September 2024

Salvesen Mindroom Research Centre
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Professor Holly Joseph and Dr Alice Mpofu-Coles who delivered the fifth annual Salvesen Lecture in November 2023

Salvesen Mindroom Research Centre annual report 2023-2024

Director's Statement

The last 12 months has delivered a step change in our Centre's global leadership on neurodiversity-affirmative research and practice. Pioneering resources LEANS and NEST – a primary school curriculum and secondary school peer support model respectively – are now in circulation across thousands of schools. We have launched an international network for neurodiversity research and been commissioned to author & edit two books on the topic. We are extending this leadership by bringing a neurodiversity lens to work in mental health research through the AMBER project, *Anti-Depressant Medications: Biology, Exposure & Response,* which is further introduced below. SMRC is clearly situated at the forefront of efforts to realise the potential of the neurodiversity paradigm shift in research and practice.

The year has seen, as usual, a number of successful transitions both into and out of our team. Michelle Dodd completed her research assistant role collecting data for the *Diversity in Social Intelligence* replication project and we were delighted to see her win a PhD studentship at Nottingham Trent University where she will be putting her skills to good use. After passing her viva, former PhD student Dr Lorena Jiménez Sánchez is now moving to be a lecturer in Developmental Psychology at the University of Edinburgh School of Philosophy, Psychology & Language Sciences. Kabie Brook also graduated with an MRes after completing an innovative project examining autistic parents' experiences of play with their autistic children. Finally, Dr Alyssa Alcorn completed her outreach and development work after four years at the SMRC – picking up a University of Cambridge Vice Chancellor's *Impact and Engagement Award* nomination along the way - and has taken up a lectureship in Psychological Science at the University of Bristol.

We have been delighted to welcome Dr Cristina Douglas to the team – her expertise in participatory and creative methods is being put to excellent use in research examining people's experiences with anti-depressants. Mark Somerville, already a part-time PhD student in SMRC, is also working in this area, as chair of the AMBER Lived Experience Advisory Panel. Dr Themis Efthimiou is another new start, contributing technical and conceptual expertise in analysis of physical movement – his work is yielding new insights from our growing library of filmed interactions between autistic and non-autistic people. Dr Charlotte Wilks joins us as part of the same project, where her focus is on delivering impact in these final six months, while Dr Molly Hugkelstone is exploring the application of these findings to clinician-patient interactions in healthcare settings. And finally Dr Charlotte Webber both joined and left the team in the past year, taking up a short contract to help launch and disseminate the *NEurodivergent peer Support Toolkit,* aka NEST.

Another departure is imminent – my own. After six years leading the SMRC I will be standing down in spring 2025 and the process of seeking my successor is underway. I have loved heading up this diverse, energetic, impactful and creative collection of researchers from all corners of the University. However new duties as a College Dean are drawing me away and I am excited to see how the Centre evolves and enriches its connections with *Salvesen Mindroom Centre*, our charity partners, in the coming years.

Professor Sue Fletcher-Watson, Director

Research Highlights

If I had to pick out a particularly juicy finding from the work published under the SMRC umbrella in the past year, it would be Holly Sutherland's study about how people guess the diagnostic status of others. Most of what we know about autistic people's behaviour comes from a non-autistic perspective, and involves observing autistic people while they interact with people who are not autistic. From this point of view, a lot of autistic behaviour can be judged as weird, sometimes even wrong. In contrast, this study included explorations of how autistic people interact with each other, and how other autistic people judged them from the outside. Specifically, Holly asked whether judges could guess who was autistic, and who wasn't. Holly found that it's much harder to tell someone is autistic when they're interacting with another autistic person. And autistic people are better at spotting other autistic people too. In other words, autistic people don't look so "weird" when they're together!

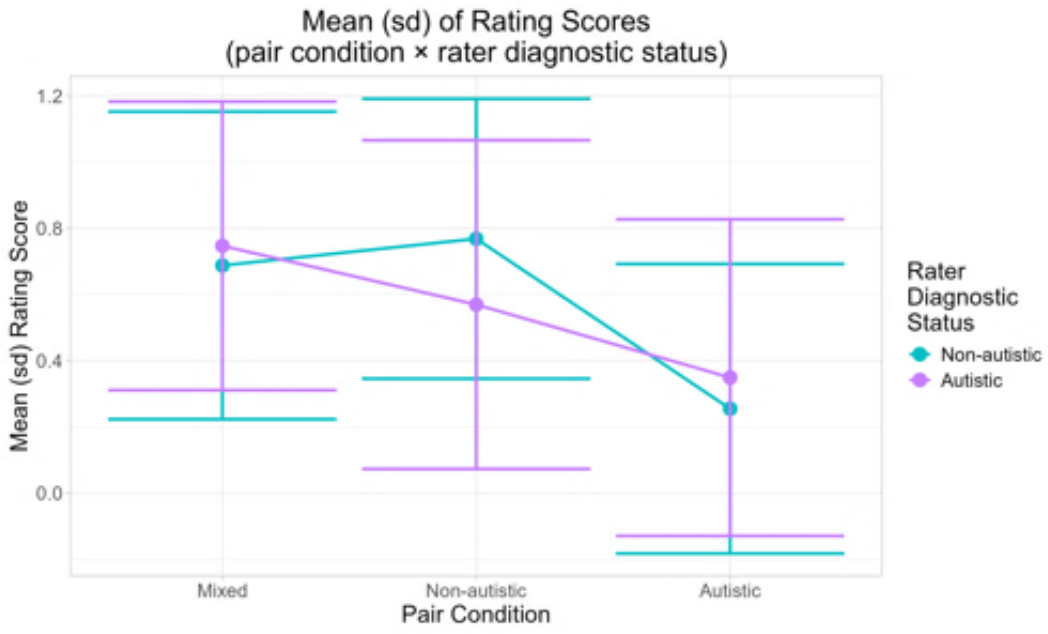


Figure 1: All raters do better at spotting autistic people as part of a mixed pair, and score well above chance (0.5). When both people in a pair are autistic, everyone scores well below chance, though the autistic people do slightly better than non-autistic raters.

Dr Rachael Wood hit two milestones this year in her work on health around pregnancy and childbirth. She and her colleagues in Public Health Scotland successfully launched a Scottish national register of babies with significant congenital and rare conditions that can affect their health and development. The register is carefully controlled and can only be accessed by authorised researchers using a Safe Haven – there's no way to identify a single person in the register. In fact this is all about the big numbers you can get from pooling everyone's information together. These conditions are so rare that it can be nearly impossible to make predictions about what might happen as children grow up – something that they and their parents would really benefit from. In

this way, this register will have a dramatic positive impact on our ability to do research into outcomes for these children, and inform future health and educational pathways. Rachael has already begun to apply this new insight in her work evaluating the national pregnancy screening programme for trisomy conditions – an important part of understanding the options parents are given and the choices they make.

The AMBER project (Anti-depressant Medications: Biology Exposure and Response) is well underway, with partners in Edinburgh, London and Queensland. Building on SMRC's expertise in participatory research, the lived experience arm of the project is being led by Sue Fletcher-Watson and Dr Iona Beange. At the time of writing, this project has just run its first session for the newly appointed Lived Experience Advisory Panel, who are keen to get to grips with the project's subject matter around personalised medicine and clinical experiences of difficult-to-treat depression. The team have also been participating in Action Learning sets to explore the implications of The NIHR's Race Equality Framework and how this can help us explore the lack of ethnic diversity in mental health research – an important barrier, which limits the global relevance of research insights. You can follow their progress on the AMBER project blog. https://blogs.ed.ac.uk/amber/

Meanwhile this has been a year of consolidation on Dr Catherine Crompton's Diversity in Social Intelligence replication study. The project is a partnership with colleagues in Nottingham and Dallas, Texas that aims to learn more about how autistic people communicate and share information with each other, and with non-autistic people. We now have the first results back from our investigations and these are under review at *Nature Human Behaviour*. The study has generated a number of "spin-off" questions too, currently being prepared for publication, such as:

Do autistic people judge their own task performance more harshly than non-autistic people, even when the performance is objectively as good?

How do non-autistic people get along in a group, when everyone else is autistic?

How do autistic people's physical movements affect their experiences of getting along with others?

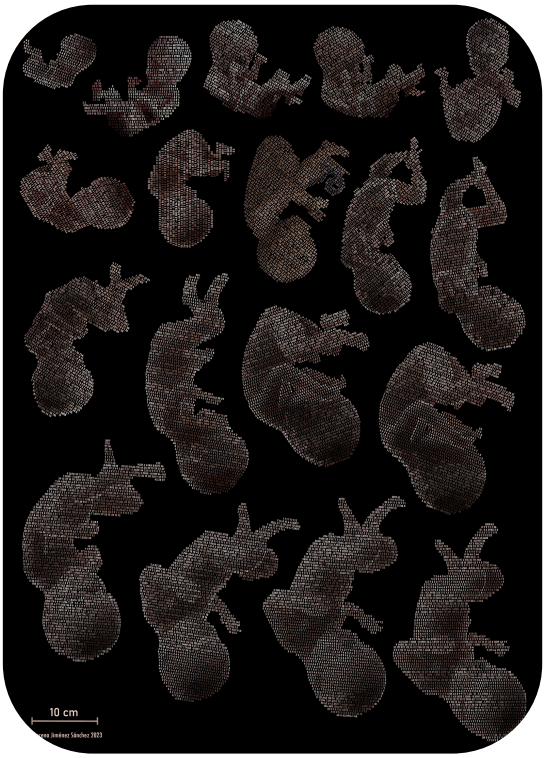
Reesha Zahir is examining the role of sleep disruption in the mental health of autistic children and adolescents, in a project supported by a community advisory team. This year she completed her own cohort study using a Somnofy device to capture precise sleep data remotely via radar. Mark Somerville has completed some in-depth qualitative work exploring the experience of camouflaging and is now building on this with new studies. These will begin to ask a crucial question – is the autistic experience of masking related to the LGBTQ+ experience of being "in the closet" and what does this look like at the intersection of these two identities? Finally, Dr Alyssa Alcorn served as an external project evaluator for the English Language Learning and Neurodiversity (ELLeN) Erasmus+ project, providing expert feedback about project outputs developed for English as a foreign language (EFL) lecturers and trainee teachers. She has also been invited to serve on the advisory committee of the ESRC project *Conceptualisations of neurodiversity and barriers to inclusive pedagogy for early career teachers* (ConNECT, 2023-27).

Outreach and Impact Highlights

In June, Catherine and team launched the NEurodivergent peer Support Toolkit (NEST). NEST is a free toolkit to help mainstream secondary schools create peer support groups for neurodivergent young people. It has been co-created by researchers at the University of Edinburgh, neurodivergent young people, and a neurodiverse group of adults. NEST groups can provide a safe and welcoming space for neurodivergent students to have fun with their peers, engage in their choice of activities, learn about neurodiversity, and explore feelings related to their own neurodivergence. We're very proud that the toolkit has already been downloaded almost a thousand times! For publications reporting on the NEST design and evaluation please read on to the next section. You can download all the NEST materials, for free, here: https://salvesen-research.ed.ac.uk/our-projects/nest-neurodivergent-peer-support-toolkit

Colleagues within the SMRC collaborate closely with the Theirworld Edinburgh Birth Cohort – a world-leading longitudinal study which aims to uncover the relationships betwee early birth and outcomes – especially why some children (even those born very early) go on to thrive, while others have difficulties in language, learning or emotional domains. This year, a group of researchers from the study, including recent SMRC graduate Dr Lorena Jiménez Sánchez, Selina Abel and Dr Melissa Thye had a spot at the Edinburgh Science Festival, and designed activities to teach children about the brain.

Creative activities for children, from the Theirworld Edinburgh Birth Cohort team, at the 2024 Edinburgh Science Festival



Lorena also put her artistic skills to work in an innovative public engagement project, inspired by the infant cohort. To celebrate the completion of participant recruitment, she created a commemorative art piece using data and design. She generated images of fetuses at various gestational ages, composed of numeric data points, like birth weight, from the study participants. These visuals illustrate fetal development, how individual contributions help form the big picture, and the power of anonymised data in research. The artworks were exhibited at **Neuroscience Day** in April 2024 and are still on display in the University's flagship Nucleus Building.

LEANS
Learning About Neurodiversity at School

In December 2023, the **Learning About Neurodiversity at School** (**LEANS**) project officially concluded after four years of design, development, evaluation and translation into impact. The LEANS resource pack, parent-carer resources, and their well-stocked, informative website remains online and free to use: https://salvesen-research.ed.ac.uk/leans As of September, the LEANS resource pack has been downloaded an amazing 10,694 times around the world. We're also proud that LEANS was the only resource to be recommended by name within a recent policy brief on inclusive schools published by the MRC Cognition and Brain Sciences Unit – and it was a shortlisted nominee for a Genius Within neurodiversity award. Once again, we would like to thank the educators, community members, and research colleagues who have generously supported this project, and all of the children who have participated in LEANS so far.

This year also saw consolidation of the legacy from the *It Takes All Kinds of Minds* (ITAKOM) conference which took place in 2023. The hosts, Salvesen Mindroom Centre, and vanue, Edinburgh International Conference Centre, jointly and deservedly won an award for inclusion from the Association of British Professional Conference Organisers. Building on this, we are now publishing a range of materials created for the conference, so that other events can use them as models and inspiration in the future. These will be accompanied by a full report based on our delegate feedback – recognizing that conferences should not just copy our successes but also learn from our mistakes! ITAKOM has also given birth to a new international mailing list - the Neurodiversity Research Network. This public list provides a platform for people around the world to connect over a shared interest in applying the neurodiversity paradigm in their research. You can sign up to the list here: https://salvesen-research.ed.ac.uk/resources/international-neurodiversity-research-network

Last but not least, November 2023 saw us hosting the fifth annual Salvesen lecture from Professor Holly Joseph and Dr Alice Mpofu-Coles. They spoke about innovative research taking place in Reading – partnerships between the University and the wider community. Specifically, Holly described her personal research journey from work which attempted to categorise reading difficulties in ever-more-precise quantitative terms, to a more recent focus on cultivating a love of reading in young children – and their parents. In doing so she has become a convert to co-production methods such as those pioneered by Alice, whose creative work, very much embedded amongst people and places, was an inspiration to the audience. To end the event, they were joined by an expert panel who brought neuroscience, education and lived experience to the discussion.

Papers and Talks

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.

As usual, the work of the Centre has been shared across an enormous number of fora, both within and beyond the University of Edinburgh – and indeed, beyond the UK. Research conferences where SMRC studies were shared included the *American Psychiatric Association* conference (New York), *Psychonomics* (San Francisco), the *Paediatric Academic Societies* (Toronto), the *Scottish Educational Research Association* (Edinburgh), the *British Psychological Society Developmental Section* conference (Bristol) and the *International Society for Autism Research* (Melbourne). In fact, despite INSAR taking place on the other side of the world in 2024, multiple SMRC projects were represented by Reesha Zahir, Charlotte Wilks, Holly Sutherland on behalf of authors who weren't able to travel so far. Despite her sabbatical, Sue was also delighted to visit Nijmegen and deliver a keynote as part of the Design Your Life symposium.

We always seize every opportunity to share our insights with the research community but especially to maximise impact from our work by speaking to practitioner and policy audiences. This year, Sue partnered with Nelly Whaley from the Salvesen Mindroom Centre to deliver a very well-received day of training at the George Watson's College Festival of Neurodiversity – a staff development event which directly responded to their attendance at ITAKOM earlier that year. Meanwhile Dr Alyssa Alcorn took part in a podcast on *Why neurodiversity is relevant for all schoolchildren* as part of their Teachers' Voices series. This was part of a series featuring educators from around the world, produced by BOLD , *"an interdisciplinary initiative dedicated to spreading the word about how children and young people develop and learn"*. Alyssa, as LEANS research and impact lead, talked about what neurodiversity is and why it matters, alongside teachers in Brazil, India, and Argentina discussing inclusive practice (and its challenges) in their contexts. You can listen for free on the BOLD website.

Listen here!

Commentaries, Book Chapters and Editorials

Alper, M., **Alcorn, A**. M., Harrison, K., Manganello, J., & Romeo, R. R. (in press). Digital media and neurodevelopmental differences. In D. Christakis & L. Hale (Eds.), *Children and screens: A handbook on digital media and the development, health, and well-being of children and adolescents*. Springer.

Fletcher-Watson, S. (2024). Reporting participatory methods and author positionality in autism. *Autism*, *28*(8), 1869-1871.

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Government Reports and Policy Documents

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Journal Articles and Preprints

Preprints

Sutherland, H. E. A., Ropar, D., **Fletcher-Watson, S**., Axbey, H., **Crompton, C.J.** How successfully do autistic and non-autistic raters guess the diagnostic status of people having conversations? Under review at *Autism,* preprint at https://osf.io/preprints/osf/pt942

Foster, S., Ackerman, R., Wilks, C., Dodd, M., Calderon, R., Ropar, D., **Fletcher-Watson, S., Crompton, C.J.,** & Sasson, N.J. Rapport in Same and Mixed Neurotype Groups of Autistic and Non-autistic Adults. Under review at *Autism*. Preprint at https://osf.io/preprints/osf/efvbc

Sutherland, H. E. A., Crompton, C.J. Long, J., & **Fletcher-Watson, S**. "Read my lips, not my body": a thematic analysis of autistic people's social communication preferences, experiences, and expectations. Under review at *Neurodiversity*. Preprint at https://osf.io/2us8a

Wolfe, K., **Crompton, C.J**., Hoffman., P., Wolters, M.K., & MacPherson, S.E. Collaborative learning in older age and the role of familiarity: Evidence from the Map Task. Under review at *Memory*. Preprint at https://psyarxiv.com/4rsaq/

Crompton, C.J., Wolfe, K., Tullo, A., Hoffman, P., Wolters, M. K., & MacPherson, S. E. Learning with (perceived) humans and computers: the role of agency beliefs in older adult collaborative learning. Under review at the *International Journal of Human Computer Interaction*. Preprint at osf.io/preprints/psyarxiv/j25mt

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Cage, E., **Crompton, C.J.**, Dantas, S., Strachan, K., Birch, R., Robinson, M., ... & Botha, M. (2024). What are the autism research priorities of autistic adults in Scotland? *Autism*, 13623613231222656.

Crompton, C. J., Fotheringham, F., Cebula, K., Webber, C., Foley, S., & **Fletcher-Watson, S**. (2024). Neurodivergent-designed and neurodivergent-led peer support in school: A feasibility and acceptability study of the neurodivergent peer support toolkit (NEST). *Neurodiversity*, 2. https://doi.org/10.1177/27546330241275248

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Garcia-Iglesias, J., **Beange, I.,** Davidson, D., Goopy, S., Huang, H., Murray, F., ... & **Fletcher-Watson, S**. (2024). Ethical considerations in public engagement: developing tools for assessing the boundaries of research and involvement. *Research Involvement and Engagement*, *10*(1), 83

Horne, M., **Marryat, L., Corby, D.H.**, Doi, L., Astbury, R., Jepson, R., Morrison, K. and **Wood, R**. 2024. Development of an outcome indicator framework for a universal health visiting programme using routinely collected data. BMC health services research, 24(1), p.728. https://link.springer.com/article/10.1186/s12913-024-11178-7

Jiménez-Sánchez, L., Cabez, M. B., Vaher, K., Corrigan, A., Thrippleton, M. J., Bastin, M. E., ... **Fletcher-Watson, S**., & Boardman, J. P. (2024). Infant attachment does not depend on neonatal amygdala and hippocampal structure and connectivity. *Developmental Cognitive Neuroscience*, *67*, 101387

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Nimbley, E., Maloney, E., Buchan, K., Sader, M., **Gillespie-Smith, K.,** & Duffy, F. (2024). Barriers and facilitators to ethical co-production with Autistic people with an eating disorder. *Journal of Eating Disorders*, *12*(1), 113. https://jeatdisord.biomedcentral.com/articles/10.1186/s40337-024-01076-y

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