FASD Research and Networking Workshop

31st January 2023 | 9am - 5pm

UNIVERSITY OF SURREY

The Cerebra Network for Neurodevelopmental Disorders

NDevR Lab

NHS Surrey and Borders Partnership NHS Foundation Trust

Welcome

The University of Surrey, in collaboration with the Surrey and Borders Partnership NHS Foundation Trust, are pleased to host this research workshop on Fetal Alcohol Spectrum Disorders (FASD). The aim of the workshop is to create greater awareness of FASD and to expand the UK FASD research network by facilitating new collaborations between researchers and professionals.

FASD represents a range of conditions caused by exposure to alcohol in utero. It is one of the most common neurodevelopmental conditions and the UK is estimated to have the seventh highest prevalence rates of FASD in the world, at 3.2% meaning that at least 250,000 children are affected. Despite the elevated risk for poor clinical outcomes in children with FASD, understanding and awareness of this population is limited. However, awareness is growing and new government guidelines specify that health services must improve access to diagnosis and provide support services to support those with FASD.

We are really excited to have this opportunity to bring together experts from across the FASD and wider neurodevelopmental disability fields. We hope that the connections made during this workshop will lead to long-term, multidisciplinary collaborations, and in doing so stimulate further research and funding into FASD.

Organising team: Dr Jo Moss, Dr Katherine Ellis, Prof Raja Mukherjee and Lucy Heap




Information

Date & Time

31 January 2023

Registration is at 9.00-9.45am

The event will end at 5pm

Location

Lecture Theatre B

Lecture Theatre Block,

Stag Hill, University of Surrey,

Guildford, GU2 7XH

Contact

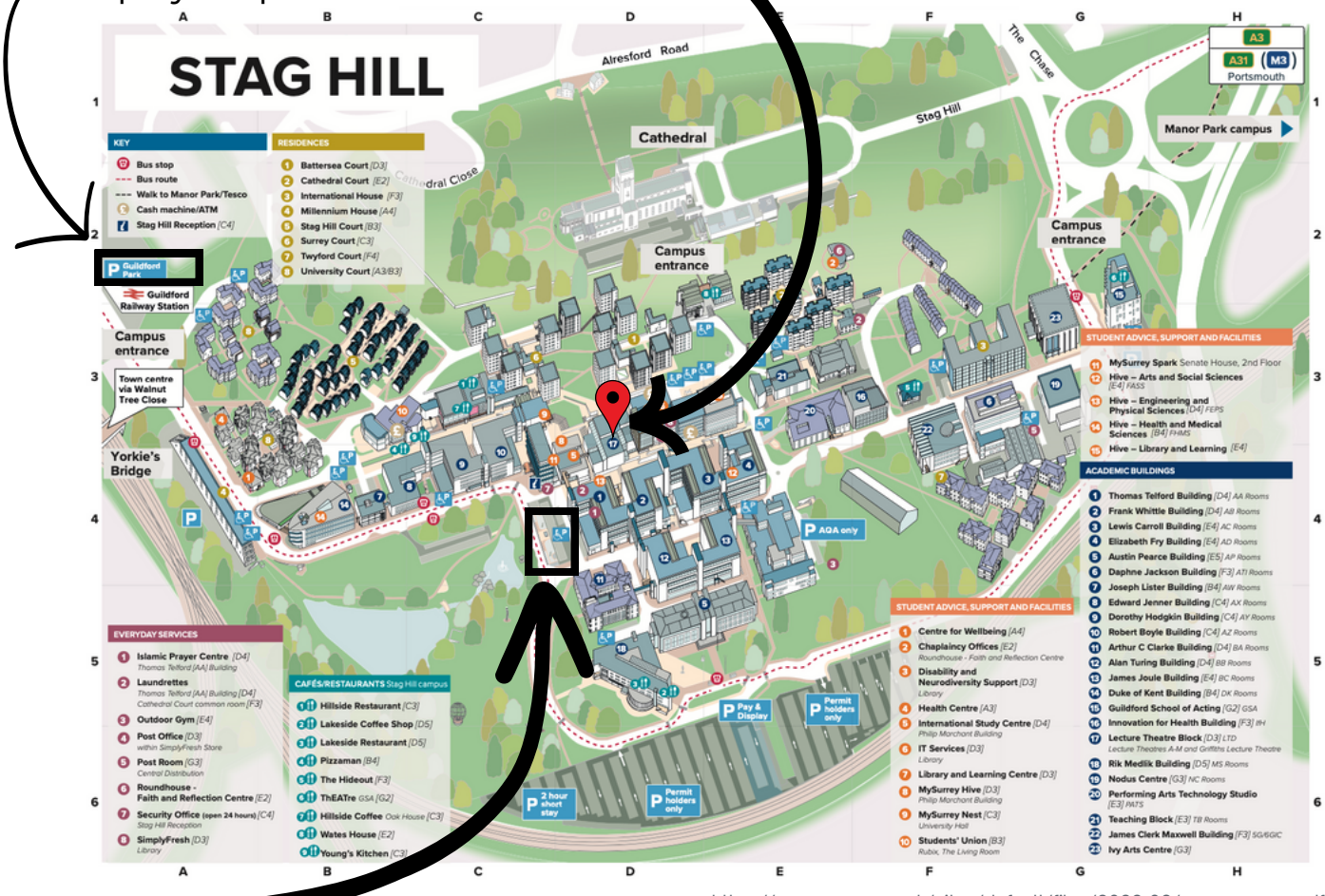
Should you have any concerns or queries prior to the event please contact Katherine Ellis in the first instance at k.ellis@surrey.ac.uk. Alternatively, please contact Lucy Heap at l.heap@surrey.ac.uk or, Jo Moss at j.moss@surrey.ac.uk.

For any queries on the day, please call

- Katherine Ellis on **07759292067**, or
- Lucy Heap on **07803366939**

Guilford Park - Pay and Display Carpark

Lecture Theatre Block



https://www.surrey.ac.uk/sites/default/files/2022-08/campus-map.pdf

Senate House Carpark - registration required

Lecture Theatre B is located in the Lecture Theatre Block, shown as building 17 on the above map.

Information

By Train

The closest train station is Guilford Railway station (location 2A on the map). The station is situated on the main line between London Waterloo and Portsmouth. Directions from the station are provided on the next page.

By Car

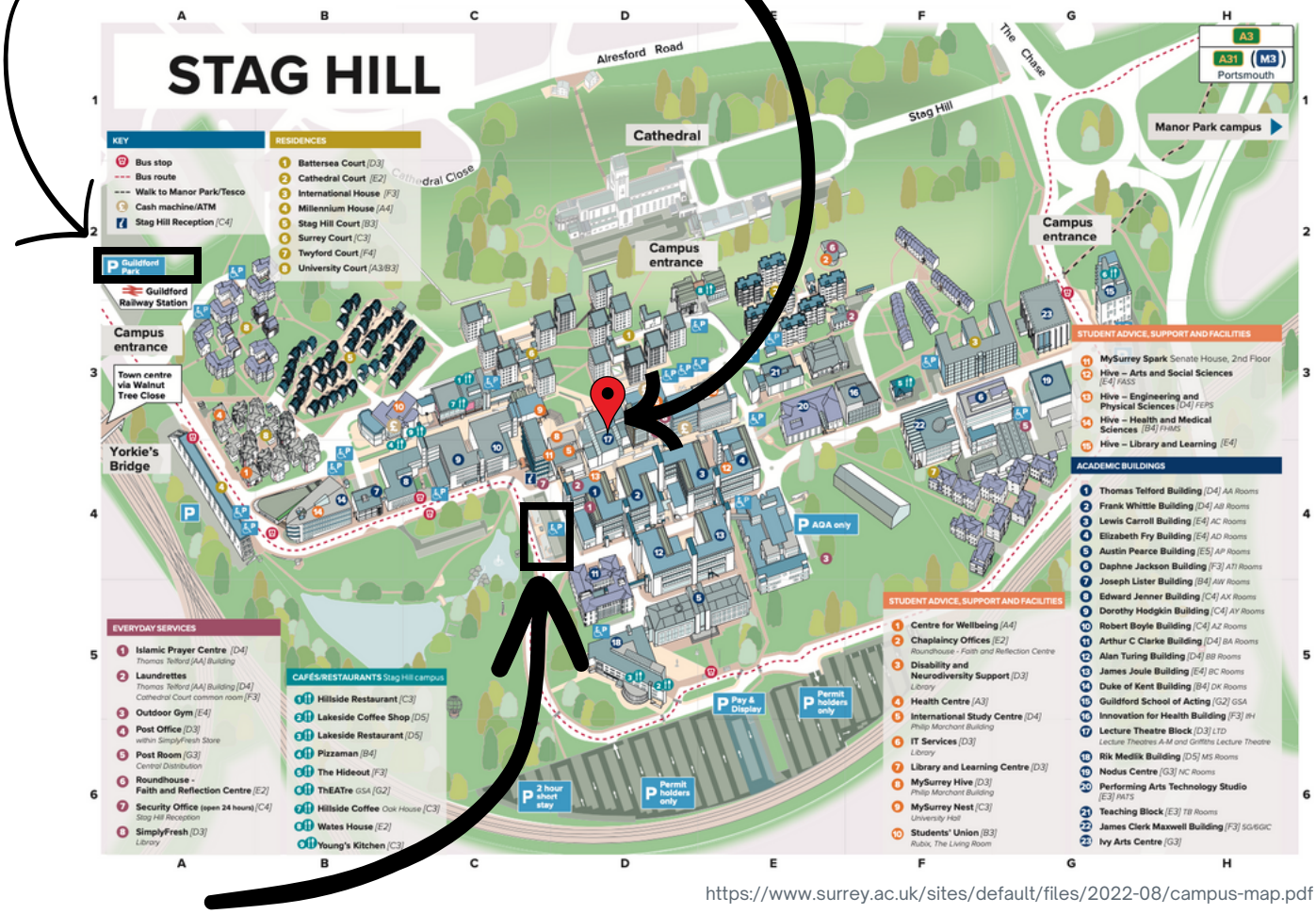
If you have registered to park on campus, you can use **Senate House Carpark** which is located next to building 11 on the map. If you would like to use Senate House Carpark, please email l.heap@surrey.ac.uk with your name, vehicle registration and duration of stay, by Tuesday the 24th of January.

There is also additional pay and display parking on campus for those who have not been able to register their vehicle.

For further information on travel by train and car, as well as by coach or from London Heathrow or London Gatwick, please visit: https://www.surrey.ac.uk/visit-university/how-get-here

Guilford Park - Pay and Display Carpark

Lecture Theatre Block



https://www.surrey.ac.uk/sites/default/files/2022-08/campus-map.pdf

Senate House Carpark - registration required

Directions

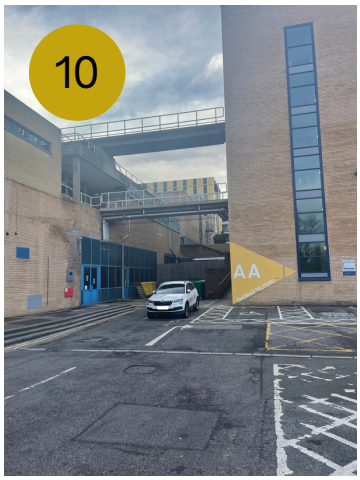
From the **station**

1. Turn right out of the station
2. Follow Guilford Park road until Grace Church
3. Turn Right after the Church
4. Follow the road towards towards the carpark
5. Walk through the carpark towards the back right
6. Exit the car park at the back right (directions continued below)

Directions

From **Guilford Park** - pay and display carpark

7. Follow the ring road round and signs for Senate House and Stag Hill reception.
8. Continue on past the lake which will be on your right
9. Cross at the crossing towards Senate House
10. Walk up the ramp between Senate House and the AA building.
11. Take the steps on the left
12. Turn right at the top of the steps
13. Continue up the steps
14. Take a left and you have arrived!



Directions

From **Senate House Carpark** - registration required

1. Exit the carpark at the back left via the steps
2. Take the steps on the left
3. Turn right at the top of the steps
4. Continue up the steps
5. Take a left and you have arrived!

The workshop will take place in Lecture Theatre B.

Programme

09.00	**Registration**	
09.45	**Welcome from Jo Moss**	
10.00	**Key-note**	**Elizabeth Elliott:** *FASD: Expanding understanding through Research Collaborations*
11.00	**Coffee break**	
		Session A Presentations - chaired by Jo Moss
11.20	**Prevalence and Profiiles**	**Robyn McCarthy**: *Prevalence study: prevalence, parents participants' experiences and the ethical dilemma of screening for FASD*
11.30		**Raja Mukherjee**: *Neurodevelopmental profiles in people with FASD. Exploratory data from a national clinic*
11.40	**ADHD and Executive Function**	**Roi Cohen Kadosh**: *Improving clinical symptoms in children with attention deficit/hyperactivity disorder using transcranial stimulation and executive functions training*
11.50		**Andrea Carrick**: *Heated behaviour in the classroom: Understanding the relationship between hot executive function and sub-clinical characteristics of ADHD, ODD and ASD (ALT) in the classroom experience of children with FASD.*
12.00		**Alexandra Carlisle**: *Comparisons of the BRIEF parental report and neuropsychological clinical tests of executive function in Fetal Alcohol Spectrum Disorders: data from the UK national specialist clinic*
12.10	**Parenting**	**Alan Price:** *SPECIFiC: Developing and testing a parenting intervention for caregivers of children with FASD in the UK*
12.20		**Stewart McDougall:** *Perspectives on Fetal Alcohol Spectrum Disorder Diagnoses in Children: The Experiences of Adoptive Parents in Scotland*
12.30	**Roundtable discussion with all Session A speakers**	
12.45	**Lunch**	

Programme

Session B Presentations - chaired by Raja Mukherjee

13.45	**Autistic Characteristics**	**Jo Moss:** *Profiles of autistic characteristics in genetic syndromes: implications for assessment and diagnosis*
13.55		**Katherine Ellis & Lauren Jenner:** *Social cognition in genetic syndromes associated with autism*
14.05	**Mental Healh**	**Kate Woodcock**: *Smartphone-enabled group psychotherapeutic experiences that enhance adolescent mental health by supporting real-world connection and sense of belonging*
14.15		**Jessica Mingins**: *Development of the Clinical Anxiety Screen for People with Severe to Profound ID (ClASP-ID)*
14.25		**Jessica Hughes**: *A parent-led intervention to reduce anxiety in autistic children with severe to profound intellectual disabilities: current data from the LADDERS pilot study*
14.35	**Crime and Extremism**	**David Gilbert**: *Implications of FASD for the Criminal Justice System*
14.45		**Clare Allely**: *How certain features of autism spectrum disorder may provide the context of vulnerability to engaging in terroristic behaviours or becoming involved in online extremist groups*
14.55	**Roundtable discussion with all Session B presenters**	
15.10	**Coffee break**	
15.30	**Workshop and discusion of future directions - chaired by Katherine Ellis.** *This workshop will begin with an overview by Lucy Heap summarising areas identified by the FASD community as key research priorities. Attendees will then work collaboratively in groups to identify research questions, study designs and potential funding opportunities that will support future work focused on these idenified priorities. The workshop will finish with a discussion on how to foster a long-term collaborative community focused on FASD research.*	
17.00	**Conference closes**	

Keynote speaker: Professor Elizabeth Elliot

Elizabeth Elliott AM FAHMS FRSN is a Distinguished Professor in Paediatrics and Child Health at the University of Sydney; Paediatric Head of the NSW Fetal Alcohol Spectrum Disorder (FASD) assessment service at Westmead Children's Hospital; and Director of the Australian Paediatric Surveillance Unit for study of rare diseases. Her Medical Research Futures Fund Fellowship focuses on disadvantaged children including in remote Aboriginal communities, where she has worked for over a decade. She consulted to the Australian Human Rights Commission's Inquiry into Children on Immigration Detention; and the WHO on guidelines for alcohol use in pregnancy; is on the WHO committee on the Burden of Birth Defects; and is UNICEF Australia's Advisor on child health. She leads a program on cerebral palsy research in Vietnam. Elizabeth is a Board Member for Royal Far West and the National Organisation for FASD and a member of the Royal Australasian College of Physicians Gender Equity committee. She is Chair of the Australian Government's FASD Advisory Committee, and a member of the Life Saving Drugs Program Expert Committee. Elizabeth led development of the Australian Guide to the Diagnosis of FASD, the FASD Hub Australia, and the FASD Australian Register, and was Co-Director of the National Health and Medical Research Council of Australia's Centre of Research Excellence in FASD. She became a Member of the Order of Australia in 2008; is an elected Fellow of the Australian Academy of Health and Medical Science and a member of its Council; and a Fellow of the Royal Society of NSW (RSN) and recipient of the RSN James Cook Medal.

Abstracts

Keynote: Fetal Alcohol Spectrum Disorder: Expanding understanding through research collaborations

Elizabeth Elliott

University of Sydney Australia.

Fetal Alcohol Spectrum Disorder (FASD) is a common but potentially preventable neurodevelopmental disorder caused by prenatal alcohol exposure (PAE), which has lifelong consequences. Its presentation is heterogeneous and may include facial dysmorphology, congenital anomalies and a range of co-morbidities. Over two decades Australian research has shifted FASD from the realm of fiction to fact and provided information on patterns of PAE and women's and health professionals' knowledge, attitudes, and practice regarding alcohol use in pregnancy and FASD. Indigenous-led research has provided population-based data on FASD prevalence in high-risk remote communities and juvenile detention and its impacts at home and school. Data linkage studies have estimated the frequency of PAE effects and pregnancy cohorts have allowed exploration of epigenetic effects and interventions to improve antenatal care regarding alcohol use. Use of 3-D facial imaging is informing pathological understanding and early diagnosis.

Using a model that could be adopted elsewhere, we have taken a systematic approach to FASD; established collaborative national research and clinical networks, consulted with caregivers, and engaged and supported health professionals. We have worked closely with the Australian government, including through the National FASD Advisory Group, and with NGOS to translate research into health practice and policy. Outcomes include a National Strategic Action Plan for FASD, the Australian Guide to the Diagnosis of FASD, the FASD Hub Australia, The FASD Australian Registry, and a range of clinic services. Opportunities for research remain and we look to a future that includes early diagnosis, effective treatment, and prevention of FASD, underpinned by a sound, current and contextual evidence-base.

Abstracts

Prevalence study: prevalence, parents participants' experiences and the ethical dilemma of screening for FASD

Robyn McCarthy (1), Raja Mukherjee (1,2), Kate Fleming (3), Jonathan Green (4), Jill Clayton-Smith (5), Alan Price (1), Clare Allely (1), Penny Cook (1)

(1) School of Health and Society, University of Salford, UK
(2) Fetal Alcohol Spectrum Disorder Service, Surrey & Borders NHS Trust, UK School of Health and Society, University of Salford, UK
(3) Institute of Population Health Sciences, University of Liverpool, UK Division of
(4) Neuroscience & Experimental Psychology, University of Manchester, UK Royal Manchester Children's Hospital, Manchester, UK
(5) Royal Manchester Children's Hospital, Manchester, UK Division of Evolution & Genomic Sciences, University of Manchester, UK

Background: Evidence on the prevalence of fetal alcohol spectrum disorders (FASD) in the UK is lacking, despite known high rates of alcohol use in pregnancy. We report on FASD prevalence in a small sample of children, and consider some of the practical and ethical barriers to carrying out studies such as this.

Methods: We carried out a two-phase active case ascertainment study in three mainstream primary schools in Greater Manchester, UK. Initial screening of children aged 8-9 years used pre-specified criteria for elevated FASD risk (small for age; special educational needs; currently/previously in care; significant social/emotional/mental health symptoms). Screen positive children were invited for detailed ascertainment of FASD using gold standard measures including facial dysmorphology, executive function and behavioural difficulties. Using qualitative interviews, we sought parents' views of their experience of taking part and analysed these thematically.

Results: Of 220 eligible children, 50 (23%) screened positive and 12% (26/220) proceeded to phase-two assessment. Twenty had a developmental disorder, of which, four had FASD and four were possible cases, leading to crude prevalence rates of 1.8% (95%CI: 1.0%,3.4%) and when including possible cases, 3.6% (2.1%,6.3%). None of these children had previously identified with a developmental diagnosis. Parents felt overall participation had been worthwhile, had a positive impact on family life and that their children either enjoyed or were indifferent to taking part. Parents of children identified as having FASD reported that receiving the results was a shock but not overly distressing.

Conclusions: FASD was found to be common in these schools, but limitations to the sampling restrict inferences to a population prevalence. Most of these children's needs had not previously been identified. Ethical concerns around screening for a stigmatised condition should not be a barrier to funding this type of study.

Abstracts

Neurodevelopmental profiles in people with FASD. Exploratory data from a national clinic

Raja Mukherjee (1,2)

(1) Fetal Alcohol Spectrum Disorders (FASD) Specialist Clinic, Gatton Place, St Matthews Rd, Redhill, England, RH1 1TA.
(2) School of Health and Society, University of Salford

Fetal alcohol spectrum disorders represent properly the most common aetiological cause of underlying broader neurodevelopmental outcomes. With UK estimates suggesting rates are between two and 4%, with some subpopulations having rates as high as 27%, it is an important consideration when understanding behavioural issues in developing children.

The National FASD clinic was established in 2009 and has continued to see people with FASD ever since. As part of that diagnostic process, diagnosis of FASD is made alongside wider mental health outcomes. This includes autism and ADHD outcomes and profiles. With the explicit permission of those seen the clinic, data is used to track outcomes and to learn new information about the condition.

Around 75% of people presenting to the clinic meet diagnostic criteria using the DISCO and direct observation during the two-day process as well as the similar number meeting diagnostic criteria for ADHD using DSM-V criteria. There profiles however are not in keeping with typical presentations and lead to their diagnoses often being missed. This presentation will update original data in this cohort and remains the basis of work undertaken to explore more about the behavioural and psychological profile of individuals with FASD

Abstracts

Improving clinical symptoms in children with attention deficit/hyperactivity disorder using transcranial stimulation and executive functions training

Roi Cohen Kadosh

School of Psychology, University of Surrey

Attention deficit/hyperactivity disorder (ADHD) is the most common neuro-developmental disorder in childhood. Symptoms of ADHD include inattention, hyperactivity, and impulsivity. ADHD is not just a childhood disorder; since up to two thirds of children who were diagnosed with ADHD meet ADHD criteria in adulthood. Various methods have been attempted to effectively ameliorate ADHD in children and adults. One of the attractive ideas is to develop interventions to create a lasting, rather than only an immediate, effect. Such a concept has important implications including increased independency of the patient, reducing the load on the caregiver and the health system, and the economic burden at the micro and macro level.

Based on previous results from my lab on healthy adults, in two double-blind clinical trials, we examined the effect of transcranial random noise stimulation (tRNS) to induce long-term effects in children with ADHD. Children completed five-day executive functions training while receiving tRNS or transcranial direct current stimulation (tDCS) in Experiment 1 or 10-day executive functions training while receiving tRNS or sham stimulation in Experiment 2. tRNS yielded a greater clinical improvement as indicated by the reduced ADHD rating scale (ADHD-RS) score from baseline, and in comparison to the changes observed in tDCS and sham. Moreover, the observed effects showed a lasting effect when examined one week (Experiment 1) and three weeks (Experiment 2) after treatment completion, suggesting a neuroplasticity-related effect. Our results provide a promising direction toward a novel intervention in ADHD, which is shown to have a lasting effect via the modulating of neuroplasticity, rather than a merely immediate effect like in current medical interventions.

Abstracts

Heated behaviour in the classroom: Understanding the relationship between hot executive function and sub-clinical characteristics of ADHD, ODD and ASD (ALT) in the classroom experience of children with FASD.

Andrea Carrick and Colin Hamilton

Psychology Department, Northumbria University

Possession of ADHD, ODD and ASD characteristics in children prenatally exposed to alcohol, contribute to challenges within the diagnostic pathway for FASD. The presentation of these characteristics, though problematic for the children affected, may not result in referral for diagnosis; focusing on referral thresholds masks the dimensional nature of these characteristics. Children with sub-referral characteristics may not receive effective support and are often identified as exhibiting challenging behaviour. In the UK children with undiagnosed SEN are more likely to experience school exclusion. Common across each condition are challenges to executive function (EFs) associated with cognitive flexibility (cold-EFs); and emotional regulation (hot-EFs). However, well intentioned classroom interventions aimed at managing self-regulation and educational inclusion, can be problematic for children whose hot-EF is challenged. This study explored the relationship between subclinical levels of ADHD, ODD, ALT, and executive function on the helpfulness of reward-based interventions for children with FASD. Data collected online of parent/carer measures of each condition (Child AQ, Vanderbilt and CHEXI) for children aged 6-12 years with suspected or diagnosed FASD (n=121). Comparison with typically developing children showed large group differences on each measure. Multiple regression analyses indicated that the possession of high, but sub-referral levels of ADHD, ODD and ALT characteristics was associated with the reward systems being perceived as unhelpful. However, this pattern was dependent upon both the EF characteristics and the whether the child had a FASD diagnosis. Thus, a dimensional approach strengthens our understanding of the child's classroom experience and help overcome barriers to effective intervention.

With grateful thanks to FASD UK and FASD Hub Scotland for the support in recruitment; and to the parents and carers of children affected by FASD for their interest and participation.

Abstracts

Comparisons of the BRIEF parental report and neuropsychological clinical tests of executive function in Fetal Alcohol Spectrum Disorders: data from the UK national specialist clinic

Zameer Mohamed, **Alexandra Carlisle**, Alexandra Livesey and Raja Mukherjee

FASD Specialist Clinic, Surrey and Borders Partnership NHS Foundation Trust, Surrey, UK

Extant literature is sparse with regards to the relationship between caregiver reports and neuropsychological tests of executive functioning in Fetal Alcohol Spectrum Disorders (FASD). The goal of this paper was determining the clinical utilities of executive functioning measures used in the United Kingdom national FASD clinic.

We examined relationships between outcomes on the Behavior Rating Inventory of Executive Function (BRIEF) and the Delis-Kaplan Executive Function System (D-KEFS), as part of an ongoing service evaluation. Profiles of executive functioning measures were reported in order to contribute to delineating a profile of executive dysfunction in FASD. Caregivers of 49 people with FASD completed the Parent BRIEF, and 61 people with FASD were administered the D-KEFS. Pearson's Correlations between all 11 BRIEF scales and the 18 selected D-KEFS subscales showed little relationship.

The BRIEF showed a profile of clinically significant elevations in all three Index scores and seven out of the eight Scale scores. Several D-KEFS tests showed below average executive functioning. Both executive function measures have separate clinical utility in demonstrating executive function deficits in FASD. The sample population used in this study also show a similar pattern to FASD populations internationally, suggesting a similar neuropsychological profile is seen in the United Kingdom. However, caregiver reports display little relationship to neuropsychological tests. These measures likely monitor different aspects of executive functioning in different settings. Future research should focus on identifying tests that better relate findings from clinical settings to behavior in daily life.

Published in Child Neuropsychology online in September 2018

To link to this article: https://doi.org/10.1080/09297049.2018.1516202

Abstracts

SPECIFiC: Developing and testing a parenting intervention for caregivers of children with FASD in the UK

Alan Price

School of Health and Society, University of Salford

Services for families affected by FASD in the UK are minimal, and there are no UK-based FASD interventions that have been shown to be effective in a randomised controlled trial (RCT). We therefore set out to develop an intervention and test it using an RCT. Caregivers of children with FASD have told us they want an FASD parenting course, to help them understand how best to support their children. In a development project, we designed a 7-week parenting course called SPECIFiC. It is delivered to caregivers using video conferencing, and sessions are two and a half hours, once per week. The sessions are delivered by two facilitators; one of whom has lived experience of caring for a child with FASD, and the other who has some experience of delivering training. The sessions include information about FASD, common difficulties in children, how best to support children, self-care and advocacy. They include slides, videos and time for group discussion, and we provide a list of helpful resources including books, websites and podcasts. We delivered SPECIFiC to nine families in a pre-feasibility study, and the course was well-received. We are now conducting a feasibility trial, delivering to 120 families in a wait-list control design. We will be collecting data on parents' stress levels, parenting self-efficacy, children's behavioural difficulties and other outcomes, as well as qualitative data. We aim to determine a signal of efficacy at this stage, and assess the feasibility of delivery and data collection, in preparation for a larger, definitive trial.

Abstracts

Perspectives on Fetal Alcohol Spectrum Disorder Diagnoses in Children: The Experiences of Adoptive Parents in Scotland

Jennifer Shields (1,2), David C. Zammit (1), Sarah Brown (1), Lindsey Gilling McIntosh (2), **Stewart McDougall** (2), Suzanne O'Rourke (2)

(1) NHS Ayrshire and Arran, Ayrshire Central Hospital, Kilwinning Rd, Irvine KA12 8SS, United Kingdom

(2) Fetal Alcohol Advisory Support and Training Team, School of Health in Social Science, The University of Edinburgh, Old Medical School, Teviot Pl, Edinburgh EH8 9AG, United Kingdom

Background: Arising from prenatal alcohol exposure, Fetal Alcohol Spectrum Disorder (FASD) can lead to a range of physical and neurodevelopmental effects. Following the development of a clinical guideline in Scotland, there has been a concerted effort to expand availability of FASD assessments within our National Health Service (NHS). The parents of these children play a crucial role in informing the development of relevant policy and services for FASD.

Aims: This study was the first to examine parents' experiences of caring for children with FASD in Scotland. It was intended to be exploratory, thereby giving voice to the issues that matter most to this population.

Methods and Procedures: Six adoptive parents, raising children diagnosed with, or identified as at-risk of having, FASD participated in semi-structured interviews. Children ranged between seven to fifteen years old. Interpretative phenomenological analysis was used to analyse transcripts and build themes based on the participants' experiences. Five participants provided further comments on the emergent themes.

Outcomes and Results: Four superordinate were themes identified: 'the fight for support,' 'a life of inequity,' 'an uncertain future,' and 'a complex psychological journey'. These reflect the complexity of the participants' experiences navigating a world which is not set up to allow themselves or their children to thrive.

Conclusions and Implications: Caring for a child with FASD in Scotland brings significant challenges, often driven by shortcomings in professional knowledge and services. These families described their futures as highly uncertain, with mental health, social support and financial wellbeing reported as being precarious. Despite this, their energy remained unstinted and their ability to both summon hope and advocate for their children in the face of adversity remained strong. These findings must be used to inform developments in policy and the planning and provision of services. Further, this study highlighted challenges in the recruitment of birth parents of individuals with FASD to research. Future research should consider additional strategies to address the under-representation of birth parents in research, and how the individual, environmental, or social barriers to their participation may be overcome.

Abstracts

Profiles of autistic characteristics in genetic syndromes: implications for assessment and diagnosis

Jo Moss

School of Psychology, University of Surrey

People with genetic syndromes associated with intellectual disability are more likely to evidence clinically significant autism characteristics compared to the wider intellectual disability population and people in the general population. However, there is significantly lower recognition of autism in clinical practice within the genetic syndrome population, contributing to poorer long-term prognosis and significant unmet need.

Detailed analyses consistently indicate that the profile and developmental trajectory of autism characteristics across these groups is highly variable, in ways which indicate some degree of syndrome specificity. These factors, in combination with the enduring challenge of identifying valid and reliable assessment of autism in people with intellectual disability, likely explain the substantially reduced and delayed recognition of autism in clinical practice for these individuals and their families.

In this talk I will discuss the factors that confound assessment and diagnosis of autism and related characteristics people with genetic syndromes and the implications of these challenges. I will also advocate that greater awareness and consideration of syndrome associated presentations and characteristics of autism will enable greater precision of assessment in these populations and improve access to appropriate support.

Abstracts

Social cognition in genetic syndromes

Katherine Ellis & Lauren Jenner

School of Psychology, University of Surrey

Atypical social cognition may underlie distinct profiles of autistic traits observed in many genetic syndromes associated with intelletual disability. 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 genetic syndromes (Cornelia de Lange, Down, fragile X, and Prader-Willi syndromes) and comparison groups of autistic and neurotypical children.

Groups showed different patterns of performance on FB tasks. Dissociation between implicit and explicit performance suggests explicit tasks mask spontaneous FB understanding. We will discuss how findings inform our understanding of the nature and cause of autistic traits in groups with atypical presentations, including those with FASD.

Abstracts

Smartphone-enabled group psychotherapeutic experiences that enhance adolescent mental health by supporting real-world connection and sense of belonging

Kate Woodcock

School of Psychology, University of Birmingham

In our fast-changing society, poor mental health and social isolation are increasing among young people, exacerbated by the pandemic. Belonging – feeling connected to and accepted by others through supportive interpersonal relationships – is key to boosting mental health and overcoming loneliness. There is a lack of evidence-based interventions addressing belonging. Digital technologies, while disrupting the social landscape, offer enormous potential for adolescent health management. This project develops Augmented Social Play (ASP), a pioneering digital mental health intervention format whose feasibility has been established through proof-of-concept prototype. ASP uses smartphones to deliver real-world group experiences that combine immersive storytelling, augmented reality, collaborative face-to-face gameplay and evidence-based psychotherapeutic methodologies to boost individuals' mental health while fostering a greater sense of belonging within the group. Collaborating across academia, industry, education, health and the arts, and working with young people, we will evolve ASP by collaborating with vulnerable adolescents to ensure we meet the widest spectrum of needs; by prototyping ASP interventions aimed at different populations and threats to mental health. Being associated with multiple sources of potential vulnerability, FAS represents one potential target population Our long-term goal is wide-scale adoption of ASP, making multiple smartphone-delivered group mental health interventions freely accessible to diverse populations and settings.

Abstracts

Development of the Clinical Anxiety Screen for People with Severe to Profound ID (ClASP-ID)

Jessica Mingins (1), Effie Pearson (1), Georgina Edwards (1), Chris Oliver (2), Jo Tarver (1), Jane Waite (1)

(1) School of Psychology, College of Health and Life Sciences, Aston University, Birmingham
(2) School of Psychology, University of Birmingham

Background: There are few assessment measures for anxiety in people with intellectual disability (ID), particularly young children or those who speak few words. Existing assessment measures have limitations, such as inclusion of behavioural indicators of distress that overlap with physical health issues (e.g. pain).

Objective: To develop an assessment tool for the detection of anxiety that is suitable for people who use few words.

Methods: 311 parents/carers of children and adults with ID completed a newly developed assessment measure. Participants with ID ranged in age from 4-83, (M= 21.59, SD= 12.00); 61.4% were male, 67% spoke no/few words, 50% had a clinical diagnosis of autism. Convergent validity data was collected using the Anxiety Depression and Mood Scale (ADAMS) and the Developmental Assessment for Individuals with Severe Disabilities – II (DASH-II).

Results: Exploratory factor analysis indicated that four factors explained 26%, 4%, 3% and 3% of the variance in scores and were labelled anxiety, pain, low mood/energy and consolability, respectively. Test-retest was excellent at subscale level. The anxiety subscale had good convergent validity with other anxiety measures ($r=.77$, $p < .001$; $r = .59$, $p < .001$) and excellent internal consistency ($\alpha=.92$). At total group level, those with a reported clinical diagnosis of anxiety scored significantly higher on the anxiety subscale.

Conclusion: There is preliminary evidence that the assessment measure may be a reliable measure of anxiety in people with the greatest support needs.

Abstracts

A parent-led intervention to reduce anxiety in autistic children with severe to profound intellectual disabilities: current data from the LADDERS pilot study

Jessica Hughes, Effie Pearson, Georgina Edwards, Megan Bird, Courtney Greenhill, Joanne Tarver, Jane Waite

School of Psychology, College of Health and Life Sciences, Aston University, Birmingham

Background: There are very few anxiety interventions for individuals with severe to profound intellectual disability (ID). Psychological approaches such as graded exposure and emotion regulation have been evidenced as effective in gradually reducing anxiety in other clinical populations.

Objectives: We have developed LADDERS, a 16-week parent-led intervention comprising of psychoeducation, graded exposure-based tasks and skills building, delivered using a person-centred approach. This proof of principle study assessed whether LADDERS reduces anxiety and avoidance-related behaviour in autistic children with severe to profound ID.

Methods: The study utilises a multiple baseline, single case experimental design. The primary outcome measure (POM) is parent report of child anxiety completed daily from baseline throughout intervention and 2 weeks post-intervention.

Results: Six parent-child dyads proceeded from baseline assessment with a 100% retention rate. Post-intervention POM data were available for 3 out of 6 participants at time of analysis. Visual inspection of POM data suggests a decrease in anxiety for 2 out of 3 participants, with the third showing a stable trend. Statistical comparison of pre- and post-intervention POM for the 2 participants with decreasing trends was conducted using Non-overlap of all Pairs (NAP). NAP effect sizes were 0.70 and 0.79, which are deemed medium effect sizes.

Conclusions: Based on preliminary data the effectiveness of the LADDERS intervention at reducing anxiety and anxiety-related avoidance in autistic children with a severe to profound ID looks promising. This intervention may have utility in broader clinical populations, such as with families of young children with intellectual disability of heterogenous aetiology

Abstracts

Implications of FASD for the Criminal Justice System

David J Gilbert (1), Clare S Allely (1), Raja AS Mukherjee (1,2), Penny A Cook (1), Gisli Gudjonsson (3)

(1) University of Salford, UK
(2) Surrey and Borders Partnership NHS Trust
(3) Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, Denmark Hill, London

Background: Individuals with FASD are nineteen times more likely to be involved with the criminal justice system (CJS) when compared to those without FASD. Interrogative suggestibility, a tendency to accept suggestions (during police interviews) from interrogators is theorised to be a weakness in this population. However, except for one small pilot study with seven participants, interrogative suggestibility has yet to be investigated in individuals with pre-natal alcohol exposure (PAE).

Aim: To assess the vulnerabilities and suggestibility of individuals with PAE during investigative interviews, compared to neurotypical controls.

Method: 27 young people (aged 11-16 years) with a diagnosis of FASD/PAE were recruited alongside 25 controls. Memory, impulsivity, IQ, and interrogative suggestibility were assessed using the Weschler Intelligence Scale for Children (WISC-V), Behaviour Rating Inventory of Executive Function (BRIEF-2), and the Gudjonsson Suggestibility Scales (GSS). Immediate and delayed suggestibility were measured one week apart with the GSS. Results are compared to the age-matched controls.

Result: Results indicate poor memory recall, high impulsivity, and high interrogative suggestibility of individuals with FASD/PAE in comparison to controls. Individuals with FASD where all in the clinically elevated range (T>70), The average IQ was 78.65 (range: 70 to 105). High interrogative suggestibility was seen in the FASD group - Mean (SD) = 13.48 (5.52) in comparison to the neurotypical control group – Mean (SD) = 7.60 (4.89).

Conclusion: The results obtained indicate significant vulnerability of the FASD population, especially during investigative interviews by the criminal justice system.

Abstracts

How certain features of autism spectrum disorder may provide the context of vulnerability to engaging in terroristic behaviours or becoming involved in online extremist groups

Clare Allely

School of Health and Society, University of Salford

Someone with ASD being involved in terrorism is rare and not well understood. This is mainly the result of very little research investigating the association between ASD and the engagement in terroristic behaviours. Al-Attar (2016a, 2016b) has outlined the role that autistic special interests, fantasy, obsessionality, the need for routine/predictability, social and communication difficulties, cognitive styles, local coherence, systemizing, and sensory processing may play in terrorism pathways and modus operandi. It is crucial that there is "an understanding of the individual's autistic functioning and how it may contextualise factors that push them towards terrorism and aspects of terrorism that may pull them in, in order to manage and reduce risk" when terrorist acts are planned or executed by individual with ASD (Al-Attar, 2020, pp. 926). There has been some research exploring how ASD can 'contextualise vulnerability and risk' (Faccini & Allely, 2017; Al-Attar, 2016a, 2016b, 2018b, 2018c, 2019; Al-Attar, 2020, pp. 926). In this presentation, I will explore the research which has explored how ASD can provide the context of vulnerability to engaging in terroristic behaviours.