CEREBRA

Working wonders for children with brain conditions

ANNUAL PROGRESS REPORT FORM

CONTENTS

1. GENERAL INFORMATION

PROJECT TITLE
Cerebra Network for Neurodevelopmental Disorders
PRINCIPAL INVESTIGATOR (S)
Professor Caroline Richards Dr Jo Moss Dr Jane Waite Dr Hayley Crawford
ORGANISATION
University of Birmingham; University of Surrey; Aston University; University of Warwick
REPORT DATE
31/01/2024
REPORT PERIOD
09/22 - 09/23

2. BACKGROUND INFORMATION

Provide a concise summary that reviews the context and scope of the project.
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 complex needs 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 provides 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. PROGRESS SUMMARY

SUMMARY OF AIMS WITH TIMELINES FROM THE ORIGINAL PROPOSAL

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 complex needs 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.

Timelines:

We are pleased to share that in the first three years of our four-year Network grant, we have achieved significant progress. Given that the Network objectives represent the broader, integrated, and dynamic aspects of a research network, it is important to note that our original grant did not stipulate specific timelines.

Nonetheless, we have successfully initiated the development of novel tools for identification, identified mechanisms underlying clinical outcomes, and begun development and adaptation of interventions. As we enter the final year of our current funding, we are on track to refine identification tools and solidify the theoretical frameworks for modelling mechanisms. We are confident that the groundwork laid so far positions us to achieve our objectives.

In the coming months, our attention will be dedicated to gathering parent/carer feedback, fine-tuning interventions and disseminating our key findings to date. Regular updates, publications, and collaboration with stakeholders remain integral to the activities of the Network. The ongoing support from Cerebra is ensuring that we are realising the full potential of the transformative research effort of the Network going forward.

ACHIEVEMENTS DURING REPORT PERIOD

Please summarise project activity over the preceding reporting period in the context of overall progress against the current project plan. Please refer to all relevant objectives (and any that have been rolled over from previous reporting periods) and briefly comment on progress against timescale/project plan.

Through 2022 and 2023, the Cerebra Network has continued to grow and thrive, delivering on our aspiration to build capacity by training the next generation of researchers and clinicians in our field. The team has expanded further, with the Network now being 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 75 students this year. Our productivity this year is evidenced by the wide-ranging research and impact activities and achievements of the staff, students and volunteers who comprise the Network. Since September 2022 we have:

- Provided research support and training to 18 Doctoral students, 8 Masters students, 11 Clinical Psychologists in training, 26 Undergraduate dissertation students and 12 Undergraduate placement students.
- Published 15 original scientific articles in peer reviewed journals, with 12 articles currently under review and a further 25 articles currently in preparation. We have also published 2 book chapters.
- Delivered 28 presentations at national and international conferences. A further 20 invited academic and professional presentations were delivered by Network members.
- Delivered 30 presentations at public engagement events and activities and hosted 4 impact events.
- Led 5 Patient and Participant Involvement activities.
- Been awarded 2 research grants which will be supported by the infrastructure of the Network. We have also continued supporting projects on 10 previously awarded research grants. This enables us to expand the scope of research and impact activities delivered by the Cerebra Network.
- Been awarded 1 collaboration and co-production grant to provide free resources and teacher training on the Be-Well Checklist and mental health to two Special Schools.
- Delivered research-led teaching drawing on Cerebra Network research across 6 undergraduate and postgraduate Psychology modules.
- Won 6 awards/prizes by network members.
- Held 17 professional and academic committee positions.

Progress against the specific objectives continues to be excellent, with delivery on all objectives on target. Specifically, in September 2022 - September 2023 we have undertaken the following work against each objective:

1.Improved *identification:*

- Launched our novel, cross-site study BEOND (Behavioural and Emotional Outcomes in Neurodevelopmental Disorders) in which we are profiling the behavioural phenotype of children and adults with rare neurogenetic conditions. Over 380 families took part in BEOND in this reporting period and 100% of these families have agreed to be contacted about longitudinal follow ups for BEOND, demonstrating our strong partnerships with families and our potential for ongoing phenotypic profiling.
- Developed and explored novel, objective research methodologies, including promising results demonstrating that actigraphy can be harnessed to objectively measure overactivity in children with rare genetic syndromes. Actigraphy data were also compared between syndrome groups and typically-developing children, demonstrating greater activity amongst

syndrome groups during early morning hours (e.g. 2am to 5am). This study provides the first evidence that actigraphy may be sensitive to overactivity amongst children with rare genetic syndromes.

- Described subjective sleep in 201 children and 175 adults with rare genetic syndromes, including syndrome groups without existing robust descriptions of sleep.
- Described the prevalence and profile of autism in a national clinic sample of 200 people with Fetal Alcohol Spectrum Disorder. These data were contrasted with data from our legacy cross syndrome data. A Cerebra placement student and Cerebra UG dissertation student received a prestigious British Psychological Society dissertation award for this work.
- Established the principles of a collaborative database which will facilitate future analysis of the sensitivity and specificity of autism diagnostic tools for use in people with genetic syndromes.
- Evaluated the utility of eye tracking technology as a tool for assessing autism characteristics in people with intellectual disability.
- Collected data on 50 children with Bardet-Biedl syndrome and 50 autistic children, evaluating the cognitive and behavioural phenotype of children with this rare syndrome as well as carer-rated child and family quality of life.
- Evidenced anxiety markers that differentiate from autism markers in 156 autistic individuals with intellectual disability.
- Completed in-depth focus groups with clinical experts in rare syndromes to inform the adjustment of scoring algorithms on a measure of anxiety, pain and low/energy withdrawal (proxy for depression).
- Developed, piloted and refined a clinical interview to supplement data collection on mental health presentation in children and adults with moderate to severe intellectual disability, with a focus on anxiety, low mood and emotional outbursts.
- Recruited 30 individuals with fragile-X and Cornelia de Lange syndromes to a direct assessment study to validate the use of a newly developed assessment tool.
- Conducted 25 interviews with families of children with intellectual disability to further understand the presentation of separation anxiety and how this relates to genetic syndrome diagnosis.
- Described sleep objectively in a sample of 8 children with CHARGE syndrome using our actigraphy paradigms - this is the first objective study of sleep in CHARGE syndrome conducted internationally.
- Described sleep objectively through actigraphy in a sample of 30 autistic children with co-occurring intellectual disability.
- Described the presence and phenomenology of self-restraint in over 130 autistic children with an intellectual disability. Findings revealed that the overwhelming majority of the sample (96%) showed some form of self-restraint.

2. *Model* mechanism:

- Collected data through BEOND that supports well-powered complex statistical modelling of the interactions between sleep and aspects of behaviour, physical health, mental health. Critically, this work is pre-registered to improve the quality of our scientific approach (OSF pre-registration) and to enhance replicability.
- Examined data from BEOND to identify distinct social profiles in fragile-X syndrome and Rubinstein-Taybi syndrome and examined associations with specific anxiety symptomatology.
- Further extrapolated the pathways to behaviours that challenge in SATB2-associated syndrome, with a focus on anxiety and cognitive characteristics (N = 37).
- Conducted the first study to use qualitative interviews with autistic young people to explore their experiences of mental health difficulties and self-harm. Key themes included the addictive nature of self-harm, difficulties with understanding and regulating emotions, the impact of late diagnosis and the need for tailored mental health intervention.

- Completed data collection using novel eye tracking technology and observational tasks to evaluate social cognitive abilities in participants with Down syndrome (n=36), Prader Willi syndrome (n=34) and autistic participants (n=22).
- Developed and piloted novel paradigms which evaluate the cognitive correlates of anxiety in people with intellectual disability and collected data on participants with Cornelia de Lange syndrome (n=17), neurotypical children (n=20) and autistic children (n=15).
- Analysed novel eye tracking data evaluating core social-cognitive abilities in 90 children with Cornelia de Lange syndrome, fragile X syndrome, autism and neurotypical children.
- Collected data through BEOND which will support analysis of the association between autism and anxiety in people with Cornelia de Lange syndrome and autistic individuals.
- Collected novel, remote executive functioning data from a final sample of 27 autistic children with intellectual disability, to facilitate modelling of the contribution of cognitive characteristics to the presence and severity of self-injurious behaviour (Sleep-Impulsivity-Behaviour study). The novel methodology highlighted the feasibility of remote executive function assessment in children with intellectual disability who are often excluded from this type of psychological research.

3. Develop *interventions*:

- We delivered 37 intervention workshops to 72 families as part of the iKNOW (Identifying and Knowing about Behaviour) study. These intervention workshops were conducted in the NHS and co-led by NHS clinicians, representing a significant translation into practice for our novel, risk-informed early intervention programme.
- Conducted in-depth focus groups with researchers and clinicians to inform the adaptation of the LADDERS anxiety intervention for individuals with rare genetic syndromes.

4. *Translate* knowledge into practice:

- Developed four service-wide educational events within the NHS to raise awareness of bespoke anxiety interventions developed within the Cerebra Network.
- Launched an online teacher training resource to support education practitioners working with children with rare genetic syndromes. Since its launch, more than 330 people have registered to use the resource from across ten different countries.
- Organised and hosted a one-day impact event on 'Self-injury in children with intellectual disability: From research to practice' for over 75 clinicians, teachers, researchers and professionals. We shared new findings from our Sleep-Impulsivity-Behaviour study. Attendees praised the expertise of presenters, the breadth of information presented and the transferability of findings for practice.

OBJECTIVE(S)/TASK(S) TO BE COMPLETED UNTIL THE END OF THE GRANT PERIOD WITH TIMELINES

Please make it clear whether objective(s)/task(s) are on track or falling behind schedule. If you feel it would be helpful, please include a Gantt chart that clearly shows any delays.

1. Completion of PhD research programmes across Network sites. *On track.*
2. Completion of first wave of BEOND data collection and analysis. *On track.*
3. Dissemination of research findings to academic and non-academic audiences. *On track.*
4. Completion of summer studentships and training of students at each site. *On track.*
5. Undertaking novel, empirical psychological research at each site focused on anxiety, sleep, behaviour and autism in rare and complex conditions to achieve each of the four Network objectives. *On track.*

ANY ISSUES OF CONCERN (ONGOING PROBLEMS) AND/OR ANTICIPATED DELAYS

Please provide a full account of any challenges affecting your project and how you are working to overcome these. Do you anticipate that the project will provide all outcomes as set out in your proposal at completion? If not, please explain what will be missing, and why.

Despite most universities now returning to normal following the COVID-19 pandemic, research continues to be impacted by the long-term effects of the pandemic. Within the Cerebra Network, research studies were protected by adapting study designs to accommodate remote methodologies. Researchers have navigated challenges such as shipping and waiting for equipment to be returned, and the inevitable delays surrounding this. While remote methods do present limitations, they have allowed research to persist amidst the evolving landscape

In alignment with the broader trends observed in research nationwide, while recruitment efforts are gradually recovering, they have not yet reached pre-pandemic levels. This reflects the impact of reduced support for families of children with complex needs during the pandemic. Many families continue to face challenges in accessing the necessary assistance due to increased strain on services post-pandemic. This reduction in support is likely affecting recruitment as some families struggle to have capacity currently to participate in research.

As we address these challenges, working closely with syndrome support charities and NHS sites to do so, the resilience of researchers and the potential for positive change underscore the importance of our shared commitment to advancing knowledge and supporting families.

CHANGES TO PROJECT

Please outline any key changes to your project (project design/methodology, management plan, project staff etc.) since your last report.

No key changes to note.

KEY FINDINGS

Please outline any key findings highlighting the importance of this research and its implications for the health outcomes and wellbeing of children living with brain conditions during the reporting period.

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. Key findings are organised against each of the Network's four core objectives. A full list of outputs, including manuscripts currently in preparation are listed on page 17.

1. ***Improved Identification:***

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. Published in *Sleep Medicine Reviews.* https://doi.org/10.1016/j.smrv.2023.101814

This systematic review and meta-analysis examined the properties of sleep measures in children with neurodevelopmental conditions, using data from 30 previous studies. The findings demonstrated greater agreement between objective and subjective measures for sleep parameters associated with sleep scheduling, relative to parameters associated with sleep duration and night awakenings. Characteristics associated with specific neurodevelopmental conditions may also affect how sleep measures quantify sleep. These results should inform sleep assessment strategies for children with neurodevelopmental conditions throughout research and clinical settings.

Newell, V., Phillips, L., Jones, C., Townsend, E., Richards, C., & Cassidy, S. (2023). A systematic review and meta-analysis of suicidality in autistic and possibly autistic people without co-occurring intellectual disability. *Molecular Autism*, *14*(1), 1-37. https://doi.org/10.1186/s13229-023-00544-7

In this meta-analytic study we calculated pooled prevalence estimates of suicidality and suicidal behaviours from existing research, for autistic people without intellectual disabilities. Data from 48,186 autistic and possibly autistic participants in 36 primary studies were meta-analysed. Pooled prevalence of suicidal ideation was 34.2%, suicide plans 21.9%, and suicidal attempts and behaviours 24.3%. Geographical location, transgender or gender non-conforming samples and type of report significantly moderated suicidal ideation, whereas age group and measure of suicidality significantly moderated suicide plans. There was a significant association between the proportion of male participants and prevalence of suicide plans, with a decrease in the proportion of males for every unit change of suicide plan prevalence. These findings have been cited in a recent NHS report: *Meeting the needs of autistic adults in mental health services.*

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*. https://doi.org/10.1007/s40474-023-00276-6

This paper provides an updated review of autism in genetic syndromes for an academic and professional audience. The review identifies genetic syndromes that are most commonly associated with autism and outlines key conceptual and clinical implications of work in the field to date. This review informs the practice of clinicians and highlights priorities for future research.

Jenner L., Farran, E.K., Welham, A., Jones, C., & Moss, J. (2023): The use of eye-tracking technology as a tool to *evaluate social cognition in intellectual disability: A systematic review and meta-analysis. Published in: Journal of Neurodevelopmental Disorders.*
https://doi.org/10.1186/s11689-023-09506-9

This systematic review evaluated findings from 49 published studies of various non-syndromic and syndromic groups with intellectual disability. A meta-analysis demonstrated a significant correlation between reduced visual attention to socially salient regions of the stimuli and greater severity of autism characteristics across selected studies. The findings highlight the utility of eye-tracking methodology to evaluate social cognitive abilities in people with intellectual disability.

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. (In review). Identifying Autism Characteristics in Genetic Syndromes; A comparison of the Social Communication Questionnaire and the Autism Diagnostic Observation Schedule. Submitted to: *Journal of Clinical Psychology.*

Using archival data (n=268), identification of autism spectrum characteristics by two measures was compared in five genetic syndrome groups. Results indicated acceptable agreement between the SCQ and ADOS, although this was comparatively reduced relative to that reported in non-syndromic autism samples. Only small improvements in sensitivity and specificity were achieved at alternative cut-off points. Analyses suggested uneven test performance across the different syndromes, suggesting that autism screening instruments may perform less well in specific genetic syndromes in which autism characteristics are common.

Mingins, J. E., Tarver, J., Pearson, E., Edwards, G., Bird, M., Crawford, H., Oliver, C., & Waite, J. (In Review). Development and Psychometric Properties of the Clinical Anxiety Scale for People with Intellectual Disabilities.

The study addresses the need for reliable anxiety assessment tools for individuals with moderate to severe intellectual disabilities, especially those with limited communication skills. The Clinical Anxiety Scale for People with Intellectual Disabilities was developed through a comprehensive process involving literature reviews, existing tool analysis, and clinician/parent interviews. The

questionnaire, completed by 311 parents/caregivers, demonstrates a four-factor structure covering anxiety, pain, low energy/withdrawal, and consolability. The anxiety factor exhibits the highest variance (26.3%) and shows robust psychometric attributes, including internal consistency, validity, test-retest reliability, and inter-rater reliability. The scale proves effective across diverse diagnostic groups, communication abilities and age ranges, making it a promising tool for assessing anxiety in individuals with moderate to severe intellectual disabilities.

Shelley, L., Jones, C., Pearson, E., Tarver, J., Richards, C., Crawford, H., Paricos, A., Greenhill, C., Woodhead, A., & Waite, J. (In review). Measures of behaviours that challenge and behavioural function in people with intellectual disability: A systematic review and meta-analysis of internal consistency, inter-rater reliability, and test-retest reliability.

This study is the first to comprehensively synthesise existing literature on the internal consistency, inter-rater reliability, and test-retest reliability of measures assessing behaviours that challenge and behavioural function in individuals with intellectual disabilities. This is essential as these measures are often employed in studies where we are examining associations between behaviour, autism, anxiety and sleep. The research evaluates the quality of evidence and considers the impact of study characteristics and biases on measurement properties. The findings highlight significant variability among measures and propose candidate measures based on current evidence. The study emphasises the need for ongoing research to examine measurement properties in intellectual disability populations. Additionally, it offers recommendations for future studies to enhance methodological quality, transparency and interpretability of findings, aiming to guide the selection of suitable and robust measures in specific settings.

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.

In this work we present the first, longitudinal objective study of sleep in children with Smith-Magenis syndrome. This work was only possible due to the continued funding of Cerebra which allowed Cerebra-funded PhD student, Georgie Agar (now a member of staff, Aston University) to follow up children recruited three years previously by Cerebra-funded PhD student, Jayne Trickett. Week-long, overnight actigraphy and questionnaire data from 13 children with Smith-Magenis syndrome and 13 age-matched typically developing children were collected at Time 1 and Time 2. Sleep parameters were found to be more disrupted in the Smith-Magenis group than the typically developing group, with significantly reduced sleep efficiency, increased wake after sleep onset and earlier get up times at both time points. This was mirrored in the questionnaire data. While typically developing sleep parameters demonstrated expected developmental changes over three years, in the Smith-Magenis syndrome group sleep parameters and variability between and within children remained largely stable.

2. Model mechanism:

Ellis K., White, S., Dziwisz, M., Agarwal, P., & Moss, J. (In review). Visual attention patterns during gaze following in neurogenetic syndromes: Cornelia de Lange and fragile X syndrome. Submitted to: *Cortex*.

Participants with CdLS and FXS, and autistic and neurotypical children participated in this study. Children with FXS showed similar gaze following abilities compared to neurotypical children but looked at the target object for comparatively less time, indicating reduced understanding of communicative intent. Both neurotypical children and children with CdLS frequently looked at the eye region, but children with CdLS were less likely to evidence gaze following abilities. Findings provide preliminary evidence of unique patterns of visual attention and gaze following strategies in children with CdLS, FXS and autistic children, which may underpin the distinct profiles of social and communication autistic traits observed between these groups.

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

SATB2-associated syndrome (SAS) is a genetic condition linked to intellectual disability and communication difficulties. Behaviours that challenge such as self-injury, aggression, and property destruction are prevalent in individuals with SAS. Parents/caregivers (N = 81) completed psychometrically robust questionnaires to examine correlates of these behaviours. Findings showed varying characteristics associated with each behaviour. Logistic regression models reveal significant correlates for self-injury, aggression, and property destruction, emphasising the need for specificity in understanding and addressing these behaviours in SAS. Correlates of significance included health difficulties, autism characteristics, impulsivity and higher levels of obsessive-compulsive, hyperactive and general anxiety characteristics. The study contributes valuable insights for tailored behavioural interventions in SAS.

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

In this study we explored the relationship between sleep and neurodevelopmental characteristics on quality of life in children with epilepsy. 36 children with epilepsy, aged 4–16 years old were recruited from two hospitals and asked to wear an actiwatch for a period of 14 days and caregivers completed a series of questionnaires assessing co-occurrences and epilepsy-specific variables. A high proportion of children with epilepsy (78.13%) presented significant sleep problems. Informant-reported sleep problems were significantly predictive of quality of life, above seizure severity and the number of antiseizure medications. Interestingly, informant-reported sleep problems were no longer significantly predictive of quality of life when neurodevelopmental characteristics were considered, indicating a possible mediating effect. Similarly, actigraphy-defined sleep (variability in sleep onset latency) displayed a similar effect but only for ADHD characteristics, whereas autistic characteristics and variability in sleep onset latency continued to exert an individual effect on quality of life.

Crawford, H., Oliver, C., Groves, L., Bradley, L., Smith, K., Hogan, A., Renshaw, D., Waite, J. & Roberts, J. (2023). Behavioural and physiological indicators of anxiety reflect shared and distinct profiles across individuals with neurogenetic syndromes. *Psychiatry Research*, 115278. https://doi.org/10.1016/j.psychres.2023.115278

Individuals with intellectual disabilities, particularly those with specific neurogenetic syndromes, experience heightened anxiety. The assessment of anxiety is hindered by a lack of suitable measures for communication impairment and overlapping features with co-occurring conditions. Using a multi-method approach, this study examined anxiety responses in individuals with fragile X syndrome (FXS: N = 27) and Cornelia de Lange syndrome (CdLS: N = 27), both at high risk for anxiety, compared to neurotypical children (N = 21). Results reveal prominent behavioural indicators such as physical avoidance and proximity seeking in FXS and CdLS, along with heightened physiological arousal measured by salivary cortisol. The FXS group showed an association between autistic characteristics and anxiety, emphasising syndrome-specific nuances in the anxiety-autism relationship. This research enhances comprehension of anxiety in individuals with intellectual disabilities and contributes to theoretical advancements in understanding anxiety and autism.

3. Intervention:

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, 13623613231196084. https://doi.org/10.1177/13623613231196084

Autistic individuals with intellectual disabilities, especially when compared to non-autistic peers

without intellectual disabilities, face a higher risk of anxiety. This anxiety often presents as challenging behaviours, prompting families to seek support services. However, caregivers encounter difficulties accessing services, compounded by a lack of research on evidence-based anxiety interventions for this population. This study applied novel participatory methods with experts by experience supporting the analysis of interview data. Caregivers' experiences of service access were explored along with considerations for developing interventions. Caregivers expressed dissatisfaction with service access, emphasising the need for flexibility in interventions to accommodate diverse family circumstances. They highlighted embedding peer support in services and developing skills applicable across the lifespan as essential considerations for improving outcomes in this underserved population.

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

People with intellectual disability show a high prevalence of behaviours that challenge. Clinical guidelines recommend that such behaviour should first be treated with non-pharmacological interventions, but research suggests off-label pharmaceuticals are commonly used. In this meta-analysis we evaluated the efficacy of non-pharmacological and pharmacological interventions for behaviours that challenge drawn from randomised controlled trials (RCTs). Across all studies, 4637 people with intellectual disability aged 1–84 years (mean age 17.2 years) were included. Small intervention effects were found for behaviours that challenge at post-intervention, behaviours that challenge at follow-up, self-injury at post-intervention, aggression at post-intervention and irritability at post-intervention. No significant differences between non-pharmacological and pharmacological interventions were found for any behaviours that challenge. Our work suggests that a broad range of interventions for behaviours that challenge are efficacious with small effect sizes for people with intellectual disability. These findings highlight the importance of precision in the measurement of behaviours that challenge, and when operationalising intervention components and dosages.

IMPACT

Please describe the anticipated impact from your study and any impact realised during the report period. Examples could include (but are not limited to) research recommendations, influence on policy, changes in practice/behaviour.

All work conducted by the Cerebra Network to date has been informed by parents, carers and people with a range of neurodevelopmental conditions. Through funding from Cerebra, which supports the infrastructure of the Network, along with our highly collaborative approach to research, we will achieve our goal of improving outcomes of children with rare and complex conditions associated with intellectual disability and/or autism. Between September 2022 and September 2023, we have continued to work directly with a wide range of charity partners and academic and non-academic beneficiaries to disseminate our research findings at conferences and events in the UK and internationally.

Over the last year, the following impact events were organised and hosted by the Cerebra Network:

- In May 2023, Network members at the University of Warwick hosted a **research and networking workshop** on anxiety in rare genetic syndromes. A key aim of the workshop was to discuss and refine research methodology in terms of identifying, modelling, and developing interventions for anxiety in people with rare genetic syndromes. The workshop was attended by over 20 delegates from 5 different institutions.

- In March 2023, Network members at the University of Birmingham hosted an impact event- **Self-injury in children with intellectual disability: From research to practice**- as part of the final phase of the SIB study. Over 75 clinicians, teachers, researchers and professionals in relevant fields attended for a one-day event consisting of presentations from experts in the field of self-injury, sleep and child development. The team received excellent feedback following the event, with all attendees who completed the feedback form rating their knowledge of both self-injury and sleep as higher than before attending the event. Additionally, attendees praised the expertise of presenters, the breadth of information presented and the transferability of findings for practice.

- In March 2023, Network members at the University of Surrey hosted an event to **launch our newly developed teacher training resource: www.findteacherresources.co.uk.** More than 160 professionals, academics and education practitioners registered to attend this online event which consisted of a presentation from Senior Educational Psychologist and project collaborator Dr Laura Wilby as well as presentations from researchers and a demonstration of the resource content. Since the event, over 330 people have registered to use the resource across ten countries. 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".

- In January 2023, Network members at the University of Surrey hosted a **research and networking workshop** on Fetal Alcohol Spectrum Disorder. A key aim of the workshop was to expand the UK FASD research network by facilitating new collaborations. We invited both experts in the field as well as those not currently working in the field but whose skills and interests would be beneficial to the FASD research community. The workshop was attended by 40 delegates from a range of disciplines (e.g. psychology, public health, criminal justice, genetics, pharmacy, neonatal health, mental health) and professions (e.g. researchers, clinical psychologists, consultant doctors, psychiatrists) from 15 institutions. Through a post-workshop survey, delegates commented on the benefits of "networking and exploring of current and future research directions" and the "shared learning with people outside of the field". Critically, 71% of respondents stated that they intended to develop a new FASD focused research project after their involvement in the workshop.

Improved practice within NHS services:

- In March through to September 2023, Network members at Aston University developed and delivered a series of four **half-day training workshops on anxiety in severe intellectual disability to mental health professionals and paediatricians** across Nottingham Healthcare NHS Foundation Trust, Birmingham Community Healthcare Trust, and Solent NHS Trust. These workshops equip frontline mental health professionals with cutting-edge knowledge of assessments and interventions developed within the Cerebra Network, so that these can be integrated into clinical practice. These Trusts serve large geographical areas including the West Midlands, Nottinghamshire, Leicestershire, Lincolnshire, South Yorkshire, Portsmouth, Southampton, Hampshire and the Isle of Wight. Feedback from an attendee was very positive indicating the importance and impact of our work: "It is a good intervention for us to offer as a service. We get a lot of referrals for children with anxiety and due to their level of intellectual disability direct work [talking therapy] would be inappropriate, the intervention has filled that void". And the following quote captures feedback on early implementation: "The manuals have been extremely helpful with structuring the appointments. I did not feel that I needed lots of time for prep as all the information I needed was there. I completed the intervention with one parent and it has

been successful as the young person is now able to access places in the community. Which is amazing as at the start of the intervention the young person and family were extremely isolated." (Clinical Nurse Specialist, CAMHS-LD, Nottingham).

Individualised consultation clinics:

- Apart from workshops, talks and training events, the Cerebra Network has hosted six consultation clinics for families of children with rare syndromes in 2023, delivered in both face to face and virtual formats. These are delivered by the HCPC registered Clinical Psychologists within the Network (Waite, Richards). For example, the Rubinstein-Taybi syndrome virtual clinic that ran on three days in July and September 2023. These virtual consultations reach families from diverse geographical locations, particularly those who are not able to travel to the syndrome support days, giving individual time to each family. The consultations provide a forum for information sharing about key behavioural and emotional characteristics associated with genetic syndrome and for signposting to evidence-based resources and services.

Integrating into rare syndrome clinics to fill the gap between research and practice:

- Dr. Waite (Aston) maintains her joint appointment at the Queen Elizabeth Hospital, actively contributing to the national Bardet-Biedl syndrome clinic, which serves 400 individuals. The efficiency of this model allows her to incorporate peer-reviewed research findings arising from the Network into the multidisciplinary service, thereby enhancing support for individuals with Bardet-Biedl syndrome. Building on the positive outcomes of this approach, discussions were initiated in 2023 with Manchester University Foundation NHS Trust to explore the possibility of contributing to the Angelman syndrome clinic in Manchester. We are delighted to confirm that the Trust has recently approved the plan, and the integration of a Network clinician into this service is scheduled to commence in 2024.

International consensus guidelines for rare genetic syndromes:

- As a direct result of the Network's esteemed international research reputation, researchers within the Network are actively contributing to the development of international clinical consensus during this funding period. This collaborative effort aims to translate research knowledge into practical applications. Given the clinical importance of these guidelines, the process typically spans several months, involving multiple drafts as consensus is achieved. While the impact is evident in the early stages, we are pleased to report that this engagement provides a significant avenue for the Cerebra Network to realise substantial future impact with support from Cerebra. We are currently engaged with working groups composing consensus guidelines for Williams, Rubinstein-Taybi, Kleefstra, SATB2-associated syndrome and Wiedemann Steiner syndromes.

Feedback Reports:

- Consistent with the standard practice throughout all Cerebra Network research projects since the inception of our research programme, personalised feedback reports are sent to families, providing a comprehensive overview of their child's behavioural, emotional, and social characteristics. In the current period, we have successfully distributed over 189 feedback reports.

New look Further Inform Neurodevelopmental Disorders:

- We are working in collaboration with web developers to craft and enhance the new Further-Inform Neurogenetic Disorders website, badged by Cerebra. Progress on this project is underway, promising a contemporary, user-friendly experience seamlessly integrated with current operating systems. The revamped site will spotlight the assessment manuals, measures, and intervention protocols developed by the Network, while continuing to emphasise our commitment to family support through concise, informative summaries. In the meantime, the existing FIND website continues to operate with over 1300 clinicians, educators and researchers registered for updates on our resources.

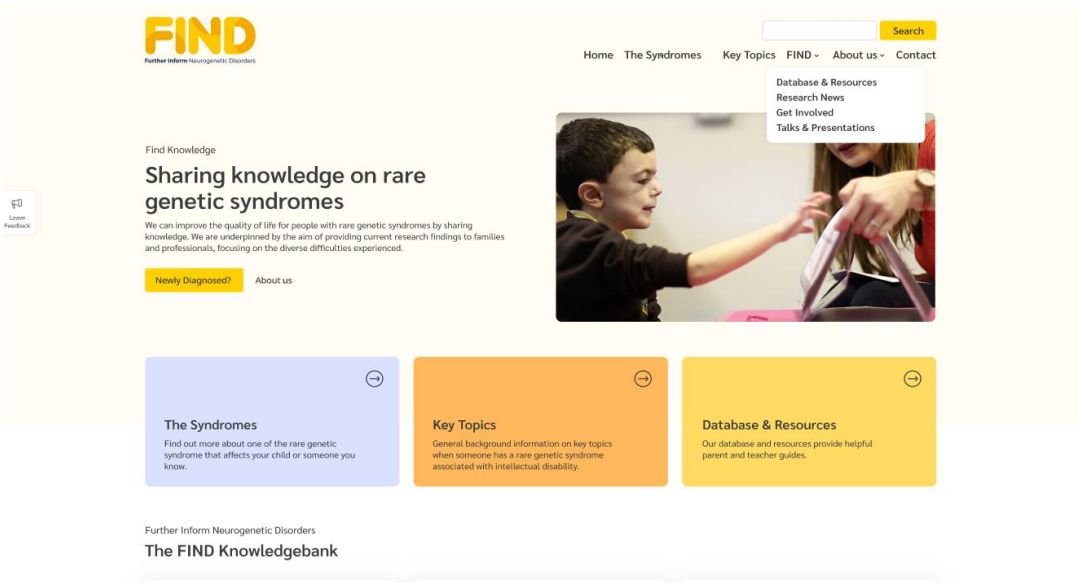

Image: Proofs of the new, enhanced FIND website

4. PLAIN ENGLISH SUMMARY

Please also provide a progress summary in lay terms (avoiding scientific jargon where possible) including any impact realised during the report period.

The Cerebra Network has continued to grow, progress, and expand in the third year of this four-year Network grant, working closely with parents, carers, and people with a range of neurodevelopmental conditions to inform our work. This year, the Network team has been supported by 25 members of staff, with the core team supervising, supporting, and training over 75 students. Across the Network, each of the four institutions leads on extensive work into autism, sleep, and mental health with a shared focus on behaviour, which we know from our previous research 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 Network, we are uniquely placed to be able to address a number of key challenges and to improve the evidence that underpins assessment and intervention.

Specifically, inadequate identification of autism, sleep problems, and mental health conditions presents a barrier to clinical diagnosis and access to relevant services. We are developing tools to improve identification and overcome these barriers. We are also developing models that indicate precise mechanisms that give rise to clinical presentations of autism, sleep disorders, and mental health conditions. This work leads us to the third key challenge - to develop and pilot interventions. We are committed to improving long-term outcomes for people with genetic syndromes associated with intellectual disability and/or autism. We do this by ensuring that meaningful 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.

We have made excellent progress on these Network objectives and our identified objectives are on track for delivery. In the current period, the Network has published 15 original scientific articles and 2 book chapters, and delivered 28 presentations at national and international conferences. Over 380 families took part in the BEOND (Behavioural and Emotional Outcomes in Neurodevelopmental Disorders) study, where 100% of families also agreed to be contacted for follow-up in the future. This will support our aim of improved identification. Progress was made on modelling mechanisms, for example, by identifying distinct social profiles in fragile-X syndrome and Rubinstein-Taybi syndrome allowing us to explore associations with specific anxiety symptoms. Interventions were implemented, adapted and refined, for example, by holding in-depth focus groups with researchers and clinicians to guide the adaptation of the LADDERS anxiety intervention for individuals with rare genetic syndromes.

We are proud to have delivered 30 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 continued our work with NHS services, 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. As in previous years, we have continued to send

personalised feedback reports to families who take part in our research, with 189 feedback reports distributed this year.

In the final year of this four-year grant, we look forward to completing our remaining objectives as outlined and will be focusing on gathering parent/carer feedback, refining identification tools, furthering developing causal models that help us to understand the processes that may underlie syndrome associated presentations and adapting interventions. In addition, 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.

5. PUBLIC INVOLVEMENT

Please describe the ways in which patients and the public have been actively involved in this research over the reporting period, including any training and support provided. How has their involvement informed and/or influenced the project?

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

- Denise Bain and Lauren Walters presented on the feasibility of the iKNOW preventive intervention programme for individuals at Clinical High Risk for Behaviours that Challenge to Occupational Therapists in the Birmingham Community Healthcare Trust, gathering feedback from these clinicians to inform future development of the intervention.
- Denise Bain and Lauren Walters presented on the feasibility of the iKNOW preventive intervention programme for individuals at Clinical High Risk for Behaviours that Challenge at the Birmingham Community Healthcare Trust Children and families division AHP day celebration. Researchers from the Network also had a stall and the opportunity to discuss iKNOW with multidisciplinary practitioners in the trust. Again, feedback from these stakeholder groups is being used to refine the iKNOW intervention.
- We have worked with a core group of families who form our Cerebra Network PPI group to gather feedback and enhance our approach to research feedback reports. They have informed the design, content and interpretation of our new-look BEOND study feedback reports, to ensure the feedback is as meaningful and accessible for families as possible.
- Hayley Trower and the team at the Warwick site are continuing to collaborate with academics, clinicians, and families throughout the development of the Behaviour Checklist.
- Lucy Heap (RA) and Kat Ellis (post-doc) conducted focus groups with 20 carers of people with FASD to identify the key priorities of individuals with FASD and their families, with a particular focus on the impacts of social competencies on day-to-day life experiences and wellbeing.

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 fueled 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 2022:

1. 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
2. Crawford H. (2023). Social Anxiety in Neurodevelopmental Disorders: The Case of Fragile X Syndrome. *American Journal on Intellectual and Developmental Disabilities, 128*(4), 302–318. https://doi.org/10.1352/1944-7558-128.4.302
3. Crawford, H., Oliver, C., Groves, L., Bradley, L., Smith, K., Hogan, A., Renshaw, D., Waite, J., & Roberts, J. (2023). Behavioural and physiological indicators of anxiety reflect shared and distinct profiles across individuals with neurogenetic syndromes. *Psychiatry Research, 326*, 115278. https://doi.org/10.1016/j.psychres.2023.115278
4. 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.
5. Hughes, J., Roberts, R., Tarver, J., Waters-Louth, C., Zhang, B., Southward, E., Shaw, R., Edwards, G., 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.* https://doi.org/10.1177/13623613231196084
6. Jenner, L., Farran, E.K., Welham, A., Jones, C., & Moss., J. (2023). The use of eye-tracking technology as a tool to evaluate social cognition in intellectual disability: a systematic review and meta-analysis. *Journal of Neurodevelopmental Disorders, 15*(1), 42. https://doi.org/10.1186/s11689-023-09506-9
7. 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*(2), 132-146. https://doi.org/10.1007/s40474-023-00276-6
8. Martin, J. A., Robertson, K., Richards, C., Scerif, G., Baker, K., & Tye, C. (2023). Experiences of parents of children with rare neurogenetic conditions during the COVID-19 pandemic: an interpretative phenomenological analysis. *BMC Psychology*, *11*(1), 1-14. https://doi.org/10.1186/s40359-023-01205-3.
9. Newell, V., Phillips, L., Jones, C., Townsend, E., Richards, C., & Cassidy, S. (2023). A systematic review and meta-analysis of suicidality in autistic and possibly autistic people without co-occurring intellectual disability. *Molecular autism*, *14*(1), 1-37. https://doi.org/10.1186/s13229-023-00544-7.

10. 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.
11. Pelton, M. K., Crawford, H., Bul, K., Robertson, A. E., Adams, J., de Beurs, D., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2023). The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: A theory-driven network analysis. *Suicide & life-threatening behavior, 53*(3), 426–442. https://doi.org/10.1111/sltb.12954
12. 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.
13. Taylor, E. L., Thompson, P. A., Manktelow, N., Flynn, S., Gillespie, D., Bradshaw, J., ... & Hastings, R. P. (2023). Mapping and identifying service models for community-based services for children with intellectual disabilities and behaviours that challenge in England. *BMC Health Services Research*, *23*(1), 1354. https://doi.org/10.1186/s12913-023-10388-9.
14. Thomas, N., Atherton, H., Dale, J., Smith, K., & Crawford, H. (2023). General practice experiences for parents of children with intellectual disability: a systematic review. *BJGP Open, 7*(3), BJGPO.2023.0010. https://doi.org/10.3399/BJGPO.2023.0010
15. 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.

Book chapters published since 2022:

1. Ellis, K., Pearson, E., Murray, C., Jenner, L., Bissell, S., … & 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
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.

Journal Articles Currently Under Peer Review:

1. Ellis, K., White, S., Dziwisz, M., Agarwal, P., & Moss, J. (under review). Visual attention patterns during gaze following in neurogenetic syndromes: Cornelia de
2. 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. *Journal of Clinical Psychology.*
3. Junges, L., Galvis, D., Richards, C., Bagshaw, A., Windsor, A., Treadwell, G., Johnson, S & Terry, J. The impact of paediatric epilepsy and co-occurring neurodevelopmental disorders on functional brain networks in wake and sleep. *PLOS One.*
4. Lacombe, D., Bloch-Zupan, A., Bredrup, C., Cooper, E., Douzgou, S., Minaur S. G., et al. (In Review). Diagnosis and Management in Rubinstein-Taybi Syndrome: First International

Consensus Statement. *American Journal of Medical Genetics: Part 2*
Lange and fragile X syndrome. *Cortex [for special issue 'Neurodevelopmental Neurodiversity']*. Preprint here: https://osf.io/preprints/psyarxiv/2aehp

5. Laverty, C., Surtees, A. & Richards, C. (In review). A qualitative interview with mothers of moderately or late preterm infants; Where are the care gaps. *BMJ Open.*
6. Marlow, K., Devine, R. & Richards, C. (In review). Self-restraint in autistic people and people with intellectual disability: a systematic review and meta-analysis. *Review Journal of Autism and Developmental Disorders*
7. Mingins, J., Tarver, J., Pearson, E., Edwards, G., Bird, M., Crawford, H., Oliver, C., Shelley, L., & Waite, J. (In review). Development and Psychometric Properties of the Clinical Anxiety Scale for People with Intellectual Disabilities (ClASP-ID). *Journal of Neurodevelopmental Disorders.*
8. Newell, V., Richards, C., Cassidy, S. & Townsend, E. (In Review) A COSMIN review of measures of self-harm for autistic people. *Clinical Psychology Reviews*
9. O'Sullivan, R., Bissell, S., Agar, G., Spiller, J., Surtees, A., Heald, M., ... & Richards, C. (In review). Exploring objective measures of overactivity in children with rare genetic syndromes. *Journal of Neurodevelopmental Disorders.*
10. Perry, V., Smith, K., Groves, L., Moss, J, Oliver, C., Knight E. Patterson, T., Rodgers, J., Waite, J., & Crawford, H. (In Review). Contrasting relationships between anxiety and intolerance of uncertainty in Cornelia de Lange and fragile X syndromes. *Journal of Autism and Developmental Disorders.*
11. Shelley, L., Jones, C., Pearson, E., Tarver, J., Richards, C., Crawford, H., Paricos, A., Greenhill, C., Woodhead, A., & Waite, J. (In review). Measures of behaviours that challenge and behavioural function in people with intellectual disability: A systematic review and meta-analysis of internal consistency, inter-rater reliability and test-retest reliability. *Clinical Psychology Review.*
12. 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., 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. Edwards, G., Tarver, J., Oliver, C., & Waite, J. Identifying correlates of anxiety in children and adults with moderate-profound intellectual disability: A questionnaire study.
6. 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.
7. 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.
8. Jenner, L., Farran, E.K., Ellis, K., White, S., & Moss, J. An Eye-Tracking Study of Spontaneous Gaze- Following In Down Syndrome, Prader-Willi Syndrome, And Non- Syndromic Autism.
9. 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?
10. 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.

11. 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
12. 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.
13. Licence, L., Martlew, R., Cook, J., Jones, C., & Richards, C. The Prevalence, Profile and Risk-Markers of Self-Harm in Autistic Individuals without Intellectual Disability: A Systematic Review and Meta-Analysis.
14. Martlew, R., Bremner, A., & Richards, C. The Prevalence and Profile of Repetitive Behaviours in Children with Neurodevelopmental Conditions: A Meta-Analysis.
15. Moss, J., Deeprose, L, Mukherjee, R., Carlisle, A., Ellis, K., Farran, E. and Mukherjee R. Prevalence and profile of autism characteristics in a Fetal Alcohol Spectrum Disorder clinic sample.
16. Pearson, E., Hughes, J., Tarver, J., Waite, J. A parent-led anxiety intervention for autistic children who speak few or no words.
17. Roberts, R., Shelley, L., Kutsch, A., Crawford, H., Oliver, C., & Waite, J. Brief report: The function of behaviours that challenge in Lowe syndrome.
18. Shelley, L., Tarver, J., Richards, C., Crawford, H., & Waite, J. Cognitive difference, responses to uncertainty and behaviours that challenge in SATB2-associated syndrome.
19. Shelley, L., Tarver, J., Richards, C., Crawford, H., & Waite, J. Using interview methodology to inform understanding of behaviours that challenge in SATB2-associated syndrome.
20. Trower, H., Bull, L., Gray, K., Liew, A., Oliver, C., & Crawford, H. Using patient and public involvement to co-produce a clinical behaviour checklist for parent/carers of children with intellectual disability and complex needs.
21. Trower, H., Bull, L., Gray, K., Liew, A., Oliver, C., & Crawford, H. The Behaviour Checklist: Understanding and monitoring the causes of behaviours of concern in children with moderate-profound intellectual disability and complex needs.
22. Trower, H., Wade, K., and Crawford, H. Physical health problems in neurogenetic syndromes: A cross syndrome analysis.
23. Waite, Powis, Beck & Oliver, C. Developmental trajectories of inhibition and task-switching in individuals with Rubinstein-Taybi syndrome.
24. 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
25. Watkins, A., Bissell, S., Martlew, R., Liew, A. & Richards, C. Prevalence of epilepsy in individuals with genetic syndromes associated with intellectual disability: a meta-analysis.

Professional and other non-academic articles and outputs

1. Lucy Deeprose (In Press). The Profile of Autism Characteristics in Fetal Alcohol Spectrum Disorder. *British Psychological Society, Wessex Branch. Tony Gale Award.*

2. 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*. https://doi.org/10.53841/bpsdev.2023.1.99.8

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, over 330 individuals have registered to use the resource, across ten 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".

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. 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, April 2023
2. 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, September 2023.
3. 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, 2023.
4. 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. 26th Society for the Study of Behavioural Phenotypes Research Symposium, September 2023.
5. 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), Egham, June 2023.
6. Jenner, L., Ellis, K., Howard, R., Farran, E., & Moss, J. Overimitation: Insights from Down syndrome, Prader-Willi syndrome, and autism [poster presentation]. 55th Gatlinburg Conference, Kansas City, April 2023.
7. 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. 55th Gatlinburg Conference, Kansas City, April 2023.
8. 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. INSAR,

Stockholm, May 2023.

9. 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 [poster presentation]. 55th Gatlinburg Conference, Kansas City, April 2023.
10. 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, April 2023.
11. 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. INSAR, Stockholm, May 2023.
12. 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 [poster presentation]. International Society for Autism Research (INSAR), Stockholm, Sweden, 2023.
13. 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, March 2023.
14. 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. 55th Gatlinburg Conference, Kansas City, April 2023.
15. Roberts, R., Waite, J., Moss, J., Oliver, C., & Pearson, E. Separation Distress in Angelman Syndrome. Neurodevelopmental Disorders Annual Seminar, London, June 2023.
16. 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, London, June 2023.
17. 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. 26th Society for the Study of Behavioural Phenotypes Research Symposium, September 2023.
18. 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, London, June 2023.
19. 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, September 2023.
20. 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, April 2023.
21. 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, 2022.
22. 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, March 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, London, June 2023.
24. Trower, H., & Crawford, H. The Checklist Project. European Association for Mental Health in Intellectual Disability, September 2023.

25. Trower, H., & Crawford, H. The Checklist Project. Study for the Society of Behavioural Phenotypes, September 2023.
26. Trower, H., & Crawford, H. The Checklist Project: The Behaviour Checklist. Neurodevelopmental Disorders Annual Seminar, London, June 2023.
27. 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 [poster presentation]. 55th Gatlinburg Conference, Kansas City, April 2023.
28. 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, 2023.

Public engagement activities

1. Ellis, K & Jenner, L. Social cognition in genetic syndromes associated with autism. FASD Research and Networking Workshop. University of Surrey, January 2023.
2. Ellis, K. Sensory differences in people with CdLS. CdLS Foundation UK and Ireland Spring Conference. Glasgow, April 2023.
3. 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. Oral presentation for the Experimental Psychological Society meeting, London, UK, January 2023.
4. 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. FASD Research and Networking Workshop. University of Surrey, January 2023.
5. 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. University of Warwick, May 2023.
6. Laverty, C. Executive functioning and self-injury in children with intellectual disability. Self-injury in children with intellectual disability: From research to practice Impact Event. University of Birmingham, March 2023.
7. 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, March 2023.
8. Mingins, J. & Waite, J. The Development of an Anxiety Assessment Measure for Individuals who Speak Few or No Words. Anxiety in Rare Genetic Syndromes. University of Warwick, May 2023.
9. Mingins, J. Development of the Clinical Anxiety Screen for People with Severe to Profound ID (ClASP-ID). FASD Research and Networking Workshop. University of Surrey, January 2023.
10. Moss J, Wilson, S & Wilby L. Launch event: Understanding the complex needs of children with genetic syndromes in educational practice. University of Surrey, March 2023.
11. Moss J. Behaviour overview and changes with age in CdLS. CdLS Foundation UK and Ireland Spring Conference. Glasgow, April 2023.
12. Moss J. Changes with age in CdLS. CdLS Foundation UK and Ireland Autumn Conference. East Midlands, October 2022.
13. 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.
14. Moss J. Understanding anxiety in Cornelia de Lange Syndrome. Online event for CdLS Foundation UK and Ireland, May 2023.
15. Moss, J. & Jones, B. Anxiety in Cornelia de Lange Syndrome. Cerebra Network Workshop: Anxiety in Rare Genetic Syndromes. University of Warwick, May 2023.
16. Moss, J. Profiles of autistic characteristics in genetic syndromes: implications for assessment and diagnosis. FASD Research and Networking Workshop. University of Surrey,

January 2023.

17. Moss, J., Crawford, H., Murray, C., & Low, K. Let's TALKBG!: BEOND Information Evening [online webinar and podcast]. KBG Foundation, March 2023.
18. Murray, C. Overview of Cerebra Network and BEOND for PKS Families. Pallister Killian Syndrome UK Family Conference, Birmingham, July 2023.
19. O'Sullivan, R. Sleep in children with neurodevelopmental conditions, and relevant sleep interventions. NHS Clinical Assistant workshop, January 2023.
20. O'Sullivan, R. The importance of sleep for children with rare genetic syndromes: DYRK1A syndrome. The Wirral DYRK1A Family Meetup & Conference, July 2023.
21. 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, March 2023
22. Richards, C. Challenging behaviour in CdLS. CdLS Foundation UK and Ireland Autumn Conference. East Midlands, October 2022.
23. Richards, C. Sleep problems in CdLS. CdLS Foundation UK and Ireland Autumn Conference. East Midlands, October 2022.
24. Roberts, R., Waite, J., Moss, J., Oliver, C., & Pearson, E. Separation Distress in Angelman Syndrome. Anxiety in Rare Genetic Syndromes. University of Warwick, May 2023.
25. Smith, K. & Thomas, N. Understanding the research priorities of families with fragile X syndrome. Fragile X Society Family Conference, Birmingham, September 2022
26. Smith, K. Anxiety in Fragile X Syndrome. Anxiety in Rare Genetic Syndromes. University of Warwick, May 2023.
27. Trower, H. & Wade, K. Understanding the research priorities for families with Cornelia de Lange syndrome. Cornelia de Lange Foundation UK and Ireland Family Conference, February 2023.
28. Trower, H. The Checklist Project: The Behaviour Checklist. Pallister Killian Syndrome UK Family Conference, Birmingham, July 2023
29. Waite, J., Roberts, R., Mingins, J., & Hughes, J. Assessment and intervention of anxiety in rare genetic syndromes. Anxiety in Rare Genetic Syndromes. University of Warwick, May 2023
30. Yuill, N., Elphick, C., Davies, A., Waite, J., & Jones, W. Panel Discussion: Behaviour in Wiedemann Steiner Syndrome. Wiedemann Steiner Syndrome International Conference, October 2022.

Invited talks

1. Ellis, K. Social cognitive assessment in genetic syndromes. *Attention, Brain & Cognitive Development lab led by Prof Gaia Scerif at the University of Oxford, UK,* April 2023.
2. Howlin, P., Waite, J., & Roche, L. Panel Discussion: Why is it so difficult to do intervention research involving individuals with genetic conditions? *26th Society for the Study of Behavioural Phenotypes Research Symposium*, September 2023.
3. 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*, May 2023.
4. Hughes, J., & Traver, J. Assessment and intervention in autistic people: Training afternoon. *Tamworth CAMHS Team,* July 2023.
5. Hughes, J., Pearson, E. & Waite, J. Anxiety in children with severe intellectual disability. *Nottingham CAMHS-LD,* Nottingham, April 2023.
6. Hughes, J., Pearson, E., & Waite, J. Anxiety in children with severe intellectual disability. *Birmingham Community Healthcare NHS Trust CPD Event,* Birmingham, August 2023.
7. Hughes, J., Smith, A., Smith, G. Mental health interventions: Why involving family members as co-researchers is essential. *Autistica Webinar Series*, May 2023.
8. Hughes, J., Waite, J., & Pearson, E. Assessment and intervention in autistic people who speak

few or no words: Training morning. *Nottingham CAMHS ID Team,* July 2023.

9. 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,* May 2023.
10. Hughes, J., Waite, J., & Pearson, E. Assessment and intervention in autistic people who speak few or no words: Training morning. *Nottingham CAMHS ID Team,* March 2023.
11. Moss, J. Heterogeneity of autism in genetic syndromes: Implications for assessment and support. *Newcomen Centre, Special Interest Group, Evalina's Children's Hospital NHS.* July 2023.
12. 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.* September 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. *Centre for Research in Intellectual and Developmental Disabilities, University of Warwick,* August 2023.
14. Waite, J. Anxiety in autistic people who speak few of no words. *National Autistic Society Annual Professional's Conference, Online,* March 2023.
15. Waite, J. Anxiety in children with severe intellectual disability. *Portsmouth NHS Trust, CAMHS-LD.* Portsmouth, September 2023.
16. Waite, J. Anxiety in rare genetic syndromes. Chromatin Disorders Day, Pan Thames Clinical *Genetics Winter School, London, November 2022.*
17. Waite, J. Mental Health in People with Learning Disabilities, *Medicine and Me, Royal Society of Medicine.* London, August 2023.
18. Waite, J. Supporting Children Who Speak Few or No Words: Mental Health and Communication, *London School of Paediatrics Online Learning Webinar,* June 2023.
19. Waite, J., Mingins, J., Hughes, J., & Pearson, E. Anxiety in People who Speak Few or No Words, *Autistica Webinar Series,* May 2023.
20. 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, January 2023.*

7. FINANCE AND COSTS

Provide itemised costings for all activities (such as salaries, supplies, travel, communications and other expenditure) during the report period.

Please see below a full budget and costings, with the costs for the reporting period in the highlighted column. Additionally, costs spent in the first half of year 4 and committed for the remainder of the grant are projected, to allow evaluation of likely underspend.

	Costs in grant budget	**Year 1**	**Year 2**	**Year 3**	**Year 4**	**Committed costs**	**Remaining costs**
		Oct 20 - Sept 21	Oct 21 - Sept 22	Oct 22 - Sept 23	Oct 23 - Dec 23	Dec 23 - Sept 24	
PhD stipend and fees	92,181.53	7,393.72	39.002.28	27,709.49	14,051.24	4,024.90	0.00
DA staff	7,517.25	1,879.75	1879.75	1879.75	469.94	1408.06	0.00
Research Fellows	611,462.50	80,245.15	104,695.60	133,563.51	56,006.52	209,834.97	27,116.75
Studentships	23,100.00	2,278.97	5,552.20	5,907.47	2,677.31	11,777.30	61.37
Running costs	94,835.00	6,349.81	13,499.46	26,897.08	4,628.31	41,738.58	1,721.76
Total	829,096.28	98,347.40	164,629.29	195,957.30	72,478.70	268,783.71	28,899.88

Comment on costs against budget for all activities. Are there any ongoing problems that are affecting your budget?

Budget spend is consistent with the headings and total costs at application. As discussed in our written budget update provided in October 2023, it is noted that spend on Research Fellow salaries and running cost are weighted slightly more heavily in this final year. This is for a number of reasons:

- The shared Network costs primarily support the impact and dissemination activities of the Network (as well as the initial setup of infrastructure and early launch events). As such, there is a natural expansion of these activities towards the end of the grant programme as we position ourselves to share our research findings from the grant funded period to both academic and parent/caregiver communities at national and international events.
- Several Cerebra Network funded staff were successful in obtaining permanent faculty positions or new postdoc roles and one member of Cerebra Network staff took parental leave. We have successfully recruited to cover these positions, but recruitment timelines led to underspend on staffing in 2022 and 2023 which is accommodated by increased spend to target in 2023 and 2024.
- Research visits and conference presentations were significantly hampered in the first two years of the grant due to the pandemic and inevitably the schedule of work had to be adjusted to account for this. This has resulted in a slightly shifted trajectory of spending in

relation to project running costs. Invoices submitted so far this year also reflect this.

- Our Cerebra Postdoctoral Researcher, Dr Effie Pearson, successfully obtained an Impact Grant from Aston University for development of the Further Inform Neurogenetic Disorders (FIND) website. This funding, coupled with Cerebra funding, has facilitated the timely rebuild of the website, a primary platform for the Network's dissemination activities. A further grant was awarded from Aston University to develop a toolkit to support the inclusion of people with moderate to severe intellectual disabilities in PPI activities within the Network and more widely. Both of these successes have bought out staff time from the Cerebra grant and have led to exponential growth in our impact potential over the last year, which will now be realised in the final year.

Overall, there is a small, projected underspend of 28,899.88, less than 4% of the total awarded 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: 31.01.24 Signature: