



Salvesen Mindroom Research Centre  
*research • learning • development*



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# Salvesen Mindroom Research Centre Annual Report 2019-2020

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## Director's Summary

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It's hard to believe that it's been only one year since I took up the role of Director of the Salvesen Mindroom Research Centre. From the very beginning it has been an enormous privilege and a pleasure to build on the legacy of Professor Anne O'Hare, and to work in such an innovative and effective partnership with the Salvesen Mindroom Centre. Rigorous research that makes a difference in the lives of neurodivergent people is my passion. Our collaboration provides the perfect context to do that work. Together, we are combining new scientific discoveries with practitioner expertise to address community priorities. Our collaborative Sharepoint site, bi-annual joint meetings and cross-project working is developing this relationship even further.

The past year has seen a series of dynamic changes in the Research Centre. We have welcomed new staff and grown our portfolio of projects. Much of this work focuses on specific diagnostic categories, because funders so often define work in this way. A key priority for the future is to move away from these restrictive conceptualisations and find funding sources that allow us to deliver work encompassing the broader community of people who experience barriers to learning. The current public health crisis makes the immediate pathway to longer-term funding unclear, but we have the resources to navigate it safely.

One major strength of our current team is its interdisciplinary breadth, drawing in routine data analysis, direct cognitive and clinical assessment, qualitative approaches and co-production methods to achieve our goals. In 2019 we extended this reach across the University of Edinburgh by inviting Associate Members to affiliate with the SMRC and support our work. This has formalised and embedded our essential connections with the Moray House School of Education, with clinical academics, and with social scientists.

As well as welcoming new people, we have had to say goodbye to some. First Tracy Stewart and now Louise Marryat have both been offered permanent posts at University of Edinburgh and University of Dundee respectively. Our sadness at seeing them leave is tempered by happiness and pride that they have each secured their long-term academic careers. In the current brutal academic job climate this is a stellar achievement and well deserved in both cases. We are delighted that both continue as Associate Members, and play key roles in on-going projects.

Our Research Centre is dedicated to making an impact on the local and national stage, as well as disseminating our work globally. To facilitate this we now have a new website in place, spearheaded by the superb Ali Irving, and have started to populate it with resources, such as our expert book reviews, that people can use right away. The inaugural Salvesen Lecture in November 2019 was also a chance to showcase our work, and our vision for the future.

I can't end this without a special thank you to Sue Davidson, the glue that holds the team together. Her good judgement, vast range of skills, knowledge of University systems and absolute reliability is a massive asset to the Research Centre for which we are all grateful.

Please read on, to find out how we are circumventing, or even dismantling, barriers to learning for the young people we serve.



Dr Sue Fletcher-Watson, Director

## Structure and Staff

Research within the SMRC is led by three principal investigators who each manage a portfolio of projects with associated staff. In addition the Research Centre benefits from core support in research governance and administration, and communications and outreach.



**Sue Fletcher-Watson**  
Director



**Sinéad Rhodes**  
Principal Investigator



**Rachael Wood**  
Principal Investigator



**Sue Davidson**  
Centre Administrator



**Alison Irving**  
Communications  
Manager



**Leila Mackie**  
Clinical Research  
Fellow



**Alyssa Alcorn**  
Research Fellow



**Catherine Crompton**  
Research Fellow



**Rachael Davis**  
Research Fellow



**Chris Eaton**  
Research Fellow



**Rebecca Iversen**  
Research Fellow



**Emily McDougal**  
Research Fellow



**Louise Marryat**  
Research Fellow



**Eamonn Walls**  
Research Fellow



**Margaret Horne**  
Statistician



**Zoe Grayson**  
Clinical Research  
Associate



**Saoirse Heron**  
Research Associate



**Lewis Montgomery**  
Research Assistant



**Jessica Oldridge**  
Research Assistant

In addition, the following students are currently undertaking postgraduate study affiliated with the SMRC: Kabie Brook; Ruth Cowie; Miranda Eodanable; Lorna Ginnell; Margarita Kanevski; Margaret Laurie; Cameron Maitland Warne; Sinéad O'Carroll; Shereen Sharaan.

Finally, the SMRC benefits from links with a range of Associate Members from across the University of Edinburgh, whose details can be found on our website. Key Associate Members include **Dr Gale MacLeod** and **Dr Martin Toye**, both based in Moray House School of Education & Sport at University of Edinburgh, and leaders of the **Beyond Behaviour** project, reported below.

## Work jointly funded by SMRC and the University

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### Attainment and Cognition

*Developing a learning difficulties cohort: educational attainment in children referred for developmental assessment for cognitive and / or motor difficulties*

**Personnel:** *Principal Investigator:* Dr Sinéad Rhodes. *Collaborators:* Dr Tracy Stewart, Dr Josie Booth, Dr Emily McDougal, Ms Jessica Oldridge. *MSc students:* Cecile Sami (2018-2019), Hannah Gracie, Mina Murat, Kayley Roarty (2019-2020)

**Funding Source:** SMRC donation funding, plus salary contributions from the University.

**Overview:** This work involves cohort development currently focused on children referred for cognitive and motor difficulties. Educational assessments focus on broad aspects of literacy (e.g. reading, spelling, written and oral expression) and mathematics and are paired with cognitive function testing (e.g. executive functions, short-and long-term memory). Social functioning and relationships are assessed in-depth including prosocial behaviour and peer relationships. Mental health is comprehensively recorded across parent and child measures with a particular focus on depression and anxiety. Co-occurrence of disorder symptoms (ADHD, DCD, ASD, and behavioural disorders ODD, CD) are recorded. This work maps on to JLA priority questions 1, 3 and 8.

**Project Status:** A sample of 53 children referred to the ADHD pathway have been recruited and tested. We are now recruiting from 3 neurodevelopmental assessment centres. Assessments involve those who do and do not receive a diagnosis. All families have consented for S Rhodes to retain details and join her learning difficulties cohort. Each child's clinical team has received a report on their behaviour, symptoms and educational profile. This was aligned with their diagnostic appointment and information used as deemed appropriate by the clinical team at point of diagnosis. *Motor difficulties arm:* This work has now been extended to recruit children referred for motor difficulties following a series of studies in the literature reporting the poor educational attainment of children with DCD / Dyspraxia / low centile motor skills. Children will be recruited from those referred for motor difficulties to Occupational Therapy or Paediatrics.

**Implications:** Initial analyses conducted for preliminary presentations of the work (e.g. IASSIDD 2019, European Developmental Psychology conference 2019) include:

- Literacy difficulties are associated with underlying cognitive difficulties in children referred for ADHD assessment. Educational interventions should target supporting these children with basic memory processes as well as more complex thinking strategies. We are targeting these difficulties within our Waterloo Foundation funded intervention.
- Different aspects of literacy (e.g. word reading versus listening comprehension) are associated with different types of strategic cognitive difficulties. Our findings suggest tailored individualised approaches are needed to target cognitive functions according to the child's literacy difficulties.
- An unusual early presentation of depression and anxiety in children with ADHD is observed, as well as a high prevalence. As early literacy difficulties have been linked to mental health symptoms in children with intellectual impairment, we will seek funding to examine this relationship in children with ADHD.
- Rates of co-occurring disorders (ASD, DCD) in children with ADHD are high. Interventions that target all relevant disorder related symptoms will be most effective.

### Beyond Behaviour

*Being disordered or just 'being bad': pathways to, and the social consequences of, (non) diagnosis of behavioural disorders amongst Scottish secondary school pupils*

**Personnel:** *Principal Investigator:* Dr Gale Macleod. *Co-Investigator:* Dr Martin Toye. *Research Assistants:* Robin Dallas-Childs and Margaret Laurie.

**Funding Source and Amount:** SMRC Scientific Advisory Board, £60,259

**Overview:** This study aims to identify what factors, influence whether children are referred from education to health for specialist assessment for diagnosis of neurodevelopmental (ND) and behavioural disorders (ADHD, ODD). We're also interested in the social consequences for the pupil of being given, or not given a clinical diagnosis for a ND or behavioural disorder.

**Key Questions.** The research questions in this study are as follows:

1. What are the factors that influence decision making about whether to refer a young person from education to health for specialist assessment?
2. How do young people, with and without a diagnosis, understand their own behaviour?
3. Are there differences between clinical and sub-clinical groups in terms of attribution of responsibility and self-esteem, and how might any differences be explained?
4. Are young people with a diagnosis viewed differently by significant adults to those without?

**Rationale and Importance:** We will identify reasons for pupils not proceeding to a diagnostic pathway, and illuminate the experiences of adolescents who present disruptive behaviour and possibly unrecognised ND conditions. This could reveal effective pathways to diagnosis of ND conditions as well as effective (or ineffective) school-based responses where diagnosis has not been sought. Through exploring the experiences of pupils, the study seeks to identify the nature of any stigmas associated with behaviour in view to reducing the use of stigmatising language when talking about behavioural needs with schools, pupils and families.

**Milestones:** Two surveys completed with parent/carers of (non) diagnosed pupils and education professionals to inform methodology; quantitative and qualitative data collection instruments developed; participant resources prepared; data management processes developed; ethical consent from the university and four local authorities; 8 schools engaged with others still in negotiation. The aim is for data collection to be completed by June 2020 with dissemination events and non peer-reviewed publications towards the end of 2020, and peer reviewed articles in 2021.

**Implications:** The process of securing ethical consent from local authorities and schools has itself highlighted an acute sensitivity to the language used to describe young people whose behaviour schools find challenging. This indicates the importance of the research, not least in the contrast of these concerns with evidence from our parental survey which suggest that some families are more comfortable with this terminology. Where deemed appropriate, participant resources have been revised to respond to these developments.

## Depression Screening in Autism

*Development of a clinical screening instrument for depression symptoms in children and adolescents with autism spectrum disorder (ASD)*

**Personnel:** *Principal Investigator:* Dr Sinéad Rhodes. *Postdoctoral Research Fellow:* Dr Chris Eaton. *Co-Investigators:* Dr Tracy Stewart, Dr Stella Chan, Dr Rachael Wood, Dr Andrew McKechnie, Dr Ereni Skouta, Prof Jacqui Rodgers, Dr Leila Mackie. *Advisor:* Prof Anne O'Hare.

**Funding Source and Amount:** SMRC Scientific Advisory Board, £66,323, plus salary contributions from the University.

**Overview:** This project involves developing self-report and parent/carer-report versions of depression screening tools for young people aged 8-18 years with autism spectrum disorder who do not have intellectual impairment. To do this, we aim to interview 20 young people with ASD, 20 parents/carers and 20 professionals involved in their care and seek their feedback on a list of depressive symptoms we have compiled (e.g. feedback on wording, clarity, relevance to depression in autism). This work maps on to JLA priority questions 3, 5, 7 and 14.

### Key Questions:

1. What is the best form of words to use when describing depression symptoms for suitability of understanding in ASD?
2. What are the overlaps between ASD and depression symptoms and how can we best characterise depression within this population?

**Rationale and Importance:** There are no depression screening tools developed specifically for young people with ASD. This is a problem because the depression profile may present differently in this population, with a lack of interest/pleasure in everyday activities as the most prominent symptom and low mood being less important (Bitsika et al., 2015). In addition, the symptoms of depression and characteristics of autism may overlap, for example, sleep disturbance, unusual eating habits, social withdrawal. A depression screening tool in ASD is needed to assist in identification of depression in this group and to provide accurate estimates of the prevalence of depression within this population.

**Milestones:** We have compiled a database of assessment tools for depression used in clinical practice and the research literature with typically young people that includes eleven measures. Self-report and parent report versions of depression symptoms have been extracted and grouped into 16 symptom categories. A research team meeting in February 2020 led to decisions to avoid use of abstract language, to focus on symptom related change from usual functioning, and to focus on symptom relevance for ASD. A draft list of depressive symptoms has been drafted from these processes. We have submitted an application for sponsorship (University of Edinburgh) and will shortly submit for ethical approval (Moray House School of Education and Sport). Once approved, we will contact local Scottish and UK-wide charities for children with ASD and distribute recruitment packs.

**Implications:** This project has the potential to inform the development of self-report and parent-report depression screening tools for young people with autism, which may enable better identification of clinical cases and accurate prevalence estimates of depression in research studies.

## Early Literacy in Autism

### *Autism Spectrum Disorder and associations with literacy skills at the start of primary school*

**Personnel:** *Principal Investigators:* Dr Louise Marryat, Dr Rachael Wood. *Co-Investigators:* Dr Josie Booth, Dr Sinéad Rhodes, Prof. Chris Weir

**Funding Source and Amount:** SMRC Scientific Advisory Board, £22,534, plus salary contributions from the University.

**Rationale and Importance:** Evidence suggests that children who are diagnosed with neurodevelopmental disorders such as autism have relatively poor reading skills. We know that this is the case by the end of primary school, and that reading difficulties experienced by children vary with autism features, and depend on whether other co-occurring conditions are present. We know little, however, about the *early* reading skills of these children. This is important because early reading skills lay the foundations for learning throughout childhood and beyond.

**Overview:** In 2018, the SAB funded the creation of a novel linked dataset containing educational records and health records. The educational records included detailed information on the early reading skills at the start of primary school and children's characteristics. This was linked to health data including weight and gestation at birth, and additional support needs, such as autism. We are currently applying for further funding to enable us to analyse these initial data on autism, and reading skills, as well to explore opportunities for extending this linkage further, either to look at early literacy skills and other conditions, and/or to extend to literacy skills in later childhood.

#### **Key Questions:**

1. What do the early literacy profiles of autistic children look like, and how do they differ from typically developing children?
2. What different profiles of early literacy do we see among autistic children, and what socio-demographic characteristics and perinatal risks affect these?
3. Can we extend data linkage to explore the impact of other neurodevelopmental conditions on early literacy, and which combinations of disorders put children most at risk of experiencing literacy difficulties?
4. Can we extend data linkage to explore the stability of literacy difficulties over time for the various high risk neurodevelopmental groups?

**Milestones:** We have completed the following: Data Protection Impact Assessment; Data Processing Agreement; Data Sharing Agreement; University level ethical approval. Next steps 2020-2021: Secure Public Benefit and Privacy Panel approval; receive Phase 1 dataset; recruit analyst; analyse initial data.

**Implications:** This research will address an important evidence gap, clarifying how the early literacy profiles of children with autism compare with those of children without, and exploring heterogeneity within the autism group. This has the potential to influence the way in which the literacy education of children with additional needs is approached. If we can improve the early literacy skills of children with ASD, we may be able to have a lasting impact across the life course.

## Social Function in Autism

*The relationships between bullying, isolation and depression across the autism spectrum*

**Personnel:** *PhD Candidate:* Mr Cameron Maitland-Warne. *Supervisors:* Dr Mary Stewart and Dr Sinéad Rhodes, and formerly Prof Anne O'Hare

**Funding Source and Amount:** SMRC Scientific Advisory Board, £58,195.

**Key Questions:** Identifying depression and social risk factors in autism

**Rationale and Importance:** Understanding social identity and depression is not well understood in autism. This work maps on to JLA priority question 9.

**Milestones:** There are three key studies. Two have been completed and the third is in progress.

Study 1 was a cross-sectional study examining social identities in autism. Social identities are the groups that we belong to that influence how we perceive ourselves and our behaviours. The study examined whether in adult autism samples feelings towards groups belonged to relate to mental well-being. Responses to questions regarding social identities were found to be similar to the rest of the population which increases confidence that we can accurately measure these feelings and their effects in autism samples. A large variety in the numbers and types of groups identified with was observed. Some reported not feeling connection with any groups, others identified with multiple groups. More strongly identifying with others who have autism and with one's family was associated with reduced depression and positive mental health. Identifying with multiple groups was associated with better mental health.

Study 2 examined whether individuals who are high in autism traits answer questions about depression differently to those low in traits. It has been previously suggested that depression may be experienced differently by the autism population. There are questions of whether typical depression measures accurately capture depression severity. This study used a method called Mokken analysis to examine how individuals respond to the commonly used depression screener the Beck Depression Inventory (BDI). Due to this analysis requiring large sample sizes, a general population sample was recruited and split depending on whether they scored low or high on autism traits. For both groups, all the items of the inventory were useful for assessing depression levels suggesting that this depression instrument is suitable for use with those high in autism traits.

Study 3 will examine social motivation and depression levels in autism and is underway.

**Implications:** These results demonstrate the importance of social groups for mental well-being in autism populations. Developing connections with others who similarly have autism may be beneficial due to a shared social identity and social communication style. Results suggest that the commonly used depression instrument the BDI may be suitable for use in autism but research needs to be conducted in those with a clinical diagnosis to verify appropriateness.

## Externally Funded Projects

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### ADHD Learning Intervention

#### *Development and feasibility of a learning intervention in children with ADHD*

**Personnel:** *Principal Investigator:* Dr Sinéad Rhodes. *Post-Doctoral Researcher:* Dr Emily McDougal. *Co-Investigators:* Dr Tracy Stewart, Dr Josie Booth, Prof. Anne O'Hare.

**Funding Source and Amount:** Waterloo Foundation Grant, £57,000; August 2019-September 2020.

**Overview:** This project involves two phases: 1) Development of learning intervention components and structure, and 2) Feasibility testing of the intervention with 20 children on the ADHD pathway and assessments with two comparison groups (20 children on ADHD medication, 20 controls). The aim is to develop learning intervention components linked to children's cognitive and symptomatic profiles. The work is co-produced with teachers and children and paired with insights from the relevant literature. This work maps on to JLA priority questions 1, 3, 4, 7.

**Project Status:** As of February 2020, phase 1 of the project is complete with 10 children tested and their teachers (N = 7). Informed by these interviews and the literature, we have successfully designed the intervention programme which will be personalized for each child (i.e. based on their own strengths and difficulties). Phase 2 of the project is underway. We have recruited 6 children to the intervention group and have collected baseline and follow up data with 10 children for the control group and 4 children for the medication comparison group. We are currently ahead of schedule for data collection with these groups. In addition to the above, we submitted a substantial ethics amendment that was approved in January 2020. This included the addition of teacher and child evaluation measures that were not included in the original application, and permission to recruit from an additional NHS site (West Lothian CAMHS team).

**Implications:** Findings are expected to support learning of children with a range of cognitive, social and behavioural difficulties arising from our tool-kit approach that can be tailored to an individual child's specific profile. Funding is currently being sought to apply it to children more broadly with learning difficulties as it will be useful for other neurodevelopmental disorders (DCD/Dyspraxia, ASD, FASD) and learning difficulties arising from other causes (e.g. prematurity).

### ADHD Learning Strategies

#### *Development and feasibility of a learning intervention in children with ADHD Part II*

**Personnel:** *Principal Investigator:* Dr Sinéad Rhodes. *Co-Investigators:* Dr Emily McDougal, Dr Tracy Stewart, Dr Josie Booth.

**Funding Source and Amount:** Waterloo Foundation £9,935, from September 2020

**Overview:** This work involves three objectives. 1. We will conduct a 3 month follow-up of our currently running learning difficulties intervention on children's developmental outcomes. Objectives 2 and 3 involve new work. 2. We will evaluate the effectiveness of our co-production work with teachers through workshops in the community. This data is expected to help inform effective co-production work in schools. 3. We will analyse pupil-teacher dyad data to thematically investigate psycho-education and strategy use in pupils with ADHD and their teacher. This work maps on to JLA priority questions 1, 3, 4, 7.

**Project Status:** We were awarded this funding on 11th March 2020. The project is expected to run from 1<sup>st</sup> September for 10 weeks. The ethics application for this extension is currently underway.

**Implications:** Findings are expected to strengthen the conclusions we can make from the currently running ADHD intervention. The work will also generate new insights into co-production work with teachers and inform use of psycho-education and strategies to improve learning in children with ADHD.

## Autism and Bilingualism

*Charting the impact of bilingualism on development in children with and without Autism.*

**Personnel:** Dr Sue Fletcher-Watson, Dr Rachael Davis, Mr Lewis Montgomery, Prof Antonella Sorace, Dr Hugh Rabagliati.

**Funding source and amount:** Economic and Social Research Council, £390,000

**Overview:** There is a dearth of empirical literature addressing how bilingualism might impact upon those with autism. What limited literature exists can be summarised as follows: bilingual exposure is unlikely to lead to poorer development of language in children with ASD and could provide an advantage in social and communicative domains. However, many parents are still concerned about the potentially harmful effects of bilingualism on development. We are collecting longitudinal data from bilingual children in order to understand the influence of bilingual exposure on changes in cognitive development in children with and without autism.

**Project Status:** Active, year 3 of 3. We have completed first time point visits, with 110 families participating. Sixty children have been seen a second time, with 100% retention. We are currently writing up three papers for publication and have presented the project at multiple workshops and conferences.



**Implications:** This study takes a step towards exploring the question of whether bilingualism can provide a naturalistic opportunity to further develop social cognitive skills. The work has implications for future clinical practice and can contribute to an evidence base for parents to make an informed choice about bilingualism for their child.

## BETA Project

*Building Evidence for Technology in Autism*

**Personnel:** *Principal Investigator:* Dr Ouriel Grynspan. *Co-Investigators:* Prof. Mark Brosnan, Dr Sue Fletcher-Watson, Dr Matthew Goodwin, Prof. Gerardo Herrera, Dr Patricia Perez-Fuster, Ms Vanessa Zervogianni.

**Funding source and amount:** Fondation Internationale de la Recherche Appliquée sur le Handicap (FIRAH), €90,000

**Overview:** Both anecdotally and from research we know that many autistic people enjoy using technology and can learn and otherwise benefit from technology-based supports. However it is very challenging for autistic people, their families and practitioners who work with them to navigate the vast range of available technologies that might prove useful. The BETA project addressed this issue by co-creating, with autistic people and their allies, tools for evaluating whether a specific app, website or other tool was grounded adequately in research evidence. The tool is now available at <https://beta-project.org/en/>, published in three languages, and accompanied by a library of evaluated digital resources.

**Project Status:** Closed. This project was completed in autumn 2019.

**Implications:** The BETA project is an excellent example of international collaboration (across the UK, France, Spain and the USA) to produce a free resource for autistic people, families and practices. This can provide a template for future projects with a broader remit, providing similar resources for the entire neurodivergent community.

## Diagnosis Support App

*The development of a mobile phone app to support parents/carers going through the autism diagnosis process*

**Personnel:** *Principal Investigator:* Dr Louise Marryat. *Co-Investigators:* Dr Dinah Aitken, Dr Sue Fletcher-Watson, Dr Sinéad Rhodes, Dr Marion Rutherford, Dr Tracy Stewart, Dr Rachael Wood in partnership with *Intelligent Mobile* and *Salvesen Mindroom Centre*, and working with *Colouring Outside the Lines*.

**Funding source and amount;** Nesta/Scottish Government, £30,000.

**Overview;** This project was based on foundational research conducted under the auspices of Prof. Anne O'Hare, founding Director of the Research Centre. It involved the design of a mobile phone app from initial idea to launch, aimed at supporting parents/carers of a child going through the autism assessment process. The app involved a co-design process, including an online survey of parents/carers, including autistic parents about content and design of the app, and discussions with clinicians and support organisations. The branding was carried out by Intelligent Mobile designers, and named 'Helping hand (help and assistance navigating diagnosis)'. Features included evidence-based content about autism and the diagnostic pathway, a diary for recording challenges such as sleep and difficult behaviours, a timeline with the likely diagnostic pathway, and signposting to other sources of support. The app was tested by parents/carers, clinicians and academics in Lothian with overwhelmingly positive feedback.

**Project Status:** Complete

**Implications:** The app launched on 24<sup>th</sup> February, with coverage of the launch on STV breakfast, lunchtime and evening news. The app is now available in Apple and Android app stores, and within 4 days had c.500 downloads. The app aims to reduce parental stress and anxiety around the diagnostic pathway, and has the potential to reduce waiting times through bringing together the required information for clinicians at appointments. Evaluation is required to see if the app will be successful in achieving its aims.



## Health Visiting Evaluation

*Evaluation of the Universal Health Visiting Pathway in Scotland: Routine Data Analysis Workstream*

**Personnel:** Dr Larry Doi, Prof. Ruth Jepson, Prof Helen Cheyne, Dr Ruth Astbury, Dr Margaret Horne, Dr Louise Marryat, Dr Rachael Wood and Ipsos Mori.

**Funding source and amount;** Scottish Government. £344,916 of which £82,840.98 to Edinburgh

**Overview;** The routine data analysis section of the evaluation of the Universal Health Visiting Pathway (UHVP) seeks to explore the implementation and impact of a new health visiting pathway across the whole of Scotland is a four year project across two phases using administrative health and child protection data. Each phase comprises an exploration of the process of implementation (e.g. coverage of visits, number of health visitors in post) and an examination of child outcomes, such as BMI and developmental scores. Phase 1 sets out baseline data, whilst Phase 2 investigates the impact of the UHVP.

**Project Status;** In progress (Year 2 out of 4). Progress this year has included the recruitment of a statistician, background research around measures to be explored and numbers of children who have (and haven't) experienced the new health visiting pathway by health board, as well as analysis planning.

**Implications:** This project will benefit policy-makers and health visitors through providing evidence of what works in health visiting, and potentially saving resource through identifying areas of practice which may not be beneficial. It will benefit children and families through evidencing the best forms of support and identifying the key ages and stages for identifying developmental difficulties, as well as any apparent gaps in the current schedule.

## Maternal Health - Child Outcomes

*Understanding the effects of prenatal maternal infections on developmental outcomes, autism spectrum disorder and learning disabilities*

**Personnel:** Dr Bonnie Auyeung, Dr Michael Lombardo, Dr Aja Murray, Dr Louise Marryat, Dr Lucy Thompson, Professor Helen Minnis and Professor Philip Wilson.

**Funding source and amount:** Baily Thomas. £109,310

**Overview:** This study examines the association of prenatal maternal infections and the onset of Autism Spectrum Disorder (ASD), learning disabilities and behavioural difficulties. This will be done through the linkage of healthcare data for each mother and child with a comprehensive series of child development measures throughout early life, providing an integrated view of maternal health during pregnancy and subsequent child development. The study will include over 30,000 complete sets of patient data (including at least 1,577 children with a confirmed diagnosis of ASD or learning disabilities), enabling the effects of maternal health on future child development and the onset of developmental and learning difficulties to be understood in much greater detail than has been possible with epidemiological studies focusing on single diagnostic criteria.

**Project Status:** In progress: currently drawing up data sharing contracts and arranging access to data.

**Implications:** Prenatal maternal infections are known to exist in all populations and this work is expected to be of international importance. Environmental risk factors (such as prenatal maternal infections) may be amenable to preventative care, leading to better neurodevelopmental outcomes and a reduced public health burden. The study will also provide a baseline from which to assess the potential impact of future treatment or intervention programmes designed to alleviate the potentially detrimental effects of prenatal maternal infections.

## Mathematics Learning in ADHD

*Cognition and mathematics in children with Attention Deficit Hyperactivity Disorder (ADHD).*

**Personnel:** *PhD Candidate* Ms Margarita Kanevski. *Supervisors:* Dr Sinéad Rhodes, Dr Josie Booth, Dr Sarah McGeown, Dr Andy Stanfield

**Funding source and amount** Carnegie-Caledonian PhD Scholarship, £66,000, funded by the Carnegie Trust for the Universities of Scotland

**Overview** Early mathematics achievement predicts a variety of outcomes during adulthood including higher education progression, socioeconomic status, and psychological wellbeing. Children with ADHD are at higher risk for developing learning difficulties in mathematics than their typically developing classmates. Previous research has focused on a select few cognitive domains. Recent conceptualisations of mathematics learning highlight that mathematics is not a unitary process, rather, there are several related yet distinct components including (1) factual knowledge, (2) conceptual understanding, and (3) procedural operations. These three components have not been comprehensively investigated in children with ADHD. This work maps on to JLA priority question 1. The primary goals of the project are:

1. Systematic review of the literature exploring the relationship between cognition and mathematics in children with ADHD.
2. Comprehensive investigation into the relationships between mathematics achievement as well as the factual, conceptual and procedural components, with a range of cognitive processes previously implicated in mathematics performance in children and documented as impaired in ADHD (i.e. memory, attention, and processing speed).

3. Data driven cluster analysis approach to group children together based on cognitive performance and assess differences between generated groups on mathematics performance.
4. Comparison of mathematics performance between children with and without co-occurring movement difficulties.

**Project Status:** Data collection has now been completed. Analysis of results and writing up this work for PhD submission / journal publications is underway. PhD submission is expected in October 2020.

**Implications** The project offers new insight on the underlying challenges faced by children with ADHD in mathematical learning facilitating novel theoretical perspectives of our understanding of cognition and mathematics learning in an ADHD sample. This project informs future research around identification of intervention strategies optimally suited to the needs of struggling learners.

## MRB Trial

*A clinical and cost effectiveness trial of a parent group intervention to manage restricted and repetitive behaviours in young children with Autism Spectrum Disorder*

**Personnel:** *Chief Investigator:* Dr Victoria Grahame. *Principal Investigators, Edinburgh Site:* Dr Leila Mackie, Dr Sue Fletcher-Watson. *Research Team, Edinburgh Site:* Dr Rebecca Iversen, Dr Eamonn Walls, Ms Saoirse Heron.

**Funding source and amount:** National Institute of Health Research, £ 1,354,000 of which £362,000 comes to Edinburgh

**Overview:** Clinical interventions available for young autistic children and their families focus overwhelmingly on supporting early social and communication development. While these are indeed crucial targets, we also know that the presence of restricted routines and repetitive behaviours make a major contribution to family stress. For parents, knowing how to respond to these behaviours is very difficult – they provide an important regulatory function for their child, but can also become extended and entrenched, with negative consequences. There are currently no robustly evidence-based interventions in this domain. The MRB trial evaluates one such intervention, which uses a group parent-training model, in a fully-powered clinical trial across three recruitment sites, of which Edinburgh / NHS Lothian is one.

**Project Status:** Active, year 3 of 4. We have completed four intervention groups with a fifth in progress. Our first 52-week follow-up appointments are underway. The study also benefits from the contribution of NRS Fellowship funded time for the clinical PI, Dr Leila Mackie.

**Implications:** This study will provide conclusive evidence about the value of the MRB intervention, which may then be adopted as part of standard NHS clinical practice.

## Parents InC

*A feasibility randomised controlled trial of a parenting support programme focussed on families affected by ADHD*

**Personnel:** *Principal Investigators:* Prof. Helen Minnis, Dr Lucy Thompson L. *Co-Investigators:* Dr Emma McIntosh, Dr Gordon Brown, Dr Hilary Maddox, Dr Caroline Haig, Prof Chris Gillberg, Dr Nicholas Watson, Dr Rachael Wood.

**Funding source and amount:** Chief Scientist Office, £277,621

**Overview:** Parents In Control (Parents InC) is a bespoke parenting programme that has been developed for the parents of children diagnosed with ADHD. A major trial of the effectiveness of this programme compared to an established generic parenting programme (Incredible Years, not specifically designed for parents of children with neurodevelopmental conditions) is planned. This initial feasibility trial is gathering the background information required to plan and deliver the full trial – for example by testing strategies for

recruiting and retaining families, directly assessing initial outcomes, and using linkage to administrative records to assess longer term outcomes.

**Project Status:** In progress (Year 3 of 3)

**Implications:** This feasibility trial is an essential step on the road to a full-scale evaluation of the benefits of this novel intervention. If the programme is shown to be acceptable for parents and achievable within existing support systems, there is potential for it to become part of national health provision. In addition this study incorporates data linkage elements – a powerful tool to enrich clinical trials in neurodevelopment within SMRC in the future.

## Peer Support

*Co-creating peer support models for autistic adolescents in school*

**Personnel:** Dr Catherine Crompton, Dr Sue Fletcher-Watson, Dr Katie Cebula.

**Funding source and amount:** Institute of Advanced Studies in the Humanities fellowship scheme, £ 12,500; Wellcome Trust/University of Edinburgh ISSF3 Public Engagement with Research Seed Fund, £1,500

**Overview:** Peer support programmes could provide a space for autistic pupils to interact with each other without having to mask their natural behaviours. In autistic adults, self-acceptance and pride in being neurodivergent is linked to lower depression scores and feeling part of an autistic community reduces suicide risk. Despite extensive findings that peer support can have substantial benefits in other conditions, there has been no formal exploration of peer support in autism. In this project we are: identifying existing informal practice of autistic peer support in Edinburgh mainstream secondary schools and charting how autistic pupils, autistic adults, and teachers describe the important aspects of autistic peer support. We will use this information and our previously published work to co-design a peer support program for autistic pupils in mainstream schools.

**Project Status:** Active, year 1 of 1. We have completed the interview phase and are moving towards the co-design activities.

**Implications:** This study will produce a comprehensive pack of co-designed, pupil-friendly materials to allow teachers and / or pupils to create and sustain autistic peer support in schools, shared freely online through national and international networks. The work can provide the foundations of development of peer support networks for other neurodivergent pupils.

## Self-Reference in ADHD

*The Self Referent Effect in Attention Deficit Hyperactivity Disorder*

**Personnel:** Dr Sheila Cunningham, Ms Zahra Ahmed, Dr Sinéad Rhodes, Ms Ailsa Gow, Ms Kirsty McMillan, Dr Jacqui Hutchison & Dr Josephine Ross

**Overview:** Using personal information relevant to oneself is known to aid memory. This study compared memory for items children with ADHD referenced to themselves versus items they referenced to other people and compared with typically-developing control groups matched for verbal and chronological age. Children aged 5-14 ( $N = 90$ ) were presented with everyday objects alongside an image of their own face (self-reference trials) or an unknown child's face (other-referenced trials). They were asked whether or not the child shown would like the object. A surprise source memory test followed, which revealed a significant self-reference effect (SRE) in typically developing children (i.e., they showed better memory for self-referenced than other-referenced objects). However, children with ADHD did not avail of this effect to support memory, suggesting a compromised ability to bind information in memory in relation to their concept of themselves. In a separate task, all three groups showed superior memory for actions physically associated with the self, suggesting a preserved enactment effect in ADHD. This work maps on to JLA priority question 4.

**Project Status:** This project completed in 2019 and a paper has been drafted for Journal of Attention Disorders and is currently under revision by co-authors.

**Implications:** The SRE has been shown to be useful in an educational context, where its effects on attention and memory can support children's learning but our findings suggest it would not be particularly useful for children with ADHD. The enactment effect has also been found useful in typically developing classrooms, and our results suggest this paradigm may be more usefully applied to support memory in ADHD within school classroom settings.

## UKPRP Network

*Harnessing cross-country administrative data to evaluate national policy impacts on maternal, infant and child health and health inequalities-MatCHNet*

**Personnel:** Dr Ruth Dundas, Prof Alastair Leyland, Dr Anna Pearce, Dr Rachael Wood, Prof Ruth Gilbert, Prof Sinéad Brophy, Dr Joanne Given, Dr Katie Harron, Dr Pia Hardelid, Prof Richard Cookson.

**Funding source and amount:** Medical Research Council UK Prevention Research Partnership Network Award, £399,999

**Overview:** This project aims to establish a UK wide network of policy makers, academics, and organisations holding relevant administrative data. The network will identify areas of divergence between the 4 UK nations in terms of social policy likely to influence maternal and early infant health, and hence subsequent child development and wellbeing. The network will also identify administrative data and innovative research methods that could be used to exploit this policy divergence to assess the impact of different approaches on population health and equity. The network will then develop proposals and associated funding bids for major cross-national follow on projects.

**Project Status:** In progress (Year 1 of 4)

**Implications:** A major challenge to effective use of routine data is a lack of co-ordination and integration of data sets and the policies that underlie them across the UK. This project turns that challenge into a strength by identifying ways in which policy differences can be used to address research questions. The work will provide the foundations for essential studies of the influence of UK policy on child health and development.

## Outreach and Impact Summary

At the Salvesen Mindroom Research Centre we are passionate about telling people about the research we're doing, what we have discovered and, most importantly, involving children and young people living with learning difficulties, and their families, in shaping and being part of our work. Over the past year our outreach work has taken a number of different forms.

### Website and Social Media

Our Research Centre website at [www.ed.ac.uk/salvesen-research](http://www.ed.ac.uk/salvesen-research) launched in October and now provides the main online presence for the Research Centre and our work. The site is designed to be the 'go to' place to find out about the values, vision and work of the Centre, the people who are part of it, our research projects and our news and events. The site is continually expanding and evolving with new content being added each week.

To further the reach of our communications, in October we launched a Twitter account @SMRCResearch. In a very short time, the account has grown to now have over 330 followers and we intend to further this reach over the coming year.

### Book reviews

Research can be a lengthy process and we wanted to have a more immediate way of sharing our expertise with the public than is normally possible for researchers. Starting in December, we began a series of book reviews of titles focused on learning difficulties. We are publishing one review per month on our website and will gradually accumulate a library that we hope will be genuinely helpful to parents and professionals. The team at the Salvesen Research Centre are working alongside us on this initiative to also share their practitioners' expertise and we also plan to share reviews from people with lived experience of learning difficulties too.

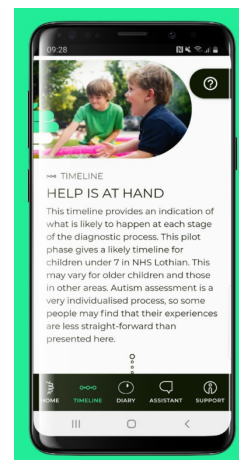
### Inaugural Salvesen Lecture

Tuesday 26th November 2019 saw our first Salvesen Lecture titled *Learning Difficulties – Whose Voice Matters? Inclusion and Empowerment in Research and Practice*. At the first of what we plan to be an annual public event, Sue Fletcher-Watson was joined by Sophie Dow to showcase how research and practice can work together to achieve positive results. Around 130 people attended the lecture with over 110 people also viewing the event online. Positive feedback we received from the event included a PhD student and former education practitioner writing that "I was blown away by the principles of the Salvesen Mindroom and after hearing you speak it has really restored my faith in the power of research to help the children and their families." Also an Edinburgh-based practitioner tweeted about the SMRC that "...It's emphasis on working directly & with key individuals/groups in order to make findings robust & implement change is inspiring." The lecture recording can be viewed here: <https://edin.ac/2wxENbf>



## Helping Hand app

Our first piece of television news coverage was provided courtesy of our new Helping Hand app launched in February. STV breakfast, lunchtime and evening news covered the launch of the app which has been designed to reduce the stress and anxiety experienced by parents of children going through the autism diagnostic pathway. The app is now available in Apple and Android app stores, and within 4 days had over 500 downloads..



## Research Priorities article published in BMJ Open

The British Medical Journal published an article on Research Priorities for Learning Difficulties project – the flagship project for the Research Centre in partnership with the Salvesen Mindroom Centre and the James Lind Alliance. Principal investigator Sinéad Rhodes is an author on the paper. At the point of completion, the project priorities achieved widespread media interest across many titles and huge interest on social media. The publication in such a renowned journal as the BMJ cements the quality of the research through peer review and allows researchers internationally to learn about the study and incorporate the findings into their own work.

## Centre Director as influencer and expert

To help further the reach of the work and activity of the Research Centre, we have also begun employing the tactic of growing the profile of the Centre's Director, Dr Sue Fletcher-Watson. On her appointment to the role, Sue brought with her an existing Twitter following of over 6,000 and being part of an active online community of people with lived experience of learning difficulties and other professionals. To grow her profile Sue has started producing public opinion pieces on stories or issues highlighted in the news, has delivered training and taken up numerous speaking opportunities. Some key examples of this include delivering training on effective curriculum design for autism, at Prior's Court school, Thatcham and speaking at the Scottish Parliament cross party working group on Autism in November. As testimony to her expertise, Sue was earlier this year, a finalist in the 'Most Impactful Researcher' category of the National Autistic Society Awards.

## Our research within the University of Edinburgh

Almost 60,000 staff and students make up the University of Edinburgh which therefore offers a huge audience for the work of the Research Centre and an opportunity to grow awareness of learning difficulties in general. Research Fellow Louise Marryat spoke about the development of the Helping Hand app to almost 200 people at the Centre for Clinical Brain Sciences away day In January. In summer 2019, Sue Fletcher-Watson and Natalie Jenkins both spoke about supporting autistic students in Higher Education at the University's Learning & Teaching Conference, providing impact on our own doorstep.

## Into 2020 and beyond

We're proud to be working alongside our charity colleagues to share our work as widely and effectively as possible. For example, in 2019 Sinéad Rhodes and Dinah Aitken delivered a joint presentation at the IASSIDD conference, on charity / research centre collaborative working, and in 2020 we hope to secure a joint workshop in the Scottish Learning Festival programme. We are excited that our outreach and impact will continue to grow in 2020/21 as we develop further our website, twitter and book reviews alongside delivering our second Salvesen Lecture and publicising more results of research.

## Academic Dissemination Summary

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### Keynote Talks

**Fletcher-Watson, S.** (May 2019) *Merging psychological theory with a neurodiversity framework for better autism interventions*. European Academy of Childhood Disability, Paris.

**Rhodes S.** (June 2019) *Myths and Evidence of ADHD*. Neuro-Developmental Disorders Annual Seminar Series (NDAS) Established Career Keynote Lecture, University of Surrey.

### Books, Book Chapters and Reports

**Fletcher-Watson, S. & Happé, F.** (2019) *Autism: a new introduction to psychological theory and current debate*. Routledge, London, UK. (194 pages)

Hedges, S. & **Fletcher-Watson, S.** (2019). Information and communication technologies as educational supports. In R. Jordan, J. Roberts & K. Hume (Eds.) *Autism and Education: An International Handbook*, London: Sage.

Knudsen, L., Currie, E., Bradshaw, P., Law, J., & **Wood, R.** (2019). Growing Up in Scotland: changes in language ability over the primary school years. ISBN: 9781787818392

### Journal Articles

#### 2020

Beange, I., Kirkham, E. J., **Fletcher-Watson, S.**, Iveson, M. H., Lawrie, S. M., Batty, G. D., Boardman, J.P., Deary, I.J., Black, C., Porteous, D.J. & McIntosh, A. M. (2020). Using a knowledge exchange event to assess study participants' attitudes to research in a rapidly evolving research context. *Wellcome Open Research*, 5(24), 24.

Boardman, J. P., Hall, J., Thrippleton, M. J., Reynolds, R. M., Bogaert, D., Davidson, D. J., Schwarze, J., Drake, A.J., Chandran, S., Bastin, M.E. & **Fletcher-Watson, S.** (2020). Impact of preterm birth on brain development and long-term outcome: protocol for a cohort study in Scotland. *BMJ open*, 10(3), e035854.

**Crompton, C. J.**, Hallett, S., Ropar, D., Flynn, E., & **Fletcher-Watson, S.** (2020). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, 1362361320908976.

Doi, L., Williams, A., **Marryat, L.** & Frank, J. (2020) Cohort study of high maternal body mass index and the risk of adverse pregnancy and delivery outcomes in Scotland. *BMJ Open*, 10 (2) e026168; DOI: 10.1136/bmjopen-2018-026168

**Fletcher-Watson, S.**, & Bird, G. (2019). Autism and empathy: what are the real links?. *Autism*, doi:1362361319883506.

Kanevski, M. Booth, J.N., McGeown, S., McDougal, E., Oldridge, J., Stewart, T., Stanfield, A., **Rhodes, S. M.** (2020). Cognitive and mathematics performance in children with attention deficit hyperactivity disorder (ADHD). PROSPERO 2020 CRD42020169708, Available from: [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42020169708](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020169708)

Theodoraki, T. E., McGeown, S. P., **Rhodes, S. M.**, & MacPherson, S. E. (2020). Developmental changes in executive functions during adolescence: A study of inhibition, shifting, and working memory. *British Journal of Developmental Psychology*, 38(1), 74-89.

Zervogianni, V., **Fletcher-Watson, S.**, Herrera, G., Goodwin, M., Pérez-Fuster, P., Brosnan, M., & Grynszpan, O. (2020). A framework of evidence-based practice for digital support, co-developed with and for the autism community. *Autism*, 1362361319898331.

## 2019

Blair, A., **Marryat, L.**, & Frank, J. (2019). How community resources mitigate the association between household poverty and the incidence of adverse childhood experiences. *International journal of public health*, 64(7), 1059-1068.

Ene, D., Der, G., **Fletcher-Watson, S.**, O'Carroll, S., MacKenzie, G., Higgins, M., & Boardman, J. P. (2019). Associations of socioeconomic deprivation and preterm birth with speech, language, and communication concerns among children aged 27 to 30 months. *JAMA Network Open*, 2(9), e1911027-e1911027.

**Fletcher-Watson, S.**, Larsen, K., Salomone, E., & COST ESSEA Working Groups. (2019). What do parents of children with autism expect from participation in research? A community survey about early autism studies. *Autism*, 23(1), 175-186.

**Fletcher-Watson, S.**, Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J.R. & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943-953.

**Laurie, M. H.**, Warreyn, P., Uriarte, B. V., Boonen, C., & **Fletcher-Watson, S.** (2019). An international survey of parental attitudes to technology use by their autistic children at home. *Journal of autism and developmental disorders*, 49(4), 1517-1530.

**Laurie, M. H.**, **Fletcher-Watson, S.**, & Manches, A. (2019). Design implications from Cognitive Event Analysis: A case study of digitally mediated interaction in autistic children. In *Proceedings of the 18th ACM International Conference on Interaction Design and Children* (pp. 476-481). ACM.

Lawder, R., Whyte, B., **Wood, R.**, Fischbacher, C., & Tappin, D. M. (2019). Impact of maternal smoking on early childhood health: a retrospective cohort linked dataset analysis of 697 003 children born in Scotland 1997–2009. *BMJ open*, 9(3), e023213.

Lim, A. K., **Rhodes, S.**, Cowan, K., & O'Hare, A. (2019). Joint production of research priorities to improve the lives of those with childhood onset conditions that impair learning: the James Lind Alliance Priority Setting Partnership for 'learning difficulties'. *BMJ Open*, 9(10).

McKenzie, K., Murray, G., Murray, A., Delahunty, L., Hutton, L., Murray, K., & **O'Hare, A.** (2019). Child and Adolescent Intellectual Disability Screening Questionnaire to identify children with intellectual disability. *Developmental Medicine & Child Neurology*, 61(4), 444-450.

McKenzie, K., Murray, G., Murray, A., Martin, R., Tanfield, Y., Delahunty, L., Hutton, L., Murray, K.R. & **O'Hare, A.** (2019). Screening for intellectual disability with the Child and Adolescent Intellectual Screening Questionnaire: a modified Delphi approach. *Developmental Medicine & Child Neurology*, 61(8), 979-983.

Maciver, D., Rutherford, M., Arakelyan, S., Kramer, J. M., Richmond, J., Todorova, L., Romero-Ayuso, D., Nakamura-Thomas, H., Ten Velden, M., Finlayson, I. & **O'Hare, A.** (2019). Participation of children with disabilities in school: A realist systematic review of psychosocial and environmental factors. *PloS one*, 14(1).

- Marryat, L.** & Frank, J. (2019) Factors associated with adverse childhood experiences in Scottish children: a prospective cohort study. *BMJ Paediatrics Open*. 3 (1) e000340; DOI: 10.1136/bmjpo-2018-000340
- Marryat, L., Wood, R.,** Whittaker, A., Frank, J., & Boardman, J. (2019). Developing a new cohort of children born to women who used opioids in pregnancy using administrative data: insights into cohort creation and early results. *International Journal of Population Data Science*, 4(3).
- Rhodes, S. M.,** Stewart, T. M., & Kanevski, M. (2019). Immediate impact of fantastical television content on children's executive functions. *British Journal of Developmental Psychology*. DOI: 10.1111/bjdp.12318.
- Sim, F., Thompson, L., **Marryat, L.,** Ramparsad, N., & Wilson, P. (2019). Predictive validity of preschool screening tools for language and behavioural difficulties: A PRISMA systematic review. *PloS one*, 14(2).
- Sim, F., Thompson, L., **Marryat, L.,** Law, J., & Wilson, P. (2019). Preschool developmental concerns and adjustment in the early school years: Evidence from a Scottish birth cohort. *Child: care, health and development*, 45(5), 719-736.
- Stewart, T. M., Hunter, S. C., & **Rhodes, S. M.** (2019). Reflective pondering is associated with executive control for emotional information: An adolescent prospective study. *Journal of behavior therapy and experimental psychiatry*, 65, 101486.

## Other Achievements and Activities

The Research Centre has a commitment to training and developing new researchers in innovative approaches to understanding learning and developmental diversity. In the past year we have seen a number of student successes.

In June 2019 PhD candidate **Thalia Theodoraki**, supervised by Sinéad Rhodes, successfully defended her thesis, titled *Investigating the development of executive functions and their relationship with educational attainment during adolescence: a study of inhibition, shifting and working memory*. This project highlighted the significance of studying cognitive functions in adolescence, and suggested that, even during the later stages of adolescence, executive functions may constitute a useful target for educational interventions aimed at improving pupils' attainment. Congratulations also go to **Rebecca Iversen** who joined the MRB trial shortly after submitting her thesis, and successfully defended it at viva in February 2020.

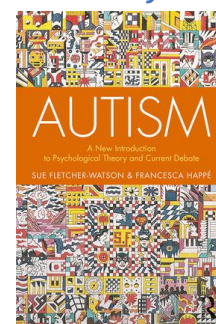
PhD candidate **Miranda Eodanable** joined Sinéad Rhodes' group in January 2020 to investigate professionals and young people's views about Fetal Alcohol Syndrome Disorder (FASD) diagnosis. Children with FASD are an under-researched group who show a range of learning difficulties that impair educational attainment. This work is expected to reveal how children and young people in Scotland are referred for FASD assessment, and how a diagnosis impacts on access to support, and on subsequent functioning such as educational attainment.

**Kabie Brook** joined Sue Fletcher-Watson's DART (Development / Autism / Research / Technology) lab group in September 2019 to pursue a part-time Masters by Research. This was funded by the innovative Charles Sharland scheme, delivered by research charity Autistica. Kabie will be asking *How do autistic parents play with their children?* and specifically investigating whether such families are poorly served by normative evaluation structures used in social care and clinical services.

Also in 2019, the University of Edinburgh won funding for a renewed **Translational Neuroscience PhD programme**, with Sue Fletcher-Watson as one of the Directors. This programme will see 30 students over 5 years coming to the University to develop neuroscience research skills embedded in a clinical knowledge base. The programme provides a model which the SMRC could one day follow, by developing a PhD programme of its own to train the next generation of interdisciplinary development & learning scientists.

In February 2020, PhD candidate Ailbhe McKinney secured funding from the newly launched University of Edinburgh **Medical Sciences and Translational Research PhD with Integrated Studies in Engagement for Impact** to join Sinéad Rhodes' research group. This project will examine the transition to adolescence in girls with neurodevelopmental disorders. Target work includes a study examining transition from primary to high-school in children with ADHD, Developmental Co-ordination Disorder, and ASD.

At the undergraduate level, Sue published a textbook, entitled **Autism: A New Introduction to Psychological Theory and Current Debate**. The book has been well received with Professor Dame Uta Frith stating that "*If you read one book on autism, this should be the one!*" – quite an accolade when one considers that she has written at least three autism books herself.



While developing early career researchers and students is key, we have also been attentive to creating connections with practitioners. Sinéad Rhodes and Emily McDougal won funding from the Wellcome Trust Institutional Strategic Support Fund, under the Public Engagement with Research stream, to carry out a series of **workshops with teachers and teaching support staff in community settings**. At the heart of this work is evaluation of the inclusion of the voices of teachers in our research which is being paired with insights from academic research to co-produce an intervention. A key objective is to strengthen and develop further a network of teachers they engage in with across the projects being conducted and planned by the Rhodes Group. This work maps on to JLA priority questions 1, 3 and 4 and will assist in plans to develop a national learning difficulties education professional – academic researcher network.

Sinéad and Emily also secured internal funding, with colleagues, to hold **a public engagement workshop on interdisciplinary collaboration and co-production in neurodevelopmental disorder research**. Invited contributions include teachers, clinicians, government representatives and individuals with lived experiences of developmental disorders/their families to share insights about interdisciplinary collaborations and co-production in neurodevelopmental disorder research. Interdisciplinary collaboration is relevant for many fields of research, in order to successfully design and conduct research, as well as implement impact outcomes upon practice and policy. This notion is particularly true for the field of neurodevelopmental disorders research, with its potential to influence the lives of many, whether through clinical practice, educational practice, or social policy. The workshop will be led by Emily McDougal and is paired with the Neurodevelopmental Disorders Conference (NDAS 2020) which is being hosted by Sinéad Rhodes at UoE in June 2020.

At the policy level, the Research Centre were delighted that PhD student (and now Beyond Behaviour researcher) **Margaret Laurie** was awarded a policy research fellowship from the British Psychological Society. This funded a 3-month secondment to the Parliamentary Office of Science and Technology (POST) in Westminster. During her time there, Margaret was tasked with producing a POSTnote on autism. POSTnotes are produced through a combination of literature review, including from academic and non-academic sources (e.g. charity and policy reports, research in non-academic outputs), and through interviews with key stakeholders across academic, non-profit and charity organisations, and policy spheres. The resulting note has been widely applauded and will influence autism policy across the UK for years to come.

## Scientific Advisory Board Report

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In the period covered by this report, the Scientific Advisory Board met twice, in March and September 2019. They funded two projects in that time. The first is reported above – Depression Screening in Autism (see page 7).

The second funded project is called **Learning About Neurodiversity For Primary School Pupils**. Feedback from the board included: *"The SAB were enthusiastic about this application and supported its funding in full ... The SAB thought this was of high strategic importance to the SMC as success will deliver an evidence-based resource pack that will enable teachers to educate primary school pupils about learning difficulties in the context of 'neurodiversity'."* The project commenced on 1<sup>st</sup> March with recruitment of a new postdoctoral research fellow, Dr Alyssa Alcorn and will be covered in more detail in the 2020/21 Research Centre report.

During 2019 the SAB application forms and guidance for applicants were refreshed. The new application form, designed with the Director, ensures that applicants justify their proposals against the 10 research priorities developed by stakeholders with the James Lind Alliance and approved by the Board. It requires confirmation from the Director that the work contributes strategically to the SMRC vision, agreed with the Board. Finally, it provides more space for applicants to give details of community partners, and share impact plans. In this way the paperwork for applying for funding to the SAB aligns with the Research Centre priorities.

It has been suggested that during 2020 the SMRC pilots support for submissions to the SAB from Members and Associate Members for small projects that will enhance impact from SMRC-funded research. The SAB will advise the Director of the suitability of this approach.

## Finance

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Since its foundation, the Research Centre has received approximately £2.1m in income, generously donated by the AEH Salvesen Trust. This funding is largely designated for specific research projects and initiatives, following review and approval by the Scientific Advisory Board. In addition, funding from the donation supports the Research Centre's principal investigators, core staff and associated costs such as outreach, travel and training.

This donation has leveraged a total of £1m investment in the Research Centre from the University of Edinburgh, for salaries, IT and other equipment and indirect costs.

In addition, principal investigators and research fellows within the Research Centre have won a total of £1.9m in external funding on projects directly relevant to the aims of the Centre. In the period covered by this report, new external funding to the Research Centre totalled £619,000.

In the coming 12 months a top priority is to secure continued funding in the Research Centre, for core as well as individual project costs. Creative funding models are required to realise the innovative vision of the Centre, which aims to identify shared experiences of people with learning difficulties, regardless of diagnosis, building and evaluating interventions to address these common targets.

Another goal is to secure the futures of the many Research Centre staff currently employed on fixed term contracts, supporting more Fellows to transition to research independence. We plan to create our own neurodiversity focused postgraduate student cohort, training a new generation of researchers in the combined scientific and social knowledge needed to examine neurodevelopment and change the lives of neurodivergent people for the better.

## Future Prospects

At the time of writing, the whole world is gripped by the Covid-19 pandemic. Our short term goal is to reassure our staff and research participants, and to protect them from immediate harm. Looking ahead, we will need to quantify the impact that the crisis has had on the Research Centre's activities. We will work with our funders and the University leadership to resume and repair the face-to-face research time that has been lost. Most importantly, during the pandemic we have a responsibility to disseminate effective information to support neurodivergent people and their families. We have begun this already with a short and simple guide explaining why schools were closing (depicted). We will follow this up in the coming weeks, working closely with our SMC partner, by sharing home learning, well-being and health resources relevant to the community we serve.

The current crisis has intensified our plans to increase the impact-focused activities of the Centre. In 2020 we will be finalising our policy briefing templates and ensuring that every discovery, derived from both research and practice, is translated into a lay summary with concrete recommendations for practitioners and policy-makers. We will combine this with direct outreach to families and to children and young people, using creative means to share research in meaningful ways. As in all our activities, the SMC will be a key partner ensuring that our work remains relevant and accessible to our stakeholders.

We will continue to use the remaining Scientific Advisory Board resource to launch projects that combine scientific rigour with direct impact, aligned with the Top Ten Priorities for learning difficulties research. Our scientific goals for the coming year include launching the first randomized controlled trial to be led within the Centre. This is a fundamental step on the pathway to becoming a global leader in the delivery of community trials, creating robust evidence embedded in real world settings. We will also recruit new staff with expertise in complex modelling to derive policy-relevant insights from the valuable data sets compiled already by the Research Centre.

Finally, the coming year will include a number of activities designed to further entrench our close relationship with the SMC. We will continue our bi-annual joint team meetings and shared outreach work, including our second Salvesen Lecture and a public debate on policy-to-practice implementation. We have commissioned a data sharing agreement to be signed off in 2020, which will enable much closer working. This includes leveraging the valuable data collected by the SMC to address research questions of mutual interest.

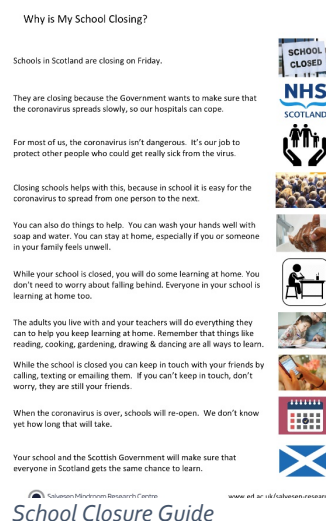
In 2020, we look forward to moving another step closer to removing educational disadvantages for people with learning difficulties.



**Dr Sue Fletcher-Watson**  
Director



**Professor Sir John Savill**  
Chair of the Scientific Advisory Board



## With Thanks to Our Funders and Partners

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