

Neurodevelopmental Disorders Annual Seminar 2022

Book of Abstracts

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KEYNOTES

1. Strengths, difficulties and diversity in the development of attentional control and executive functions amongst children with a family history of autism and/or ADHD

Author: Alex Hendry

Autism and ADHD frequently co-occur, and cluster within families. Both autism and ADHD have been associated with difficulties with executive functions (higher order thinking skills, which include inhibitory control, working memory and cognitive flexibility). These difficulties appear to negatively impact on quality of life, but their developmental underpinnings are poorly understood. In my research I have been investigating atypical development of attentional control as a potential precursor to executive function difficulties amongst toddlers with a first-degree relative with autism or ADHD (and who are therefore at elevated likelihood of being neurodivergent themselves). I will present data illustrating the heterogeneity of attentional control development in this population within the first 3 years of life, and links between attentional control development, executive functions and broader outcomes. I will also present evidence of strengths associated with a family history of ADHD, and with low inhibitory control. I will then outline some of the ways in which my latest research aims to support the development of executive function skills in children with a family history of autism or ADHD in a way that enables neurodivergent children to flourish, and be valued and supported as individuals with diverse strengths and difficulties.

2. Language, cognition and well-being in atypical children

Author: Nikki Botting

A substantial minority of children have atypical language development. In particular my work focusses on individuals with Developmental Language Disorder (DLD), who have marked difficulties developing language and communication in the absence of obvious causes, and who represent around 7% of the population. This group is of interest not only in terms of their language, but also in terms of their wider cognitive and wellbeing profiles which may serve to inform us about typical as well as atypical development: Although individuals with DLD have a primary difficulty with language, they also experience more pervasive issues such as memory impairments and emotional health problems. In this presentation, I will try to present and synthesise some recent research documenting these issues in DLD, mainly focussing on the longitudinal Manchester Language Study on which I was co-investigator for over 20 years. This study followed a cohort of young people with DLD from 7 to 24 years of age, as well as a typical cohort of age matched peers from 16 to 24 years. The talk will then bring in findings from other groups who also have atypical language, in order to highlight and discuss some potential pathways between language and wider aspects of development.

Oral Session 1

Session 1 a: Co-occurrences

1. Transdiagnostic Profiles of Behaviour and Communication Relate to Academic and Socio-emotional Functioning and Neural White Matter Organisation

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Abstract

Background. Behavioural and language difficulties co-occur in multiple neurodevelopmental conditions. Our understanding of these comorbidities has arguably been slowed by an overreliance on study designs focused on comparing different deficit/diagnostic groups, which limit the conclusions we can draw because they fail to capture the overlap across different neurodevelopmental disorders and the heterogeneity within them.

Methods. In this study, we recruited a large transdiagnostic cohort of children with complex needs ($N = 805$) to identify distinct subgroups of children with common profiles of behavioural and language strengths and difficulties. We then investigated whether and how these data-driven groupings could be distinguished from a comparison sample ($N = 158$) on academic, socio-emotional, and neural white matter characteristics.

Results. We identified three distinct subgroups of children, each with different levels of difficulties in structural language, pragmatic communication, and hot and cool executive functions. Relative to the comparison sample, all three subgroups performed poorer on standardised academic achievement tests and were rated as having more socio-emotional difficulties, potentially representing three alternative but related developmental pathways to difficulties in these areas. The children with the weakest language skills had the most widespread difficulties with academic learning, whereas those with more pronounced difficulties with hot executive skills experienced the most severe difficulties within the socio-emotional domain. Each data-driven subgroup could be distinguished from the comparison sample based on both shared and subgroup-unique patterns of neural white matter organisation.

Conclusion. These findings advance our understanding of commonly co-morbid behavioural and language problems and their relationship to behavioural outcomes and neurobiological substrates.

Presenting author: Silvana Mareva, silvana.mareva@mrc-cbu.cam.ac.uk

2. Neuropsychiatric risk in children with intellectual disability of genetic origin: IMAGINE - The UK National Cohort Study

Jeanne Wolstencroft¹, Marianne Van Den Bree², Jeremy Hall², Michael Owen², David Skuse¹,
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3 University of Cambridge, School of Clinical Medicine, Cambridge, UK

Abstract

Background: Children with intellectual disability (ID) frequently have multiple co-morbid neuropsychiatric conditions and poor physical health. Genomic testing is increasingly recommended as a first-line investigation for these children.

Aim: To determine the impact of genomics, inheritance and socioeconomic deprivation on neuropsychiatric risk in children with intellectual disability of genetic origin as compared to the general population.

Methods: IMAGINE is a prospective study using online mental health and medical assessments in a cohort of 2770 children with ID and pathogenic genomic variants, identified by the UK's National Health Service.

Results: Assessments completed on 2397 young people with ID (4-19 years, M 9.2, SD 3.9) with a rare pathogenic genomic variant. 1339 (55.9%) were male. 1771 (73.9%) of participants had a pathogenic copy number variant (CNV), 626 (26.1%) a pathogenic single nucleotide variant (SNV). Participants were representative of the socioeconomic spectrum of the UK general population. The relative risk of co-occurring neuropsychiatric diagnoses, compared with the UK national population, was high: Autism Spectrum Disorder 29.2 (95% CI 23.9 to 36.5), Attention Deficit Hyperactivity Disorder 13.5 (95% CI 11.1 to 16.3). In children with a CNV, those with a familial variant tended to live in more socioeconomically deprived areas. Both inheritance and socioeconomic deprivation contributed to neuropsychiatric risk in those with a CNV.

Conclusion: Children with genomic variants and ID are at a greatly enhanced risk of neuropsychiatric difficulties. CNV variant inheritance and socioeconomic deprivation also contribute to the risk.

Presenting author: Dr Jeanne Wolstencroft, Research Fellow, j.wolstencroft@ucl.ac.uk

3. Autism-related phenotypes in genetic syndromes: a machine learning approach

Bozhilova, N.^{1,2}, Welham, A.³, Adams, D.⁴, Bissell, S.², Bruining, H.⁵, Crawford, H.^{6,2}, Eden, K.², Nelson, L.², Oliver, C.², Powis, L.², Richards, C.², Waite, J.^{7,2}, Watson, P.⁹, Wilde, L.⁸, Woodcock, K.², Moss, J.^{1,2}

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Abstract

Genetic syndromes were previously associated with distinct autistic characteristics, leading to diagnostic uncertainty and limited access to autism-related support. However, previous research either included small sample sizes ($n=254$) or compared two syndrome groups only. Autism-related profiles (based on Social Communication Questionnaire (SCQ) scores) were evaluated across thirteen genetic syndromes (Angelman $n=154$, Cri du Chat $n=75$, Cornelia de Lange $n=199$, Fragile X $n=297$, Prader-Willi $n=278$, Lowe $n=89$, Smith-Magenis $n=54$, Down $n=135$, Sotos $n=40$, Rubinstein-Taybi $n=102$, 1p36 $n=41$, Tuberous Sclerosis Complex $n=83$ and Phelan-McDermid $n=35$ syndromes). Each syndrome group was predicted to evidence a distinct autism profile. To test this, a classification algorithm via support vector machine (SVM) was applied to ~1500 individuals diagnosed with one of the thirteen genetic syndromes (Age: 16 ± 10.93 years; Self-help score 6.53 ± 1.93). The algorithm was also applied to a sample of autistic individuals without a known genetic syndrome ($n=254$). Self-help skills and age were included as additional predictors. The genetic syndromes were associated with specific autism profiles, with 55% model accuracy. Nevertheless, certain syndrome groups (i.e., Angelman, Fragile X, Prader-Willi, Rubinstein-Taybi and Cornelia de Lange) showed greater behavioural specificity than others (i.e., Cri du Chat, Lowe, Smith-Magenis, Tuberous Sclerosis Complex, Sotos, Phelan-McDermid). The inclusion of the non-syndromic autism reference group, self-help skills and age did not change the model accuracy. These findings extend previous findings of distinct, but overlapping autistic characteristics in genetic syndromes, and encourage the development of new assessment tools, which will be able to capture the phenotypic variability across genetic syndromes.

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4. The importance of studying autonomic arousal and emotional regulation in neurodevelopmental conditions: evidence from the SAAND study and recent systematic reviews and meta-analyses

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Abstract

Dysregulated autonomic arousal (an index of how physiologically active/reactive our body is in a specific situation) is likely to underlie socio-emotional, attentional and cognitive mechanisms in several neurodevelopmental conditions. Evidence of dysregulated autonomic arousal in autistic people, people with ADHD, mood disorders and conduct problems, has been in fact reported in recent systematic reviews and meta-analyses, which will be discussed during the presentation. In the SAAND study, we investigated heart rate variability in 106 children/adolescents (10.81 ± 2.06 years; 66% males) with autism, ADHD, co-occurring autism/ADHD, and neurotypical controls; during resting-state, a passive auditory oddball task and an active response conflict task. Children with ADHD showed hypo-arousal (reduced sympathetic activity) compared to those without ADHD during resting-state (main effect of ADHD: $F_{1,69} = 8.687$; $p = 0.004$; $\eta_p^2 = 0.112$) and during the auditory oddball task ($F_{1,72} = 4.786$; $p = 0.032$; $\eta_p^2 = 0.062$), while autistic children showed hyper-arousal (reduced parasympathetic activity) compared to non-autistic children during the active task (main effect of Autism: $F_{1,52} = 4.895$; $p = 0.031$; $\eta_p^2 = 0.086$). Children with co-occurring ADHD and autism showed the same dysregulation patterns found in children with 'pure' conditions, namely reduced parasympathetic activity during the active task and reduced sympathetic activity during resting-state and the passive task. Irrespective of diagnosis, hyper-arousal was associated with more severe parent-reported difficulties in social interactions and communication, greater anxiety and reduced global functioning. These findings highlight the importance of investigating autonomic arousal in neurodevelopmental conditions (including ADHD and autism) and the need of adopting dimensional or transdiagnostic research frameworks, such as the Research Domain Criteria (RDoC), to better understand neurodevelopment.

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Session 1b: Participant's Voices

1. Co-production for a PhD project: Understanding the transition to adolescence in girls with neurodevelopmental conditions.

Presenting author:

1. Ailbhe McKinney, Child Life and Health/Centre for Clinical Brain Sciences, University of Edinburgh, a.m.mckinney@sms.ed.ac.uk

Co-authors:

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3. Prof Stella Chan, University of Reading s.chan3@reading.ac.uk
4. Sarah O'Brien, PhD candidate, Kings College London, sarahobq@gmail.com
5. Dr Sinead Rhodes, Child Life and Health/Centre for Clinical Brain Sciences, University of Edinburgh, sinead.rhodes@ed.ac.uk

Abstract

Background: Co-producing research with people with neurodevelopmental disabilities leads to a more feasible and acceptable design. Furthermore, co-produced research has become a critical agent for change in how people with disabilities can advocate for their rights, after a history of being excluded from decision making.

Aims: Within the scope of a PhD, with small funds, a lack of training, and a short timeframe, it can be difficult to commit to a co-produced project and instead revert to traditional methods. This presentation will aim to give early career researchers strategies on how to conduct co-production for a PhD project.

Methods: Co-production for this PhD thesis was designed in three phases: 1. connecting with relevant groups, 2. setting research priorities, and 3. designing a feasible project.

Results: Lessons learnt included recruitment strategies (through social media, contacting individuals, collaborating with charities), how to design co-production activity workshops, how to include feedback and how to evaluate impact.

Conclusion: While there are barriers to designing a co-produced PhD thesis, the following guidelines can be helpful in overcoming them: creating connections early in a PhD programme, committing to a small amount of training in the first semester about the principles and practise of co-production and conducting co-production in parallel with a literature review. Benefits of a co-produced PhD will also be highlighted such as a higher quality PhD, learning new skills, and the opportunity to spend time with a clinical population before ethical approval.

2. IMAGINE-ID personalised research reports: understanding participant's view of their real-world impact

Harriet Housby, Hannah Aissa, IMAGINE ID Consortium, David Skuse & Jeanne Wolstencroft

All authors: Great Ormond Street Institute of Child Health, University College London, London, UK

Abstract

Background: Children and young people (CYP) with intellectual disability (ID) of known genetic origin experience complex physical and mental health problems. IMAGINE-ID is a longitudinal UK cohort study exploring the needs of these CYP. Little is known about real-world impact of research participation for this cohort. IMAGINE-ID create personalised reports summarising their CYP's strengths and difficulties. We asked families for feedback regarding the usefulness of their reports.

Methods: 1027 of the CYPs caregivers completed an online 'study impact' survey. The survey assessed report usefulness (using a 4-point Likert scale) and four areas of potential impact: shareability (report sharing), utility (using report as supporting evidence e.g., EHCP), clinical impact (change in clinical care) and psychological impact (change in understanding of the child).

Results:

57.9% of participants (N=590) reported sharing their report. A multiple regression predicted report usefulness from the four impact scales. The model was significant ($F(4,585) = 144$, $p < .001$, $R^2 = .493$) with predictors accounting for 48.7% of the variance in usefulness. Families who reported higher usefulness also report greater psychological impact ($\beta = 0.61$, $p < .001$) and greater utility ($\beta = 0.12$, $p < .001$). Neither the clinical impact ($\beta = 0.06$, $p = .128$), nor shareability ($\beta = 0.06$, $p = .089$) were significant predictors of usefulness.

Conclusions: Families found their report useful in changing their understanding of their child and as supporting evidence. Further analyses are needed to adjust for potential confounds in CYP characteristics (e.g., level of ID, behavioural difficulties etc.).

Presenting author: Harriet Housby, Research Assistant harriet.housby.18@ucl.ac.uk

3. In their own words – Using Photovoice to Capture how Children with Intellectual Disabilities are coping after Covid.

Grace Khawam¹, Hope Christie¹ & Karri Gillespie-Smith¹

1. *University of Edinburgh*

Abstract

Background: The first UK-wide lockdown was implemented on 23rd March 2020, to reduce the spread of Covid-19. Although this prevented widespread virus-related deaths, the closure/suspension of schools, clinical services and respite put significant pressures on autistic children who have Intellectual Disabilities (ID) and their parents. Despite the whole of the UK began coming out of lockdown in April 2021, there still remains significant reductions in services and support for autistic children and their families potentially impacting their mental health. To date there has been no research carried out asking the children with ID about their own experiences during this time.

Aims: This project explores how children with ID are coping throughout ease of lockdown, and whether there are still issues impacting their mental health and wellbeing.

Method: Photovoice sessions were carried out between December 2021 and March 2022, with 10 children who have ID; ages ranged from 7-18 years (M=14.1; SD=4.40). Three photovoice sessions were carried out weekly on the Teams platform, and included multimodal participatory visual techniques, including drawing, storytelling and photography. The children were in groups of 2-3 and were instructed to take images to provide a narrative of their experiences of Covid, transition phases and their current feelings. Thematic analysis of the images produced was carried out.

Results & Conclusions: The results of the thematic analysis will be presented. The researcher will also exhibit images produced by the children, and discuss the captions and quotes given by the children to explain the images they produced and/or created.

Presenter – Grace Khawam; Email – gkhawam@exseed.ed.ac.uk

4. Exploring social and sensory differences in autistic and non-autistic individuals with anorexia nervosa and their parents.

Authors:

Presenting author: Emy Nimbley, E.Nimbley@sms.ed.ac.uk

Co-authors:

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Abstract

Background: Accumulating research evidence has established an overlap between autism and eating disorders, particularly anorexia nervosa (AN). Recent evidence proposes a broad range of autism-specific mechanisms, including differences in social and sensory processing (Brede et al, 2020). The current study will explore social and sensory differences in both autistic and non-autistic individuals with anorexia in an attempt to untangle common and autism-specific mechanisms in acute and recovered stages of anorexia.

Methods: Autistic and non-autistic individuals (18+ years) will be interviewed with a parent/primary caregiver. While previous studies have adopted a multi-perspective approach (e.g., Babb et al, 2021), to date no study has explored these perspectives as dyads. Dyadic interviews not only provide multiple perspectives but also allows for interaction of perspectives (Morgan et al, 2015). Interviews will be analysed using Interpretative Phenomenological Analysis (IPA; Smith et al, 1996). A co-author and expert by experience assisted in the development of the interview schedule, as well as in the development of the themes.

Results: Thus far, 5 dyads (out of 12) have been interviewed. Preliminary findings suggest both common and autism-specific factors. Difficulties with social relationships, socio-emotional communication and social isolation were common across both autistic and non-autistic participants. Social comparisons appear to play more of a role for non-autistic individuals, while only autistic participants reflected that they sometimes perceived their interactions to be more different than in deficit. Differences in interoception were reported across both groups, however autistic participants generally displayed more pronounced sensitivities across multiple senses.

Presentation: The presentation will discuss study rationale, as well as a detailed methodological approach, rooted in the lived experiences of autistic individuals with anorexia. Initial findings will be presented, and clinical implications including the increased awareness of neurodiverse presentations and communication in ED services and the development of person-centred, autism-specific interventions will be discussed.

Oral Session 2

Session 2 a: Syndromes

1. The Relationship between Anxiety and Intolerance of Uncertainty in Cornelia de Lange and Fragile X Syndrome

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Abstract

People with Cornelia de Lange syndrome (CdLS) and fragile X syndrome (FXS) often experience co-occurring anxiety and autism. Recent studies suggest that intolerance of uncertainty (IU) is a risk factor for the development and maintenance of anxiety, and that it mediates the relationship between autism characteristics and anxiety in autistic people. Discerning the relationship between IU, anxiety, and autism characteristics is essential to informing anxiety interventions and theoretical developments for people with CdLS and FXS. This study investigates the relationship between IU, anxiety, and autism characteristics in people with CdLS ($n = 33$, $M_{age} = 13.92$ years) and FXS ($n = 30$, $M_{age} = 20.63$ years). Parent-reported anxiety was determined using the Anxiety Scale for Children-ASD (ASC-ASD) and the Anxiety, Depression and Mood Scale (ADAMS). Autism characteristics and IU were assessed using the Social Responsiveness Scale-Second Edition (SRS-2) and the Intolerance of Uncertainty Scale-Parent Version, respectively. Hierarchical multiple regression analyses indicated that both autism characteristics [$p \leq .002$] and IU [$p < .001$] significantly predicted anxiety scores in both CdLS and FXS. Mediation analyses revealed that IU mediated the relationship between autism characteristics and anxiety in CdLS [$p < .01$], similar to the relationship seen in autistic people. This relationship was not seen in FXS [$p > .05$], suggesting that other factors may contribute to the anxiety-autism relationship in FXS, and that additional work is needed to understand the underlying factors that contribute to the relationship between anxiety, IU, and autism characteristics in rare genetic syndromes.

Presenting Author: Kayla Smith, BS; Email: kayla.smith@warwick.ac.uk

2. Friendships in Williams syndrome – Hearing the voice of adults with WS

Authors: Ellen Ridley (presenter), Isabella Molnar, Deborah Riby, Mary Hanley

All authors: Centre for Neurodiversity & Development, Department of Psychology, Durham University, Durham, UK.

Abstract

Background: Despite evidence that people with Williams syndrome (WS) have a strong desire for social connections (Thurman & Fisher, 2015), we know that interpersonal relationships also raise challenges for many people. Yet little research has been carried out on the nature of friendships for people with WS. Previous evidence has relied on parent/caregiver reports, examination of adult outcomes and inferences from standardised measures of social behaviour (e.g. Elison et al. 2010; Davies et al. 1998). Far less emphasis has been placed on taking a qualitative approach or to what people with WS themselves have to say about their friendships and interactions with others.

Aims: The current study aimed to explore the conceptualisation of 'friendship' in adults with WS, together with their associated experiences of friendships, capturing first-hand insights.

Methods: Ten adults with WS (aged 18-30 years) took part in the study. The interviews followed a semi-structured format, probing participants' reflections on friendships. Given the variation in the richness of participants' accounts, qualitative content analysis was chosen as an appropriate analysis.

Results: The interviews have been transcribed and analysis is currently underway. The findings will be presented at the conference. The voice of adults with WS has been neglected in research on social behaviour and social interactions to date and the results from this study provide a useful starting point for discussing more creative qualitative methodologies. The results will be embedded within the literature of social interactions and friendships.

3. Neurodevelopmental profiles of infants and toddlers with Down syndrome, fragile X syndrome, and Williams syndrome

Dean D'Souza¹, Annette Karmiloff-Smith², & Hana D'Souza^{3,4}

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² *Birkbeck, University of London*

³ *Newnham College, University of Cambridge*

⁴ *Cardiff University*

Abstract

Neurodevelopmental disorders are a group of disorders in which the development of the central nervous system is disturbed. In adults, each disorder has its own distinct profile of relative strengths and weaknesses across cognitive and behavioural domains. But little is known about how these profiles emerge and develop over time.

The aim of the study is to compare the early emerging cognitive and behavioural profiles of three different neurodevelopmental disorders: Down syndrome (DS), fragile X syndrome (FXS), and Williams syndrome (WS). DS, FXS and WS were chosen for comparison because older children and adults with these disorders are often reported as having contrasting profiles: e.g., social anxiety in FXS and over-friendliness in WS.

Thirty-five infants (~16 months) and 62 toddlers (~30 months) with DS, FXS, or WS were tested on the Mullen Scales of Early Learning (MSEL; Mullen, 1995). The MSEL measures gross motor ability, fine motor skill, visual reception, receptive language, and expressive language, and was selected for its high internal validity (.91) (Mullen, 1995) and because it does not require the child to understand speech in order to succeed on non-language tasks – an important feature given that language delay is common in all three disorders.

We will present and contrast the MSEL profiles of each neurodevelopmental disorder – at both ~16 months and ~30 months. Understanding the emerging profiles of DS, FXS, and WS in infants and toddlers is important because it may pave the way to early, time-sensitive, and syndrome-specific interventions.

Presenting author: Dean D'Souza (dean.dsouza@city.ac.uk)

4. Cross-sectional and longitudinal assessment of cognitive development in Williams syndrome

Emily K. Farran¹, Harry R. M. Purser², Christopher Jarrold³, Michael S. C. Thomas⁴, Gaia Scerif⁵, Vesna Stajonovik⁶, Jo Van Herwegen⁷

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⁵*University of Oxford*

⁶*University of Reading*

⁷*UCL Institute of Education*

Abstract

Williams syndrome (WS) is a rare genetic syndrome. As with all rare syndromes, obtaining adequately powered sample sizes is a challenge; one way to address this challenge is to collaborate across labs. Here we present legacy data from seven UK labs. This enabled us to investigate and compare the cross-sectional and longitudinal developmental trajectories of verbal and non-verbal development in the largest sample of individuals with WS to-date. In Study 1, we report cross-sectional data from N=102, N=103 and N=209 children and adults with WS for performance on Ravens Coloured Progressive Matrices (RCPM), the Pattern Construction subtest of the British Ability Scales (PC) and the British Picture Vocabulary Scales (BPVS) respectively. In Study 2, we report longitudinal data from N=41 (RCPM), N=17 (PC) and N=54 (BPVS) children and adults with WS who had been tested on at least three timepoints on these measures. Cross-section data demonstrated higher BPVS mental age than RCPM mental age, reflecting the WS characteristic cognitive profile. Both cross-sectional and longitudinal data showed developmental progression for both domains. Cross-sectional data indicated steeper development in verbal than non-verbal ability (particularly at the younger end of the range of ages in our sample). This was not mirrored statistically in the longitudinal data at a group level, yet there was a large amount of heterogeneity in non-verbal longitudinal progression. Cross-sectional and longitudinal data are discussed with reference to: validating cross-sectional developmental patterns using longitudinal data; the importance of individual differences in understanding developmental progression.

Presenting Author: Emily Farran

Session 2b: Interventions and Supports in Schools

1. Coproduction of the Edinburgh Psychoeducation Intervention for Children and Young People (EPIC)

Presenting Author: Sinead Rhodes, *University of Edinburgh*

Co-Authors:

Emily McDougal, *University of Surrey*

Tracy Stewart, *University of Edinburgh*

Josie Booth, *University of Edinburgh*

Christina Efthymiou, *University of Edinburgh*

Abstract

Background: Interventions focused on cognitive function in children with Neurodevelopmental difficulties (NDDs) such as ADHD and autism typically focus on single components. The multidimensional nature and phenotypic variability of cognitive profiles in children with Neurodevelopmental difficulties necessitates the development of a multicomponent tailored intervention approach.

Aims: We aimed to coproduce a novel tool-kit intervention with children, parents, teachers and clinicians of children with Neurodevelopmental difficulties to improve cognition, learning and wellbeing.

Methods: Phase 1: Across interviews and workshops 'EPIC' principles, materials, and strategies were *co-produced* with children with Neurodevelopmental difficulties, their parents, teachers and clinicians linking to established research evidence on cognitive function in NDDs. Phase 2: 11 children with NDDs completed an 8 week (16 session) EPIC intervention involving psychoeducation and pairing of strategies with cognitive difficulties (e.g. mind-maps, chunking). Pre and post intervention data on cognitive measures (CANTAB, BRIEF) and educational attainment (WIAT) as well as parent and teacher questionnaires (Conners, AQ, SDQ, self-perception) were compared with a matched control group.

Results: Quantitative data identified that an 8 week 'EPIC' intervention improved cognition (short-term and working memory) and literacy (receptive vocabulary, oral word fluency, listening comprehension). Parent reported child behavioural difficulties and aggression and teacher reported scholastic competence improved in the intervention group. Qualitative data will be reported in a linked presentation.

Conclusion: EPIC improves a range of aspects of cognition, learning, and behaviour in children with Neurodevelopmental difficulties with particularly positive impacts to memory and literacy.

2. Co-producing Educational Guidelines for Learners with Williams Syndrome with young children

Fionnuala Tynan¹, & Jo Van Herwegen²

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Abstract

Williams syndrome (WS) is a rare genetic neurodevelopmental disorder with a prevalence of between 1 in 7,500 and 1 in 20,000 (Udwin et al., n.d.) and thus most practitioners and teachers have never worked with a child with WS before, as such professional guidelines to inform and support educational practitioners are required. However these guidelines are often written by academic or medical experts or at best with input from parents of children with WS. In this study we ran focus groups with children with WS aged 4 to 19 years old to find out what they want to know about their learning profile and to discuss learning, education and schooling with learners with WS. This information will then be used to create new educational guidelines for individual with WS to help learners with WS to understand their condition, to appreciate that their learning challenges are part of WS and to know that other learners with WS share their experiences. In this talk we will present the results from these focus groups as well as discuss lessons learned and best practice related to running focus groups with young children with WS.

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3. An evaluation of Learning About Neurodiversity at School (LEANS): A new resource for teaching about neurodevelopmental differences and promoting acceptance in mainstream primary schools

¹**Alcorn, Alyssa M.** *Salvesen Mindroom Research Centre, University of Edinburgh*

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Mandy, William *Division of Psychology & Lang Sciences, UCL*

Aitken, Dinah *Salvesen Mindroom Centre*

Murray, Fergus *Consultant and educator, Autistic Mutual Aid Society Edinburgh (AMASE)*

Peacock, Liam J. J. *LEANS project youth research representative*

Fletcher-Watson, Sue *Salvesen Mindroom Research Centre, University of Edinburgh*

Abstract

Background: The wellbeing and participation of school pupils with neurodevelopmental conditions may suffer when teachers and peers have limited understanding and acceptance of their needs and experiences. The LEANS project developed a resource pack for mainstream primary classes (P5-P7) to teach about *neurodiversity*, as a higher-level concept covering many neurodevelopmental differences. These resources were designed with neurodiverse educators. They aim to increase understanding of differences and their impact on school experience, and to promote inclusive actions and attitudes.

Aims: To assess whether LEANS resources were successful in teaching neurodiversity concepts, and in changing pupils' attitudes and intended actions.

Methods: Seven P5-P7 classes delivered LEANS, across four mainstream Scottish primaries (Aug-Dec 2021). Using opt-in recruitment, 62 children's LEANS quizzes and demographics were shared with researchers (female=36, mean age 9.84 years). 17.74% of participants had reported additional support needs (e.g. formal diagnoses such as autism, undiagnosed challenges).

Results: Teachers administered bespoke measures of neurodiversity knowledge and attitudes to their classes, before and after LEANS. Post-test scores illustrated that participating pupils could demonstrate knowledge of the neurodiversity concepts contained in LEANS, and expressed more inclusive and accepting attitudes and intended actions following LEANS participation, at statistically significant levels. Quiz analyses were pre-registered: <https://osf.io/38jrh>

Conclusion: Per quiz scores and school feedback, LEANS appears to be a successful tool for introducing neurodiversity concepts in primary schools, offering a basis for ongoing classroom discussion and facilitating longer-term changes in knowledge and attitudes. LEANS resources will be freely available online from June 2022.

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4. Results from the I-SOCIALISE Study: a cluster randomised controlled trial investigating the social competence and isolation of children with autism participating in LEGO® based therapy ('play brick therapy') groups in mainstream school environments

Authors: Barry Wright MD¹, Ellen Kingsley MSc², Cindy Cooper PhD³, Katie Biggs MSc³, Matthew Bursnall PhD³, Han-I-Wang PhD¹, Tim Chater BSc (Hons)³, Elizabeth Coates PhD³, M. Dawn Teare PhD⁵, Kirsty McKendrick BSc (Hons)³, Gina Gomez de la Cuesta ClinPsyD⁴, Amy Barr MSc³, Kiera Solaiman BA³, Anna Packham MSc³, David Marshall PhD¹, Danielle Varley MSc¹, Roshanak Nekooi MSc², Steve Parrott MSc¹, Shehzad Ali PhD¹, Simon Gilbody PhD¹, Ann Le Couteur FRCPsych⁵

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Abstract

Background: Autistic children and young people (CYP) often approach social interactions differently to neurotypical children. LEGO® based therapy (Play Brick Therapy) is a child-led group social skills programme which provides social opportunities for autistic CYP.

Aims: Primary objective: to evaluate the clinical effectiveness of LEGO® based therapy on the socio-emotional skills of autistic CYP in mainstream school settings compared with usual support.

Methods: Participants were autistic CYP aged 7-15 in mainstream schools in Northern England. Each recruited school was remotely cluster randomised to the intervention arm (12 weekly sessions of LEGO® based therapy delivered in school and usual support from school, GPs, and other professionals) or the control arm (usual support only). The primary outcome measure was the social skills scale of the Social Skills Improvement System completed by the CYP's teacher/teaching assistant 20-weeks post-randomisation.

Results : The study recruited 250 CYP: 127 allocated to the intervention arm and 123 to the control arm. A minimal clinically important difference (MCID) of 9-10 points change on the primary outcome was pre-specified. Intention to treat analysis found a modest positive effect of 3.74 points ($p=0.06$, 95% CI: -0.16, 7.63) for the intervention arm. Other analyses were also carried out on primary and secondary objectives.

Key conclusion: Although the change score did not meet the MCID, a modest positive clinical effect for the intervention arm was found. Other study results were also positive. Consideration should be given to the contribution of LEGO® based therapy to social skills of autistic CYP in mainstream school settings.

Presenting author: Ellen Kingsley – Research Fellow with LYPFT, COMIC research, IT Centre Innovation Way, York, YO10 5NP, e.kingsley@nhs.net

Oral Session 3

Session 3 a: Other Neurodevelopmental Disorders

1. UK research update on tuberous sclerosis complex (TSC): An exploration of TSC-associated neuropsychiatric disorders (TAND)

Presenting author: Dr Stacey Bissell (s.l.bissell@bham.ac.uk), School of Psychology, University of Birmingham, UK

Co-authors: Dr Caroline Richards (School of Psychology, University of Birmingham, UK), Prof Chris Oliver (School of Psychology, University of Birmingham, UK), Dr Lucy Wilde (School of Psychology and Counselling, The Open University, UK), Prof Petrus de Vries (Center for Autism Research in Africa, University of Cape Town, South Africa)

Abstract

Background: Tuberous sclerosis complex (TSC) is a multisystem neurodevelopmental disorder characterised by benign tumour growth, epilepsy, and autism. TSC-associated neuropsychiatric disorders (TAND) is a term that encapsulates the behavioural, psychiatric, intellectual, scholastic, neuropsychological and psychosocial characteristics of TSC. This research update summarises recent studies that have explored the behavioural level of TAND, with a specific focus on poor sleep and daytime behaviours (e.g. overactivity).

Methods: A number of research methodologies will be presented that have explored sleep and behaviour in children aged 4-15 years with TSC. Measures include informant-report questionnaires (e.g. Modified Simonds and Parraga Sleep Questionnaire), direct measures of behaviour (e.g. Autism Diagnostic Observation Schedule, second edition) and remote methodologies using overnight actigraphy and mobile app technology.

Results: Several key findings will be reported. Compared to older children with TSC, younger children evidenced higher levels of stereotyped behaviour and overactivity but lower levels of insistence on sameness. Children with TSC obtained higher informant-report daytime sleepiness scores compared to typically developing children ($p < .01$), but there were no significant differences on objective actigraphy sleep parameters (e.g. sleep efficiency). Actograms of some children with TSC indicated a fragmented morning sleep pattern of early waking and late morning napping.

Conclusions: This research update highlights the importance of adopting a multifaceted approach to TAND behavioural research. Behavioural research utilising remote technologies could address several TAND research gaps. Potential mechanisms that underlie both higher levels of daytime behaviour and poor sleep in TSC (e.g. adverse effects of antiepileptic medications) warrants further investigation.

2. Distress and coping in children with neurodevelopmental disabilities and their parents during covid and recovery: A longitudinal study

Karri Gillespie-Smith¹, Hope Christie¹ & Grace Khawam¹

1. University of Edinburgh

Abstract

Background: Caregivers of a child with Neurodevelopmental Disabilities are more vulnerable to mental health difficulties. These difficulties are influenced by the child's challenging behaviours (an indicator of child distress), and the caregiver's coping strategies; factors impacted by the COVID-19 pandemic.

Aims: The current study had several aims - to explore which child and parent groups are more likely to show higher levels of psychological distress; to examine the coping strategies implemented by parents during covid and recovery phases to better understand what coping strategies led to poorer mental health outcomes.

Methods: 85 Parents of children with ID (mean age = 11 years 9 months) and 72 parents of children without ID (mean age = 11 years 2 months) were asked to complete a survey between Aug-Dec 2021 and then were asked to complete it 2-3 months later.

Results: Regression analyses showed that demographic details including socio-economic status and number of children in the house was related to greater psychological distress in the parents. In addition, children's challenging behaviours and parental coping strategies such as self-blame and denial lead to higher levels of parental anxiety, stress and depression. This was observed at both time points.

Key conclusions: Despite lockdown easing and services returning to 'normal' we still see significantly high levels of psychological distress in both children with neurodevelopmental disabilities and their caregivers. More support, respite and targeted interventions are needed for these children and their parents to reduce the poor mental health outcomes.

Presenter – Karri Gillespie-Smith; Email – karri.gillespie-smith@ed.ac.uk

3. Tonic pupil dilation during sustained attention in children with ADHD

Presenting Author: Ursula Schöllkopf (1), contact: ursula.schoellkopf@lin-magdeburg.de

Co-Authors: Kerstin Krauel (2,3), Andreas Widmann (1,4), Nicole Wetzel (1,3)

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(4) Wilhelm-Wundt Institute for Psychology, Leipzig University, Leipzig, Germany

Abstract

With a worldwide prevalence of around 5 %, attention deficit hyperactivity disorder (ADHD) belongs to the most common childhood-onset neurodevelopmental disorders. ADHD is characterized by symptoms of impaired attention, hyperactivity and impulsivity but despite the continuous scientific effort, little is known about the neural underpinnings of ADHD symptoms. Influential models postulate that a deficit in the regulation of activation states contributes to cognitive impairments in ADHD. In particular, recent studies pronounce the role of an unstable regulation of brain arousal in that respect. The level of arousal can be modulated by the tonic and phasic activity of the Locus Coeruleus-Norepinephrine (LC-NE) system. The pupil is closely linked to the activity of norepinephrine neurons in the Locus Coeruleus and therefore provides a promising tool for the investigation of arousal-related attention mechanisms in ADHD. In this study, we investigated slow changes of tonic pupil dilation across a visual sustained attention task in children with and without ADHD. Individuals with ADHD showed significantly reduced performance compared to controls. The pupil diameter was initially similar in both groups but decreased during the task in controls but not in children with ADHD. In conclusion, our results indicate a dysregulation of tonic activity of the LC-NE system and an insufficient adaptation to the requirements of the task with time in ADHD.

4. Object interaction and sensorimotor prediction in children with developmental coordination disorder

Buckingham, G. [1], Allen, K. [1], Vine, S.J. [1], Arthur, T.G. [1], Harris, D.J. [1], Wood, G. [2], Tsaneva-Atanasova, K. [1] & Wilson, M.R. [1]

[1] University of Exeter

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Abstract

Developmental Coordination Disorder (DCD) is characterised by a broad spectrum of difficulties in performing motor tasks, in the absence of any physical or sensory impairment. It has recently been proposed that a selective deficit in sensorimotor prediction and feed-forward planning might underpin these motoric impairments. The purpose of this study was to use a naturalistic object lifting paradigm to investigate whether deficits in sensorimotor prediction might underpin the broad spectrum of difficulties individuals with DCD face when interacting with objects in their environment. We examined perceptions of heaviness and fingertip force application in children aged 8-12 years with DCD (n=48) and without DCD (n=53). We examined these measures in the context of the size-weight illusion paradigm, where participants lifted objects which varied in their apparent, but not actual, weight. In typically-developing populations, these stimuli elicit a powerful expectation-based weight illusion, with the smaller objects feeling heavier than the larger objects, as well as characteristic prediction-driven lifting behaviour with larger objects gripped and lifted with a higher rate of force than smaller objects. Overall, participants showed the expected perceptual and sensorimotor behaviours – small object felt heavier, and were initially lifted with lower rates of force, than large objects. We found no evidence for a difference in the magnitude of perceptual or sensorimotor effects between children with and without DCD. Our results find no evidence to support the proposal that DCD represents a selective deficit in sensorimotor prediction and feed-forward planning, in a task which is appropriate for this population.

Presenting Author: Gavin Buckingham

Session 3 b: Genetics

1. Fragile X Syndrome: A Longitudinal Analysis of Genetic Modifiers and Behavioural Trajectories Over Three-Years

Authors:

Lydia Cartwright- Warwick Medical School student

Dr Crawford- University of Warwick

Abstract

Background: Despite being a monogenic disorder, the phenotypic profile of Fragile X syndrome (FXS) is variable, with behaviours differing in severity and frequency amongst those affected. Two prior studies have explored individual differences in single nucleotide polymorphisms (SNPs) to explain within-disorder variation in FXS. A priori testing of SNPs provides a method of analysing genotype-phenotype associations in rare syndromes whereby sample sizes are often too small to detect associations using genome-wide association studies. These prior studies revealed a role of the 5-HTTLPR (serotonin) and COMT (dopamine) SNPs in behavioural variation in FXS cross-sectionally. However, the associations between SNPs and behavioural *trajectories* in FXS remain unknown.

Study: Therefore, this study explored relationships between three SNPs selected a priori (5-HTTLPR, COMT and monoamine oxidase A (MAOA)) with the trajectories of clinically relevant behaviours in 42 males with FXS. Numerous behaviours (e.g. autism symptomology, property destruction, aggression, stereotyped behaviour and mood/interest and pleasure) were measured at two time points across three years via a series of informant-based questionnaires.

Results: Results revealed the AA COMT genotype to display fewer repetitive and stereotyped behaviours over time than the AG or GG genotypes, the S/S serotonin genotype displayed fewer stereotyped behavioural trajectories than the L/S or L/L genotypes, and the three-repeat MAOA group demonstrated fewer communication deficits over three years than the four-repeat group.

Conclusions: This is the first study to document variation within SNPs and behavioural trajectories in FXS, with results suggesting an important role of SNPs when considering longitudinal behavioural patterns in FXS. This work may facilitate individualised and early interventions programmes for those with FXS.

2. Face looking in young children with Down syndrome in the context of parent-child interaction

Hana D'Souza^{1,2*}, Lauryna Filatovaite³, Foteini Petrato⁴, Dan Brady⁵, Annette Karmiloff-Smith⁶, Mark H. Johnson¹, Michael S. C. Thomas⁶, Elian Fink⁷ & LonDownS Consortium

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Abstract

Introduction: Faces are thought to play a special role in early development. In fact, a number of interventions with atypically developing or 'at-risk' populations encourage young children to focus on others' faces in order to facilitate interaction and learning. However, much of the available evidence on face looking in young children with disorders comes from tightly controlled laboratory studies or from anecdotal evidence. This study focused on face looking during naturalistic play with objects in young children with Down syndrome (DS) and their parents.

Participants: Sixty-three parent-child dyads participated in this study. Young children with DS between 32 and 62 months ($n=43$) were matched on mental age to typically developing (TD) infants and toddlers ($n=20$).

Methods: We examined face looking in young children and their parents during 10-minute free play with objects. Children were also administered the Mullen Scales of Early Learning.

Results & Discussion: The children spent less time than their parents looking at faces. Also, DS dyads showed more face looking than TD dyads. Irrespective of group (TD, DS) or agent (parent, child), face looks tended to be short (on average less than 1 second long). Parents showed more face looks than children, and dyads with DS showed more face looks than dyads with TD children. This profile of face looking suggests that the parents, especially of children with DS, were monitoring their children's behaviour.

Understanding face looking in DS in a naturalistic context is a crucial step towards reframing some of the existing interventions and beliefs of parents and practitioners.

3. Discovery Of 42 Genome-Wide Significant Loci Associated With Dyslexia

Catherine Doust¹, Pierre Fontanillas², Else Eising³, Scott D Gordon⁴, Zhengjun Wang⁵, Gökberk Alagöz³, Barbara Molz³, 23andMe Research Team², Quantitative Trait Working Group of the GenLang Consortium, Beate St Pourcain^{3,6}, Clyde Francks^{3,6}, Riccardo E Marioni⁷, Jingjing Zhao⁵, Silvia Paracchini⁸, Joel B Talcott⁹, Anthony P Monaco¹⁰, John F Stein¹¹, Jeffrey R Gruen¹², Richard K Olson¹³, Erik G Willcutt¹³, John C DeFries¹³, Bruce F Pennington¹⁴, Shelley D Smith¹⁵, Margaret J Wright¹⁶, Nicholas G Martin⁴, Adam Auton², Timothy C Bates¹, Simon E Fisher^{3,6} & Michelle Luciano^{1*}

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Abstract

Reading and writing are crucial life skills but up to 1 in 10 children are affected by dyslexia, which can persist into adulthood. Family studies of dyslexia suggest heritability up to 70%, yet no convincing genetic markers have been found. Our genome-wide association study of 51,800 adults self-reporting a dyslexia diagnosis and 1,087,070 controls identifies 42 independent significant loci: 15 in genes linked to cognitive ability/educational attainment; 27 novel and potentially specific to dyslexia. Twenty-three loci (13 novel) were validated in independent cohorts of Chinese and European ancestry. Genetic aetiology of dyslexia was similar between sexes, and genetic covariance with many traits was found, including ambidexterity, but not neuroanatomical measures of language-related circuitry. There was especially strong genetic correlation with attention deficit hyperactivity disorder but not autism spectrum disorder. Dyslexia polygenic scores explained up to 6% of variance in reading traits, and might in future enable earlier identification and remediation of dyslexia.

*Presenting author: Michelle Luciano

4. Sensory Processing in Genetic Syndromes Associated with Autism

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Abstract

Genetic syndromes, Sotos syndrome (Sotos), Tatton-Brown Rahman Syndrome (TBRS) 16p11.2 deletion, and 16p11.2 duplication, have a high likelihood of autism symptomatology. However, there has been limited investigation into the way in which individuals with these syndromes process sensory information. The aims of this study were to investigate how sensory information is processed by children with these four syndromes, and to determine whether other clinical features predict the level of sensory processing differences experienced.

Parents/caregivers of 36 children with Sotos, 20 children with TBRS, 38 children with 16p11.2 deletion, and 31 with 16p11.2 duplication completed the Child Sensory Profile 2 (CSP-2) and the Sensory Behaviour Questionnaire (SBQ) along with other standardised questionnaires assessing autistic traits (SRS-2), ADHD traits (Conners 3), anxiety (SCAS-P) and adaptive behaviour (VABS-3).

For all four syndromes CSP-2 data indicated frequent differences in the processing of body position (response to joint/muscle position), touch, and movement information. Differences in the processing of oral information (response to tastes or smells) were also reported in 16p11.2 deletion and 16p11.2 duplication but these were not as evident in Sotos and TBRS. In terms of association with other clinical features, increased sensory processing differences were found to be associated with increased autistic traits in all four syndromes, with maladaptive behaviour in Sotos, and with increased anxiety in 16p11.2. deletion.

These findings demonstrate that sensory processing differences have profound effects in children with Sotos, TBRS, 16p11.2 deletion, and 16p11.2 duplication and should be carefully considered by clinicians, parents, and educators.

Presenting author: Harriet Smith harriet.smith@sheffield.ac.uk

Poster Session 1

Room 1

1. Investigating Developmental Prosopagnosia across the Lifespan

Judith Lowes: *Psychology, Faculty of Natural Sciences, University of Stirling*

Professor Peter J.B. Hancock: *Psychology, Faculty of Natural Sciences, University of Stirling*

Dr Anna K. Bobak: *Psychology, Faculty of Natural Sciences, University of Stirling*

Abstract

Developmental prosopagnosia (DP) is a lifelong neurodevelopmental condition characterised by severe face recognition problems. Individuals with DP can experience profound negative psychosocial consequences including anxiety, feelings of embarrassment and social isolation. DP is widely reported to be a heterogenous condition, both in presentation and severity. Two sub-types of DP, one affecting both face perception *and* memory, the other affecting only face memory, have been proposed in adults but it is not currently known whether these sub-types are also observed in children and adolescents.

This study is a large-scale systematic investigation of the nature and patterns of the underlying face processing deficits in DP across lifespan. Participants were 23 individuals aged 8 -71 years who reported difficulties recognising familiar faces and 119 age-matched controls. Participants completed an online battery of 11 neuropsychological tests tapping the multiple stages of face processing from detection and categorising of age and gender, through face matching to face recognition and identification. Results were analysed at group and individual case level. We present the main findings and compare patterns of results across four age groups 6 - 13, 14 - 35, 36 - 59 and 60 – 74 years. A key conclusion is that the current gold standard tests for DP, whilst useful, may lack sensitivity and specificity and that using a wider range of tests can be helpful to classify DP.

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2. Neurodevelopmental conditions & bilingual families: Access to information and support

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Background: While research has made progress in better understanding the needs of children with neurodevelopmental conditions, one population is still largely underserved: bilingual families. Although research suggests bilingualism does not have negative consequences for these children, parents are still concerned that bilingualism could have detrimental effects. Understanding what elements feed into these concerns would help us efficiently support these children and their families.

Objectives: This study aims at identifying 1) where bilingual parents of children with neurodevelopmental conditions find information regarding bilingualism; and 2) how the attitudes of their support network inform their language practices.

Methods: UK-based bilingual parents of children with a neurodevelopmental condition completed an online survey including quantitative and qualitative questions about their demographics, language profile, and attitudes towards bilingualism. Data collection is currently ongoing.

Results: 21 parents already completed the survey (18 females, mean age = 46.48 years, 3 autistic parents). Preliminary analysis showed that the few parents who had received information about bilingualism (9 parents) did so through support groups and the internet. Most parents indicated that clinicians and teachers were either supportive of bilingualism or did not have an opinion.

Conclusions: The preliminary results suggest that bilingual parents still do not have access to a clear pathway of support to find information regarding their specific situation, and that many professionals do not have access to up-to-date information either. For more optimal support to these children, there needs to be dedicated effort placed on training professionals and providing clear access to information for parents.

The results will be used to design and test training interventions aimed at improving face recognition in individuals with DP.

Presenting author: Bérengère G. Digard, Berengere.Digard@ed.ac.uk

3. Exploring the concordance of objective and subjective measures of sleep in children with neurodevelopmental disorders: a systematic review and meta-analysis

Mr Rory O'Sullivan. *University of Birmingham.*

Dr Stacey Bissell. *University of Birmingham.*

Dr Anna Hamilton. *University of Birmingham.*

Prof Andrew P Bagshaw. *University of Birmingham.*

Dr Caroline Richards. *University of Birmingham.*

Abstract

INTRODUCTION: Objective and subjective sleep measures are common throughout paediatric sleep research, and these tools often assess similar sleep parameters (e.g. sleep duration and night awakenings). The concordance of objective and subjective sleep parameter estimates has been extensively examined in typically-developing (TD) populations; however this is less understood in neurodevelopmental disorder (NDD) populations, despite the heightened prevalence and severity of sleep difficulties. Concordance estimates from TD studies may not generalise to NDD populations due to differences in sleep and caregiving contexts, sleep characteristics, and measurement error. Therefore, this study aims to (1) synthesise the existing literature to delineate the concordance of objective and subjective estimates of sleep in children with NDDs, and (2) compare this to concordance estimates from TD studies.

METHODS: A pre-registered systematic review and meta-analysis will be conducted (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42022307499). The NDD populations of interest include children (<18 years) diagnosed with autism, attention-deficit hyperactivity disorder, intellectual disability or rare genetic syndromes. Concordance will be quantified via Pearson's r correlation coefficients and differences in means. Random-effects or quality-effects meta-analytic models of concordance statistics will be calculated for each sleep variable, within each NDD group and the TD group. If the data allow, subgroup analyses will be conducted for each subjective and objective measure comparison (e.g. actigraphy-questionnaire, polysomnography-questionnaire).

CONCLUSION: Outlining the concordance of objective and subjective sleep estimates in children with NDDs, this study aims to foster improvements in data interpretation and methodological design amongst NDD sleep research, and increase accessibility of sleep research to NDD populations.

Presenting author: Mr Rory O'Sullivan, email: rxo165@student.bham.ac.uk

4. Executive Functioning and Depression Symptoms in Adults with ADHD and DCD

Maria Broletti, Christina Efthymiou, Emily McDougal, Aja Murray, Sinead Rhodes

University of Edinburgh

Abstract

Background: ADHD and Developmental Coordination Disorder (DCD) are two highly co-occurring neurodevelopmental conditions. Individuals with either or both conditions may encounter difficulties with executive functioning (EF) and are also more susceptible to poorer mental health than neurotypical peers, which continues into adulthood. Previous research has suggested a link between EF and depression symptoms; however, this has only been investigated separately in ADHD and DCD, and has not yet been examined in adult DCD. This planned study will provide a comparison of, and investigate the relationship between, EF and depression symptoms among adults with single and co-existing diagnoses.

Methods: We aim to recruit 138 adults diagnosed with ADHD, DCD, and combined ADHD+DCD to complete an online questionnaire. Measures will include the Adult ADHD Self-Report Scale (ASRS), the Adult Developmental Coordination Disorder/Dyspraxia Checklist (ADC), the Mood and Feelings Questionnaire (MFQ), and the Behaviour Rating Inventory of Executive Function-Adult Version (BRIEF-A).

Results: As a planned study, expected results will be presented. Group differences in EF and depression symptoms will be explored. Significant correlations between EF, depression symptoms and ADHD/DCD symptoms are predicted across groups, which may be followed up with mediation analyses to test the mediating role of EF.

Conclusion: This study hopes to further our understandings of the overlap between adult ADHD and DCD with regards to cognitive profiles and mental health, as well as inform of the role executive dysfunction may have in increasing levels of depression.

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5. . Cognitive predictors of individual differences in children's language acquisition

Presenting author:

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Co-authors:

Ewa Dabrowska, *University of Birmingham and Friedrich Alexander University*

Nick Riches, *Newcastle University*

Abstract

Consensus from children's language acquisition literature suggests that grammatical processing is entirely implicit. Grammatical deficits, typically seen in children with developmental language disorder (DLD), are attributed to impairment of the neural regions underlying procedural memory. Although we do not dispute these theories, we believe that both implicit and explicit processes are involved in language acquisition, in differing stages and degrees. Our research investigates implicit learning in children with and without DLD, as a predictor of linguistic ability. 97 children (73 typically developing children and 24 children with DLD), aged 6;9 -10;8 years participated in our online study. We used the Tower of Hanoi puzzle as a measure of the speed of automatization, and cognitive tasks measuring statistical learning, non-verbal intelligence, and working memory. Results were compared with performance on language tasks including grammatical processing, vocabulary, sentence production, and lexical and fluency measures from a narrative and spontaneous speech task. Initial results indicate that intelligence and working memory are robust predictors of linguistic ability in both groups. Grammar and vocabulary were strongly correlated overall, indicating that they do not rely on distinct learning processes. In the DLD group, we found a strong correlation between intelligence, working memory and vocabulary, and a stronger relationship between these predictors and grammar. Implicit learning did not predict linguistic ability in either group, and the speed of automatization showed an unexpected negative relationship with grammar in the DLD group. Overall, our findings support that non-verbal intelligence is a strong predictor of children's grammatical processing ability.

6. Identifying and Knowing about Behaviour (i-KNOW): a study protocol for assessing the feasibility of the i-KNOW programme for individuals at Clinical High Risk for behaviours that challenge.

Anna Hamilton^{1,2}, Laura Groves^{1,3}, Denise Bain^{1,6}, Chloe Brown¹, Debbie Allen⁴, Vivien Cooper⁵, Louise Daniel⁶, Megan Evison¹, Joanna Garstang⁷, Chris Jones¹, Kiran Kaur¹, Raman Kaur⁷, Ashley Liew⁶, Joe McCleery⁹, Chris Oliver^{1,2}, Lucy Phillips¹, John Rose¹, Melissa Samuels⁷, Doug Simkiss^{7,8}, and Caroline Richards^{1,2}

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⁹ Center for Autism Research, Children's Hospital of Philadelphia

Abstract

Background: Behaviours that challenge (BtC) are common in individuals with intellectual disability with prevalence and severity increasing with age. Thus, early identification of individuals at risk of BtC, and delivery of preventative interventions are crucial. We have developed a clinical algorithm (i-RISC) to identify individuals at risk of no, low or high severity BtC, *before* BtC emerges. To complement this, The Identifying and Knowing about Behaviour (i-KNOW) preventative intervention, which can be delivered at two levels of intensity based on level of risk, has also been developed. Research is now required to evaluate the feasibility of delivering the i-RISC and i-KNOW programme in clinical practice (<https://osf.io/j5x4q>).

Aims: To evaluate the feasibility and acceptability of using the i-RISC algorithm and i-KNOW intervention in an NHS clinical setting. A secondary aim will be to explore preliminary effectiveness.

Methods: A repeated measures design (pre- and post-intervention) will be employed. Family caregivers of children (aged 1-8years) with confirmed or suspected developmental difficulties ($n=300$) will be assessed for eligibility using the i-RISC algorithm and stratified into i-KNOW intervention workshops (risk of high severity BtC; estimated $n=45$) or remote learning (risk of low severity BtC; estimated $n=200$).

Results: Feasibility will be assessed through appraisal of recruitment and return rates, retention rates, and adherence and fidelity to the i-KNOW intervention. Acceptability of the intervention and preliminary efficacy will also be evaluated.

Conclusion: Results of this feasibility study will inform a future trial to assess efficacy of the i-RISC and i-KNOW programme in community practice.

Presenting author: Dr Anna Hamilton, a.hamilton@bham.ac.uk

Room 2

7. Coproduction of the Edinburgh Psychoeducation Intervention for Children and Young People (EPIC): Acceptability and Feasibility Data

Presenting Author: Claire Tai, *University of Edinburgh*

Co-Authors:

Emily McDougal, *University of Surrey*

Tracy Stewart, *University of Edinburgh*

Josie Booth, *University of Edinburgh*

Christina Efthymiou, *University of Edinburgh*

Ailbhe McKinney, *University of Edinburgh*

Sinead Rhodes, *University of Edinburgh*

Abstract

Background: The 'EPIC' intervention improves cognition, learning and well-being in children with Neurodevelopmental difficulties across an 8 week period of delivery at home and school. Ensuring interventions are also acceptable and enjoyable for children alongside being feasible for parents and teachers is important to identify during their development.

Aims: Using quantitative and qualitative methods we aimed to identify if the 'EPIC' play and activity based cognitive focused intervention was acceptable and feasible for children with Neurodevelopmental difficulties, their parents and teachers.

Methods: Children with NDD and their teachers were interviewed pre and post involvement about their knowledge of NDD and strategies used in a pilot study of the EPIC intervention. Parent insights were also sought. Children also completed ratings of their enjoyment and progress with strategies they learned and applied. Barriers and facilitators to intervention adherence and progress were also recorded.

Results: Children and their teachers showed a greater understanding of neurodevelopmental difficulties post intervention with greater reference to cognitive function. Teachers reported improvements in the children's use of strategies over the 8 weeks with children described as having developed their own strategies to help regulate themselves to new task demands. Children showed improvements in their ratings of enjoyment and progress with strategies (e.g. mind-maps, chunking) across the 8 week intervention period. Facilitators to intervention delivery included teacher use via a 'whole-class' approach, active learning activities, parent involvement and use of easily available materials.

Conclusion: EPIC is acceptable and feasible for children with NDD, their parents and teachers.

8. Sensory processing in autism and ADHD and its association to attention, anxiety and adaptive functioning.

Alokananda Rudra^{1,2}, Mary Hanley^{1,2}, Deborah Riby^{1,2}.

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Abstract

Background: Differences in sensory processing can have a significant impact on daily life. This has been well-documented for autistic children and young people (1,2) but less well so for people with ADHD, or co-occurring autism and ADHD

Aim: The aim of this study is to take a transdiagnostic approach to understand sensory processing in neurodevelopmental conditions (autism, ADHD, autism-ADHD) and how these are related to other key aspects of functioning (anxiety, attention, adaptive behaviour).

Method: 93 Parents of children [autism N=30; autism+ADHD N=16; ADHD N=16; and neurotypical N=31] between the ages of 6-11 years [mean age =8.5, s.d=1.6; 31 females, 62 males] were recruited. Participants completed 5 widely used standardised questionnaire measures (Social Responsiveness Scale, Conners Comprehensive behaviour rating scale, Vineland adaptive behaviour scale, Spence Children's Anxiety Scale and Sensory profile 2 caregiver questionnaire) by post. Analyses are underway, and while group comparisons will be made across measures, the main focus will be cluster analysis to explore if there are profiles of specific difficulties emerge in the whole group (e.g. greater sensory, anxiety, attention, and adaptive behaviour difficulties), and whether these fall across diagnostic boundaries.

Conclusion: Understanding the impact of sensory differences in daily life is really important, because they can have a significant effect on daily life. This research addresses a gap in the literature by taking a transdiagnostic approach to understanding sensory differences and their impact on anxiety, attention and adaptive behaviour.

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9. Young people's experiences of Fetal Alcohol Spectrum Disorder: a photovoice study

Miranda Eodanable, Sinead M Rhodes, Katie Cebula

University of Edinburgh

Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disability that is caused exclusively by prenatal alcohol exposure. It is associated with a discourse of stigma towards biological mothers and perceived negative experiences for individuals diagnosed with FASD. However, limited research has explored the experiences of adolescents with FASD regarding their disability or their views about a FASD diagnosis. A Photovoice study was therefore conducted online with 8 young people (age 12-19 years; 2 female, 6 male) in the UK. Parents (n=7; 4 adoptive, 2 foster carers and 1 birth parent) completed a screening measure of Intellectual Disability and a background questionnaire regarding their children. The Photovoice procedure included individual interviews with young people about activities across home, school and the community and their photos, a group training session, episodes of photo-taking and concluded with a group interview session. Participant-led analysis suggested: the significance of family relationships in terms of nurture, adult support, and daily living activities; and a continuous need for adjustments across school, home and the community. Researcher-led analysis using Interpretative Phenomenological Analysis indicated a distinct individual process for the young people in terms of disability identity development, where the identity extends to a wider FASD community in later adolescence. Study findings also emphasised that young people with FASD can contribute to a wider academic, public, and professional understanding of FASD disability. While parents play a significant role in educating their children on FASD, there are also implications for the role of professionals in supporting children's understanding.

Presenting author: Miranda Eodanable (Miranda.eodanable@ed.ac.uk)

10. Title of the presentation: An overview of a feasibility home-based motor control and learning intervention study for young autistic children.

Tugce Cetiner, Jo Van Herwegen, & Spencer J. Hayes

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University College London*

Abstract

The Background of the Study and Aim:

Autistic children experience difficulties when performing challenging (Harris, Little & Akin-Little, 2017) motor skills like handwriting (Fuentes, Mostofsky & Bastian, 2009). Autistic individuals demonstrated (Foster et al., 2020) better motor performance when imitating novel movements following blocked practice (i.e., the same trial type is performed across a practice; e.g., A, A, A), compared to random practice (i.e., different trial types are performed across a practice; e.g., A, C, B). We will examine the effects of practice structure on the acquisition and transfer of handwriting letters during a feasibility of new home-based motor intervention study: "Autism Early Intervention for Motor Skills (AIMS)".

Method

Design: 2 Group [BR; RB] x 2 Letter type [Novel (Gokturk); Familiar (English)] x 3 Phase [Pre-Test, Post-Test 1, Post-Test 2] mixed design.

Participants: Autistic children aged between 4 and 5.

Procedure: AIMS will be implemented at home by parents across 6-weeks, 5 days a week, 10 minutes per day. During AIMS, children will learn to perform the Gokturk letter writing activities using experimental storybooks. Across weeks 1 to 3, the BR group will receive blocked practice and the RB group random practice. Across weeks 4 to 6, the BR group will receive random practice and RB group blocked practice.

Measures: Letter-writing (Gokturk and English) will be quantified to examine feedforward and feedback control using kinematic analysis in the Pre-Test, Post-Test 1 (after week 3), and Post-Test (after week 6).

Presenting author: Tugce Cetiner , tugce.cetiner.19@ucl.ac.uk

11. Proband traits of ASD and ADHD associate with infant sibling temperament development

Halkola, H.¹, Pickles, A.¹, Begum Ali, J.², Gui, A.², Pasco, G.¹, Johnson, M.³, Charman, T.¹, Jones, E. J. H.², and The BASIS and STAARS Teams

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²*Centre for Brain and Cognitive Development, Department of Psychological Sciences, Birkbeck, University of London*

³*Department of Psychology, University of Cambridge*

Abstract

Background: Autism and ADHD are both highly heritable neurodevelopmental conditions. Previous prospective studies have shown associations between temperament measures of fear/shyness and later autism traits, while activity level and attention associate with later development of ADHD traits. Only a few previous studies have investigated how autism and ADHD traits of older siblings associate with temperament in their infant siblings.

Aims: To explore how proband autism and ADHD traits associate with the development of early childhood predictors of autism and ADHD in infant siblings with a family history of autism.

Methods: The study included 411 infant participants and their older siblings with autism and/or ADHD or neither. Parents rated infant fear/shyness, activity and attention using Infant/Early Childhood Behavior Questionnaire, and proband autism and ADHD traits using the Social Communication Questionnaire and Conners 3 parent questionnaire, respectively.

Latent growth curve models tested how autism family history and proband traits of autism and ADHD associated with the development of fear/shyness, activity, and attention in infants at 8, 14 and 24 months.

Results: Higher proband autism symptoms associated with higher level of initial fear/shyness in infants, while more ADHD symptoms associated with higher initial infant activity level. Infants with probands with higher ADHD traits had higher scores in initial attention, but lower change in attention over time, while family history of autism associated with lower initial attention and higher level of change over time.

Key conclusion: Proband traits of autism and ADHD relate to temperament trajectories of their infant sibling in a distinctive manner.

Presenting author: Hanna Halkola, hanna.halkola@kcl.ac.uk

12. Assessing vocabulary outcomes in infants with an elevated likelihood of autism spectrum disorder: A comparison of parental report versus researcher administered testing

Zsofia Belteki^{1*}, Emma Ward², Jannath Begum Ali², Tony Charman³, Greg Pasco³, Ellen Demurie⁴, Petra Warreyn⁴, Jan Buitelaar⁵, Sabine Hunnius⁵, Sven Bolte⁶, Terje Falck-Ytter^{6,7}, Maja Rudling⁷, Carlijn van den Boomen¹, Alicja Radkowska⁸, Przemek Tomalski⁹, Caroline Junge¹, Ewa Haman⁸

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Abstract

Infants with an elevated likelihood (EL) of autism diagnosis due to family history often have lower vocabulary scores than their typical likelihood (TL) peers across various language assessment types. These assessments can differ in how they test for infants' vocabulary size. For example, whereas the MacArthur-Bates Communicative Developmental Inventory (CDI) relies on parental reports of vocabulary size, The Mullen Scales of Early Learning (MSEL) relies on researcher-administered tests. In these analyses, we assess whether the language scores that infants receive on the CDI and MSEL are comparable, and whether the comparability across the measures differs depending on the infants' group classification (EL and TL). In total, 263 EL and 141 TL 14-month-old infants from the Eurosibs longitudinal prospective dataset were included in the analyses. Infant's percentile scores on the CDI and the MSEL were compared. For receptive vocabulary, a significant interaction between method and group was observed ($\beta = 8.94$, $SE = 4.25$, $t = -2.1$, $P < .04$), indicating that the disparity between CDI and MSEL scores was larger for TL compared to EL infants. This interaction between method and group was not observed for expressive vocabulary, ($\beta = 0.39$, $SE = 4.46$, $t = .088$, $p = .93$). These results may indicate that the MSEL is under-estimating the true ability of the infants. The under-estimation of true ability may be more pronounced in the LL infants, because their vocabulary scores tend to be higher than those of EL infants.

Room 3

13. Tactile sensitivity: Sex differences and impact on social and interpersonal difficulties in autistic adults

Reece Chan, Alexandra Mladenovic, Deirdre Birtles

Royal Holloway, University of London

Abstract

Tactile sensitivity is reported in autistic adults but there has been little research on sex differences or on the impact of tactile sensitivity on social and interpersonal difficulties. The current study explored tactile experiences of autistic adults to better understand their social challenges, and sex difference in tactile sensitivity using a mixed methods approach. Autistic adults (N = 67; males = 30) completed an online survey measuring tactile sensitivity and autistic traits (AQ-short). Factorial ANOVA was used to explore differences in tactile sensitivity between males and females with high (Scores ≥ 84) and low (< 84) autistic traits. Data from three open-ended questions on situations and clothing that were problematic for participants were coded and analysed using thematic analysis with a focus on social and interpersonal difficulties (N = 12). Quantitative analysis showed no difference in tactile sensitivity between males and females but individuals with high levels of autistic traits had higher tactile sensitivity. A significant interaction was observed where males with high autistic traits had higher tactile sensitivity. Three overarching themes were identified; 1) Nature of the tactile situation, where participants expressed concerns over involuntary contact, violation of personal space and the impact of context; 2) coping tactics included avoidance, camouflage and ability to self-balance; 3) interpersonal consequences was focused on how symptoms and coping strategies led to negative interactions with others. Greater recognition of the impact of tactile sensitivities on autistic adults is needed along with a willingness to accept individual differences and promote autism-friendly tactile environments.

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14. Phenotypic Characteristics and variability in CHARGE Syndrome: A PRISMA Compliant Systematic Review and Meta-Analysis and supporting interview study

Andrea T. Thomas^{1,2*}, Jane Waite^{2,3}, Caitlin A. Williams⁴, Jeremy Kirk⁵, Chris Oliver¹, Caroline Richards^{1,2}

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Background: CHARGE syndrome (OMIM #608892) is a phenotypically complex genetic condition characterised by multi-system, multi-sensory impairments. Behavioural, psychological, cognitive and sleep difficulties are not well delineated.

Aims: To investigate the prevalence of physical, behavioural, psychological, cognitive and sleep characteristics and conditions in CHARGE syndrome, and to explore potential associations with biopsychosocial factors.

Methods: The study is a two-stage mixed methods design:

-Stage 1: A meta-analysis was conducted to elucidate the prevalence of characteristics and conditions in CHARGE syndrome. Pooled prevalence estimates were calculated using reliable, prespecified quality weighting criteria, and meta-regression was conducted to identify directional associations between characteristics.

-Stage 2: Psychometrically robust interviews were conducted with parents to explore potential functions of behaviours that challenge identified in Stage 1 and associations between age and adaptive behaviour.

Results:

-Stage 1: Of the 47 eligible studies, data could be extracted for 1,583 participants. Prevalence estimates were highest for developmental delay (84%), intellectual disability (64%), aggressive behaviour (48%), self-injurious behaviour (42%) and sleep difficulties (45%). Meta-regression indicated significant associations between sleep difficulties and growth deficiency, and sleep difficulties and gross motor difficulties.

-Stage 2: Provisional results from the first 10 participants indicate that the most common functions associated with behaviours that challenge include Reinstatement of Routine/Repetitive Behaviour (63%) escape from demands (58%), and pain or discomfort (58%).

Conclusions: Our comprehensive review of diagnostic signs, behavioural, psychological, cognitive and physical characteristics, conditions and comorbidities in CHARGE syndrome, supported our interview study, provides an empirically based foundation to further research and practice.

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15. Visual Attention to Faces and Temporal Frequency: A Prospective Longitudinal Study of Infants with a Family History of Autism and ADHD

Authors: M. A. Agyapong¹, M. H. Johnson^{2,3}, T. Charman¹, E. J. H. Jones², and the BASIS/STAARS Team^{1,2}.

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²*Centre of Brain and Cognitive Development, Department of Psychological Sciences, Birkbeck College, University of London*

³*Department of Psychology, University of Cambridge*

Abstract

Background: Throughout infancy, there are developmental changes in infant's face-scanning patterns. This shapes and reflects their processing of social information like language. The temporal structure of events also influences visual attention. However, it is unclear how mouths moving at different frequencies affects visual attention, particularly in the development of autism and ADHD.

Aims: To investigate attention to eyes, mouth and temporal structure (i.e. information presented at different frequencies), in infants at familial typical-likelihood (TL) and elevated-likelihood (EL) of autism and/or ADHD.

Methods: This prospective study included 161 infants (70 females); 29 TL controls, 80 EL-Autism, 31 EL-ADHD and 21 EL-Autism+ADHD. At 5-, 10- and 14-month timepoints, infants were presented with three 10-second videos of face pairs. Each stimulus flashed at low, mid or high frequencies to show the mouth opening and closing in every other frame.

Results: A Generalised Linear Mixed Model assessed the main effects and interactions of autism and ADHD familial likelihood, age and frequency on eye-mouth index (EMI). There was no effect of EL-Autism, but EL-ADHD infants looked more to the eyes than the mouth compared to TL-ADHD infants. EMI significantly decreased as age increased, and there was no effect of temporal frequency.

Conclusions: Infants with typical- and elevated-likelihood of autism show similar EMI. Increased looking to the eyes in EL-ADHD infants may reflect early difficulties in modulating attention. Temporal frequency is not a key modulator of EMI. Overall, infants look more at the mouth as they get older, which is consistent with language emergence.

Presenting author: Mary Abena Agyapong (PhD Student), mary.agyapong@kcl.ac.uk

16. Tackling the health inequalities experienced by people with a learning disability who are homeless

Karen McKenzie (*Northumbria University*), Matt Kaczmar (*Cruddas Park Surgery*), Alex Shirley (*Changing Lives*), George Murray (*Northumbria University*), Dale Metcalfe* (*Northumbria University*), and Rachel Martin (*Northumbria University*).

Abstract

It is thought that people with learning disability often experience homelessness. However, many people who are homeless do not have their learning disability recognised or diagnosed. Feasibility studies show that screening tools for learning disability might be appropriate to use in homeless services. If so, this would significantly improve detection of people with learning disability and better inform support offered to them.

The current study has two components. First a quantitative arm, evaluating performance of the Learning Disability Screening Questionnaire (LDSQ) in a homeless service. Second, a qualitative component, interviewing stakeholders in the area (e.g., development workers, clinicians), outlining a pathway for the LDSQ's integration into homeless services.

The study is ongoing, at present it indicates that it is not uncommon for people who are experiencing/have experienced homelessness to have an unidentified learning disability. It evidences that the LDSQ, when used in this capacity, has good agreement with adaptive assessments and successfully identifies people who are likely to have an undiagnosed learning disability. The research has already had a direct impact on people, with people being added to the learning disability register and having their action and treatment plans adjusted accordingly.

The qualitative components are forming the basis of a pathway. They indicate that people are open to the idea of using such tools, if done in the right way, and provide ideas of how and where such screening tools could be integrated into the existing systems.

This project is funded by NIHR ARC North East and North Cumbria.

Presenting author: Dale Metcalfe (Northumbria University; dale.r.metcalfe@northumbria.ac.uk)

17. What is the impact of shielding on children and young people in IMAGINE-ID?

Hannah Aissa, Harriet Housby, IMAGINE ID Consortium, David Skuse & Jeanne Wolstencroft

All authors: *Great Ormond Street Institute of Child Health, University College London, London, UK*

Abstract

Background: IMAGINE-ID is a UK cohort study of children and young people (CYP) aged between 6-26 with intellectual disability (ID) of genetic aetiology. Due to their complex physical health presentations, they were more likely to have been shielding than the general population during the COVID-19 pandemic.

Methods: 1063 caregivers completed the Strengths and Difficulties Questionnaire (SDQ) and the Coronavirus Health and Impact Survey (CRISIS) between May-December 2021.

Results: On CRISIS 40.5% (n=431) of caregivers reported that their child had been shielding during the pandemic. CYP who had been shielding had significantly higher scores on the parent-rated SDQ emotional problems subscale ($p=.002$); and significantly lower prosocial behaviour subscale scores ($p<.001$) compared to those who were not shielding. There were no significant group differences between scores on the other SDQ subscales: conduct problems, hyperactivity or peer problems.

84.5% (n=898) of CYP faced challenges due to the pandemic. The most commonly reported challenges were social distancing (n=256; 24.1%), anxiety (n=229; 21.5%), loneliness (n=146; 13.7%) and low mood (n=71; 6.7%). There was no association between reported biggest challenge and shielding status ($p=.5$).

Conclusion: CYP experienced a range of challenges during the pandemic. Those who were shielding were reported to have greater emotional difficulties and worse prosocial skills than those who were not shielding. Our analysis did not control for pre-pandemic SDQ scores. Further analyses are needed to establish whether emotional and pro-social difficulties were associated with shielding behaviour or associated with the characteristics of those children and/or parents that choose to shield their children.

Presenting author:

Hannah Aissa, Undergraduate Placement Student, h.aissa@ucl.ac.uk

18. Screening for gastric pain in people with Neurodevelopmental Disorders and Intellectual Disability

Kelly Wade*, Chloe Brown, Caroline Richards

University of Birmingham

Abstract

Background

Painful gastric health conditions are known to be more prevalent in people with neurodevelopmental disorders (NDD) and intellectual disability (ID) than their typically developing peers. One oft cited barrier to effective treatment for health conditions in this group is effective detection and diagnosis. This set of studies report on the development and validation of a behavioural screening tool for gastric pain.

Method

Following the development of the Gastric Distress Questionnaire in 2007 the tool was integrated into a large longitudinal caregiver report survey gathering data on children (n=562) and adults (n=191) with a range of genetic syndromes associated with NDD and ID. In 2017 a clinical study was undertaken attempting to validate the GDQ against clinical diagnosis of gastroesophageal reflux disease and other gastric health conditions in children with ID referred to a gastro-enterology clinic.

Results

Children whose parents reported them having reflux in the four weeks prior to completing the GDQ scored significantly higher than those without parent reported reflux ($p < .001$). Further analysis of survey data determined an appropriate cut off score for the use of the GDQ as a screening tool which might identify children in need of further clinical investigation. Children referred to the gastro-enterology clinic were all found to score well above the suggested cut off.

Conclusion

The GDQ is a promising screening tool for identifying children who may benefit from clinical investigation for gastric health conditions. However, thorough clinical validation of this tool poses a number of practical and ethical challenges.

***Presenting author** – contactable at k.a.wade@bham.ac.uk

Poster Session 2

Room 1

19. All-cause and cause-specific mortality in people with autism spectrum disorder: a systematic review

Laurence Forsyth¹, Marc McSorley¹, and Ewelina Rydzewska²

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²*Clinical & Health Psychology, School of Health in Social Science, University of Edinburgh*

Presenting author: Laurence Forsyth

Abstract

Background: The current literature suggests that individuals with autism spectrum disorders (ASD) experience an increased risk of mortality compared to the general population.

Aims: The main aim of this systematic review was to synthesise relevant studies in order to identify whether individuals with ASD experience an increased risk of mortality compared to the general population. The additional outcome was to establish which specific causes of death are more prevalent in ASD individuals compared to the general population.

Methods: Medline, Embase, CINAHL and PsycINFO databases were searched. There were no time limiters applied to the search. Strict inclusion/exclusion criteria were used to double screen the papers for eligibility. The review included a systematic data extraction and double quality assessment and was registered with PROSPERO (CRD42021219582).

Results: 18 of the 8,395 retrieved papers were included in the review. All 18 studies reported an increased risk of mortality for individuals with ASD. The highest standardised mortality ratio for people with ASD was 5.6 (95% CI= 2.5-10.5). The most common causes of deaths were from external causes, suicide and neurological diseases.

Conclusions: Individuals with ASD appear to be at a significantly higher risk of mortality when compared to the general population. The causes of death amongst the ASD population are markedly different to the general public. It is vital that ASD individuals receive adequate care from healthcare systems to ensure that potentially modifiable co-occurring conditions are actively assessed for, diagnosed, and treated.

Keywords: *autism spectrum disorders, mortality, systematic review*

20. Interactions between Alterations in Infant Excitation/Inhibition Balance and Executive Attention Predict Autistic Traits in Childhood

Virginia Carter Leno¹, Jannath Begum-Ali², Amy Goodwin¹, Luke Mason², Greg Pasco¹, Andrew Pickles¹, Shruti Garg³, Jonathan Green³, Tony Charman¹, Mark H. Johnson^{2,4}, Emily J. H. Jones² and the EDEN and STAARS Teams⁺.

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Abstract

Background: The heterogeneity of autism may be in part due to interactions between early risk features (e.g., alterations in E/I balance) and later developing resilience factors (which may buffer the impact of early cortical atypicalities).

Aims: 1) To test for differences in E/I balance in 10-month-old infants with neurofibromatosis type 1 (NF1) and infants at enhanced familial likelihood for neurodevelopmental outcomes, 2) To test whether emerging executive functioning abilities moderate the association between infant E/I balance and toddler neurodevelopmental traits.

Methods: At-rest electroencephalography (EEG) recordings were collected from infants who; had a diagnosis of NF1 (N=21), or were at typical (N=24), or elevated likelihood for neurodevelopmental outcomes (by virtue of having a family history of autism (N=67), ADHD (N=24), or both (N=19)). A subgroup of infants (N=94) also completed assessments of executive attention, neurodevelopmental traits in toddlerhood. E/I balance was measured by estimating the aperiodic slope of the power spectrum (e.g., 1/f). Group differences were tested using mixed-effect models. Moderation by executive attention was tested by including an aperiodic slope*24-month executive attention interaction in a regression predicting 36-month autism and ADHD traits.

Results: Infants with NF1 displayed steeper aperiodic slopes, suggestive of enhanced inhibition. Elevated likelihood infants did not exhibit alterations in E/I balance. The aperiodic slope* executive attention interaction was significant, such steeper aperiodic slopes predicted greater 36-month autism traits, but only in infants who had lower executive attention abilities.

Conclusion: Results highlight the importance of considering interacting risk and resilience factors when seeking to understand neurodevelopmental outcomes.

Presenting author: Virginia Carter Leno, virginia.carter_leno@kcl.ac.uk

21. Literacy profiles of Autistic pupils at the start of primary school in a representative Scottish sample.

Helen Corby, Josie Booth, Sinead Rhodes, (*all University of Edinburgh*),
Louise Marryat (*University of Dundee*), Rachael Wood (*Public Health Scotland*).

Abstract

Background: Previous research has explored literacy skills in children with autism, finding that in some areas, autistic children have difficulties compared to their allistic peers. While early literacy skills lay the foundations for later reading competence, there is comparatively little research on this in samples of young autistic children.

Aims: This study aims to explore the early literacy skills of autistic children, drawing a comparison with their allistic peers. Data will be drawn from a linked dataset of Scottish children aged 4-5 years old, which brings together children's health data and detailed local education data for the first time.

Methods: Scores on the York Assessment of Reading for Comprehension (YARC) will be used to create literacy profiles. We will use routinely collected health data to identify factors associated with performance in early literacy. Furthermore, we will explore whether autistic children have similar or different profiles of early literacy skills compared to allistic children, along with determining the different profiles within children with autism, who are known to be a diverse group.

Findings: Analysis will be completed by June 2022.

Conclusions: Understanding the early literacy skills of autistic children could help identify the areas in which they could benefit from greater support. This in turn could improve the development of reading competence. The implication of these findings will be discussed, particularly those relevant to education, teachers and schools.

Presenting author: Helen Corby - dcorby@exseed.ed.ac.uk

22. A systematic review and meta-analysis of the prevalence of suicidality in autistic and possibly autistic people without co-occurring intellectual disability.

Victoria Newell (*University of Nottingham*), Sarah Cassidy (*University of Nottingham*), & Caroline Richards (*University of Birmingham*).

Abstract

Background

Suicidality is highly prevalent in autistic people without co-occurring intellectual disability, but exact estimates vary widely across research and have not yet been synthesised meta-analytically. Moreover, high levels of autistic traits are found in adults who have attempted suicide, yet few studies have examined the prevalence of suicidality in possibly autistic people.

Aims

1) Calculate pooled prevalence estimates for suicidality in autistic people and possibly autistic people without co-occurring intellectual disability; 2) Evaluate the influence of person and study characteristics on heterogeneity; and 3) Determine the quality of evidence.

Methods

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed, and the review was prospectively registered with PROSPERO (registration no. CRD42021266451). PubMed, OVID (PsycINFO, Embase, MEDLINE) and Web of Science were systematically searched from 1992 to January 25, 2022. Studies reporting suicidality prevalence rates (suicidal ideation, suicide plans, suicidal attempts and behaviours) were selected for inclusion if published, written or available in English, used an observational design, and employed quantitative methods.

Results

The final selection included 41 studies. Findings from the meta-analysis are forthcoming. Random effects models will be used to calculate pooled prevalence estimates for each element of suicidality with 95% confidence intervals. This will be followed by subgroup analyses and meta-regressions to explore heterogeneity.

Conclusions

The current review has implications for understanding and preventing suicide in autistic and possibly autistic people. Future research should aim to adapt measures of suicidality, identify unique risk factors, and extend existing theories of suicide.

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23. Sensory processing and eating behaviours in autism: A systematic review

Presenting author: Emy Nimbley, E.Nimbley@sms.ed.ac.uk

Co-authors:

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- Fiona Duffy: Fiona.Duffy@ed.ac.uk

Abstract

Background: Atypical eating behaviours, such as picky eating or fear of trying new foods, are frequently reported in autism across the lifespan. Early accounts and studies of aversions to food based on sensory features, combined with the reporting of taste and smell sensitivities in autistic individuals, have led to a possible link being proposed between sensory processing and atypical eating behaviours in autism (Cermak et al, 2010). Thus far, the literature has been hindered by significant heterogeneity in terminology and frequent use of non-autism specific measures.

Objectives: The current review aims to provide clearly defined and conceptualised eating behaviours and to identify, evaluate and synthesize up-to-date literature to provide an evidence-based answer to the following question: is there a relationship between sensory processing and eating behaviours in autism?

Methods: Five electronic databases were searched: psychINFO, Scopus, PubMed and Web of Science were used to search for published studies, while ProQuest Dissertation and Theses was used to search for unpublished studies. Risk of bias was assessed for each included study.

Results: 26 papers reporting on 25 studies were included in the current review. Across studies, there was consistent evidence of a relationship between sensory processing and a broad range of eating behaviours. Taste sensitivities were particularly implicated, as well as hypersensitivities, with early evidence to suggest this was more pronounced in autism compared to neurotypical peers and that this relationship extends across development. Findings also highlighted tentative evidence to suggest a multi-dimensional impact of the relationship, particularly with regards to emotion.

Discussion: Study findings are discussed in relation to broader methodological and conceptual considerations and limitations. A broader investigation of multi-sensory issues in autism will allow for a better understanding of different eating behaviours. Possible implications for interventions and the development of eating disorders are also discussed.

24. Neuronal gating of tactile input and sleep in infants at typical and elevated likelihood for autism spectrum disorder

Anna De Laet¹, Elena Serena Piccardi^{2,3}, Jannath Begum-Ali², Tony Charman⁴, Mark H. Johnson^{2,5}, Emily J.H. Jones², Rachael Bedford^{6*}, Teodora Gliga^{1,2*} and the STAARS Team^ϕ

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Abstract

Sleep problems in Autism Spectrum Disorder (ASD) emerge early in development, yet the origin of different sleep difficulties remains unclear. Here, we characterise developmental trajectories in sleep onset latency and night awakenings in infants at elevated likelihood (EL) for ASD (who have an older sibling with ASD) and infants at typical likelihood (TL) for ASD. Further, we test whether the ability to gate tactile input associates with variation in sleep onset latency and awakenings. Parent-reported night awakenings and SOL at 5, 10 and 14 months were analyzed using generalized estimating equations. Gating of tactile stimulation, measured at 10 months using an EEG tactile suppression index (TSI), was entered as a predictor of sleep both concurrently at 10 months and longitudinally at 14 months. Number of night awakenings and SOL decreased in TL infants over time, but not in infants at EL for ASD. Compared to TL infants, infants at EL had significantly more night awakenings and longer sleep onset latency at 10 and 14 months. The TSI predicted sleep onset latency concurrently at 10 months, independent of ASD likelihood status, but not longitudinally at 14 months. The TSI did not predict night awakenings concurrently or longitudinally. These results imply that infants at EL for ASD wake up more frequently during the night and take longer to fall asleep from 10 months of age. At this age, sensory gating predicts sleep onset latency, but not night awakenings, suggesting sensory gating differentially affects neural mechanisms of sleep initiation and maintenance.

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Room 2

25. How does visual attention to social and non-social information influence learning and memory for autistic children and adolescents?

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Abstract

Autism is characterised by a distinct profile of strengths and weaknesses across cognitive domains, including attention and memory (Ames and Fletcher-Watson, 2010; Boucher et al., 2012). It is widely recognised that such strengths and difficulties may manifest differently in social and non-social contexts (Chita-Tegmark, 2016; Guillon et al., 2014). Previous studies that have explored these cognitive signatures have focused on either attention or memory, with the majority of studies focusing on attention alone. As a result, little is known about how attention and memory interact in autism. For example, how does attention influence learning and memory? Furthermore, how does social (or conversely, non-social) information in one's environment shape this relationship?

The objectives of the study were to: (1) examine how autistic children and young people attend to, learn, and remember information in the presence of social and non-social information, using behavioural and eye-tracking measures, and (2) explore how individual differences (e.g. social functioning and anxiety) influence attention and memory.

Thirty-one autistic children / young people and 31 neurotypical children / young people ($M_{age} = 11.67$ years; $N = 62$) completed a visual search and memory task, including scenes containing social or non-social information. First, in the learning phase, participants searched for target objects embedded in social or non-social scenes. Second, in the memory phase, they recalled the locations of the targets by placing them in the remembered locations within the same scenes. Both behavioural and eye gaze measures were recorded throughout the task. Parents completed the Social Responsiveness Scale – 2, and Spence Child Anxiety Scale, as respective measures of social functioning and anxiety.

Search time and memory precision measures showed that all children and young people learned and remembered information equally well in social and non-social contexts. In both learning and memory phases, eye-tracking revealed that *all* children gave significantly more attentional priority to and engaged more with the social than non-social information. Further, improvements in search time speed were significantly related to better memory precision in social scenes only. Individual differences in social functioning and anxiety moderated these effects in autistic children. Specifically, levels of social functioning

($r(24) = .42, p = .043$) and anxiety ($r(24) = .45, p = .027$) were positively related to the duration of looking to the social information in the memory phase.

Contrary to expectations, results indicate that all children and young people showed similar attentional profiles and memory profiles in social and non-social contexts, at least when social stimuli are not the explicit target of attention. Combining eye-gaze and behavioural data, we suggest that social information may be used by all to aid learning and memory. Critically, individual differences measures suggest that autistic children and young people experiencing more anxiety and social difficulties may be more hypervigilant to social information. We suggest that this hypervigilance may be useful in guiding memory (Doherty et al., 2017). These results shed novel insights into the interaction of attention, learning, and memory in autistic children, and provide a framework for understanding how social information may be used to facilitate these processes.

26. “Autistic kids do get a little lonely”: social interactions, friendships, and eye contact in autistic adolescents

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Abstract

Differences in social interactions have been reported for some autistic teenagers relative to neurotypicals, particularly in domains such as eye contact, initiating friendships, and social interactions. However, existing research has predominantly emphasised social interactions with unfamiliar people or has examined eye contact outside everyday social experiences (e.g., using experimental contexts). It remains unclear the extent to which this existing research maps onto the direct lived experiences of autistic adolescents, particularly given the complexities and context-dependent nature of naturalistic social behaviours. This necessitates the inclusion of the ‘autistic voice’ when exploring potential difficulties in everyday social interactions, friendships, and eye contact.

To aid providing this voice, 15 co-constructed online semi-structured interviews were conducted via Microsoft Teams with autistic adolescents (ages 12-17, mean age 15) about their lived experiences of social interactions, friendships, and eye contact. Our results, analysed through reflexive thematic analysis, highlighted a need for shared understanding; emphasising that a shared neurotype may facilitate but be neither necessary nor sufficient for successful friendships. Likewise, we describe the use of eye contact as a context-dependent and idiosyncratic social tool with adaptations by both autistic and non-autistic adolescents within friendship dyads. Findings will be explored in relation to notions of double-empathy, equifinality in social interactions, the role of neurotypical behaviour in facilitating social interactions with autistic people, and communication across and within neurotypes.

27. Pain in Autistic Children: Interviews with Child-Parent Dyads

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Dr Ben Rosser, Supervisory Team, *School of Psychology, Liverpool John Moores University*

Dr Michelle Failla, Supervisory Team, *College of Nursing, Ohio State University*

Professor Helen Poole, Supervisory Team, *School of Psychology, Liverpool John Moores University*

Dr David Moore, Lead Supervisor, *School of Psychology, Liverpool John Moores University*

ABSTRACT

Despite up to 14% of paediatric chronic pain cases involving autistic children highlighting a clear health disparity to address, research understanding pain experience in autistic children remains sparse. This study explores pain experiences of autistic children from both the autistic child's and their parent/guardian's perspective. Doing so, this study addresses knowledge gaps regarding how autistic children understand their pain and seek care from others. Six parent-autistic child dyads each completed an online questionnaire and a follow-up online semi-structured interview. Questionnaires collected demographical information and identified an experience of pain for each autistic child to discuss within the interview. Semi-structured interviews gained insight of each autistic child's pain experiences, behaviours, emotions, and cognitions from their own, and parents' perspective. Interpretative phenomenological analysis was used to analyse verbatim transcripts, acknowledging the principal investigators own lived experience as an autistic person. At present provisional analyses suggest trust stands as a key factor to whether an autistic child discloses pain, with participants highlighting a small collective of individuals the autistic child will go to when in pain. Additionally autistic children report finding medical communication exclusive, and that 'masking' becomes significantly more challenging when in pain. Our interviews suggest autistic children might be especially vulnerable when in pain: here it is critical carers and healthcare providers build trust to encourage pain disclosure. Moreover, carers and healthcare providers must engage with the child on their own terms to support discussion and pain management while minimising distress and permitting the child to 'be themselves'.

NOTE: Data is preliminary, and data collection is still ongoing at time of submission and will end with a total of 10 parent-child dyads.

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28. Differential Eye Gaze Cue Processing in Autism Spectrum Disorder

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Abstract

While previous research has explored the extent to which eyes are used to guide attention in people with Autism Spectrum Disorder (ASD), it is nonetheless unclear how eyes can direct attention when stimuli are presented centrally and peripherally. The present research evaluated the ability of eye gaze as a social cue to orient attention in adults with ASD. It looked at endogenous and exogenous cueing and evaluated differential effects. Participants responded via keyboard press and were required to detect a target that was congruently or incongruently cued by the direction of the eyes presented in a schematic face. Faces were presented either centrally or peripherally using five different stimulus onset asynchronies (SOAs). In the central condition, eye gaze shifted to the right or left, while in the peripheral condition the pupils appeared either in the right or left face. Reaction time (RT) and accuracy were compared between subjects with ASD and without ASD. Results thus far indicate faster RTs for central cueing at all SOAs tested, with an interaction between face condition, SOA, and ASD diagnosis (all $p < .05$). Findings will be discussed in relation to current theories suggesting differences in how people with autism differentially process eye gaze and symbolic cues.

29. Examining the interaction of autism diagnosis and anxiety on daily functioning through tactile processing sensitivity: A moderated mediation model

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Abstract

Despite high amounts of autism literature there is limited attention devoted to the impact of tactile sensitivity, specifically issues related to clothing on daily functioning in autistic adults. The current research explored differences in clothing focused tactile sensitivity between autistic and non-autistic adults whilst investigating the mediating role of tactile sensitivity on the relationship between autism diagnosis and daily functioning and whether anxiety moderated the proposed model. A sample of autistic (n = 69) and non-autistic (n = 224) adults were recruited to complete an online questionnaire. Multivariate analysis of variance revealed autistics had significantly higher levels of tactile sensitivity and anxiety and lower levels of daily functioning compared to non-autistic adults. The moderated mediation demonstrated that anxiety did not moderate the indirect effect of diagnosis upon daily functioning through the tactile sensitivity factors. The relationship between autism diagnosis and daily functioning was mediated by tactile sensitivity but anxiety did not moderate diagnosis and daily functioning relationship. However, there are implications to be considered regarding the sensory support provided to autistics and environmental adaptations that can be made to limit general anxiety and its influence upon processing sensitivities and daily functioning in autistics. The findings confirm sensory processing difficulties persist into adulthood of autistics, specifically tactile clothing sensitivities. Although tactile sensitivity impacts daily functioning, the impact of other sensory processing sensitivities is unknown and should be identified to gain a comprehensive view of this influence on autistics' daily functioning and wellbeing.

Keywords: Autism, Tactile sensitivity, Clothing, Anxiety, Daily Functioning, Adults

30. Sensory hyper- and hypo-reactivity in early infancy may have differential developmental pathways to autism characteristics in childhood

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Background: In infants at elevated familial likelihood for autism outcomes, increased perceptual sensitivity and fearfulness in the first two years of life predict later Restrictive Repetitive Behaviours (RRB) and Social Communication Interaction (SCI) traits. However, previous measures were not designed to differentiate between sensory hypo- and hyper-reactivity.

Aims: To examine longitudinal associations between infant anxiety, sensory hypo- and hyper-sensitivity between 10-24 months and RRB and SCI at 36 months.

Methods: The sample consisted of 161 infants, 101 of which were designated elevated likelihood (47% female) as they had an older autistic sibling. The remainder had no known immediate autistic family members (typical likelihood, n=60; 38% female). Parents rated infant's traits of early anxiety using the Infant/Early Childhood Behavior Questionnaire, sensory hypo- and hyper-sensitivity using the Infant Toddler Sensory Profile, and RRB and SCI using the Social Responsiveness Scale.

Cross-lag models tested directionality of the pathways from anxiety and hypo and hyper-sensitivity at 10-24 months, and RRB and SCI at 36 months. Mediation models were used to test the hypothesis that anxiety mediates the association between sensory processing and autism characteristics.

Results: Increased sensory hypo- and hyper-sensitivity at 24 months was associated with higher levels of RRB and SCI at 36 months. The association between sensory hyper-reactivity and RRBs was mediated by anxiety at 24-months, but anxiety did not mediate any paths from sensory hypo-reactivity.

Conclusion: Sensory hypo- and hyper-sensitivity in infancy relate to later autism traits, and for hyper-reactivity this may be in part due to mediating effect of anxiety.

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31. How social value orientation affects stigma towards autistic people, comparing China with the UK

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Abstract

Cultural differences in background and knowledge of autism can impact the expression of negative behaviours and attitudes towards autism stigma. Previous studies exploring whether culture influences autism stigma have not excluded the confounding of participant differences, such as participants' autism knowledge scores, nor have they attempted to conduct systematic research on how culture and other relevant factors influence autism stigma in countries with significantly different cultural backgrounds, such as China and the UK. We recruited 804 and 794 non-autistic adult participants in China and the UK and used questionnaires to measure participants' autism stigma, autism knowledge, and cultural orientation (Culture orientation scale; Autism Social distance scale; Autism Stigma and Knowledge Questionnaire). After excluding differences between two countries other than cultural orientation, the results found that Chinese participants still had a higher stigma towards autism than British participants. A multi-group comparison of the structural equation models found no consistency between the data models for the UK and Chinese participants, indicating that factors within the Chinese context influence the autism stigma differently from the British culture. Data from UK participants indicated that male participants had higher autism stigma than females. Participants who had more knowledge about autism, familiarity with the autistic population or prior autism training showed reduced stigma towards autism. The more participants' cultural orientation favoured egalitarian individualism or hierarchical collectivism, the lower the level of autism stigma; the more participants favoured hierarchical individualism, the higher the level of autism stigma. Our findings show that cultural orientation influences stigma towards autism.

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Room 3

32. Social Vulnerability in Children with Autism Spectrum Condition and Wiedemann-Steiner Syndrome

Jess Marshall and Nicola Yuill

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Abstract

This study examined social vulnerability in two neurodevelopmental disabilities, Autism Spectrum Condition (ASC) and Wiedemann-Steiner Syndrome (WSS). Children with WSS are reportedly often highly sociable but there is minimal research on their typical social behaviour. The study aimed to establish whether ASC children or those with WSS are socially vulnerable compared to typically developing (TD) children and to identify similarities and differences in social vulnerability between these three groups. Parents of 127 children aged 4-to-17 years (omitting a further 7 responses not meeting criteria, and 8 children with dual diagnoses) responded to an online survey including the Social Vulnerability Questionnaire (Fisher et al., 2012): ASC ($N = 35$), WSS ($N = 24$) and TD ($N = 61$).

Non-parametric tests were used, given non-normal data distribution. Kruskal-Wallis tests (with adjusted p-values for multiple comparisons) revealed higher overall social vulnerability in children with a diagnosis compared to TD children. Mann-Whitney U tests identified similarities and differences in social vulnerability between ASC and WSS; children with WSS displayed less risk awareness and higher vulnerable visual appearance (small to medium effect size) compared to ASC children. Groups were similar in reported potential for emotional abuse, need for social protection and credulity. These findings document social vulnerability in WSS which was previously unexplored, laying the foundations for future research into distinctive and shared social profiles of children with WSS and subsequent interventions tackling social differences.

Presenting author: Jess Marshall

33. Autistic Students and Camouflaging in Groupwork: Prevalence and Effects on the Value of Learning.

Presenting Author: Sophie Kennedy, *Abertay University*. 1803073@abertay.ac.uk

Dr Janet McLean, *Abertay University*

Abstract

Group work is commonly assigned to students within university, but students with neurodevelopmental disorders such as autism can struggle to engage with this type of work. Several studies have investigated the prevalence and impacts of camouflaging behaviours in autistic people, but none have specifically examined camouflaging in autistic students within group work.

The aim of this project was to investigate the prevalence and impacts of social camouflaging among autistic students in higher education and how this affects their perceptions of the value of group work to their education.

Participants were current students, aged 18+ years, English-speaking, and identified as autistic. This study used a mixed-methods design. First, 41 participants were surveyed using a 30-item questionnaire. It contained the 25-item Camouflaging Autistic Traits Questionnaire (Hull et al., 2018), which measured the intensity of camouflaging behaviours, as well as 5 additional questions about the frequency of their engagement in both group work and camouflaging behaviours. Second, 6 participants who showed camouflaging behaviours, participated in semi-structured interviews, which were analysed using thematic analysis (Braun & Clarke, 2006).

Preliminary results suggest that non-binary people and females camouflage more intensively than males, that autistic students find group work is more energy-intensive when they are camouflaging, and that they camouflage less when they are working with familiar people. Conclusions are to be confirmed but indicate that autistic students would benefit from working in groups with familiar peers so that some of the energy they spend on camouflaging behaviours can be refocused on the group's task.

34. Attitudes Towards Autism: A Comparison of Attitudes and Knowledge Towards Autism Based on Adult Sibling Experiences

Victoria Morris and Carrie Ballantyne*

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Abstract

Objective: Previous sibling relationship studies focused on child/adolescent negative attitudes, despite positive attitudes being present when a sibling was knowledgeable of autism. However, little is known the quality of sibling relationships in adulthood and what factors influence it. The present study addressed whether having an autistic sibling could predict attitudes and knowledge towards autism.

Method: 109 participants (18+), 56 (mixed: autistic & non-autistic) & 53 (matched: non – autistic & non-autistic) sibling types took part in a mixed method study. Participants completed The Knowledge about Childhood Autism among Health Workers and Societal Attitudes Toward Autism Questionnaires. Open ended questions were asked about experiences of having an autistic sibling.

Result: Independent t-tests found a non-significant difference of attitudes towards autism however, found a significant difference in total knowledge and Knowledge Domain 3 of autism. Linear regressions found sibling type (mixed) was the only predictor for Domain 3 and total knowledge of autism. The thematic analysis identified four themes based on sibling experiences: Robbed Childhood, Sibling over Self, The Future and Autism Awareness.

Conclusion: The study has shown having an autistic sibling increases knowledge of specific autistic behaviours but does not change general attitudes towards autism, adding to what we know about autistic sibling relationships from the perspective of the adult population.

Key Words: *Autism, Adulthood, Sibling relationships, Attitudes, Knowledge*

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35. Characterization of Expressive Language Development Using Large-Scale Data in Mandarin-Speaking Children with Autism Spectrum Disorder

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Abstract: Language impairment is a central characteristic of children with Autism Spectrum Disorder (ASD), with expressive language abilities being heterogeneously deficient across individuals. Since linguistic communication is a key predictor of life-long learning and living, understanding the development of expressive language is of high clinical, educational and practical importance. However, current research using small sample sizes and case-controls are suboptimal for revealing group characteristics. Therefore, large-scale data is necessary to further our understanding of expressive language abilities in this population. Our study aimed to characterize and examine the precursors of expressive language skills in autistic, Mandarin-speaking children, and test the effectiveness of a smartphone application-based intervention program. Using the application, "Xinyudi," we collected parent reported Putonghua Communicative Development Inventory Toddler Form (PCDI-T) from 2690 18–72 month-old Mandarin-speaking children in China (2217 autistic, 432 learning-disabled, and 41 intellectually-disabled). Compared to the learning-disabled children, autistic children performed significantly more poorly in multiple measures of vocabulary, grammar and sentence skill. Decontextualized language and grammatical use of language partially mediated vocabulary's relationship to mean length of utterance and sentence complexity. After a 3-month intervention program, autistic children demonstrated significantly better decontextualized language and grammar skills. Our large-scale data strongly implicates the relationship between vocabulary and grammar outcomes in autistic children, while our intervention program demonstrates the effectiveness of this smartphone-based application in improving autistic children's expressive language. Altogether, our technology enables our findings and intervention to be applicable and accessible to a wider population.

Key words: Decontextualized language, Grammar skills, Mean length of utterance (MLU), Sentence complexity, Vocabulary

36. 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

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Abstract

Aims: There is currently little research into anxiety interventions for autistic children with severe to profound intellectual disability (Vereenooghe et al., 2018), despite the extensive evidence base for the neurotypical population without ID (NICE, 2013). The LADDERS project, funded by Autistica, seeks to apply existing understanding of the mechanisms maintaining anxiety to an intervention designed for autistic children with severe-profound intellectual disability who speak few or no words, to reduce anxiety.

Methods: The study utilises a multiple baseline, single case experimental design. Participants are primary caregivers of children aged 4-15. Participants take part in a 16-week intervention consisting of psychoeducation, individual formulation and goal setting, development of tailored strategies and the implementation of graded exposure tasks. Outcomes from the intervention will be measured primarily through the completion of daily diaries; additional measures will determine the overall impact of anxiety on a weekly basis, and the prevalence of anxiety, low mood, and other mood/behavioural markers before and after the intervention. Families will also participate in a 2-month follow up interview to determine the feasibility and acceptability of the intervention.

Results: This study is currently in progress. The baseline and preliminary data for three participants taking part in the study will be analysed and presented. The intervention has been shown to be feasible and acceptable in the early stages of the study, however the process of the intervention has demonstrated areas of learning and improvement.

Conclusions: These reflections will be explored with points of learning presented for researchers developing future clinical interventions.

Presenter: Jessica Hughes, j.hughes11@aston.ac.uk

37. Development of a clinical screening instrument for depression symptoms in children and adolescents with autism spectrum disorder

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Abstract

Depression is common in children and young people (CYP) with autism spectrum disorder (ASD). Currently available measures to screen for depression symptoms have been developed for, and validated with, typically developing CYP. Mental health difficulties may present differently in ASD and important features of depression may not be identified using traditional tools. We aimed to develop a brief screening tool to enable clinicians from diverse backgrounds to identify depression symptoms more accurately in CYP with ASD.

Items from 11 existing depression measures were extracted. An expert panel (developmental and clinical psychologists, psychiatrists, speech and language therapist) utilised clinical and research knowledge relating to depression and autism to identify a pool of 25 individual items for further consultation with autism professionals, CYP with ASD and their parents. Interviews were conducted with young people with ASD (aged 9-18 years) without co-occurring intellectual disability and their parents (N=16 dyads), and ASD practitioners (N=18) to ascertain the content validity, necessary adaptations, acceptability and readability of the items using a co-production model.

Those items deemed to have greatest face validity, acceptability and readability following triangulation of findings from interviews with the three informant groups comprise the final item scale. To ensure multi-informant integration, child and parent report versions of the depression screener were developed.

This Neurodevelopmental Depression Inventory is a novel depression symptom screening tool we hope will have direct impact in routine clinical services and help advance research. We aim to validate the tool and to ascertain suitability for CYP with other Neurodevelopmental Disorders.

Session 3

Room 1

38. Diverse profiles of health conditions in ten genetic syndromes associated with intellectual disability

Remsha Hanif^a, Chris Oliver^b, Leah Bull, Mary Heald, Jo Moss, Laurie Powis, Caroline Richards^b, Jane Waite^c, Alice Welham, Lucy Wilde, Kate Woodcock, Hayley Crawford^a

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Abstract

Individuals with genetic syndromes associated with intellectual disability (ID) have higher unmet health needs than those without ID. Contributing to this health inequality are the profound effects of ID on the ability to communicate effectively with health care professionals, and the lack of exposure and clinical knowledge about genetic syndromes amongst health care professionals. Increased awareness of the health conditions that are associated with different genetic conditions will result in enhanced monitoring and early treatment. As yet cross-syndrome comparisons of health conditions across multiple groups have not been conducted. The Health Questionnaire was used to obtain information from 505 parent/carers of individuals with 10 genetic syndromes associated with ID; Angelman (AS), Lowe (LS), Phelan-McDermid (PMS), Prader-Willi (PWS), Sotos (SS), Fragile X (FXS), Cornelia de Lange (CdLS), 1p36 and 8p23 syndromes and Tuberous Sclerosis Complex (TSC).

One-way ANOVAs and Bonferroni corrections were used to conduct between group comparisons which identified a varied profile of health conditions for each genetic syndrome group. Results of interest included significantly higher levels of eye problems ($p < .001$) and liver/kidney problems ($p < .001$) in LS, ear problems in SS ($p < .01$) and epilepsy/seizures in TSC ($p < .01$) compared to other groups. The greatly varied presentation of health conditions across genetics syndromes highlights syndrome-specific profiles of health conditions. These findings will facilitate communication of risk factors with healthcare professionals to go some way towards addressing the lack of confidence experienced when supporting individuals with rare genetic syndromes.

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39. Eye-tracking technology as a tool to evaluate social cognition among individuals with an intellectual disability: a systematic review and meta-analysis

Lauren Jenner¹, Rachel Howard², Ridhi Sahni³, Prof Emily Farran⁴, Dr Jo Moss⁵

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Abstract

Relatively little is known about social cognition in intellectual disability, particularly whether it relates to social functioning and co-occurring autism. A limitation has been that traditional social-cognitive tasks place a demand on domain-general cognition and language. Eye-tracking can provide information about social-cognitive processes, without verbal demands or explicit responses – appearing more suitable for groups with varied intellectual and verbal abilities. We aimed to characterise and evaluate the use of eye-tracking as a tool to measure social cognition among individuals with an intellectual disability. Searches were conducted in PsycINFO, MEDLINE, Embase and Web of Science, for peer-reviewed studies and grey literature published between 2000–2022. Findings were also requested through relevant mailing lists. We identified 48 studies of idiopathic and syndromic intellectual disability. Eye-tracking was used to measure expression discrimination (24.49%), social preference (24.49%), social scene scanning (16.33%), facial recognition (14.29%), gaze following (6.12%), gaze avoidance/preference (6.12%), face scanning (4.08%), overimitation (2.04%) and false-belief reasoning (2.04%). Most studies utilised a passive-viewing paradigm, however, some also required responses to questions about the stimuli viewed. Eye-movement data alone indicated differences in social-cognitive processes, particularly when compared to neurotypical samples. The results from 11 studies will be presented as meta-analyses on the strength of association between eye movement data and (i) social adaptive functioning and (ii) autism characteristics. The review emphasises the importance of using accessible protocols to support more inclusive research. Also, the need to develop a bank of open-access, validated eye-tracking stimuli, to encourage replication of findings and opportunities for data sharing.

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40. The impact of MYT1L-syndrome on behaviour and cognition: a parent/caregiver perspective

Louis Stokes | Megan Freeth | Alisdair McNeill

The University of Sheffield

Abstract

MYT1L-syndrome is a rare genetic syndrome associated with deletions at chromosome 2p25.3. Although there are observational studies outlining characteristic symptoms of the syndrome, there are, at present, no in-depth research studies published that investigate cognitive or behavioural phenotypes of affected individuals. This research aims to fill this knowledge gap through an analysis of the impact of MYT1L-syndrome according to the parents/caregivers of affected individuals. Nineteen parents/caregivers of individuals diagnosed with MYT1L-syndrome participated in a semi-structured interview. The interviews were transcribed verbatim and then thematically analysed following the 6-step process outlined by Braun & Clarke. The analysis resulted in the following three overarching themes and subthemes: 1. behaviour (sensory responses, challenging and unusual behaviours, anxiety, executive functioning and emotion regulation, perceived autistic traits, social relationships and motor); 2. speech, language, and communication; 3. cognitive ability and profile (intellectual disability, memory and encoding, numeracy and literacy). The findings demonstrate first and foremost how heterogeneous the impact of MYT1L-syndrome is on behaviour and cognition. The results highlight the multi-faceted cognitive impact of MYT1L-syndrome, including intellectual disability, increased anxiety, and a hypersensitivity to sound, light and noise. Furthermore, the analysis recognised the profound, and often far-reaching, behavioural challenges experienced by affected individuals, including behavioural outbursts, self-injurious behaviour, perceived autism spectrum disorder traits and challenges forming and maintaining social relationships. This research acknowledges the cognitive and behavioural impact of MYT1L-syndrome, and the impact that this has on activities of daily living for both the individual and their wider support network.

Presenter: Louis Stokes, Sheffield Institute for Translational Neuroscience (SITraN), University of Sheffield, lsstokes1@sheffield.ac.uk.

41. Teaching mathematics to children with Down syndrome and children with Williams syndrome: Parent and teacher views

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Mathematical interventions to support children with Down syndrome (DS) and those with William syndrome (WS) are scarce. Little is known about the teaching practices used in the school and home setting to support mathematical development for both populations². The current study is the first to triangulate the views of parents and teachers using a mixed-methods research design firstly to obtain a better understanding of the current practices used by teachers and parents to support mathematical abilities of children with DS and WS aged 5-11 years, and secondly to explore the teaching needs of those who support them.

Parents and teachers of children with DS and WS will participate in an online survey between March and April 2022. This survey will investigate participant views on the strengths and difficulties in mathematical abilities for those with DS and WS, along with issues relating to teaching approaches, strategies and interventions, homework and resources. This study will further examine the expectations of parents and teachers regarding progress in maths for individual children, and levels of confidence to support mathematical learning in primary school-aged children. In a follow-up focus group, parents and teachers will discuss specific interventions, and elaborate on barriers and facilitators for implementing maths interventions in the home or school setting. Both quantitative and qualitative methods will be used to analyse findings from the survey and focus group. Preliminary findings from this study and how they can inform the future design of mathematical interventions for children with DS and WS will be discussed in a poster presentation.

² Ranzato, E., Tolmie, A., & Van Herwegen, J. (2021). The home learning environment of primary school children with down syndrome and those with williams syndrome. *Brain Sciences*, 11(6), 733-. <https://doi.org/10.3390/brainsci11060733>

42. Psychometric Properties of the Clinical Anxiety Screen for People with Severe to Profound Intellectual Disabilities

Jessica Mingins^a, Dr Effie Pearson^a, Dr Georgie Edwards^a, Prof Chris Oliver^b, Megan Bird^a, Dr Jo Tarver^{a*} & Dr Jane Waite^{a*}

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Abstract

Background: Despite evidence of high rates of anxiety in people with neurodevelopmental disorders and severe to profound ID, there are few valid measurement tools for anxiety in this population. Previous work by the Cerebra network has led to the development of a parent report questionnaire to assess anxiety in this group, the Clinical Anxiety Screen for People with Severe to Profound Intellectual Disabilities (CIASP-ID).

Aims: To examine the psychometric properties of the CIASP-ID.

Methods: Participants were recruited by research team invites, Autistica's mailing list, NHS Trusts, and snowball sampling. 308 caregivers of people with various neurodevelopmental disorders who speak few to no words completed a battery of questionnaires including the CIASP-ID and other measures of anxiety, low mood, adaptive functioning, repetitive behaviours, challenging behaviours, physical health and sensory sensitivities. Data on test-retest reliability was available for 78 people with ID and data on inter-rater reliability was available for 20 people with ID.

Results: Test-retest reliability of the measure was good, with 71% of the 69 items producing a spearman's correlation of 0.6 or above. We will present further preliminary data on the psychometrics of the measure including inter-rater reliability, as well as factor structure and convergent validity.

Conclusions: Results of these analysis will be used to shorten the assessment tool. There is preliminary evidence that the CIASP-ID may be a reliable measure for assessing anxiety in people with severe to profound ID. Helping to assess anxiety earlier will ultimately lead to increased wellbeing for this population and their caregivers.

Presenting Author: Jessica Mingins

43. Performance on implicit and explicit false belief tasks in children with Cornelia de Lange and fragile X syndromes

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Abstract

Atypical social cognition may contribute to distinct profiles of autistic traits observed in Cornelia de Lange (CdLS) and fragile X syndromes (FXS). However, traditional tasks have high language and executive function demands that may mask social cognitive abilities.

We compared performance profiles on an implicit anticipatory-looking false belief (FB) task and a battery of traditional explicit FB tasks in children with CdLS (N=9) and FXS (N=9), and autistic (N=23) and neurotypical (N=34) children.

Neurotypical children (Median score=.28, $p < .01$) and children with CdLS (Median=.33, $p = .02$) showed more anticipatory-looking towards the target compared to autistic children (Median=-.19). Despite a strong anticipatory-looking time bias (Median=.75, IQR=1.54), large within-group variation led to no differences between FXS children and other groups. Neither chronological age (CA) nor receptive language ability were correlated with anticipatory looking in any group.

Neurotypical children had higher explicit FB scores compared to all other groups ($p < .01$). Both chronological age ($r = .37$, $p < .01$) and receptive language ability ($r = .49$, $p < .01$) were correlated with explicit FB scores in the neurotypical group, whereas a moderate but nonsignificant correlation was found between receptive language ability and explicit FB scores in autistic children ($r = .32$, $p = .06$). Differences in explicit FB scores were maintained even when groups were comparable on receptive language ability ($p < .01$) and CA ($p < .01$).

Groups showed different patterns of performance on FB tasks. Dissociation between implicit and explicit FB task performance suggests that explicit tasks may mask spontaneous FB understanding in children with CdLS. The profile of social-cognitive abilities may differ across syndromal and non-syndromal autism profiles.

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Room 2

44. Involving adolescents experiencing intellectual disability in the adaptation of self-report health and wellbeing measures

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Abstract

Background & Aims: Health and wellbeing are important concepts for adolescents experiencing intellectual disability (ID), given the health inequities that exist within this population. In comparison with their non-intellectually disabled peers, they are more likely to experience diminished mental health, chronic conditions, reduced quality of life, lower socioeconomic status, and social inclusion. To reduce health inequalities, the early identification of adolescent's difficulties is essential. However, the measurement of health and wellbeing is primarily based on proxy reports, with adolescents experiencing ID excluded from communicating their *own* unique perceptions. There is a need to develop self-report measures suitable for use with adolescents experiencing ID, and guidance on how to do this. This poster addresses this gap by offering methodological and practical guidance, in the context of using participatory research (PR) methods, for the adaptation of self-report measures for adolescents experiencing ID.

Methods: A qualitative methodological approach was followed. 15 school staff members and 35 adolescents (aged 12-18 years) in special education participated in a series of co-design workshops to adapt two standardised health and wellbeing measures: Kidscreen-10 and the short Warwick Edinburgh Mental Wellbeing Scale.

Results & Conclusions: When adapting self-report health and wellbeing measures for adolescents experiencing ID the following methodological issues should be considered: simplifying item wording; inclusion of pictorial communication symbols and visual prompts; changing the wording of items from past to present tense; asking questions rather than statements; replacing five-point Likert scales with dichotomous or three-point Likert response scales; presenting one item at a time during administration; developing alternate formats of the survey to ensure inclusivity. We recommend employing PR methods with atypical populations to suitability co-adapt measures in collaboration with stakeholders to ensure they are understood by adolescents with ID to self-report.

45. A comparative framework analysis of the experiences of families caring for children with intellectual disabilities during the Covid-19 pandemic in the UK

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Abstract

Background: We investigate the experiences of parents caring for children with intellectual and developmental disabilities and confirmed genetic disorder during the COVID-19 pandemic. Little is known of this group's experiences of the pandemic over time.

Methods: Participants were identified using opportunity sampling from the IMAGINE-ID UK national cohort. Semi-structured telephone interviews were conducted with parents in Spring of 2020 (T1) and Spring 2021 (T2). We used framework analysis to compare themes in interviews about impact of pandemic on families at each timepoint. Parents completed the Strengths and Difficulties Questionnaire (SDQ) on their child's behavioural adjustment and reported on their own wellbeing using the Hospital and Anxiety Depression Scale (HADS).

Results: 23 mothers took part in both interviews (child mean age=9.95, males=60.8%). Key themes at T1 were: (1) managing complex needs and behaviour, (2) mixed emotions about the benefits and challenges of the pandemic and (3) accessing individualized support. At T2, these themes were less frequent and 3 new themes were identified: (1) rise in children's anxiety, (2) concerns for functional and social skills, and (3) academic concerns. There were no significant differences between the child SDQ or the parent HADS between T1 and T2.

Conclusion: Families concerns for their children changed during the pandemic. Initial concerns with managing complex behaviour and accessing support were replaced with concerns about managing their child's emotional wellbeing and staying on track with their child's development. Further research is needed to monitor the long-term impact of the pandemic on this group of particularly vulnerable children.

Presenting author: Zahra Fatima, MSc Student, zahra.fatima.21@ucl.ac.uk

46. The prevalence and correlates of self-restraint in individuals with autism and/or intellectual disability: a systematic review and meta-analysis

Katherine Marlow, Georgie Agar, Christopher Jones, Rory T. Devine, and Caroline Richards

All authors: *University of Birmingham, UK*

Abstract

Background: Self-restraint refers to purposeful restriction of one's own bodily movements, and is observed in individuals with neurodevelopmental conditions. Anecdotal and empirical evidence suggests that self-restraint co-occurs with self-injurious behaviour, however small sample sizes limit understanding of prevalence and function. The present meta-analysis aimed to synthesise existing literature and estimate the pooled prevalence of self-restraint, and the strength of the association between self-restraint and self-injurious behaviour.

Methods: This meta-analysis was conducted in accordance with the latest PRISMA guidelines, and was preregistered on PROSPERO (<https://tinyurl.com/self-restraint-meta>). Six databases were searched from the earliest possible dates to February 2021. Backwards citation searches were conducted in efforts to capture all relevant papers. 'Grey' literature was searched in attempt to reduce publication bias.

Results: 21,567 papers were retrieved. 15 samples from 13 records were meta-analysed. Pooled prevalence estimates of self-restraint in individuals with autism and/or ID was 39%, 95% CI [26.25, 51.59]. Self-restraint occurred in 34% of individuals known to self-injure and 13% of those who did not self-injure. Holding onto objects and others were the most prevalent topographies (both 32%) and choosing mechanical restraint was the least prevalent (1%). Self-restraint and self-injury were positively correlated, $r = 0.21$, 95%CI [0.14, 0.27].

Conclusions: Findings highlight the considerable prevalence of self-restraint in neurodiverse populations. High co-occurrence of self-restraint and self-injurious behaviour indicates the need for better identification and assessment of self-restraint in clinical settings. The notable prevalence of self-restraint in the absence of self-injury suggests need for better understanding of the multiple functions of self-restraint.

Presenting author: Katherine Marlow, second year PhD student.
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47. The profile of anxiety in Angelman syndrome

Dr Effie Pearson¹, Georgina Edwards¹, Dr Joanne Tarver¹, Megan Bird¹,
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² School of Psychology, University of Birmingham, Birmingham, UK.

Abstract

Background: Anxiety has been clinically and anecdotally reported in Angelman syndrome (AS), but very few empirical studies have described the profile and associated risk factors. This study aims to 1) describe the profile and triggers of anxiety in AS and 2) explore which characteristics may influence anxiety in AS.

Method: A questionnaire study was conducted with 40 parents/carers of individuals with Angelman syndrome ($m_{age} = 21.8$, $SD = 11.4$). Measures of anxiety, triggers of anxiety and characteristics associated with anxiety were included and were validated for people with intellectual disability.

Results: The most endorsed triggers of anxiety across individuals with AS were 1) Injections, needles and blood ($n = 16$, 40%), 2) others being upset or cross with someone else ($n = 13$, 32.5%) 3) Others being upset or cross with them ($n = 12$, 30%). A multiple regression analysis was used to explore predictors of anxiety in AS. The model significantly explained variance in scores on the generalised anxiety subscale of the Anxiety Depression and Mood Scale (ADAMS) ($F(5,32) = 12.298$, $p < .001$, $adj R^2 = .604$). Out of the five characteristics included in the model, only genetic aetiology ($B = -2.450$, $p = .020$) and intolerance of uncertainty ($B = .170$, $p < .001$) significantly predicted ADAMS generalised anxiety subscale scores.

Conclusion: This study highlights that across individuals with Angelman syndrome individuals with a non-deletion aetiology may be more at risk of experiencing anxiety. Additionally, intolerance of uncertainty may contribute to the development and maintenance of anxiety, which aligns with findings across individuals with intellectual disability. However, autism severity did not. These findings have implications for informing prevention and support strategies for individuals with AS experiencing anxiety.

Presenting Author: Dr Effie Pearson

48. Exploring relative strengths in individuals with Down's Syndrome: Spatial thinking and its role in mathematics

Katie A. Gilligan-Lee ⁽¹⁾, Emily K. Farran ⁽¹⁾, Su Morris ⁽¹⁾

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Abstract

Background: There is a convincing evidence that mathematics outcomes can be improved through training spatial abilities in typically developing (TD) children. At present, a lack of information on spatial-mathematics associations, and mathematical development in people with Down syndrome (DS) hinders the translation of these interventions to DS groups.

Aims: We aim to 1) profile strengths and weaknesses in mathematics in DS relative to typical development; 2) investigate differences in mathematics development (mathematical reasoning, arithmetic, and geometry) between people with DS and typical development; 3) explore whether spatial ability predicts attainment on different mathematics measures in DS groups?

Methods: Participants include 36 participants with DS (58% male; 10-35 years) and 131 TD children (53% male; 4-11 years). Participants completed verbal and non-verbal IQ measures, spatial tasks assessing different sub-domains of spatial thinking (mental rotation, mental transformation, mental folding, scaling, perspective taking and exploration), and mathematics tasks assessing mathematical reasoning, arithmetic, and geometry.

Results: For all mathematics measures, developmental trajectories revealed similar developmental onset and similar rates of development for DS and mental-age matched TD groups. After controlling for verbal skills, spatial skills explained between 5.8% and 18.1% of the variation in mathematical performance across different mathematics tasks.

Conclusion: Mathematical development in DS groups mirrors that of mental-age matched TDs. What is unknown is why this development appears to hit a ceiling. Strong spatial-mathematical relations were observed for the DS group, similar to those seen for TDs. This is the vital theoretical knowledge needed to support the use of spatial intervention for improving mathematics for individuals with DS.

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49. Delayed cognitive and behavioural development in infants with Tuberous Sclerosis Complex is associated with early epilepsy severity

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[Introduction] Tuberous Sclerosis Complex (TSC) is a multisystem genetic disorder characterised by epilepsy, autism, intellectual disability, and behavioural difficulties. The developmental trajectory of adaptive behaviour, cognitive and language skills has not been characterised in early TSC. Tracking these changes is key to understanding the role of epilepsy in later developmental outcomes.

[Methods] The Early Development in Tuberous Sclerosis Study employed a prospective, longitudinal design to track development at up to 7 timepoints in infants aged between 3 and 24 months old with TSC (n=33), compared to typically developing (TD) infants (n=34). Parent-report questionnaires and observational measures were used to collect data on infant's adaptive behaviour, cognitive ability, language and epilepsy severity.

[Results] Infants with TSC showed lower adaptive behaviour scores from 18 to 24 months old ($p < .01$) and lower cognitive ability scores between 10 and 24 months ($p < .01$), indicating a main interaction effect of group (TSC/TD) over time. Increased epilepsy severity in TSC infants' first year of life was associated with lower adaptive behaviour scores at 24 months old (n=22, $p < .01$), and lower cognitive ability scores at 10 months ($p = .002$) and 14 months old ($p = .006$). Lower language scores were observed by 24 months old in TSC infants ($t = 4.01$, $p < .001$), but were not associated with epilepsy.

[Conclusion] Adaptive behaviour and cognitive ability in infants with TSC reflects a normative developmental trajectory up to 10 months old, and then slows considerably before reaching toddlerhood. Delayed language skills present slightly later than other developmental domains. The association between seizures and later adaptive functioning and cognitive delay supports early interventions which reduce seizure severity.

Presenting author:

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Room 3

50. The profile of aggressive behaviour in children and adults with SATB2-associated syndrome: Use of an exploratory caregiver interview

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³ Warwick Medical School, University of Warwick

Abstract

Background: SATB2-associated syndrome (SAS) is a genetic disorder associated with alterations to the SATB2 gene. Clinical characteristics include intellectual disability, severe speech delay, and palatal and dental problems. Aggressive behaviour is frequently reported (estimated prevalence of 77%); however, understanding of this behaviour is limited.

Methods: An in-depth semi-structured interview was developed to understand more about potential antecedents, consequences, and the impact of aggressive behaviour in SAS. To date, 22 interviews have been completed, while 35 caregivers have completed questionnaire measures of adaptive ability, behaviour, and behavioural function (overall: 60% male; M_{age} 11.41 years; range 3.5-33 years; 22.9% verbal).

Results: Questionnaire data indicated that 88.6% of individuals had shown aggressive behaviour within the last month. Frequently reported aggression topographies were pull/grab (n=26), hit with body part (n=22), and hit with object (n=16). Frequently endorsed behavioural functions were reinstatement of routine/repetitive behaviour (n=26), access to tangibles (n=25), escape from demands (n=24), and pain/discomfort (n=19). Aggression severity positively correlated with the number of endorsed behavioural functions ($r_s = .461$, $p = .009$). Self-help and language ability scores negatively correlated with indicators of aggression severity ($r_s = -.463$, $p = .009$ and $r_s = -.383$, $p = .034$).

Discussion: Analysis of ongoing caregiver interviews will further delineate the profile and emergence of aggressive behaviour specifically in SAS, given evidence of differing aggression profiles across syndrome groups. Use of in-depth interview methodology alongside standardised questionnaire measures will enable more in-depth insight into behaviour, and possible cognitive, biological, and environmental factors influencing behaviour overtime. Findings have potential to inform the implementation of tailored behavioural interventions.

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51. Williams syndrome: Feeding and eating difficulties during infancy and early childhood

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POSTER WITHDRAWN by the AUTHORS

52. Examining social vulnerability and its relationship with the cognitive and behavioural profile of Williams syndrome

Ellen Ridley (presenter), Isabelle Blair, Maria Iliesi, Deborah Riby, Mary Hanley

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Abstract

Background: The Williams syndrome (WS) social phenotype is associated with a strong desire for social connection alongside difficulties navigating the nuances of social interactions (Thurman & Fisher, 2015). Heightened social vulnerability has been emphasised in empirical research and anecdotal reports from parents/caregivers (Lough et al., 2016; Riby et al., 2017). While research has begun to outline some of the predictors of social vulnerability (e.g. Fisher et al., 2013), a greater understanding of the factors that contribute to social vulnerability is important.

Aim: The current study examined social vulnerability in children and young people with WS, and its relationship with aspects of the cognitive and behavioural profiles.

Method: The study included 33 parent/caregivers of children and young people with WS (10-17 years) and a comparison group of 41 parents/caregivers of neurotypical children (6-17 years). Parent data were collected on vulnerability, and cognitive and behavioural profiles were captured using standardised measures of adaptive behaviour, social skills, executive function skills and anxiety.

Results: The data have been collected and the analysis is underway. Final analyses will be presented at the conference. We hypothesise that levels of social vulnerability will be significantly heightened in WS sample compared to a neurotypical sample and will be related to individual-level differences in social skills, anxiety and adaptive behaviour. Parent qualitative data will also be presented, focusing on examples of social vulnerability and protective strategies. This study will provide useful insight for understanding social vulnerability and supporting children and young people with WS in their everyday social interactions.

53. “Everything just stopped unless you kicked down doors to get the support” - Exploring the impact of COVID-19 Pandemic and Lockdown on Parents and Their Children with Intellectual Difficulties

Hope Christie¹, Grace Khawam¹ & Karri Gillespie-Smith¹

1. University of Edinburgh

Abstract

Background: The first UK-wide lockdown was implemented on 23rd March 2020, to reduce the spread of Covid-19. Although this prevented widespread virus related deaths, the closure/suspension of schools, clinical services and respite put significant pressures on autistic children who have Intellectual Disabilities (ID) and their parents. England began coming out of Lockdown in March 2021 with Wales, Scotland and Northern Ireland following suit in April 2021. Despite the whole of the UK being out of lockdown, there still remains significant reductions in services and support for autistic children and their families potentially impacting their mental health.

Aim: This project explores how children with ID and their parents are coping throughout ease of lockdown, and whether there are still issues impacting their mental health and wellbeing.

Methods: 15 UK-based Parents of children with ID (moderate, severe and profound) were interviewed about their experiences of covid and recovery phases including what they and their children have found positive and negative throughout the various phases. Interviews were conducted either via Microsoft Teams or over the phone. Interviews were then transcribed and analysed using Inductive Thematic Analysis.

Results & Conclusions: Themes that emerge will be discussed during the presentation, within the context of existing covid literature, and future implications will be discussed. Parents of children with ID need continued monitoring and support (specifically mental health support) by increasing service check-ins, resources and improving access to services and respite. Support is vital for this vulnerable group who are still very much experiencing difficulties following lockdown.

Presenter – Hope Christie; hchrist5@exseed.ed.ac.uk

54. Technology use, independent living and cognitive thinking skills in people with Williams Syndrome

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Abstract

Background: Cognitive and educational training studies show that technology-based interventions can improve performance in typical populations. However, the use of technology-based training for those with Williams Syndrome (WS) is limited by a lack of research on technology-use in this group.

Aims: The first aim of the study is to investigate patterns of technology-use (overall technology-use, gaming and social media use) in people with WS including patterns across age groups and parental concerns. A second aim is to investigate whether technology-use predicts daily living skills, communication skills, and social and relationship skills in WS after controlling for executive functions?

Methods: Participants were 141 parents/caregivers of people with WS aged between 5 and 60 years of age (53% female). All participants completed a series of online questionnaires including a technology-use questionnaire, the Vineland Adaptive Behaviour Scales and The BRIEF measure of executive functions.

Findings: 94% of caregivers felt that technology played an important role in their son/daughter's life. This number was lower for gaming (36%) and social media (37%). Many respondents reported that their child preferred a touch screen to a mouse (75%) and required setting changes (e.g., colour contrast, cursor size/speed) before using technology. Parents/caregivers concerns were not linked to frequency of technology-use. We are currently analysing data on the associations between technology-use and independent living but will present these at the conference.

Conclusions: These findings should be used to improve the design of technology-based interventions and learning programmes for individuals with WS, e.g., using touchscreen rather than mouse, and increasing engaging features (colours, movements, sounds).

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