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# Salvesen Mindroom Research Centre annual report 2020-2021

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## Director's Summary

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The past year, my second as Director of the Salvesen Mindroom Research Centre, has been extraordinary to say the least. Plans have had to shift and evolve as government guidelines and our understanding of the Covid-19 pandemic have changed. It has been difficult to gain any sense of stability in this time, and collaborative and community work like ours has been dramatically affected. We have benefitted from unflagging support from our Centre co-ordinator Sue Davidson, and from Kate McAllister and Ali Irving in communications and outreach, but still the year has put huge pressure on the entire Research Centre team, and on our partners.

Nonetheless, I am enormously impressed by what members and associates of the Research Centre have been able to achieve since March 2020. Many face-to-face data collection plans have pivoted smoothly to online, while in other cases a thoughtful decision has been made to temporarily pause research where the risks or constraints were too great. We are fortunate that our philanthropic funding has given us the flexibility to adapt our plans to the situation, as needed. In the past year there has been no discernible drop in productivity, with outgoing papers and talks and incoming prizes and funding seemingly undiminished.

The partnership with the Salvesen Mindroom Centre continues to go from strength to strength, especially supported by Alyson Miller and Dinah Aitken. I am grateful for their time, their patience and their collaborative drive. This past year we have submitted two major funding proposals together, and co-developed a roadmap to becoming 'the go-to place' for neurodiversity expertise. Insights derived from our research and practice are now being encapsulated in our shared policy briefing series and our book review library grows month by month. These co-ordinated outputs build on our unique combination of expertise and directly serve the community and shape policy. I was delighted to find that the quality of our partnership has been recognised by a shortlisting for a Community Engagement Award at the University of Edinburgh.

However, this pride in our visible success should not distract us from the greatest achievement of the past year, which is found in our capacity to nurture and protect each other as a team. Members of the Research Centre have been scattered to the four winds by lockdown measures and have not seen their colleagues in person all year. It is extremely difficult to evaluate - let alone respond to - each other's needs when we aren't together, and every individual has been uniquely impacted by the pandemic. I am proud that a combination of trust, goodwill and willingness to experiment with various technological solutions has allowed us to keep in touch and continue to support each other.

As ever, there have been some goodbyes in the past year - always a sadness, but also a delight to see people moving onto greater things. Saoirse Heron is now enrolled on an MSc in Applied Psychology, Jessica Oldridge is an assistant psychologist in NHS Tayside and Eamonn Walls is working in a research role at the Scottish Parliament. Christopher Eaton and Rebecca Iversen have taken up research posts at the Universities of Cardiff and Oslo respectively.

Please read on to find out how we are using research to achieve our vision of a future where neurodivergent people flourish.



Professor Sue Fletcher-Watson, Director

## Our Members

Membership of the Research Centre draws from all Colleges of the University of Edinburgh and includes those leading donation-funded work, and associates aligned with the Centre's research focus and ultimate goals. In addition the Research Centre benefits from core support in research governance and administration, communications and outreach.

Key members, all of whom play pivotal roles in the research reported here, are shown below.



**Alyssa Alcorn**  
Research Fellow



**Bonnie Auyeung**  
Research Fellow



**Josie Booth**  
Principal Investigator



**Katie Cebula**  
Principal Investigator



**Catherine Crompton**  
Research Fellow



**Robin Dallas-Childs**  
Research Fellow



**Sue Davidson**  
Centre Administrator



**Rachael Davis**  
Research Fellow



**Berengere Digard**  
Communications Assistant



**Chris Eaton**  
Research Fellow



**Sue Fletcher-Watson**  
Director



**Karri Gillespie-Smith**  
Principal Investigator



**Karen Goodall**  
Principal Investigator



**Saoirse Heron**  
Research Associate



**Margaret Horne**  
Statistician



**Leila Mackie**  
Clinical Research Fellow



**Gale MacLeod**  
Principal Investigator



**Louise Marryat**  
Principal Investigator



**Kate McAllister**  
Communications Manager



**Sarah McGeown**  
Principal Investigator



**Lewis Montgomery**  
Research Assistant



**Sinead O'Carroll**  
Communications Assistant



**Jessica Oldridge**  
Research Assistant



**Sinead Rhodes**  
Principal Investigator



**Rachael Wood**  
Principal Investigator



## 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, in partnership with CAMHS Neuro-Developmental Disorders assessment teams.

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

**Overview:** This work has involved cohort development currently focused on children referred for cognitive and motor difficulties. Educational assessments focus on 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 have been assessed e.g. prosocial behaviour and peer relationships. Mental health has been comprehensively recorded across parent and child measures with a particular focus on depression and anxiety. Co-occurrence of disorder symptoms have been recorded. This work maps on to JLA priority questions 1, 3 and 8.

**Project Status:** Research assistant Jessica Oldridge has now finished working on the project (February, 2021). External funding is currently being sought to continue the project. A sample of 65 children referred to the ADHD pathway have been recruited and tested from 3 neurodevelopmental assessment centres. Assessments involved those who do and do not receive a diagnosis. All families have joined S Rhodes' learning difficulties cohort. Each child's clinical team received a profile report aligned with their diagnostic appointment and information was used as deemed appropriate. *Motor difficulties arm:* This work has been extended to recruit children referred for motor difficulties. Once funding has been secured children will be recruited from Occupational Therapy and Paediatrics.

**Implications:** Initial analyses conducted for preliminary presentations of the work (e.g. IASSIDD 2019, European Developmental Psychology conference 2019, Maths Cognition Learning Society, 2020) 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.
- 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 are linked to mental health symptoms in children with intellectual impairment, we are seeking funding to examine this 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:** In Spring 2020 the scheduled start of data collection coincided with the beginning of the national COVID-19 lockdown and at the end of March, the closure of schools. In consultation with participating schools, the decision was taken to pause the study until it would be both practically possible and ethically appropriate to re-start. Online data collection options were explored but ruled out for being too significant a risk to the integrity of data. Schools indicated unanimous support for this approach and confirmed their commitment to re-engage once a pathway to normal school operations was made clear.

The aim is for data collection to commence in October 2021. With phased re-opening of Scottish secondaries due from March 2021, this will provide time for schools to adjust back to a good degree of normal operations. Data collection will be completed by March 2022 with dissemination events and non peer-reviewed publications towards Autumn 2022, and peer reviewed articles in 2023.

**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*

**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. *Other collaborators:* Jessica Oldridge and Allan Piper. *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 who do not have intellectual impairment.

**Rationale and Importance:** There are no depression screening tools developed specifically for young people with autism. 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. 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 is needed to assist in identification of depression in this group and to provide accurate estimates of the prevalence of depression within this population. This work maps on to JLA priority questions 3, 5, 7 and 14.

**Project Status and milestones:** Interviews with children, parents and professionals are now completed. We have interviewed 16 young people with autism, 16 parents and 18 professionals involved in their care and obtained their feedback on a list of compiled depressive symptoms (e.g. feedback on wording, clarity, relevance to depression in autism).

Post-doctoral researcher Christopher Eaton finished his contract in January 2021. S Rhodes is now analyzing the data and completing the work. Preliminary analyses were presented at the British Academy of Childhood Disability conference in March 2021 and will be presented at the IASSIDD conference in July 2021. Full analysis is expected to be completed during 2021 and a parent and child screener produced.

**Preliminary Findings:** Five items were deemed to have face validity, acceptability following triangulation of findings from interviews with the three informant groups and will be included unaltered in the final scale. Five items were deemed not understandable and required adaptation by all 3 participant groups. The other 15 items were deemed generally understandable but suggestions made to reword to maximally optimise understanding. An autism specific item (restricted diet changes) added by the team relating to 'eating fewer types of food' was well understood by participants and deemed relevant to depression. Parents and professionals indicated the need for suicide and self-harm items to be included and as separate items. Appropriateness of wording has been influenced by qualitative feedback.

**Next Steps:** This Neurodevelopmental Depression Inventory is a novel depression symptom screening tool we hope will have direct impact in routine clinical services for children and adolescents with autism. External funding will be sought to conduct further work to validate the tool and to ascertain suitability for those with other neurodevelopmental disorders.

## 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 Scientific Advisory Board funded the creation of a novel linked dataset containing educational records and health records. The linked dataset includes the results of detailed testing of the emerging literacy skills of children in Primary 1 in a City of Edinburgh school in 2013/14 to 2016/17, alongside children's birth records (indicating their gestation at delivery and birthweight), and community paediatrics records (indicating diagnosis of autism).

#### **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?

**Milestones:** We have recently completed the complex range of governance permissions required to bring these records together and use them for research. Specifically, we have secured the following: ethical approval, Data Privacy Impact Assessment; Data Sharing Agreement between the City of Edinburgh Council and University of Edinburgh; Data Processing Agreement between the City of Edinburgh Council and National Records of Scotland; and approval from the Public Benefit and Privacy Panel for Health and Social Care.

Leadership of the project's next phase will pass to Josie Booth from the Moray House School of Education. The education and health data will be made available in de-identified form within the NHS national safe haven environment by summer 2021. We are currently recruiting an SMRC post-doctoral research fellow to work on analysis of these data, alongside other projects.

**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 autism, we may be able to have a lasting impact across the life course.

In addition, we hope this project will demonstrate the potential value of bringing education and health data together for research. In time we hope that this project will lead to a follow-on programme of related work, for example exploring literacy and numeracy trajectories of children with different neurodevelopmental risks and conditions.



## Learning About Neurodiversity at School (LEANS)

*Learning about learning difficulties for primary school pupils and their teachers: co-designing and evaluating an evidence-based open access resource in a neurodiversity framework*

**Personnel:** *Principal Investigator:* Prof. Sue Fletcher-Watson *Postdoctoral Research Fellow:* Dr Alyssa M. Alcorn *Collaborators:* Dr Dinah Aitken, Dr Sarah McGeown, Prof. William Mandy, Mx Fergus Murray, Mr Liam J. J. Peacock.

**Funding Source and Amount:** SMRC Scientific Advisory Board, £84,426, plus £3,600 from a University Covid-response Research Adaptation Fund.

**Rationale and Importance:** In primary school, children already learn about societal issues like climate change or religious diversity, drawing on free resources and lessons from organisations like the World Wildlife Fund. Currently, there are no equivalent resources for mainstream primary pupils and their teachers to learn about *neurodiversity*. Neurodiversity means that we are all different in how we think, feel, and learn, because our brains process information differently. Neurodiversity provides a positive framework for talking about difficulties that impact learning, and for celebrating differences while recognising needs.

**Overview:** Working together with neurodiverse educators and community members, the LEANS project is developing a free neurodiversity resource pack for mainstream primary schools. The pack includes hands-on **activities for the whole class**, exploring how neurodiversity can affect different aspects of school experience—from how we concentrate in class, to navigating friendships. These activities are closely integrated with **story content** about a fictional, neurodiverse classroom as they encounter key ideas in LEANS. A **Teacher Handbook** gives staff guidance for teaching this topic safely and accessibly. We will evaluate this pack in schools in Autumn 2021 (estimated), to assess how well it works at teaching neurodiversity concepts under real classroom conditions.

### Key Questions:

1. What content should a neurodiversity curriculum include for children aged 8-11?
2. Do key stakeholders view the planned resources as *useful*, *acceptable* and *feasible*?
3. Can the completed LEANS resources successfully teach neurodiversity concepts to primary school pupils, with potential to encourage positive actions and attitudes toward neurodiversity and neurodivergent people?

**Milestones:** We have completed the first two project phases addressing questions 1 and 2. Draft resources and illustrations are in progress. Next steps are to complete the resource pack materials and conduct a school-based evaluation. We plan to launch the resource in early 2022.

**Implications:** This research addresses a gap in available educational resources, and directly facilitates inclusion and anti-stigma goals. Explicitly teaching about differences in thought, learning, sensory processing, and social interaction has the potential to improve acceptance and daily school experiences for both children and staff—especially for those with neurodevelopmental conditions and other learning differences. Teachers consulted during LEANS development are confident that these are lessons with lifelong impact for understanding others and oneself. The resources will be released as a set of downloadable files for free, worldwide, making them available to the widest possible audience.



## The Neurodiversity Alliance

*Creating and evaluating peer support models for neurodivergent adolescents in mainstream secondary schools*

**Personnel:** *Principal Investigator:* Dr Catherine Crompton. *Collaborators:* Dr Katie Cebula, Dr Karen Goodall

**Funding source and amount:** SMRC Scientific Advisory Board, £80,724.

**Rationale and Importance:** 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.

**Overview:** Building on previous externally-funded work (see Peer Support Models, page x) we will co-design a neurodiversity-informed peer support model for use in mainstream secondary schools. This will draw on models already developed by the LGBTQ+ community, interview data from our IASH-funded research, and working with neurodivergent young people.

The peer support model is intended to nurture a positive outlook on neurodivergent identity, a sense of belonging and self-advocacy skills. This model will be trialled in three schools, and evaluated to investigate its impact on neurodivergent pupils' educational engagement, inclusion, and wellbeing.

### Key Questions

1. What are the key components of a neurodiversity peer support program in secondary school for neurodivergent pupils and other stakeholders?
2. Is a peer support program feasible and acceptable to neurodivergent pupils and other stakeholders, and what are the associated barriers and bridges to engagement?
3. What is the impact of a neurodiversity peer support program on educational engagement, inclusion and wellbeing?
4. What are the perspectives of neurodivergent pupils and other stakeholders on how peer support systems in secondary school should be delivered in the future?

**Project Status:** Closed. We will begin the SMRC-funded Neurodiversity Alliance project in May 2022 (intentionally postponed for 1 year due to the pandemic).

**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, and an evidence base for their use. We anticipate that creating a peer support model *with* neurodivergent young people, based on their priorities, will have significant impact not only for research, practice, and education, but also on how future interventions are designed.

## 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 spectrum disorder

**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. All have been completed and Cameron submitted his PhD in March 2021.

Study 1 examined whether individuals who are high in autism traits answer questions about depression differently to those low in traits. 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 2 was a cross-sectional study examining social identities in autism. 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. 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. The academic paper written up from this study has recently been accepted by the Journal 'Autism'.

Study 3 investigated a method for assessing social desire i.e. explicit and conscious wishes regarding social interaction and relationships in both an autism and non-autism adult samples. We examined a measure that was adapted to assess motivations towards socialising. It was found that on average less social desire was reported by the autism than the non-autism sample. However, there was wide variability in the levels of social desire reported, with the autism sample scoring at both the minimum and maximum score for the scale. This contradicts some interpretations of the social motivation theory of this population all being disinterested in social relationships.

**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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### Autism and Bilingualism

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

**Personnel:** Prof. 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 plus UKRI Covid Mitigation funding, £24,000

**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 autism 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, following an ESRC extension. We have completed data collection at the two timepoints, with 110 families participating in the first timepoint, and a total of 75 children at the second timepoint (due to COVID-19). Four papers are due to be submitted by the end of March, with the further three papers by the end of the project. We have received funding to continue with qualitative aspects of the project (see the Firah project, below).

**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 practise and can contribute to an evidence base for parents to make an informed choice about bilingualism for their child.

### Autism and Bilingualism: Children's Experiences

*Charting the experience of bilingualism for autistic children*

**Personnel:** Dr Rachael Davis, Prof. Sue Fletcher-Watson, Prof. Antonella Sorace

**Funding source and amount:** Fondation International a la Recherche sur le Handicap, €49,808.52.

**Overview:** Emerging evidence suggests that bilingualism may confer advantages across a number of cognitive domains. Yet, it is clear that research findings have not filtered into practice or subsequent recommendations for autistic children and their families. Furthermore, research is currently limited as it disregards the child's own views and attitudes on bilingualism, focusing solely on language and cognitive outcomes. Important questions therefore remain about how autistic children view the impact of bilingualism on their cultural identity, societal inclusion and quality of life. In this project, we will develop an autism-specific interview tool to understand bilingualism from perspective of the child and deploy it to capture new insights. We will then make a set of guidelines that combine the child's perspective on cultural identity and quality of life, with the existing literature and our own new data that focus on the linguistic and cognitive impacts of bilingualism for autistic children.

**Project Status:** This work will be starting on 01/08/2021 for twelve months.

**Implications:** This research will directly address the priorities of both families and practitioners; contributing to and developing evidence-based resources that will enable these stakeholders to make informed choices with and for their children. Our interview tool will be open access for future use in research and practice. Our guidelines will be disseminated across nine European countries through our project partners Autism Europe and Bilingualism Matters, and with their international stakeholder networks.

## Embracing Complexity in Neurodevelopment

*Using existing cohorts and generative neural networks to model neurodevelopmental diversity*

**Personnel:** Dr Duncan Astle, Prof. Sue Fletcher-Watson, Dr Danyal Akarja, Dr Elia Benhamou.

**Funding source and amount:** James S MacDonnell Foundation, £150,000

**Overview:** Between 14-30% of children and adolescents worldwide experience cognitive or behavioural barriers to learning, that vary widely in scope and impact. Research is needed that comprehends the multifactorial pathways that give rise to these barriers, and thereby provides a foundation for the creation, evaluation and implementation of appropriate interventions. Rather than searching for what 'causes' any diagnosis, we expect that multiple neurocognitive pathways converge on common barriers to learning, irrespective of diagnostic status. Moreover, there may be shared pathways that make children vulnerable to multiple barriers.

The proposal has three overarching aims, to:

1. apply a data-driven approach that abandons the constraints of diagnostic nosology
2. identify neurocognitive pathways to barriers with the greatest impact on learning and everyday life, irrespective of rigid diagnostic criteria
3. develop generative models of neurodevelopment that integrate levels of analysis (e.g. cognition, neurophysiology, genetics)

Two ambitious components are designed to address these three aims. The first is an analysis of existing large-scale data from community samples. The second is a theoretical modelling project.

**Project Status:** This work was launched in January 2021. A lead postdoctoral researcher, Elia Benhamou, has been employed and work is underway to gather relevant cohorts (component 1) as well as on specification of generative neural networks (component 2).

**Implications:** the linked assumptions that diagnostic categories reflect underlying reality, and the hunt for "core deficits" to explain diagnostic profiles, have constrained our study of the cognitive barriers faced by children and young people, and limited our theories about underpinning mechanisms

## 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 3 out of 4). Progress this year has been obtaining ethical approval for Phases 1 and 2, respectively, accessing aggregate data for Phase 1 process and outcome elements of the evaluation and we are currently analyzing those data and writing up the reports (due Summer 2021). In addition, we have produced statistical analysis plans for Phase 2 process and outcomes, respectively, and published an overall protocol paper. Finally, we are currently in the process of completing the remaining governance applications in order to access the Phase 2 individual level data.

**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, Prof. Helen Minnis and Prof. Philip Wilson.

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

**Overview:** This study examines the association of prenatal maternal infections and the onset of autism, 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 autism 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.

## 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, Prof. Sue Fletcher-Watson. *Research Team, Edinburgh Site:* Ms Saoirse Heron, Mr Lewis Montgomery.

**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 4 of 4. We have completed six intervention groups and have complete follow-up data from five of these. The study also benefits from the contribution of NRS Fellowship funded time for the clinical PI, 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.

## Neurodiverse Interactions

### *Investigating Information and Skill Transfer in Neurodiverse Groups using Diffusion Chain Methodology: A Replication Study*

**Personnel:** Dr Catherine Crompton, Prof. Sue Fletcher-Watson, Dr Dani Ropar, Dr Noah Sasson

**Funding source and amount:** Templeton World Charity Foundation, £429,423

**Overview:** Many anecdotal reports indicate that autistic people feel more comfortable and relaxed in autistic company. Our Diversity in Social Intelligence study examined this empirically for the first time, using a cultural learning paradigm and investigating the transmission of information between autistic-autistic pairs, non-autistic control pairs, and mixed pairs. This research found that an autism-specific environment facilitates interaction for autistic people. Our key findings indicated that (1) Autistic people transfer information to and from other autistic people as effectively as non-autistic people share information with each other; (2) information sharing selectively breaks down when pairs are mis-matched: when one person is autistic and the other non-autistic, (3) feelings of rapport between people of the same neurotype accompany these info-sharing benefits; and (4) external observers can detect the lack of rapport apparent in mixed autistic / non-autistic interactions.

This new study will directly replicate the Diversity in Social Intelligence project in two parallel sites that are independent of the initial study, allowing us to answer the big question of whether the Diversity in Social Intelligence findings are replicable in new samples and two countries. Also, the increased sample size will allow us to examine the impact that demographic factors might have on communication between autistic and non-autistic people.

**Project Status:** This project will start on 1 August 2021 and run for three years.

**Implications:** Our original study found that autistic people's social behaviour can include effective communication and effective social interaction. This replication will allow us to examine the robustness of these results, and will yield deeper insights into interactions between autistic and non-autistic people. These results have profound implications for the characterisations of autism as a disorder, with practical implications for policy makers, practitioners, educators, clinicians and psychologists.

## Peer Support Models

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

**Personnel:** Dr Catherine Crompton, Prof. 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:** Completed.

**Implications:** We completed a qualitative study, conducting interviews with autistic adults who have recently left school, eliciting their views on autism-specific peer support frameworks and the related benefits and challenges of peer support. These findings have formed the basis of the Neurodiversity Alliance project (page 10), where we will co-design a peer support framework for autistic adolescents, trial

it across schools and evaluate its efficacy. Peer support is a low-cost and sustainable method of support in many populations and this study will examine its efficacy with neurodivergent adolescents.

## PEERS Cultural Adaptations

*Investigating the cultural acceptability of an American social communication skills programme for use in Scotland and making appropriate adaptations*

**Personnel:** Dr Leila Mackie, Prof. Sue Fletcher Watson

**Funding Source:** Chief Scientist Office, NHS Researcher Support Fellowships

**Overview:** PEERS (Programme for the Enrichment and Evaluation of Relational Skills) was developed in California, USA by Elizabeth Laugeson and Fred Frankel. It is an evidence-based programme that targets social communication skills, specifically the ability to make and maintain friendships in teenagers around the ages of 13 to 16 years old. Here in Edinburgh we have been running PEERS since 2014 and have received a lot of positive feedback but have been aware of areas of the programme that do not sit so well due to cultural differences. We are carrying out interviews with families who have participated in PEERS to identify their areas of concern/ misfit. We will then interview neurotypical teenagers to gain their views of Scottish cultural norms and expectations around these areas. We will use this information to make appropriate adaptations to their programme. Our next step will be to seek funding to carry out a randomised controlled trial on the adapted version.

**Project Status:** Active. Approval received from Research Ethics Committee, under review by the Caldicott Guardian. Interviews are due to be carried out during Spring 2021.

**Implications:** This project is highly clinically relevant as it seeks to further adapt and improve an evidence-based programme that already proved to be feasible to run and to be acceptable to families and professionals involved.

## Road to Recovery

*Understanding the impact of COVID and recovery phases on children and young people with Intellectual Disabilities and their families.*

**Personnel:** Dr Karri Gillespie-Smith, Dr Karen Goodall, Dr Doug McConachie, Dr Carrie Ballantyne, Dr Jo Van Herwegen, Dr Tom Gallagher-Mitchell, Dr Joanna Moss, Dr Caroline Richards, Dr Laura Outhwaite, Dr Hayley Crawford Warwick.

**Funding Source:** Economic and Social Research Council, £222,606

**Overview:** Intellectual disabilities are characterised by social, cognitive, and adaptive skill difficulties, which are associated with challenging behaviours, and communication problems. Elevated levels of mental health issues have been reported in young people with intellectual disabilities, and their parents. The COVID-19 response strategy entailed limiting access to education, respite care, and specialist services, reducing available support for families, with unknown consequences. These routine changes and reduction in access to services will continue for some time despite the recent implementation of the UK wide vaccination programme, further compounding mental health outcomes in children with ID and their parents.

As we move into COVID transition phase, this project will: 1) identify the family structure and social demographics of families who have a child with intellectual disabilities who are at greater risk of parent and child negative mental health outcomes; 2) explore the lived experiences of children and young people with intellectual disabilities and their caregivers during COVID and transition phases 3) understand the children and young people's and parents' experience of the recovery phase, including the lasting effects of COVID.

**Project Status:** newly funded, due to commence during 2021

**Implications:** The relative vulnerability of children with intellectual disabilities was highlighted by a recent report from the Children's Society which indicated that children with intellectual disabilities are more susceptible to wellbeing and mental health issues as a result of COVID and require urgent support in adapting to routine changes and understanding what is going on. This research directly addresses those needs.

## Secondary Visual Supports

*Implementation and evaluation of a Visual Supports Resource and Training Pack for use in mainstream secondary schools*

**Personnel:** Dr Leila Mackie, Prof. Sue Fletcher Watson, with additional practitioner support from Julie Baxter, Morag Burns, Zoe Grayson.

**Funding Source:** applying to Nuffield Foundation

**Overview:** Visual Supports such as visual timetables and environmental labels are recognised to be a highly effective means of support to people with a range additional support needs across the lifespan. Locally, projects focusing on developing the consistent use of Visual Supports in primary schools and at home have been highly successful. A clear next step is the implementation of Visual Supports in mainstream secondary schools, where there is a high level of need but as yet a lack of research. Through focus groups with pupils and teachers, we propose to refine our existing resources and develop effective training for this setting and staff group; trial implementation while gathering feedback to further fine tune the resources; evaluate effectiveness of a finalised resource in three trial schools.

**Project status:** A visual support resource has been developed by the team. We are seeking external funding to map barriers to deployment, develop teacher training, and evaluate the use of the training and supports in school.

**Implications:** This project is an excellent example of close researcher/ practitioner partnership. As we plan to create free, downloadable resources available for all. This should significantly influence evidence-based practice for schools across the UK to better support young people with a range of additional support needs.

## 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 2 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.

## Vulnerable Children Database

### *Edinburgh Child Protection Dataset*

**Personnel:** Dr Louise Marryat, Dr Rachael Wood, Dr Jaqueline Stephens, Dr Jaqueline Mok, Dr Richard Chen, Dr Chris Weir, Dr Charlotte Kirkwood, Dr Sharon Vincent.

**Funding source:** Child Protection Training and Research Fund, Royal Hospital for Children & Young People

**Overview:** This project involves the archiving and initial analysis of a clinical dataset comprising every child who came into contact with Edinburgh community paediatrics child protection team between 1995 and 2015 (n. 27,625 referrals; n. 16,112 children). Children who were referred for an additional assessment at a Suspected Child Abuse and Neglect (SCAN) clinic are also captured in the SCAN database (referrals n. 4698, children n. 3729).

**Project Status:** In progress. Data are now in the Lothian Safe Haven and quality control checks and adjustments to create the research dataset have been made. Data documentation to sit alongside the dataset is in the final draft. Analyses of the data have been completed and an initial descriptive paper on the dataset is currently being written up for publication (aim to submit in spring 2021).

**Implications:** Once available in the safe haven, this dataset will be able to be linked with routine medical, and potentially education and other datasets. This will open up a huge amount of opportunities for researchers to explore various topics, including around the associations between neurodevelopmental disorders, child maltreatment and future outcomes.



*An illustration from one of the LEANS project stories, used to help children learn about neurodiversity*



## Outreach and Impact Summary

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Effective outreach involves a number of different steps. We must not only share our findings with relevant communities, but also give them the tools they need to understand and implement that knowledge, and then work with them to incorporate their experiences back into new research questions. In the past year, we have created and seized opportunities for new ways to both share what we find, and build new partnerships to implement this knowledge.

### *Joint Working for New Resources*

Our **partnership with the Salvesen Mindroom Centre** charity continues to go from strength to strength. This year, our team were able to support a number of the Charity's activities such as development and promotion of the Back To School Toolkit, updating of the *It Takes All Kinds of Minds* resources to flag Covid-related issues, and more recently creation of research summaries to augment existing highly-regarded training materials. Perhaps most importantly, in 2020 the Charity was approached by the General Teaching Council Scotland to produce a teacher-facing professional guide on [Understanding Neurodiversity](#). We were delighted to advise on this and also to follow-up with neurodiversity training for Charity staff, trustees and external advisors.

### *The PsychologiCALL Podcast*

In 2020 we launched our podcast, [PsychologiCALL](#). This responded directly to the pandemic, and particularly to the needs of furloughed colleagues at the Salvesen Mindroom Centre charity, and to students pivoting to remote working. At the same time as these groups were being cut off from their professional and intellectual development opportunities, there was an explosion of public discourse about child and adolescent development and wellbeing. The podcast provides a way to feed research evidence into those debates, as well as supporting the neurodiversity research and practice community. It is now hosted on a professional podcasting service, Buzzsprout, and has been downloaded by **2000 listeners**. Each episode features a conversation between our Director, Sue, who hosts the podcast, and a UK-based developmental psychologist about a recent piece of published work. Season 2 completes during April 2021 and we are planning Season 3.



### *Maximising Online Reach*

We promote podcast episodes via our [twitter](#), which has **doubled its follower count** since last year. Our website also continues to increase its value and impact. One year in, we have twelve **book reviews** featured on the site, with new ones added each month. Half of these are generated by the charity and we are finding it such a valuable way of harnessing and sharing the expertise of the direct help and support team. The library of reviews is starting to grow into an important resource that is helping to raise the profile of our partnership as well as support the community. In the past year we have also created a research centre [newsletter](#), and we are already reaching ~650 subscribers with our quarterly updates.

Research Centre members have lent their expertise on a range of online platforms to promote evidence-based practice. In April-June 2020, Alyssa Alcorn participated in the Psychology Zone of online public engagement programme *I'm a Scientist, Stay at Home*. This was a special Covid-19 edition of a programme that connects scientists with school classrooms through live chats and online questions. Members of the Centre, including former student Bérengère Digard and postdoctoral fellow Rachael Davis recently won funding to deliver a practitioner [webinar on autism and bilingualism](#). The event – supported by The Patrick Wild Centre – sold out after only two days of promotion on social media, and the organisers switched digital platforms to increase capacity. Rachael Wood took part in a British Medical Association webinar on [Covid-19 in Schools](#), sharing findings from her unique routine data exploration, which shows strong evidence that teachers are at no higher risk of Covid, even when schools are open.

## Shaping Policy via a New Briefing Series

A new policy briefing series is coming soon to our website. We have worked with a graphic designer to produce a template for briefings on research findings, from projects led by both the Research Centre and the Charity. The audience for these briefings is not only policy-makers at the level of government or local authorities, but also head teachers, clinical service leads and even individual practitioners and parents who all define 'policy' for their classroom, clinic or home. The briefings follow a standardised model, allowing readers to become familiar with the structure and easily find the content they want. They are specifically designed to extract **practical, actionable recommendations** from research and to support implementation, not only dissemination.

## The Salvesen Lecture 2020



The second annual Salvesen Lecture took place on Tuesday 17th November 2020. The Lecture – entitled, ***Beyond the Label: Mapping Brain Diversity in Childhood*** – was presented by Duncan Astle of the University of Cambridge. We were particularly pleased to incorporate opening remarks from University Principal, Prof Peter Mathieson, and closing remarks from Alastair Salvesen. Due to the pandemic, this year's lecture took place online and was shown as a film. Dr Astle's

compelling overview of the science was interwoven with the viewpoints of young people who took part in the project. Whilst we lost the opportunity to meet in person, the online lecture was more accessible, and audience members joined from around the globe. An audience member emailed to say "*The entire package was a triumph - technologically flawless..., informative and thought provoking.*" There were almost 550 sign-ups with many staying on for the entirety to enjoy the lively Q&A session that followed, with a panel drawn from the Research Centre and the Charity. The event also attracted a dynamic discussion on Twitter, with one PhD student tweeting, "*Very inspiring #SalvesenLecture today. It was stunning to see how easily developing brains change their profile by forming or not forming certain hubs.*" The lecture recording has now been viewed by almost 900 people and is available on [our YouTube channel](#). Dr Astle and our Director have since won funding to extend some of the work presented in the lecture.

## Connections in the Community

As the world adapts to online interactions, some barriers to engagement have been broken down and this has afforded opportunities for the Research Centre to forge **new community connections**. In the past year we have created new links with Canongate Youth, LGBT Youth Scotland, the Harris Trust and Selkirk High School. Through these connections, Research Centre members have delivered talks to peer-support groups for autistic teenagers, and autistic parents. Most recently, the Research Centre set up a series of webinars for educators, on the topic of **mental health and neurodiversity**, hosted by Selkirk High School. Feedback includes "*Every teacher should watch this series of talks*" and "*This is best continuing professional development opportunity I have ever had*". The incredibly positive response to these sessions means we are now seeking ways to build that programme further.

## Academic Dissemination Summary

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*The following section includes publications built upon work presented in the report above, and otherwise central to the Research Centre's vision, but it is not a comprehensive account of all papers published by all members and associates of the Centre.*

### Keynote and Invited Talks

**Crompton, C.** *The effects of neurotype-matching on self and observer rated rapport.* Tizard Centre and Participatory Autism Research Collective, March 2021

**Fletcher-Watson, S.** *Neurodiversity and the pupil "creeping... unwillingly to school"?* British Neuroscience Association Festive Symposium, December 2020.

**Stock S. & Wood, R.** *Covid-19 in Pregnancy.* University of Edinburgh College of Medicine and Veterinary Medicine, March 2021

### Books, Book Chapters and Reports

**Alcorn, A., & Fletcher-Watson, S.** (in press). Choosing and using technologies to support autistic children and young people. In J. Gainsborough (Ed.), *Effective Support and Education of Autistic Young People*, Jessica Kingsley Press, London.

**Davis R., den Houting J., Nordahl-Hansen A. & Fletcher Watson, S.** (in press) Intervention and Social Development: Helping Autistic Children. In P Smith & C Hart (Eds), *The Handbook of Child Social Development*, Wiley-Blackwell, London.

### Journal Articles

#### 2021

Cairney, D. G., Kazmi, A., Delahunty, L., **Marryat, L., & Wood, R.** (2021). The predictive value of universal preschool developmental assessment in identifying children with later educational difficulties: A systematic review. *PLOS One*, 16(3), e0247299

**Davis, R., & Crompton, C. J.** (2021). What Do New Findings About Social Interaction in Autistic Adults Mean for Neurodevelopmental Research? *Perspectives on Psychological Science*, doi:1745691620958010.

Dawson, M., & **Fletcher-Watson, S.** (2021). Commentary: What conflicts of interest tell us about autism intervention research—a commentary on Bottema-Beutel et al. (2020). *Journal of Child Psychology and Psychiatry*, 62(1), 16-18.

Dean, B., Ginnell, L., Boardman, J. P., & **Fletcher-Watson, S.** (2021). Social cognition following preterm birth: a systematic review. *Neuroscience & Biobehavioral Reviews*, <https://doi.org/10.1016/j.neubiorev.2021.01.006>

Doi, L., Morrison, K., Astbury, R., Eunson, J., Horne, M. A., Jepson, R., **Marryat, L., Ormston, R. & Wood, R.** (2020). Study protocol: a mixed-methods realist evaluation of the Universal Health Visiting Pathway in Scotland. *BMJ Open*, 10(12), e042305.

Fenton L, Gribben C, Caldwell D, Colville S, Bishop J, Reid M, White J, Hutchinson S, Robertson C, Colhoun HM, **Wood R**, McKeigue PM, McAllister DA. Risk of hospitalisation with COVID-19 among teachers compared to healthcare workers and other working-age adults. A nationwide case-control study. MedRxiv 2021, doi: <https://doi.org/10.1101/2021.02.05.21251189>

**Fletcher-Watson, S., Brook, K., Hallett, S., Murray F., and Crompton, C.** (in press) Inclusive Practices for Neurodevelopmental Research. *Current Developmental Disorders Reports*.

Grahame, V., Dixon, L., **Fletcher-Watson, S.**, Garland, D., Glod, M., Goodwin, J., ... & Wood, R. (in press). A Clinical and Cost Effectiveness Trial of A Parent Group Intervention To Manage Challenging Restricted and Repetitive Behaviours In Young Children With Autism Spectrum Disorder: Study Protocol For a Randomized Controlled Trial. *Trials*.

Maitland, C. A., **Rhodes, S.**, O'Hare, A., & Stewart, M. E. (in press). Social Identities and Mental Well-being in Autistic People. *Autism*. doi: 10.1177/13623613211004328

Miller, J. E., Goldacre, R., Moore, H. C., Zeltzer, J., Knight, M., Morris, C., Nowell, S., **Wood, R.**, Carter, K. W., Fathima, P., de Klerk, N., Strunk, T., Li, J., Nassar, N., Pedersen, L. H., & Burgner, D. P. (2020). Mode of birth and risk of infection-related hospitalisation in childhood: A population cohort study of 7.17 million births from 4 high-income countries. *PLoS Medicine*, 17(11), e1003429.

Nolte K, **Fletcher-Watson S**, Sorace A, Stanfield A, & Digard B. (in press). Perspectives and experiences of autistic multilingual adults: A qualitative analysis. *Autism in Adulthood*

Sharaan, S., **Fletcher-Watson, S.**, & MacPherson, S. E. (2021). The Impact of Bilingualism on the Executive Functions of Autistic Children: A Study of English–Arabic Children. *Autism Research*, 14(3), 533-544.

**Wood, R.**, Thomson, E., Galbraith, R., Gribben, C., Caldwell, D., Bishop, J., Reid, M., Shah, A.S., Templeton, K., Goldberg, D., Robertson, C., Hutchinson, SJ, Colhoun, HM, McKeigue, P M & McAllister, D. A. (2021). Sharing a household with children and risk of COVID-19: a study of over 300,000 adults living in healthcare worker households in Scotland. *Archives of Disease in Childhood*, <http://dx.doi.org/10.1136/archdischild-2021-321604>

## 2020

Astle, D., & **Fletcher-Watson, S.** (2020) Beyond the 'core deficit hypothesis' in developmental disorders. *Current Directions in Psychological Science* <https://doi.org/10.1177/10.17863/CAM.52138>

**Crompton, C. J.**, Sharp, M., Axbey, H., **Fletcher-Watson, S.**, Flynn, E. G., & Ropar, D. (2020). Neurotype-Matching, but Not Being Autistic, Influences Self and Observer Ratings of Interpersonal Rapport. *Frontiers in Psychology*, 11, 2961.

**Crompton, C.**, Ropar, D., Evans-Williams, C., Flynn, E., & **Fletcher-Watson, S.** (2020). Autistic peer-to-peer information transfer is highly effective. *Autism*. <https://doi.org/10.1177/1362361320919286>

Dean, B., Ginnell, L., Ledsham, V., Tsanas, A., Telford, E., Sparrow, S., **Fletcher-Watson, S.** & Boardman, J. P. (2020). Eye-tracking for longitudinal assessment of social cognition in children born preterm. *Journal of Child Psychology and Psychiatry*, <https://doi.org/10.1111/jcpp.13304>

Digard, B. G., Sorace, A., Stanfield, A., & **Fletcher-Watson, S.** (2020). Bilingualism in autism: Language learning profiles and social experiences. *Autism*, <https://doi.org/10.1177/1362361320937845>

## Other Achievements and Activities

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The Research Centre values student contributions and takes its training and development roles seriously. As a result, we were delighted to **host a number of student placements** in the past year, from the Universities of Stirling, East Anglia and our own Translational Neuroscience PhD programme. These students made fantastic contributions to a range of research projects including LEANS and the Neurodiversity Alliance, and also had the chance to be exposed to our participatory and impact-focused way of working. One student told us: *"I feel like I was lucky to get to work with such a wonderful team on a project that I really believed in"*. Perhaps it was this generous person who nominated Sue Fletcher-Watson for a College **Inspiring Others Award**?

During the summer of 2020, the Research Centre also hosted two secondary school students completing remote projects through the Nuffield Future Researchers programme, supervised by Alyssa Alcorn. This programme connects students from disadvantaged backgrounds with mentorship and **hands-on STEM research experience**. They undertook literature reviews related to neurodiversity and psychoeducation, providing valuable context for the ongoing LEANS work.

Meanwhile Rachael Wood and Louise Marryat worked with medical students David Cairney and Aun Kazmi, on a systematic review asking which measures of early child development in the general population hold the best predictive value. The work has **powerful implications for developmental surveillance** aspects of universal child health programmes and has been published in *PLOS One*.

2020 was also an absolute banner year for the Research Centre in terms of **postgraduate student achievements**. No less than six students underwent their PhD vivas and all have now graduated (though the reward of a proper 'cap and gown' graduation ceremony awaits). As a result, we are delighted to welcome Dr Margaret Laurie, Dr Bérengère Digard, Dr Mihaela Dragomir, Dr Sinéad O'Carroll, Dr Shereen Sharaan and Dr Bethan Dean into the glories of postdoctoral life. These students are now working in research and practice roles – special mention has to go to Maggi Laurie who has become an Evidence Specialist at The LEGO Foundation – what an amazing job!

These six were not the only Centre members to see a change in their professional circumstances in the past year. Catherine Crompton won a prestigious Chancellor's Fellowship at the University – a post that will fund her for five years and provide a pathway to a permanent academic role. Rachael Wood was promoted to honorary Reader, and Sue Fletcher-Watson became Professor of Developmental Psychology. These achievements, while being personal to each individual, also show that **the Research Centre is an environment that nurtures excellence**.

To keep us all on our toes, **four new students** joined the Centre in the past year too: Lorena Jimenez Sanchez, Heather Love, Mark Somerville and Holly Sutherland. All have made fantastic progress in their projects which span topics from autism and mental health, to new drug treatments for rare genetic syndromes and the neural basis of mother-child relationships to outward signs of friendship in autistic people.

The Centre continues to develop as **a beacon of expertise in neurodiversity**. In the past year we hosted three Rising Stars seminars, providing a prestigious platform for early career researchers in neurodevelopmental research to showcase their expertise. We also welcomed international leader in disability rights Ari Ne'eman to deliver an online lecture about *Operationalising Neurodiversity*. And last, but by no means least, Bérengère Digard won the runner-up spot for Neurodiversity Research of the Year – a well-deserved tribute to her excellent work.



## Scientific Advisory Board Report

In the period covered by this report, the Scientific Advisory Board met twice, in March and September 2020. They funded three projects in that time. One of these – The Neurodiversity Alliance – is reported above.

Another funded project was **Charting pathways and outcomes of children with learning difficulties using Big Data**. This project builds on a range of routine data programmes described above: Early Literacy in Autism; the Health Visiting Evaluation and the Vulnerable Children Database. The funding allows us to recruit a skilled postdoc to capitalise on these newly-created and linked datasets and use them to address crucial questions about early life and later outcomes. The SAB commented that *"The applicant has worked hard to establish access to the data sets needed and should now be supported to harvest important findings from asking good questions"*. The start date of this project was postponed while final data permissions were secured but we are now advertising the post and will be interviewing candidates in May.

The third and final funded project in this period was called **Gender differences in repetitive behaviours and restricted interests in autistic children**. This project was to have been led by Saoirse Heron, but subsequent to winning the award she won a place on a highly-competitive Masters programme. As a result, we hope to take forward the research with her as a part of her postgraduate studies.

During 2020 the SAB welcomed one new member, Bonnie Auyeung. Dr Auyeung is a Reader and Chancellor's Fellow at the University of Edinburgh where her work is focused around two central themes: the role of prenatal factors on psychological and neural postnatal development and interventions to alleviate developmental difficulties. Prior to her move to the University of Edinburgh, Bonnie worked at the Autism Research Centre at the University of Cambridge where she remains Director of Psychoneuroendocrinology. We were all delighted to incorporate Bonnie's expertise on the Board.



*Sue Fletcher-Watson speaking about the importance of stakeholder perspectives, pre-pandemic*

## 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 has been largely designated for specific research projects and initiatives, following review and approval by the Scientific Advisory Board. In addition, funding from the donation supported Research Centre principal investigators, core staff and associated costs, up to and including December 2021. We are now spending down the remainder of this funding, which has either been committed to research projects by the Scientific Advisory Board, or is being used to maintain core functions, such as project co-ordination, communications and outreach.

The original donation leveraged a total of £1m investment in the Research Centre from the University of Edinburgh, for salaries, IT and other equipment and indirect costs. This is now joined by investment in Research Centre principal investigator Catherine Crompton, via her competitively-awarded Chancellor's Fellowship, worth approximately £280,000 over five years.

Principal investigators and research fellows associated with Research Centre have won a total of £2.4m in external funding on projects directly relevant to the aims of the Centre. In the period covered by this report, new external funding of Research Centre affiliates totalled £852,000. The Research Centre has also won NHS Education training contracts worth £50,000 in the past year. In addition, four new PhD students in the Centre have brought in more than £300,000 worth of competitively-won studentship and research funding this year.

It is clear from this narrative summary that the Research Centre has a track record of successfully winning funding for both basic and translational science, as well as supporting students and early career researchers to fund their own ideas. A core aim is to continue this level of success, building on the strong foundations laid down in first five years of research activity. External funding proposals affiliated with the Centre should build in budget contributions which will allow the Centre to maintain and indeed grow its reputation for efficient, effective and excellent research.

In the coming year, we hope to build on a proposal submitted to the Nuffield Foundation, but sadly not funded, to develop a programme of neurodiversity-related research activities. While previous projects have involved the Charity as a named contributor, we hope that these will be more authentically co-developed and co-led with proposals drawing on diverse perspectives and funding flowing into both Centres. One small but important example of this is a bid for Knowledge Exchange funding from the Economic and Social Research Council, being developed by Alyssa Alcorn in partnership with Dinah Aitken. This funding will allow us to develop a sustainable model for LEANS delivery by creating a network of skilled practitioners and empowering parents to introduce LEANS in their school.

In order to preserve the impact and engagement work of the Centre, which goes well beyond what is usual in the field, we also need to think creatively about funding models. Traditional research funding does not tend to offer the kind of support we need to overcome implementation barriers and deliver not just local, but national and international impact. Philanthropic and venture capital support may have a role to play in this, though the Centre is also committed to making resources available for free, which may limit potential for commercial partnerships or spin-outs. It remains to be seen how fertile the ground is for charitable investment post-pandemic, but we have faith in our unique research-practice model and a commitment to our vision which we trust will carry the day.

## Future Prospects

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The Salvesen Mindroom Research Centre would not exist without the generosity of Alastair Salvesen whose founding donation led to its creation, and to our partnership with the Salvesen Mindroom Centre charity. This funding has enabled a degree of creativity and a climate of enrichment that is rare in the often cut-throat world of academic research funding. It is our responsibility now to ensure that the seedlings planted in that time grow and flourish.

A key priority is to ensure that the transition to a more traditional funding model – reliant on individual grants for specific, time-bound projects and delivered by staff on fixed-term contracts – does not result in mission drift away from our core vision. Our goal to eliminate the educational, and societal inequalities experienced by neurodivergent people requires us not only to make new, foundational discoveries but also to translate and implement those discoveries. To do this we need to maintain a razor-sharp focus on work that addresses community priorities, and delivers true impact. It is not enough to disseminate, we must make real change.

A key way to hold ourselves to this commitment will be the creation of a Stakeholder Reference Group. This has been a long ambition of the Centre, delayed due to the unexpected and often overwhelming pressures of the past year. However, we are now in a stronger position than ever to deliver this, and we expect to hold our first meetings of the group in summer and autumn 2021. In doing so, we will build on the lessons learned during the LEANS co-design phase. This provided us with an opportunity to develop an effective and inclusive model for remote engagement with a neurodiverse group.



Speaking of which, during the past year, the neurodiversity paradigm has become an increasingly prominent part of our internal processes and public face. Together with the Charity, we have charted a pathway to making this integration more explicit, positioning ourselves as leaders in the understanding and application of a neurodiversity framework. Key targets in the coming 12 months include: directly

addressing the topic of neurodiversity in the next Salvesen Lecture; adopting neurodiversity-friendly employment processes; and co-authoring an article on the application of neurodiversity in schools. These activities will change not only our position in the global research-practice community, but should also impact our internal processes and interpersonal behaviour.

Looking further ahead, we are thrilled to be partnering with the Charity in general, and Sophie Dow in particular, to deliver an international conference on neurodiversity, tentatively called *It Takes All Kinds of Minds*. This long-standing Mindroom slogan is a sign of how prescient and progressive the charity has always been. There could not be a better encapsulation of the benefit of neurodiversity in our world.

None of what we have achieved this part year, nor what we plan for the future, would be possible without conversation, collaboration and commitment. Whatever the future holds, we thank everyone who is supporting our innovative Centre making a big difference.

Professor Sue Fletcher-Watson  
Director

Professor Sir John Savill  
Chair of the Scientific Advisory Board

## Thanks to Our Funders and Partners

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**The Baily Thomas**  
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