PPI group work, we have conducted focus groups with a wide range of professionals including occupational therapists, clinical psychologists and education practitioners. For example, we conducted focus groups with a broad range of clinical professionals to devise collaborative ways of translating findings into local services for the mental health projects. We also sought feedback on the feasibility of the iKNOW preventive intervention programme for individuals at Clinical High Risk for Behaviours that Challenge and conducted focus groups with teachers, SENCOs and teaching assistants on the utility and feasibility of our teacher training resource.

Our PPI work extends to stakeholder organisations. For example, we worked with the Rubinstein Taybi Syndrome Support group, Fragile X Society and the Cornelia de Lange Syndrome Foundation UK and Ireland to identify research priorities. We also hosted stakeholder and networking events with parents, carers and clinicians to obtain feedback on developing research agendas, priorities and optimal dissemination strategies, ultimately increasing the impact of our work.

> *"The Cerebra Network have attended all our major events and taken the opportunity to proactively gather feedback and listen to patient concerns. This approach ultimately benefits Fragile X families by positively influencing the way in which health and social service practitioners deliver their services"*

While most PPI work conducted within the Network has been carried out with parents/carers and professionals we have also made significant progress in our agenda for inclusive research practices. For example, members of our research team have received training in the use of TalkingMats, a visual communication framework which supports people with communication difficulties to express their feelings and views, facilitating effective communication about the things that really matter to them. We have also conducted a systematic review of inclusive research practices with people with ID, which has supported the development of a toolkit of techniques that can be applied to support young people with ID to contribute information on areas of need to them. We also published an invited commentary on inclusive research practices for people with ID in autism focused research (Jenner & Moss, 2024).

We have ensured our research findings are made available to stakeholders through the FIND website, teacher training resource, presentations at syndrome support group family conferences,

Cerebra parent guides and individualised feedback reports.

> *"The Sleep Guide was incredibly helpful in improving my autistic daughter's sleep routine, which in turn allowed us as parents to get more rest. The format, information and practical advice made it easier to implement strategies tailored to her needs. Having access to other guides such as anxiety and behaviours that challenge is also comforting, as it's reassuring to know there's a wealth of information to draw from. In a time where professional support is limited, these resources have been a lifeline for our family."*

Our extensive PPI work over the last four years evidences our commitment to working with patients and the public to inform and conduct our research.

This section was informed by a public contributor.

6. PUBLICATIONS AND OTHER OUTPUTS

PUBLICATIONS RESULTING DIRECTLY FROM WORK OF THIS GRANT

List of papers (**published, in press, in preparation or submitted**) resulting **directly** from the work of this grant. **Do not** include publications that are **unrelated** to the research funded through this grant. Please use the following format - Lead author(s), publication title, journal name, year published, DOI/PMID and specify whether each paper is published, in press, in preparation or submitted.

The Cerebra Network Grant: A Catalyst for Research Success and Collaboration

The Cerebra Network grant has been a linchpin in propelling the success of our postdoctoral researchers, PhD students, Masters students and research assistants. The grant has fuelled a surge in impactful outcomes directly tied to its objectives. Our researchers' achievements in disseminating knowledge and establishing collaborations are attributed directly to the Cerebra Network grant. By strategically investing in our researchers and the Network infrastructure, the grant has positioned our Network as a dynamic hub of influential research.

Peer reviewed articles published since 2020:

1. Ellis, K., White, S., Dziwisz, M., Agarwal, P., & Moss J. (2024). Visual attention patterns during a gaze following task in neurogenetic syndromes associated with unique profiles of autistic traits: Fragile X and Cornelia de Lange syndromes. *Cortex, 174,* 110-124. https://doi.org/10.1016/j.cortex.2024.02.012
2. Jenner, L., & Moss, J. (2024). Commentary: The exclusively inclusive landscape of autism research. *Nature Reviews Psychology, 3,* 570-572. https://doi.org/10.1038/s44159-024-00343-8
3. Marlow, K., Agar, G., Jones, C., Devine, R. T., & Richards, C. (2024). 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,* 1-20. https://doi.org/10.1007/s40489-024-00450-5
4. Mingins, J. E., Tarver, J., Pearson, E., Edwards, G., Bird, M., Crawford, H., Oliver, C., & Waite, J. (2024). Development and psychometric properties of the Clinical Anxiety Scale for People with Intellectual Disabilities (ClASP-ID). *Journal of Neurodevelopmental Disorders, 16*(1), 43. https://doi.org/10.1186/s11689-024-09554-9
5. O'Sullivan, R., Bissell, S., Agar, G., Spiller, J., Surtees, A., Heald, M., ... & Richards, C. (2024). Exploring an objective measure of overactivity in children with rare genetic syndromes. *Journal of Neurodevelopmental Disorders, 16*(18). https://doi.org/10.1186/s11689-024-09535-y
6. Agar, G., Oliver, C., Spiller, J., & Richards, C. (2023). The developmental trajectory of sleep

in children with Smith-Magenis syndrome compared to typically developing peers: A 3-year follow-up study. *Sleep Advances, 4*(1), zpad034. https://doi.org/10.1093/sleepadvances/zpad034

7. 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. https://doi.org/10.1002/ajmg.a.62867
8. 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*, 3. https://doi.org/10.1186/s13229-022-00530-5
9. Groves, L., Jones, C., Welham, A., Hamilton, A., Liew, A., & Richards, C. (2023). Non-pharmacological and pharmacological interventions for the reduction or prevention of topographies of behaviours that challenge in people with intellectual disabilities: A systematic review and meta-analysis of randomised controlled trials. *The Lancet Psychiatry, 10*(9), 682-692. https://doi.org/10.1016/S2215-0366(23)00197-9
10. Hughes, J., Roberts, R., Tarver, J., Warters-Louth, C., Zhang, B., Southward, E., Waite, J & Pearson, E. (2023). "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. *Autism, 28*(5), 1231-1244. https://doi.org/10.1177/13623613231196084
11. Jenner, L., Farran, E., Welham, A., Jones, C., & Moss, J. (2023). The use of eye-tracking technology as a tool to evaluate social cognition in people with an intellectual disability: A systematic review and meta-analysis. *Journal of Neurodevelopmental Disorders, 15,* 42. https://doi.org/10.1186/s11689-023-09506-9
12. Jenner L., Richards, C., Howard, R., & Moss, J. (2023). Heterogeneity of autism characteristics in genetic syndromes: Key considerations for assessment and support. *Current Developmental Disorders Reports, 10,* 132-246. https://doi.org/10.1007/s40474-023-00276-6
13. 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, 67,* 295-305. https://doi.org/10.1111/jir.13004
14. O'Sullivan, R., Bissell, S., Hamilton, A., Bagshaw, A., & Richards, C. (2023). Concordance of objective and subjective measures of sleep in children with neurodevelopmental conditions: A systematic review and meta-analysis. *Sleep Medicine Reviews*, 101814. https://doi.org/10.1016/j.smrv.2023.101814
15. Shelley, L., Waite, J., Tarver, J., Oliver, C., Crawford, H., Richards, C., & Bissell, S. (2023). Behaviours that challenge in SATB2-associated syndrome: Correlates of self-injury, aggression and property destruction. *Journal of Autism and Developmental Disorders*, 1-16. https://doi.org/10.1007/s10803-023-06123-2
16. Waite, J., Beck, S. R., Powis, L., & Oliver, C. (2023). The executive function account of repetitive behavior: Evidence from Rubinstein-Taybi syndrome. *American Journal on Intellectual and Developmental Disabilities, 128*(1), 49-65. https://doi.org/10.1352/1944-7558-128.1.49
17. Winsor, A. A., Richards, C., Seri, S., Liew, A., & Bagshaw, A. P. (2023). The contribution of sleep and co-occurring neurodevelopmental conditions to quality of life in children with epilepsy. *Epilepsy Research, 194*, 107188. https://doi.org/10.1016/j.eplepsyres.2023.107188
18. Agar, G., Bissell, S., Wilde, L., Over, N., Williams, C., Richards, C., & Oliver, C. (2022). Caregivers' experience of sleep management in Smith–Magenis syndrome: A mixed-methods study. *Orphanet Journal of Rare Diseases, 17*(1), 1-15. https://doi.org/10.1186/s13023-021-02159-8
19. Agar, G., Oliver, C., & 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, 21*(3), 1-19. https://doi.org/10.1080/15402002.2022.2076681

20. Bissell, S., Oliver, C., Moss, J., Heald, M., Waite, J., Crawford, H., Kothari, V., Rumbellow, L., Waltes, G., & Richards, C. (2022). The behavioural phenotype of SATB2-associated syndrome: A within-group and cross-syndrome analysis. *Journal of Neurodevelopmental Disorders,* 14, 1-21 https://doi.org/10.1186/s11689-022-09426-0
21. Edwards, G., Jones, C., Pearson, E., Royston, R., Oliver, C., Tarver, J., Crawford, H., Shelley, L., & Waite, J. (2022). Prevalence of anxiety symptomatology and diagnosis in syndromic intellectual disability: A systematic review and meta-analysis. *Neuroscience & Biobehavioral Reviews, 138*, 104719. https://doi.org/10.1016/j.neubiorev.2022.104719
22. 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 (2022). https://doi.org/10.1186/s11689-022-09462-w
23. 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, 12*(1), 1-17. https://doi.org/10.1186/s13229-021-00426-w
24. 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. https://doi.org/10.1186/s11689-021-09362-5
25. 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, 65*(6), 601-607. https://doi.org/10.1111/jir.12829
26. 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, 97*, 103555. https://doi.org/10.1016/j.ridd.2019.103555
27. Oliver, C., Adams, D., Allen, D., Crawford, C., Heald, M., Moss, J., Richards, C., Waite, J., Welham, J., Wilde, L., and 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. https://doi.org/10.1016/j.paed.2020.09.003

Book chapters published since 2020:

1. Ellis, K., Pearson, E., Murray, C., Jenner, L., Bissell, S., Trower, K., Smith, K., Groves, L., Jones, B., Williams, N., McCourt, A., & Moss, J. (2023). The importance of refined assessment of communication and social functioning in people with intellectual disabilities: Insights from neurogenetic syndrome research. In M.M. Channell & L.J. Mattie (Eds.), *International Review of Research in Developmental Disabilities, 64*, 97-170. Academic Press: UK. https://doi.org/10.1016/bs.irrdd.2023.07.003
2. 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. Academic Press: UK. https://doi.org/10.1016/bs.irrdd.2022.05.004
3. 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*, 667-680.

Springer Nature: Switzerland. https://doi.org/10.1007/978-3-030-65574-7_55

Journal articles currently under peer review:

1. Yuill, N., Elphick, C., Marshall, J. Jones, W., D., Waite, J., & Vine, H. (In Review). Social behavioral profiles and relationships in Wiedemann-Steiner syndrome: Parent reports on 25 cases. *International Journal of Developmental Disabilities*.

Journal articles currently in preparation:

1. Armitage, E., Richards, C., Jones, C., & Waite, J. Correlates of depression across syndromes associated with intellectual disability.
2. Armitage, E., Richards, C. Jones, C. & Waite, J. Prevalence of depression in rare genetic syndromes associated with intellectual disability.
3. Blumer, G., McGibbon, E., & Moss, J. Cognitive and behavioural profiles of Bardet-Biedl syndrome (BBS).
4. Blumer, G., McGibbon, E., & Moss, J. Social, emotional and behavioural profiles of Bardet-Biedl syndrome (BBS) with an autistic comparison group.
5. Ellis, K., Dziwisz, M., Jones, B., Pendered, S., Griva, C., Perry, R., Moss, J., & White, S. Performance on explicit and implicit mentalizing tasks in children with Cornelia de Lange and fragile X syndromes.
6. Ellis, K., Moss, J., Stefanidou, C., Apperly, I & Oliver, C. Social cognition, social interaction and social behaviour in Cornelia de Lange, fragile X and Rubinstein-Taybi syndromes.
7. Edwards, G., Tarver, J. & Waite, J. Predictors of anxiety in people with autism and severe intellectual disabilities.
8. Evans, G. , Moss, J., Welham, A., Cochran, L., Crawford, H. , Ellis, K. , Karim, A., Kihle, A., Naerland, T., Oliver, C., Wester Oxelgren, U. , Warner, G., & Howlin, P. Identifying autism characteristics in genetic syndromes: A comparison of the Social Communication Questionnaire and the Autism Diagnostic Observation Schedule.
9. Griva, C., Moss, J., & Gooch, D. Investigating the prevalence and profile of ADHD and the effectiveness of CPT-3 Attention Tool, in children and young people with Stuge-Weber syndrome.
10. Griva, C., Moss, J., & Gooch, D. What is the prevalence and profile of ADHD in individuals with common genetic syndromes? A systematic review and meta-analysis.
11. Greenhill, C., Tarver, J., Agar, G., Halstead, L., & Waite, J. The correlates of anxiety in people with Rubinstein-Taybi syndrome
12. Groves, L. Davies, G., Oliver, C., Allen, D., Bamford, C., Bell, L., Brown, C., Cooper, V., Daniel, L., Garstang, J., Jones, C., McCleery, J., Liew, A., Rose, J., Simkiss, D., Steenfeldt-Kristensen, C., Welham, A., & Richards, C. The development and validation of models of risk for behaviours of concern in children with developmental disabilities: A novel machine learning approach.
13. Jenner, L. IPWSO Mental Health Network. Improving mental health and wellbeing for people with PWS. *IPWSO Special Initiative.*
14. Jenner, L., Ellis, K., Farran, E., & Moss, J. Overimitation: Insights from Prader-Willi syndrome, Down syndrome, and autism.
15. Jenner, L., Ellis, K., Farran, E., & Moss, J. Use of directional gaze cues in Prader-Willi syndrome, Down syndrome, and autism.
16. Jenner, L., Farran, E. K., Ellis, K., White, S., & Moss, J. Comparing explicit and implicit mentalising in Down syndrome, Prader-Willi syndrome, and non-syndromic autism: Parallel dissociations In performance?
17. Jenner, L., Farran, E. K., Morris, F., & Moss, J. The presence and profile of autism characteristics in Down syndrome and Prader-Willi Syndrome: A comparative and descriptive analysis.
18. Laverty, C., Marlow, K., Agar, G., Bagshaw, A., Devine, R.T., Symons, F., Wright, C., &

Richards, C. Adaptive functioning is a stronger predictor of self-injurious behaviour than specific executive function substrates in autistic children with a co-occurring intellectual disability: Evidence from a novel tele-health battery.

19. Laverty, C., Martlew, R., Marlow, K., Agar, G., Bagshaw, A., Devine, R., Symons, F., Wright, C., & Richards, C. Associations between aggressive behaviours and executive function differences in autistic children with intellectual disability: Findings from the SIB study.
20. Martlew, R., Bremner, A., & Richards, C. The prevalence and profile of repetitive behaviours in children with neurodevelopmental conditions: A meta-analysis.
21. Mazhar, A., Ellis, K., Moss, J., & White, S. J. Effects of bilingualism, household size and siblings on theory of mind development in Pakistani and British children.
22. Mingins, J., Tarver, J., Agar, G., Moss, J., Richards, C., Crawford, H., & Waite, J. Confirmatory factor analysis of the Clinical Anxiety Scale for People with Intellectual Disabilities.
23. Mingins, J., Tarver, J., Agar, G., Moss, J., Richards, C., Crawford, H., & Waite, J. Anxiety across rare genetic syndromes associated with intellectual disabilities.
24. Moss, J., Deeprose, L., Mukherjee, R., Carlisle, A., Ellis, K., Farran, E., & Mukherjee, R. Prevalence and profile of autism characteristics in a Fetal Alcohol Spectrum Disorder clinic sample.
25. O'Sullivan, R., Bissell, S., Bagshaw, A., & Richards. C. Associations between sleep and daytime difficulties in children with rare genetic syndromes: A large-scale cross-syndrome survey.
26. O'Sullivan, R., Bissell, S., Bagshaw, A., & Richards. C. Examining cross-sectional and temporal associations between sleep, impulsivity, overactivity and response inhibition in children with rare genetic syndromes.
27. Pearson, E., Hughes, J., Tarver, J., & Waite, J. A parent-led anxiety intervention for autistic children who speak few or no words
28. Pearson, E., Hughes, J., Roberts, R., & Waite, J. Separation anxiety in Angelman syndrome.
29. Roberts, R., Shelley, L., Kutsch, A., Crawford, H., Oliver, C., & Waite, J. Brief report: The function of behaviours that challenge in Lowe syndrome.
30. Waite, J., Powis, L., Beck, S. R., & Oliver, C. Developmental trajectories of inhibition and task-switching in individuals with Rubinstein-Taybi syndrome.
31. Walters, L., Groves, L., Allen, D., Bain, D., Cooper, V., Daniel, L., Garstang, J., Jones, C., Kaur, K., Khan, A., Liew, A., McCleery, J., Oliver, C., Rose, J., Simkiss, D., & Richards, C. Assessing the feasibility of the i-KNOW (identifying and knowing about behaviour) preventive intervention programme for individuals at clinical high risk for behaviours that challenge.

Professional and other non-academic articles and outputs since 2020:

1. Deeprose, L. (2024). The profile of autism characteristics in Fetal Alcohol Spectrum Disorder. *British Psychological Society Branch Awards, 2*(1), 31-34. https://doi.org/10.53841/bpsba.2024.2.1.31
2. Moss J and Snellgrove H (2024). Supporting the complex needs of children with Genetic Syndromes in educational practice: A new online resource for teachers and education practitioners. *Centre for Educational Neuroscience:* http://tinyurl.com/4hxur5u2
3. Snellgrove, H., & Moss, J. (2023). Supporting the complex needs of children with Genetic Syndromes in educational practice: A new online resource for teachers and education practitioners. *Developmental Psychology Forum, 99*, 8-9. https://doi.org/10.53841/bpsdev.2023.1.99.8

Number of **published or in press** papers: 27 papers, 3 book chapters, 3 non-academic articles.

Number of papers **in preparation or submitted**:32

OTHER OUTPUTS RESULTING DIRECTLY FROM WORK OF THIS GRANT

For example, contributions to guidelines or policies, or technologies, tools, databases or other resources created.

Teacher Training Resource:

Between 2022 and 2023 we developed a novel e-training resource which is specifically designed for education practitioners who are supporting children with intellectual disability associated with a rare genetic syndrome (Welcome | Teacher training (findteacherresources.co.uk). The resource was launched in March 2023 at an online event attended by 160 practitioners and has been identified as a potential impact case study for the next REF cycle. To date, almost 500 individuals have registered to use the resource, across seventeen countries and early feedback has been very positive. For example, one user said "many thanks for this wonderful resource. In a low-income country such as ours, we rely on prepared materials that are universal in thought and can be implemented." Another user felt that the resource provided information that was "key for our undergraduate and postgraduate education students". We have leveraged funding from Cerebra to bid for additional finance support from the University of Surrey Higher Education and Innovation Research Fund which has enabled us to evaluate the impact and feasibility of this training module.

Cerebra Guides and Factsheets

With Cerebra, we have produced the following factsheets and guides:

- Weighted blankets for Sleep Difficulties in Children with Neurodevelopmental Conditions (2021). Richards, C., Agar, G. & Sutherland, D.
- The Be Well Checklist (2022). Oliver, C., Adams, D., Allen, D., Crawford, H., Heald, M., Moss, J., Pearson, E., Richards, C., Waite, J., Welham, A., Wilde, L., & Woodcock, K.
- Communication with Children with Severe or Profound Intellectual Disabilities: A Guide for Parents (2021) Buell, A., Bradshaw, J., Bissell, S., Chadwick, D., & Allen, D.
- Self-injury in children with intellectual disability (2024). Richards, C., Laverty, C., Agar, G., Marlow, K., Oliver, C., & Daniels, L.

We have also updated the Cerebra Guides on anxiety and sensory processing, and the Cerebra research summary on autism in genetic syndromes and provided peer review for Cerebra Guides on Cognitive Difference: Cognitive Inflexibility and Impulsivity and Emotional Outbursts.

Further Inform Neurogenetic Disorders (FIND) website (www.findresources.co.uk): we have leveraged funding from Cerebra to bid for additional financial support from Aston University and the University of Birmingham in 2023/2024 to rebuild and refresh the website. The infrastructure/build for the site is complete and the content for five syndromes have been externally peer reviewed. The content is being uploaded and finalised and will be relaunched in 2025 along with video resources.

Actigraphy data cleaning protocol

Our extensive programme of sleep research has highlighted inconsistencies in the application and cleaning of actigraphy data. These differences lead to variability in sleep estimates and 'noise' in the data that confound between group comparisons. We therefore developed a standardised, structured actigraphy data cleaning protocol, and published this as an appendix to one of our sleep papes (Agar, Oliver & Richards, 2022) to encourage greater transparency and consistency in

actigraphy reporting.

OTHER PUBLICATIONS/OUTPUTS THAT HAVE BEEN FACILITATED OR SUPPORTED BY THIS GRANT

Please list any other publications or outputs that have been indirectly supported by this grant, indicating for publications whether they are in preparation, submitted, in press or published.

Peer reviewed articles published since 2020:

1. Gillespie-Smith, K., Goodall, K., McConachie, D., Van Herwegen, J., Crawford, H., Ballantyne, C., Richards, C., Gallagher-Mitchell, T., Moss, J., Khawam, G., Outhwaite, L., Marriott, E., Steindorsdottir, F., & Christie, H. (2024). A longitudinal study looking at the impact of COVID-19 restrictions and transitions on psychological distress in caregivers of children with intellectual disabilities in the UK. *Journal of Child Psychology and Psychiatry Advances,* e12261. https://doi.org/10.1002/jcv2.12261
2. Herring, J., Johnson, K., Scerif, G., Weight, E., Richstein, J., Crawford, H., Robinson, H., Gawarammana, R., & Ellis, K. (2024). The joys of fragile X: understanding the strengths of fragile X and delivering a diagnosis in a helpful, holistic way. *Neurodiversity,* 2: 1-13. https://doi.org/10.1177/27546330241287685
3. Johnson, K., Stanfield, A. C., Scerif, G., McKechanie, A., Clarke, A., Herring, J., Smith, K. & Crawford, H. (2024). A holistic approach to fragile X syndrome: integrated guidance for person-centred care. *Journal of Applied Research in Intellectual Disabilities, 37*(*3), e13214.* https://doi.org/10.1111/jar.13214
4. Junges, L., Galvis, D., Windsor, A., Treadwell, G., Richards, C., Seri, S., Johnson, S., Terry, J. R., & Bagshaw, A. P. (2024). The impact of paediatric epilepsy and co-occurring neurodevelopmental disorders on functional brain networks in wake and sleep. *PLOS One, 19*(8), e0309243. https://doi.org/10.1371/journal.pone.0309243
5. Lacombe, D., Bloch-Zupan, A., Bredrup, C., Cooper, E., Douzgou, S., Minaur S., … Hennekam R. C. (2024). Diagnosis and Management in Rubinstein-Taybi Syndrome: First International Consensus Statement. *Journal of Medical Genetics, 61*(6), 503-519. https://doi.org/10.1136/jmg-2023-109438
6. Laverty, C., Surtees, A., Sutherland, D., & Richards, C. (2024). A qualitative interview with mothers of moderately or late preterm infants in the UK: Where are the care gap?. *BMJ Open, 14*(7), e076057. https://doi.org/10.1136/bmjopen-2023-076057
7. Marlow, K., Agar, G., Jones, C., Devine, R. T., & Richards, C. (2024). 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*, 1-20. https://doi.org/10.1007/s40489-024-00450-5
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Journal articles currently under peer review:

1. Cartwright, L., Scerif, G., Oliver, C., Beggs, A., Stockton, J., Wilde, L., & Crawford, H. (In Review). Genetic determinants of longitudinal behavioural trajectories in rare conditions: the case of fragile X syndrome. *Behavioural Brain Research.*
2. Perry, V., Smith, K., Groves, L., Moss, J., Oliver, C., Knight, E., Patterson, T., Rodgers, J., Waite, J., & Crawford, H. (In review). The relationship between anxiety and intolerance of uncertainty in Cornelia de Lange and fragile X syndromes. *Journal of Intellectual Disability Research.*
3. Majid, M., Harris, B., Roy, A., Egglestone, S. R., & Crawford, H. (In review). Physical healthcare for people with intellectual disabilities: A psychiatry multidisciplinary team perspective. *British Journal of Psychiatry Open.*

Journal articles currently in preparation:

1. Edwards, G., Tarver, J., Oliver, C., & Waite, J. Identifying correlates of anxiety in children and adults with moderate-profound intellectual disability: A questionnaire study.
2. Greenhill, C. Tarver, J., Agar, G., & Waite, J. The phenomenology of anxiety and low mood in people with Rubinstein-Taybi syndrome
3. Greenhill, C., Tarver, J., Agar, G., & Waite, J. The phenomenology of emotional outbursts in people with Rubinstein-Taybi syndrome
4. Perry, V., Thomas, N., Smith, K., Knight, E., Patterson, T. & Crawford, H. Factors associated with anxiety in autism: A systematic review.
5. Shelley, L., Tarver, J., Richards, C., Crawford, H., & Waite, J. Cognitive difference, responses to uncertainty and behaviours that challenge in SATB2-associated syndrome.
6. Shelley, L., Tarver, J., Richards, C., Crawford, H., & Waite, J. Using interview methodology to inform understanding of behaviours that challenge in SATB2-associated syndrome.
7. Smith, K., Waite, J., Trower, H., Roberts, J., Smith, J., Thomas, N., & Crawford, H. Factors associated with anxiety in fragile X syndrome: A systematic review.
8. Trower, H., Bamford, C., Jones, C., Crawford, H., Richards, C. Risk factors of behaviours that challenge in intellectual disability: A meta-analysis.
9. Trower, H., Oliver, C., Bull, L., Gray, K., Hanna, H., Liew, A., Muller, S., McDonald, S., Krupinski, C., & Crawford, H. Using patient and public involvement to develop a clinical behaviour checklist for parents of children with moderate-profound intellectual disability.
10. Trower H., Oliver, C., Gray, K., Liew, A., & Crawford, H. The feasibility and acceptability of The Behaviour Checklist to monitor causes of behaviours that challenge in paediatric clinical services.
11. Trower, H., Wade, K., Hanif, R., Adams, D., Bissell, S., Bull, L. et al. A cross-syndrome analysis of physical health problems in neurogenetic syndromes.

Professional and other non-academic articles and outputs since 2020:

1. Ellis, K. (2024). Learning disability: Beyond the cognitive. *Psychologist, 37*, 72-75.

DISSEMINATION OF RESULTS

List where and by whom your findings have been disseminated. This may include conferences and workshops, but may also include other engagement events, for example related to patient & public involvement.

Peer reviewed national and international conference presentations/posters:

1. Ndiaye, S., Deeprose, L., Mukherjee, R., Ellis, K., Carlisle, A., Farran, E., & Moss J. Autism and related characteristics in a UK clinic sample of individuals with Fetal Alcohol Spectrum Disorders. *7th European Fetal Alcohol Specturm Disorders (EUFASD) Alliance Conference, Madrid, Spain, September 2024.*
2. Pearson, E., Roberts, R., Waite, J., & Oliver, C. A caregiver-reported profile of separation distress and attachment-related behaviours in Angelman syndrome. *Study of Behavioural Phenotypes (SSBP), Bali, Indonesia, September 2024.*
3. Shelley, J., Tarver, J., Crawford, H., Richards, C., & Waite, J. Exploring the profile of executive function within SATB2-associated syndrome to inform models of behavioural outcomes. *Study of Behavioural Phenotypes (SSBP), Bali, Indonesia, September 2024.*
4. Trower, H., Oliver, C., Liew, A., Gray, K., Garstang, J. & Crawford, H. Thinking differently about behaviour in children with intellectual disability: The checklist project. *Life and Medical Sciences Post-Doc Symposium, University of Warwick, Coventry, England, September 2024.*
5. Williams, N., Tuomainen, H., Weiss, J., Gray, K., Trower, H., Pandher, P., & Crawford, H. Clinician knowledge, confidence and approaches used in the provision of psychological therapy to autistic individuals and individuals with intellectual disability in Child and Adolescent Mental Health Services: Mental Health Provider Survey. *Study of Behavioural Phenotypes (SSBP), Bali, Indonesia, September 2024.*
6. Smith, K., Trower, H., Waite, J., & Crawford, H. Characterising and disentangling profiles of social anxiety and social motivation in fragile X syndrome. *Warwick Medical School Postgraduate Research Symposium, Coventry, England, June 2024.*
7. Ellis, K., Moss, J., Dziwisz, M., Jones, B., Pendered, S., Griva, C., Perry, R., & White, S. Performance on explicit and implicit mentalizing tasks in children with Cornelia de Lange and fragile X syndromes. *56th Gatlinburg Conference, Kansas City, USA, April 2024.*
8. Jenner, L., Farran, E., Ellis, K., Howard, R., White., S. & Moss, J. Explicit and implicit mentalising in Down syndrome, Prader-Willi syndrome, and autism. *Down Syndrome Education International Research Forum, Online, April 2024.*
9. Jenner, L., Farran, E., Ellis, K., White., S., & Moss, J. Spontaneous gaze-following in Down syndrome, Prader-Willi syndrome, and non-syndromic autism. *56th Gatlinburg Conference, Kansas City, USA, April 2024.*
10. O'Sullivan, R., Bissell, S., Agar, G., Spiller, J., Surtees, A., Heald, M., … & Richards, C. Exploring an objective measure of overactivity in children with rare genetic syndromes. *International Pediatric Sleep Association (IPSA), Glasgow, Scotland, April 2024.*
11. O'Sullivan, R., Bissell, S., Agar, G., Spiller, J., Surtees, A., Heald, M., … & Richards, C. Exploring an objective measure of overactivity in children with rare genetic syndromes. *20th Seattle Club Conference, Birmingham, England, December 2023.*
12. Douglas, A., Smith, K., Moss, J., Richards, C., Waite, J., Wade, K., & Crawford, H. Behavioural profile of anxiety in fragile X syndrome. *Study of Behavioural Phenotypes (SSBP), Online, September 2023.*
13. Hughes, J., Pearson, E., Tarver, J., Edwards, G., Bird, M., Greenhill, C., & Waite, J. A parent-led intervention to reduce anxiety in autistic children with severe to profound intellectual disabilities: current data from the LADDERS proof-of-concept study. *Study of Behavioural Phenotypes (SSBP), Online, September 2023.*
14. Shelley, L., Tarver, J., Crawford, H., Richards, C., & Waite, J. Associations between executive functioning,intolerance of uncertainty and behaviours that challenge in SATB2-associated syndrome. *Study of Behavioural Phenotypes (SSBP), Online, September 2023.*

15. Smith, K., Waite, J., Wade, K., Richards, C., Moss, J., & Crawford, H. The relationship between autism characteristics, intolerance of uncertainty, and anxiety in fragile X syndrome. *Study of Behavioural Phenotypes (SSBP), Online, September 2023.*
16. Trower, H., Bamford, C., Jones, C., Richards, C., Corke, L., Flett, W., Williams, N., & Crawford, H. A systematic review of risk markers for self-injurious behaviour, aggression, and destruction in individuals with intellectual disability. *European Congress of Mental Health in Intellectual Disabilities (EAMHID), Helsinki, Finland, September 2023.*
17. Trower, H., & Crawford, H. The Checklist Project. *European Congress of Mental Health in Intellectual Disabilities (EAMHID), Helsinki, Finland, September 2023.*
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19. Jenner, L., Ellis, K., Farran, E., & Moss, J. Implicit and explicit false-belief reasoning in Down syndrome, Prader–Willi syndrome, and autism. *Neurodevelopmental Disorders Annual Seminar (NDAS), London, England, June 2023.*
20. Roberts, R., Waite, J., Moss, J., Oliver, C., & Pearson, E. Separation distress in Angelman syndrome. *Neurodevelopmental Disorders Annual Seminar (NDAS), London, England, June 2023.*
21. Shelley, L., Tarver, J., Crawford, H., Richards, C., & Waite, J. Executive functioning and intolerance of uncertainty in relation to externally directed behaviours that challenge in SATB2-associated syndrome. *Neurodevelopmental Disorders Annual Seminar (NDAS), London, England, June 2023.*
22. Smith, K., Waite, J., Wade, K., Richards, C., Moss, J., & Crawford, H. The relationship between autism characteristics, intolerance of uncertainty, and anxiety in fragile X syndrome. *Neurodevelopmental Disorders Annual Seminar (NDAS), London, England, June 2023.*
23. Thomas, N., Crawford, H., Dale, J., & Atherton, H. Perspectives of Using general practice to Support the Health of parents of children and young people with intellectual disability. (PUSH study). *Neurodevelopmental Disorders Annual Seminar (NDAS), London, England, June 2023.*
24. Trower, H., & Crawford, H. The Checklist Project: The Behaviour Checklist. *Neurodevelopmental Disorders Annual Seminar (NDAS), London, England, June 2023.*
25. Edwards, G., Tarver, J., & Waite, J. Shared pathways to anxiety in individuals with moderate-profound intellectual disability: The role of characteristics associated with a diagnosis of autism. *International Society for Autism Research (INSAR), Stockholm, Sweden, May 2023.*
26. Laverty, L., Agar, G., Marlow, K., Wright, C., Devine, R., Symons, F., Bagshaw, A., & Richards, C. The SIB Study – Exploring the links between executive function and self-injurious behaviour in autistic children with a co-occurring intellectual disability. *International Society for Autism Research (INSAR), Stockholm, Sweden, May 2023.*
27. Marlow, K., Laverty, L., Agar, G., Wright, C., Devine, R., Symons, F., Bagshaw, A., & Richards, C. Understanding self-restraint and self-injurious behaviour in autistic children with intellectual disability: Exploring models of impaired inhibitory control. *International Society for Autism Research (INSAR), Stockholm, Sweden, May 2023.*
28. Mingins, J., Pearson, E., Edwards, G., Oliver, C., Bird, M., Tarver, J., & Waite, J. Development of an assessment tool to detect anxiety in autistic individuals who speak few to no words. *International Society for Autism Research (INSAR), Stockholm, Sweden, May 2023.*
29. Waite, J., Pearson, E., Hughes, J., Tarver, J., Edwards, G., Oliver, C., Bird, M., & Greenhill, C. A parent-led intervention to reduce anxiety in autistic children with severe to profound intellectual disabilities: Current data from the Ladders pilot study.*International Society for Autism Research (INSAR), Stockholm, Sweden, May 2023.*
30. Bissell, S., O'Sullivan, R., Williams, C., Spiller, J., Wilde, L., Bagshaw, A., Hill, C., de Vries, P., Oliver, C., & Richards, C. A multi-method approach to studying sleep in children with tuberous sclerosis complex: Questionnaire and actigraphy findings from the eSNORE study. *55th Gatlinburg Conference, Kansas City, USA, April 2023.*
31. Jenner, L., Ellis, K., Howard, R., Farran, E., & Moss, J. Overimitation: Insights from Down

syndrome, Prader-Willi syndrome, and autism. *55th Gatlinburg Conference, Kansas City, USA, April 2023.*

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33. Marlow, K., Agar, G., Jones, C., Devine, R., & Richards, C. The prevalence and correlates of self-restraint in individuals with autism and/or intellectual disability: A systematic review & meta-analysis. 5*55th Gatlinburg Conference, Kansas City, USA, April 2023.*
34. Marlow, K., Laverty, L., Agar, G., Wright, C., Devine, R., Symons, F., Bagshaw, A., & Richards, C. Understanding self-restraint and self-injurious behaviour in autistic children with intellectual disability: exploring models of impaired inhibitory control. *55th Gatlinburg Conference, Kansas City, USA, April 2023.*
35. O'Sullivan, R., Bissell, S., Hamilton, A., Bagshaw, A., & Richards, C. Concordance of objective and subjective measures of sleep in children with neurodevelopmental conditions: A systematic review and meta-analysis. 5*55th Gatlinburg Conference, Kansas City, USA, April 2023.*
36. Thomas, A., Waite, J., Williams, C., Kirk, J., Oliver, C., & Richards C. Phenotypic characteristics and variability in CHARGE syndrome: A PRISMA compliant systematic review and meta-analysis. *55th Gatlinburg Conference, Kansas City, USA, April 2023.*
37. Wade, K., Trower, H., Oliver, C., Bull, L., Heald, M., Moss, J., Powis, L., Richards, C., Waite, J., Welham, A., Wilde, L., Woodcock, K., & Crawford, H. Physical health problems in neurogenetic syndromes: a cross syndrome analysis. *55th Gatlinburg Conference, Kansas City, USA, April 2023.*
38. Moss J. Improving evidence-based practice in schools for children with genetic syndromes: developing an online bespoke training resource for education practitioners. *Down Syndrome Education and Research Forum Conference, Online, March 2023.*
39. Thomas, N., Crawford, H., Dale, J., & Atherton, H. Perspectives of Using general practice to Support the Health of parents of children and young people with intellectual disability. (PUSH study). *Southwest Society for Academic Primary Care (SAPC), Birmingham, England, March 2023.*
40. Jones, B., Askew, C., Ellis, K., & Moss, J. Anxiety and autism in Cornelia de Lange Syndrome - Overview of PhD. *Naturalistic Experimentation Workshop, Birkbeck University, London, England, September 2022.*
41. 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. *Society for the Study of Behavioural Phenotypes (SSBP), Oslo, Norway, September 2022.*
42. Trower, H. The Checklist Project: Co-developing a clinical behaviour checklist for children with intellectual disability. *British Association for Community Child Health Conference, Leicester, England, September 2022.*
43. Bozhilova, N et al. Profiles of autism characteristics in genetic syndromes. *Autistica Research Festival, Online, July 2022.*
44. 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 Research Festival, Online, July 2022.*
45. Thomas N., Atherton, H., Dale, J., & Crawford, H. Understanding the experiences of parents of children with disabilities interactions with general practice: A systematic review. *Society for Academic Primary Care (SAPC), University of Central Lancashire, Preston, England, July 2022.*
46. Bissell, S. UK research update on Tuberous Sclerosis Complex (TSC): An exploration of TSC-Associated Neuropsychiatric Disorders (TAND). *Neurodevelopmental Disorders Annual Seminar (NDAS), Edinburgh, Scotland, June 2022.*
47. Bozhilova, N., et al. Autism-related phenotypes in genetic syndromes: A machine learning approach. *Neurodevelopmental Disorders Annual Seminar (NDAS), Edinburgh, Scotland,*

June 2022.

48. 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 (NDAS), Edinburgh, Scotland, June 2022.*
49. 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 (NDAS), Edinburgh, Scotland, June 2022.*
50. 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 (NDAS), Edinburgh, Scotland, June 2022.*
51. 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 (NDAS), Edinburgh, Scotland, June 2022.*
52. Mingins, J., Waite, J., Crawford, H., & Tarver, J. Triggers and correlates of anxiety in Cornelia deLange syndrome. *10th biennial Virtual CdLS Foundation Symposium on CdLS and Cohesin and Related Genes, Online, June 2022.*
53. 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 BiennialScientific Virtual Symposium on Cornelia de Lange Syndrome, Cohesin and Related Genes, Online, June 2022.*
54. 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 (NDAS), Edinburgh, Scotland, June 2022.*
55. 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 (NDAS), Edinburgh, Scotland, June 2022.*
56. Thomas N., Atherton, H., Dale, J., & Crawford, H. General practice and its role in supporting the mental and physical health of parents who care for children with intellectual disability. *Warwick Medical School Postgraduate Research Symposium, Coventry, England, June 2022.*
57. 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, University of Surrey, Guildford, England, April 2022.*
58. Bozhilova et al. Autism-related phenotypes in genetic syndromes. *Society for the Study of Behavioural Phenotypes Annual Conference (SSBP), Online, September 2021.*
59. Bozhilova, N., Oliver, C., Richards, C., Waite, J., Powis, L., Crawford, H., et al. Autism-related phenotypes in genetic syndromes: A machine-learning study. *Society for the Study of Behavioural Phenotypes (SSBP), Online, September 2021.*
60. 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. *International CHARGE Syndrome Virtual Symposium, Online, July 2021.*
61. 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. *6th International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Europe Congress, Online, July 2021.*
62. 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. Online, June 2021.*
63. Agar, G., Oliver, C., & Richards, C. Overnight parent-child proximity in relation to poor sleep in children with Angelman and Smith-Magenis syndromes. *54th Gatlinburg*

Conference, Online, April 2021.

64. Bissell, S., Oliver, C., Moss, J., Heald, M., Waite, J., Crawford, H., et al. The behavioural phenotype of SATB2-associated syndrome (SAS): A cross-syndrome comparison with Angelman syndrome (AS) and autism. *54th Gatlinburg Conference, Online, April 2021.*
65. Crawford, H., Beggs, A., Karakatsani, K., McCleery, J., Moss, J., Sandhu, P., et al. Self-injurious behaviour in males with fragile X syndrome: Genetic modifiers and persistence over time. *54th Gatlinburg Conference, Online, April 2021.*
66. Ellis, K., Dziwisz, M., Webster, B., Hamilton, A., White, S., & Moss, J. Overimitation in Cornelia de Lange and fragile X syndromes. *54th Gatlinburg Conference, Online, April 2021.*
67. 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 Gatlinburg Conference, Online, April 2021.*
68. Moss, J., Dziwisz, M., Ellis, K., Agarwal, P., & White, S. Gaze following in fragile X syndrome. *54th Gatlinburg Conference, Online, April 2021.*
69. Agar, G., Oliver, C., Trickett, J., & Richards, C. The developmental trajectory of sleep on children with Smith-Magenis syndrome compared to typically developing peers. *6th International Pediatric Sleep Association Congress, Online, February 2021.*
70. Edwards, G., Tarver, J., Potter, P., Malhi, P., Oliver, C., & Waite, J. Correlates of anxiety in autistic individuals with moderate-profound intellectual disability or those who speak few or no words. *Autistica Research Festival, Online, July 2020.*
71. 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 Research Festival, Online, July 2020.*

Public engagement activities:

1. Richards, C. Understanding and reducing sleep problems in rare syndromes. *Cerebra Online Webinar, Online, November 2024.*
2. Waite, J. Anxiety in people with Cornelia de Lange Syndrome. *Cornelia de Lange Syndrome UK and Ireland Family Conference, Virtual Presentation, Dublin, Ireland, October 2024.*
3. Waite, J. Anxiety in people with genetic syndromes and severe to profound intellectual disabilities. *Syngap1 4th UK Annual Conference, Manchester, England, October 2024.*
4. Richards, C. Sleep (and behaviour) in people with Smith-Magenis syndrome. *Smith Magenis Family Conference, Derbyshire, England, August 2023.*
5. Waite, J. Anxiety and Behaviour. *Angelman Syndrome Family Conference, Coventry, England, August 2024.*
6. Richards, C. Understanding and reducing sleep problems in rare syndromes. *Kleefstra Syndrome Family Conference, Crewe, England, July 2024.*
7. Waite, J. The Be-Well Checklist. *Kleefstra Syndrome Family Conference, Crewe, England, July 2024.*
8. Waite, J., Autism and anxiety in rare genetic syndromes. W*iedemann-Steiner Syndrome Family Meeting, Doncaster, England, July 2024.*
9. Waite, J. Behaviours that challenge in SAS. *SATB2-Associated Syndrome Family & Medical Conference, Virtual Presentation, Sandusky, USA, July 2024.*
10. Waite, J. Mental health in people with intellectual disabilities: Professionals stakeholder event. *Aston University, Birmingham, England, July 2024.*
11. Waite, J. & Jess, M. Understanding Behaviour in Cornelia de Lange syndrome. *Professionals Virtual Workshop, Online, July 2024.*
12. Williams, N., Tuomainen, H., Weiss, J., Gray, K., Trower, H., Pandher, P., & Crawford, H. Clinician knowledge, confidence and approaches used in the provision of psychological therapy to autistic individuals and individuals with intellectual disability in Child and Adolescent Mental Health Services: Mental Health Provider Survey. *CAMHS Mental Health Support Team Nottinghamshire, Nottinghamshire, England, July 2024.*

13. Williams, N., Tuomainen, H., Weiss, J., Gray, K., Trower, H., Pandher, P., & Crawford, H. Clinician knowledge, confidence and approaches used in the provision of psychological therapy to autistic individuals and individuals with intellectual disability in Child and Adolescent Mental Health Services: Mental Health Provider Survey. *NHS England, July 2024.*
14. Greenhill, C. & Waite, J. Learning more about Rubinstein-Taybi syndrome. *RTS UK Conference, Drayton Manor, England, June 2024.*
15. Waite, J. Healthy Hacks Workshop. *RTS UK Conference, Drayton Manor, England, June 2024.*
16. Waite, J. Understanding Rubinstein-Taybi syndrome & international consensus statement. *RTS UK Conference, Drayton Manor, England, June 2024.*
17. Waite, J. The Be-Well Checklist. *Wolf Hirschhorn Syndrome Family Conference, East Midlands Airport, England, May 2024.*
18. Moss, J., & Austin, D. Understanding and Reducing Diagnostic Overshadowing in Children with Genetic Syndromes Associated with Intellectual Disability. *Cerebra Online Webinar Series, Online, November 2023.* https://www.youtube.com/watch?app=desktop&v=9yHqxpUFPAU&feature=youtu.be
19. Moss, J. Behaviour overview and changes with age in CdLS. *Basingstoke, England, October 2023.*
20. Waite, J., Cornelia de Lange Syndrome: Anxiety Workshop. *Cornelia de Lange Syndrome Foundation UK and Ireland Conference, Southampton, England, October 2023.*
21. Waite, J., Parent Well-Being Workshop. Cornelia de Lange *Cornelia de Lange Syndrome Foundation UK and Ireland Conference, Southampton, England, October 2023.*
22. Murray, C. Overview of Cerebra Network and BEOND for PKS Families. *Pallister Killian Syndrome UK Family Conference, Birmingham, England, July 2023.*
23. O'Sullivan, R. The importance of sleep for children with rare genetic syndromes: DYRK1A syndrome. *The Wirral DYRK1A Family Meetup & Conference, The Wirral, England, July 2023.*
24. Trower, H. The Checklist Project: The Behaviour Checklist. *Pallister Killian Syndrome UK Family Conference, Birmingham, England, July 2023.*
25. Moss, J. Improving evidence-based practice in schools for children with neurogenetic conditions: Developing an online bespoke training resource for education practitioners. *FRIO Research Celebration Event, June 2023.*
26. Moss J. Improving evidence-based practice in schools for children with neurogenetic conditions: an online bespoke training resource for education practitioners. *FRIO Research Celebration Event [awarded the flash talk prize], June 2023.*
27. Hughes, J., Pearson, E., Tarver, J., Edwards, G., Bird, M., Greenhill, C., & Waite, J. LADDERS: A parent-led anxiety intervention for autistic children who speak few or no words. *Anxiety in Rare Genetic Syndromes Workshop, University of Warwick, Coventry, England, May 2023.*
28. Mingins, J., & Waite, J. The Development of an Anxiety Assessment Measure for Individuals who Speak Few or No Words. *Anxiety in Rare Genetic Syndromes Workshop, University of Warwick, Coventry, England, May 2023.*
29. Moss, J. Anxiety in people with CdLS. *Online Webinar, May 2023.*
30. Moss J. Understanding anxiety in Cornelia de Lange Syndrome. *Virtual event for CdLS Foundation UK and Ireland, Online, May 2023.*
31. Moss, J. & Jones, B. Anxiety in Cornelia de Lange Syndrome. *Anxiety in Rare Genetic Syndromes Workshop, University of Warwick, Coventry, England, May 2023.*
32. Roberts, R., Waite, J., Moss, J., Oliver, C., & Pearson, E. Separation Distress in Angelman Syndrome. *Anxiety in Rare Genetic Syndromes Workshop, University of Warwick, Coventry, England, May 2023.*
33. Smith, K. Anxiety in Fragile X Syndrome. *Anxiety in Rare Genetic Syndromes Workshop, University of Warwick, Coventry, England, May 2023.*
34. Waite, J., Roberts, R., Mingins, J., & Hughes, J. Assessment and intervention of anxiety in rare genetic syndromes. *Anxiety in Rare Genetic Syndromes Workshop, University of Warwick, Coventry, England, May 2023.*
35. Ellis, K. Sensory differences in people with CdLS. *CdLS Foundation UK and Ireland Spring Conference, Glasgow, Scotland, April 2023.*
36. Moss J. Behaviour overview and changes with age in CdLS. *CdLS Foundation UK and Ireland*

Spring Conference, Glasgow, Scotland, April 2023.

37. Marlow, K. Self-Restraint in children with intellectual disability. Self-injury in children with intellectual disability. *From Research to Practice Impact Event, University of Birmingham, Birmingham, England, March 2023.*
38. Moss, J., Crawford, H., Murray, C., & Low, K. Let's TALKBG!: BEOND Information Evening [online webinar and podcast]. *KBG Foundation, Online, March 2023.*
39. Moss J., Wilson, S., & Wilby, L. Launch event: Understanding the complex needs of children with genetic syndromes in educational practice. *University of Surrey, Guildford, England, March 2023.*
40. Richards, C. Self-injury in intellectual disability: what do we know? Self-injury in children with intellectual disability. *From Research to Practice Impact Event, University of Birmingham, Birmingham, England, March 2023*
41. Trower, H. & Wade, K. Understanding the research priorities for families with Cornelia de Lange syndrome. *CdLS Foundation UK and Ireland Family Conference, February 2023.*
42. Ellis, K., & Jenner, L. Social cognition in genetic syndromes associated with autism. *Fetal Alcohol Spectrum Disorders (FASD) Research and Networking Workshop, University of Surrey, Guildford, England, January 2023.*
43. Ellis, K., Moss, J., Dziwisz, M., Jones, B., & White, S. (2023). Performance on implicit and explicit false belief tasks in children with CdLS and FXS. *Experimental Psychological Society, London, England, January 2023.*
44. Hughes, J. A parent-led intervention to reduce anxiety in autistic children with severe to profound intellectual disabilities: current data from the LADDERS pilot study. *Fetal Alcohol Spectrum Disorders (FASD) Research and Networking Workshop, University of Surrey, Guildford, England, January 2023.*
45. Mingins, J. Development of the Clinical Anxiety Screen for People with Severe to Profound ID (ClASP-ID). *Fetal Alcohol Spectrum Disorders (FASD) Research and Networking Workshop, University of Surrey, Guildford, England, January 2023.*
46. Moss, J. Profiles of autistic characteristics in genetic syndromes: implications for assessment and diagnosis. *Fetal Alcohol Spectrum Disorders (FASD) Research and Networking Workshop, University of Surrey, Guildford, England, January 2023.*
47. O'Sullivan, R. Sleep in children with neurodevelopmental conditions, and relevant sleep interventions. *NHS Clinical Assistant Workshop, January 2023.*
48. Richards, C. Challenging behaviour in CdLS. *CdLS Foundation UK and Ireland Autumn Conference, East Midlands, England, October 2022.*
49. Richards, C. Sleep problems in CdLS. *CdLS Foundation UK and Ireland Autumn Conference, East Midlands, England, October 2022.*
50. Moss J. Changes with age in CdLS. *CdLS Foundation UK and Ireland Autumn Conference, East Midlands, England, October 2022.*
51. Waite, J. Panel Discussion/Q&As. *Wiedemann Steiner Syndrome Conference, Baltimore, USA, October 2022.*
52. Yuill, N., Elphick, C., Davies, A., Waite, J., & Jones, W. Panel Discussion: Behaviour in Wiedemann Steiner Syndrome. *Wiedemann Steiner Syndrome International Conference, October 2022.*
53. Crawford, H., Stanfield, A., & Johnson, K. The development of integrated guidance for fragile X syndrome.*Fragile X Society Family Conference, Birmingham, England, September 2022.*
54. Moss J. Fragile X premutation associated conditions: An overview. *Fragile X Society Family Conference, Birmingham, England, September 2022.*
55. Moss J. Understanding autism in fragile X syndrome. *Fragile X Society Family Conference, Birmingham, England, September 2022.*
56. Richards, C., & Agar, G. Sleep in Smith Magenis Syndrome. *SMS Foundation, Sweden, September 2022.*
57. Smith, K. & Thomas, N. Understanding the research priorities of families with fragile X syndrome. *Fragile X Society Family Conference, Birmingham, England, September 2022.*
58. Waite., J. Research into behaviour, cognition and emotion in Angelman syndrome: Future Directions. *Angelman Syndrome UK Conference, Coventry, England, August 2022.*

59. Shelley, L. Behaviours that challenge in SATB2-associated syndrome: A research update. *SATB2Gene Trust UK National Conference, Luton, England, July 2022.*
60. Crawford, H., & Smith, K. Anxiety in fragile X syndrome. *Fragile X Society Family Conference, Thomley, England, June 2022.*
61. Pearson, E., & Hughes, J. Making sense of behaviour: Workshop. *RTS-UK Family Conference, Birmingham, England, June 2022.*
62. Waite, J. Making Sense of Behaviours that Challenge. *Wiedemann Steiner Syndrome Family Conference, Baltimore, USA, June 2022.*
63. Waite, J. Research into behaviour, cognition and emotion in Rubinstein-Taybi syndrome: Past, present and future. *RTS-UK Family Conference, Birmingham, England, June 2022.*
64. Waite, J. Anxiety in Smith Magenis syndrome. *Smith Magenis Foundation UK Conference, Solihull, England, May 2022.*
65. Crawford, H., & Trower, H. The Checklist Project: A clinical checklist for identifying the causes of behaviours that challenge in children with a moderate-profound intellectual disability. *CdLS Foundation UK and Ireland Conference, Reading, England, April 2022.*
66. Moss J. Understanding autism in Cornelia de Lange syndrome. *CdLS Foundation UK and Ireland Conference, Reading, England, April 2022.*
67. Waite, J. Cornelia de Lange Syndrome: Anxiety Workshop. *CdLS Foundation UK and Ireland Conference, Reading, England, April 2022.*
68. Waite., J. Making sense of behaviours that challenge in Rubinstein-Taybi syndrome. *Spanish RTS Syndrome Support Group, March 2022.*
69. Moss, J., Crawford, H., Richards, C., & Waite, J. Be-Well Checklist Launch Event. *Cerebra, January 2022.*
70. Bozhilova, N. Autistic traits in children with genetic syndromes. I am a psychologist. Get me out of here?! *British Psychological Society Virtual Event, Online, November 2021.*
71. Thomas, A. & Oliver, C. Behaviours and CHARGE Syndrome: Clinical and research perspectives. *CHARGE Family Support Group, Online, November 2021.*
72. Ellis, K., & Jenner, L. Thinking styles in Cornelia de Lange syndrome. *CdLS Foundation UK and Ireland Conference, Online, October 2021.*
73. Jenner, L. Social cognition and autism in Down syndrome. *Down Syndrome Research Foundation Virtual livestream and Q&A, Online, October 2021.*
74. Moss, J., Crawford, H., Waite, J., Groves, L., & Oliver, C. Behaviour, Anxiety and Autistic Traits in Cornelia de Lange syndrome. *CdLS Foundation UK and Ireland Conference, Online, October 2021.*
75. Crawford, H. Introducing the Cerebra Network for Neurodevelopmental Disorders. *Fragile X Society Family Conference, Online, September 2021.*
76. Agar, G. & Bissell, S. Sleep and behaviour in genetic syndromes. *Cerebra Network Launch Event, June 2021.*
77. Bissell, S., Richards, C., & Hill, C. The importance of sleep in children with tuberous sclerosis complex. *Tuberous Sclerosis Association Virtual webinar, Online, June 2021.*
78. Bozhilova, N., & Moss, J. Autism-related phenotypes in genetic syndromes: A machine-learning study. *Cerebra Network Launch Event, June 2021.*
79. Ellis, K. Assessing social cognition in genetic syndromes associated with intellectual disability. *Cerebra Network Launch Event, June 2021.*
80. Ellis, K., Scerif, G., Moss, J., Crawford, H., & Stanfield, A. Co-production with individuals with FXS and their families. *Fragile X Syndrome Research Meet-up, Online, June 2021.*
81. Jenner, L. Thinking styles in autism and genetic syndromes. *Cerebra Network Launch Event, June 2021.*
82. Moss, J. Autism in genetic syndromes: challenges and future directions. *Cerebra Network Launch Event, June 2021.*
83. Waite, J. & Crawford, H. Mental health in genetic syndromes. *Cerebra Network Launch Event, June 2021.*
84. Moss, J., Crawford, H., Waite, J., Groves, L., & Oliver, C. Understanding Behaviour in Cornelia

de Lange syndrome. *CdLS Foundation UK and Ireland Conference, Online, May 2021.*

85. Waite, J. Mental health in Bardet-Biedl syndrome. *BBS UK Virtual Conference, Online, May 2021.*
86. Tarver, J., & Waite, J. Research into assessments and interventions for anxiety for autistic individuals who speak few or no words. *All-Island ID CAMHS Network Meeting, Online, April 2021.*
87. Jenner, L. Blog post on Down syndrome research (https://blogs.surrey.ac.uk/cogdev/2021/03/18/online-down-syndrome-research-forum-2021/). *Online Down Syndrome Research Forum, March 2021.*
88. Crawford, H. Anxiety in fragile X syndrome: A research update. *Fragile X Society Family Support Conference, Online, October 2020.*
89. Moss, J., Crawford, H., Waite, J., Groves, L., & Oliver, C. Behaviour in Cornelia de Lange syndrome: A research update. *CdLS Foundation UK and Ireland Conference, Online, October 2020.*
90. Ellis, K. & Dziwisz, M. Interview on autism, fragile X syndrome and Cornelia de Lange syndrome (https://thegoodthebadandtheugly.co.uk/dr-kat-ellis-research-on-autism-fragile-x- syndrome-and-cornelia-de-lange-syndrome/). *Virtual podcast, January 2020.*

Invited talks:

1. Waite, J. Outcome measures for anxiety, cognition and emotion. *Angelman Syndrome Scientific Conference, Coventry, England, August 2024.*
2. Moss J. Autism spectrum disorder in FASD. *Surrey and Boarders Partnership NHS Trust FASD Clinical Away Day, July 2024.*
3. Trower, H. Thinking differently about behaviour in children with intellectual disability: The checklist project. *Aston University, Birmingham, England, July 2024.*
4. Moss J. Autism in genetic syndromes: navigating the boundaries of the autism spectrum. *National Autism Conference, Oslo, Norway, June 2024.*
5. Ellis, K. Social cognitive assessment in genetic syndromes. *Wellbeing and Language Lab led by Prof Courtenay Norbury at University College, London England, May 2024.*
6. Richards, C. Behaviours that challenge in children with intellectual disability. *Keynote at Child and Adolescent Intellectual Disability Psychiatry Network Annual Conference, Coventry, England, May 2024.*
7. Trower, H. Thinking differently about behaviour in children with intellectual disability: The checklist project. *The Centre for Research in Intellectual and Developmental Disabilities (CIDD), University of Warwick, Coventry, England, May 2024*.
8. Richards, C. Understanding and preventing behaviours that challenge in children with intellectual disability. *Learning Disability, Autism & SEND Programme Conference, West Midlands, Coventry, England, March 2024.*
9. Howlin, P., Waite, J., & Roche, L. Panel Discussion: Why is it so difficult to do intervention research involving individuals with genetic conditions? *Society for the Study of Behavioural Phenotypes (SSBP), Online, September 2023.*
10. Moss, J. Understanding heterogeneity of autism in individuals with genetic syndromes associated with intellectual disability. *Autism Special Interest Group, South London and Maudsley NHS Foundation Trust, London, England, September 2023.*
11. Waite, J. Anxiety in children with severe intellectual disability. *Portsmouth NHS Trust, CAMHS-LD, Portsmouth, England, September 2023.*
12. Hughes, J., Pearson, E., & Waite, J. Anxiety in children with severe intellectual disability. *Birmingham Community Healthcare NHS Trust CPD Event, Birmingham, England, August 2023.*
13. Perry, V., Smith, K., Groves, L., & Crawford, H. The relationship between anxiety, autism characteristics, and intolerance of uncertainty in Cornelia de Lange and fragile X syndromes. *The Centre for Research in Intellectual and Developmental Disabilities (CIDD), University of Warwick, Coventry, England, August 2023.*

14. Waite, J. Mental health in people with learning disabilities, medicine and me. *Royal Society of Medicine, London, England, August 2023.*
15. Hughes, J., & Tarver, J. Assessment and intervention in autistic people: Training afternoon. *Tamworth CAMHS Team, Tamworth, England, July 2023.*
16. Hughes, J., Waite, J., & Pearson, E. Assessment and intervention in autistic people who speak few or no words: Training morning. *Nottingham CAMHS ID Team, Nottingham, England, July 2023.*
17. Moss, J. Heterogeneity of autism in genetic syndromes: Implications for assessment and support. *Newcomen Centre, Special Interest Group, Evalina's Children's Hospital NHS, London, England, July 2023.*
18. Thomas, N., Crawford, H., Dale, J., & Atherton, H. Exploration of the role of general practice in supporting the mental and physical needs of parents who care of a child or young person with intellectual disability: A mixed methods study. Cerebra Network, University of Surrey, Guildford, England, June 2023.
19. Waite, J. Supporting children who speak few or no words: Mental health and communication. *London School of Paediatrics Online Learning Webinar, June 2023.*
20. Hughes, J., & Pearson, E. LADDERS: What have we learnt from developing interventions for anxiety experienced by autistic children who speak few or no words. *Autistica Webinar Series, Online, May 2023.*
21. Hughes, J., Smith, A., & Smith, G. Mental health interventions: Why involving family members as co-researchers is essential. *Autistica Webinar Series, Online, May 2023*.
22. Hughes, J., Waite, J., & Pearson, E. Assessment and intervention in autistic people who speak few or no words: CPD Training morning. *Birmingham Community Paediatric Team, Birmingham, England, May 2023.*
23. Waite, J., Mingins, J., Hughes, J., & Pearson, E. Anxiety in people who speak Few or no words. *Autistica Webinar Series, Online, May 2023.*
24. Ellis, K. Social cognitive assessment in genetic syndromes. *Attention, Brain & Cognitive Development Lab Led by Prof Gaia Scerif at the University of Oxford, Oxford, England, April 2023.*
25. Hughes, J., Pearson, E. & Waite, J. Anxiety in children with severe int*ellectual disability. Nottingham CAMHS-LD, Nottingham, England, April 2023.*
26. Hughes, J., Waite, J., & Pearson, E. Assessment and intervention in autistic people who speak few or no words: Training morning. *Nottingham CAMHS ID Team, Nottingham, England, March 2023.*
27. Waite, J. Anxiety in autistic people who speak few or no words. N*ational Autistic Society Annual Professional's Conference, Online, March 2023.*
28. Waite., J. & Crawford, H. Rare genetic syndromes: Why mental health is everyone's responsibility. *The Unusual Suspects – Rare Disease in Everyday Medicine, Medics for Rare Diseases, Royal Society of Medicine, London, England, January 2023.*
29. Waite, J. Anxiety in rare genetic syndromes. *Chromatin Disorders Day, Pan Thames Clinical Genetics Winter School, London, England, November 2022.*
30. Crawford, H., Trower, H., & 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, London, England, October 2022.*
31. Richards, C. Sleep, pain and challenging behaviour. *Southampton Sleep Training Conference, Online, September 2022.*
32. 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, Birmingham, England, June 2022.*
33. Crawford, H., Identification of anxiety in people with intellectual disability: what does anxiety look like?. *CEDAR Seminar, University of Warwick, Coventry, England, June 2022.*
34. Crawford, H., Mental health in rare genetic syndromes. *Birmingham and Solihull Mental Health Foundation Trust Academic Meeting, June 2022.*
35. 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.*

36. Crawford, H., & 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, Guildford, England, May 2022.*
37. Crawford, H., & Smith, K. Research on anxiety in fragile X syndrome. *Fragile X Workshop, University of Oxford, Oxford, England, April 2022.*
38. Moss J. Females with FXS and the FXp. *Fragile X Research Workshop, University of Oxford, Oxford, England, April 2022.*
39. 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, Guildford, England, March 2022.*
40. 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.*
41. Moss J. Understanding atypical patterns of autism in individuals with genetic syndromes associated with intellectual disability. *CEDAR, University of Warwick, Coventry, England, February 2022.*
42. Richards, C. Self-injurious behaviour in children with intellectual disability: From research to practice. *Paediatric Mental Health Association, UK, January 2022.*
43. Bissell, S. Sleep and neurodevelopmental disorders in clinical practice: Sleep in children with tuberous sclerosis complex. *NHS Southampton Children's Sleep Disorder Service Training, Online, November 2021.*
44. Bozhilova, N. Profiles of autistic characteristics in thirteen genetic syndromes: A machine learning approach. *DevELOP Group Seminar Series, University of Surrey, Guildford, England, November 2021.*
45. Ellis, K. Online research with children with and without an intellectual disability. *Be Online Conference, Online, June 2021.*
46. Ellis K. Understanding social difficulties in boys with FXS. *Fragile X Syndrome Research Workshop, Online, June 2021.*
47. Moss, J. Autistic traits and mental health in females with the FX-p. *Fragile X Syndrome Research Workshop, Online, June 2021.*
48. 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.*
49. Richards, C. Bissell, S., & Agar, G. Sleep matters - Children with neurodevelopmental conditions. *The Association for Child and Adolescent Mental Health, Online, June 2021.*
50. Moss, J. Autism in Down syndrome: Prevalence, profile and clinical implications. *Down Syndrome Research and Education Forum, March 2021.*
51. Richards, C. Sleep in neurogenetic conditions. *University College London, London, England, March 2021.*
52. Richards, C. Sleep, measurement complexity and neurodevelopmental conditions. Institute for Mental Health, *University of Birmingham, Birmingham, England, March 2021.*
53. Jenner, L. Identifying social-cognitive mechanisms that underlie autism in genetic syndromes. *Cognition Genes & Developmental Variability (CoGDeV) Lab Meeting, University of Surrey, Guildford, England, February 2021.*
54. Jenner, L. An introduction to understanding autism in genetic syndromes. *Psychology PhD Conference, University of Surrey, Guildford, England, December 2020.*
55. Moss, J. Autistic traits and mental health in females with the fragile X premutation: maternal status vs. genetic risk. *DevELOP Group Seminar Series, University of Surrey, Guildford, England, November 2020.*
56. Richards, C. Managing behaviours in SATB2-associated syndrome. *SATB2 Gene Foundation, Online, November 2020.*
57. Richards, C. Sleep, measurement complexity and neurodevelopmental conditions. *University of Cambridge, Cambridge, England, November 2020.*

58. Richards, C. & Agar, G. Sleep and behaviour in Smith-Magenis syndrome. *Parents and Researchers Interested in Smith Magenis Syndrome Virtual Summit, Online, June 2020.*
59. Moss, J. Neurodevelopmental disorder research at the University of Surrey. *Surrey Research and Clinical Network for Neurodevelopmental Disorders Workshop, May 2020.*
60. Richards, C. Behavioural phenotypes and applied behaviour analysis of challenging behaviour. *Applied Behaviour Analysis Programme, Online, May 2020.*

Parent/Carer articles and guides:

1. Richards, C., Laverty, C., Agar, G., Marlow, K., Oliver, C & Daniels, L. (2024) Self-injury in children with intellectual disability: A Guide for Parents. *Cerebra.*
2. Waite, J. (2024). Review and update to 'Sensory Processing: A Parent Guide'. *Cerebra*.
3. 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*.
4. Moss, J., Oliver C and Ignatova, G (2022). Review and update to 'Research summary- Autism in genetic syndromes: Implications for assessment and interventions. *Cerebra.*
5. Wade, K. (2022). Review and update to 'Pain: A Parent Guide'. *Cerebra*.
6. Waite, J. (2022). Review and update to 'Anxiety: A Parent Guide'. *Cerebra*.
7. Oliver, C., Adams, D., Allen, D., Crawford, H., Heald, M., Moss, J., et al. (2021). Be-Well checklist. *Cerebra.*
8. Sutherland, D., Agar, G., & Richards, C. (2021). Weighted blankets for sleep difficulties in children with neurodevelopmental conditions: A parent guide. *Cerebra*.

7. Finance and Costs

Complete this section outlining the overall cost incurred within the research programme including salaries, supplies, travel, communications, and other expenditure.

Please see below a full budget and costings, with final underspend noted.

	Budget	Year 1 Oct 20 - Sep 21	Year 2 Oct 21 - Sep 22	Year 3 Oct 22 - Sep 23	Year 4 Oct 23 - Sep 24	Remaining
PHD	92,181.53	7,393.72	39,002.28	27,709.49	18,076.04	0.00
DA Staff	7,517.25	1,879.75	1,879.75	1,879.75	1,409.81	468.19
Research Fellow	611,462.50	80,245.15	104,595.60	133,564.51	198,153.78	94,903.46
Studentship	23,100.00	2,278.97	5,552.20	1,311.47	- 349.55	14,306.91
Running costs	94,835.00	6,349.81	13,499.46	31,492.08	19,208.91	24,284.74
Total	**829,096.28**	**98,147.40**	**164,529.29**	**195,957.30**	**236,498.99**	**133,963.30**

Comment on costs against budget for all activities, including detailed information on any shortfall in spend.

The underspend across budget lines was incurred largely through Covid-19 restrictions affecting travel, dissemination, recruitment and participant testing. Underspend was also due to changes to staffing (national furlough scheme, staff leaving posts and delays in reappointment) conferred by the Covid-19 pandemic in the first two years of the grant and due to staff maternity leave. The final underspend is consistent with the agreed resolution between Cerebra and University of Birmingham (email dated 03.06.2024 from Dr Steve Taylor). Despite the underspend on costs, our use of remote methodologies, alternative recruitment routes and online dissemination has ensured that we met all of the aims outlined in the grant.

8. Additional Comments

Please note any additional comments relating to this report or anything that has not been covered in any other section.

9. Disclaimer

PLEASE NOTE: An electronic signature is required

I certify that the statements and data included in this report are true, complete and accurate to the best of my knowledge.

Date: 22.11.24

Signature: Dr Jane Waite, Professor Caroline Richards, Dr Jo Moss & Dr Hayley Crawford