



MSP Richard Lochhead, meeting with Professor Sue Fletcher-Watson and Dr Alyssa Alcorn at the University of Edinburgh "Research Café" stall, at the It Takes All Kinds Of Minds conference in March 2023

Salvesen Mindroom Research Centre

annual report

2022-2023

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Director's Statement

The academic year 2022-2023 had as its centrepiece, for both the Salvesen Mindroom Centres, our international neurodiversity conference, *It Takes All Kinds of Minds*. The conference was an overwhelming success – and one to which people across both Centres gave hundreds of hours of hard work and creative input. A fuller report on the conference is included below but suffice to say that delegates described it as “*an outstanding event*”, “*a complete and utter treat*” and “*absolutely the most affirming and hopeful space I have ever been privileged to be part of as a neurodivergent person.*” We could not have been more delighted to receive this exceptional feedback.

As usual in academia, where degrees and grant awards mean so many colleagues stay with us for only a few years, the past year has seen a number of farewells. Dr Francesca Fotheringham, who expertly led our work on peer support in secondary schools, has left us for a role at Kirkcaldy High, where pupils and staff alike will benefit hugely from her expertise. Likewise, Dr Elizabeth Kirkham moved on from her work on mental health data science to a permanent role in the department of Health in Social Sciences, here at the University of Edinburgh. We are delighted that she will stay linked to the Centre even as her career evolves. Dr Yu Wei Chua, formerly affiliated with the Centre through her role in the Theirworld Edinburgh Birth Cohort, is now following a career path in the charity sector where her skills will no doubt be invaluable. Roseanne Morris's part-time role, exploring the perspectives of autistic children on being bilingual, also came to an end as the funded period expired and she has now expanded her assistant psychology post in NHS Lothian. And last but by no means least, Dr Helen Corby completed her work on the early literacy project and has moved on to a permanent role in Research Data Scotland. As ever, it is a pleasure to see through these individual career pathways, how closely connected our work is to policy and practice in education, health and social care. We are proud that working with us offers our colleagues so many options for their next steps.

New arrivals in the past year include Lou McConnell, joining me in a personal assistant role to help manage my diary and personal professional resources. After just one week in post she is already proving invaluable and a pleasure to work with. She will work closely with Sue Davidson of course, the lynchpin of our group, recently promoted to Research and Outreach Co-ordinator – a well-deserved recognition of the importance and breadth of her role. Dr Iona Beange has also formally joined the group, having worked alongside us for years. We are excited to benefit from her wealth of experience in public engagement and science communication methods.

The year ahead holds a nine-month sabbatical for me personally and so over the months immediately preceding this report I have been arranging to hand over a number of roles, including stepping down as Co-Director of Research Ethics for the College of Medicine and Veterinary Medicine. I am excited about how this coming year will give me space to reflect and build on the successes of not only the past 12 months, but all four and a half years that I have now led the SMRC.



Professor Sue Fletcher-Watson, Director

Research Highlights

One of the most impressive research achievements this year grew out of a Masters dissertation project, led by Valeria Garau. The project focused on **monotropism theory** – an autistic-led psychological theory of autism, which has to date received little attention from the research establishment. Valeria’s work changed that by co-creating, with autistic collaborators, the first ever self-report monotropism questionnaire. Launching the study online, we recruited more than 1,000 participants in less than a month! The findings, illustrated below, show that as predicted, **autistic people score much higher on the monotropism questionnaire than non-autistic people**. We also found that monotropism scores were higher in people with ADHD, regardless of whether they were also autistic or not – depicted in Figure 2. All this reinforces that idea that monotropism holds great potential for the way we understand the differences between people with and without autism or ADHD. The questionnaire is published and available for re-use, while the research report is awaiting journal publication. The public response has been overwhelming, reaching thousands via community-generated TikTok, Twitter / X, and other social media posts.

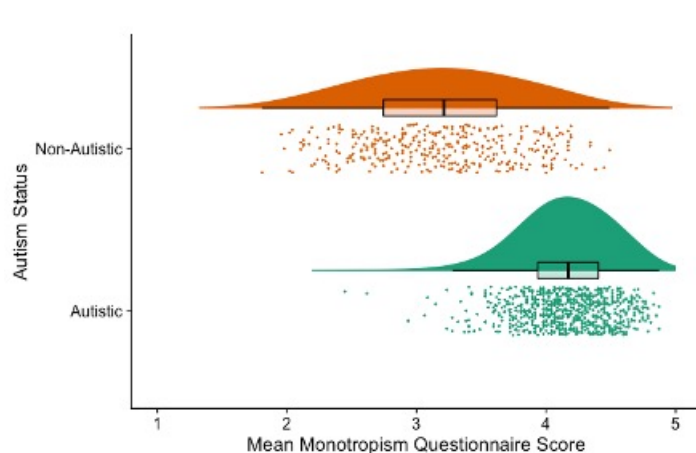


Figure 1: higher monotropism questionnaire scores for autistic compared with non-autistic people

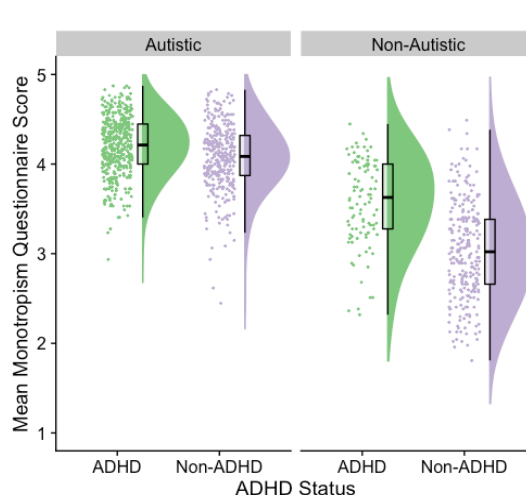


Figure 2: monotropism scores are higher for people with ADHD, in the autistic and non-autistic groups.

Another major success this year has been progress on the **Diversity in Social Intelligence** replication study, thanks to the dedication of project researcher Michelle Dodd. The project is a partnership with colleagues in Nottingham and Dallas, Texas. It aims to replicate the ground-breaking discoveries of SMRC Principal Investigator Dr Catherine Crompton, who found that autistic people, contrary to clinical expectations, communicate and share information between each other as effectively as non-autistic people. Over the past year we have collected data from over 300 participants, half of whom are autistic. This is no mean feat given that we needed to secure six participants to come in on each “research day” to take part in our complicated group tasks. The main analysis for this study has been accepted in prestigious journal *Nature Human Behaviour* as a **Stage One Registered Report**. This means that regardless of our actual results, if we deliver the methods and analysis as planned, the journal will also publish the findings. This is an exceptional achievement for the team and the study will be a true world first for autism research.

This year marked the re-start of **Beyond Behaviour** after a pause in the study due to Covid-related school closures. Data collection has begun with pupils, staff and parent/carers in a number of

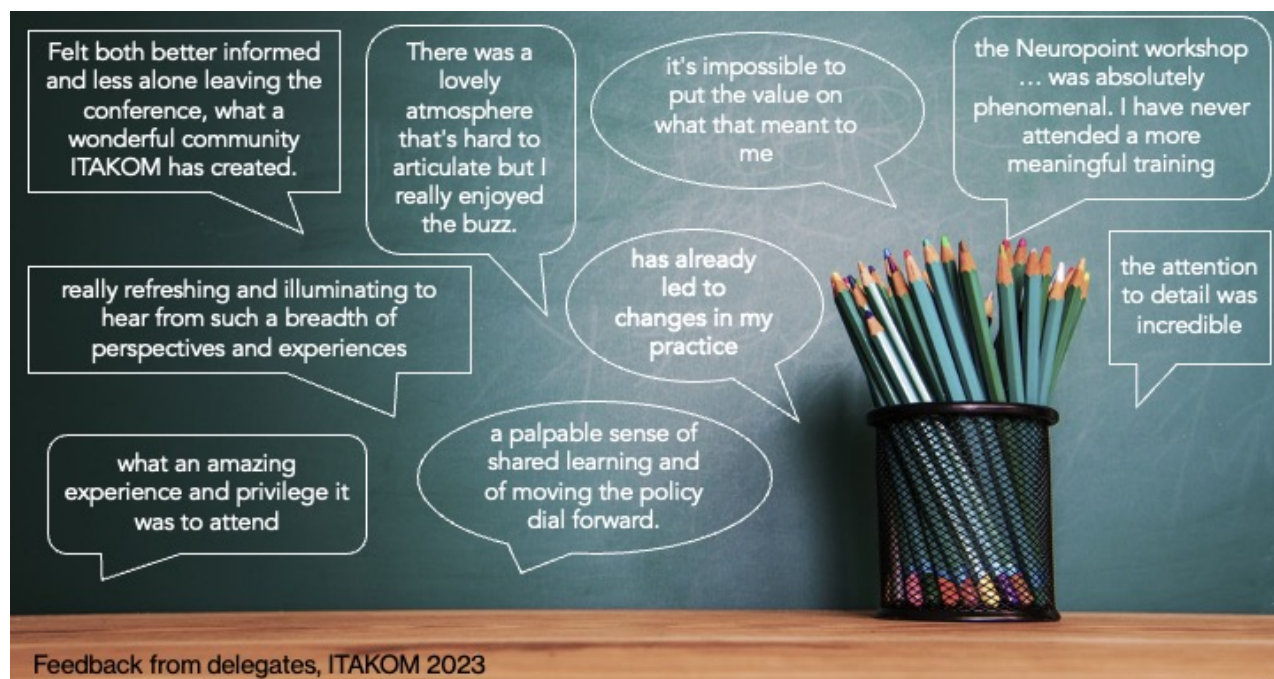
Scottish secondary schools. The aim is to explore why some pupils, who at times require additional support to manage their behaviour in school, are referred for a clinical diagnosis (e.g. ADHD) and others are not. The study is also interested in the social consequences for the pupil of being given, or not given a clinical diagnosis. The team is delighted that the project is now affiliated to the Schools Health & Wellbeing Improvement Research Network ([SHINE](#)), which links over 600 Scottish schools with research that addresses the health and wellbeing of pupils. In May this year, Prof. Gale Macleod, the study lead, and Dr Robin Dallas-Childs spoke at the SHINE annual conference, addressing delegates including teachers, mental health professionals and education leaders.

A new project involving Sue Fletcher-Watson and Dr Iona Beange is starting up at the time of writing: [Anti-depressant Medications: Biology Exposure and Response](#), or [AMBER](#). The Wellcome Trust funded project draws on rich expertise within the SMRC in participatory methods and incorporates an ambitious plan for involvement and co-production. During this five-year programme we will pioneer new methods of engagement and deliver participatory research on attitudes to personalised medicine and clinical experiences of difficult-to-treat depression. We will also make new connections with relevant communities who can help us understand the lack of ethnic diversity in participation in mental health research – an important barrier which limits the relevance of new insights for the global majority, non-white population. This work will lay foundations for clinical advancements and feed into participatory work elsewhere in the SMRC. Another new project funded by UKRI and NIHR has started at the University of Edinburgh led by Karri Gillespie-Smith (associate member) and Fiona Duffy. This project - [Enhancing Eating Disorder research networks: The Eating Disorders and Autism Collaborative](#) (EDAC), aims to bring together Eating Disorder and Autism researchers to engage in inter-disciplinary work. This network will set the foundation for pioneering research in eating and/or feeding disorders in autistic people with and without learning disabilities.

PhD students in the Centre continue to make impressive progress on a range of important topics, using diverse methods. Holly Sutherland has presented her research [examining communication with and between autistic people](#), at a wide range of events including the recent *Scottish Autism Research Group* meeting. She is mid-way through an ethnographic study taking place in social care services, extending the growing evidence-base on autistic interaction, by capturing something of the experiences of autistic people with a learning disability. Her office-mate, 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. Alongside her analysis of existing data from the ALSPAC cohort, she is now on the cusp of launching her own data collection, using the exciting new Somnofy device to capture precise sleep data remotely via radar. Lorena Jiménez Sánchez's PhD thesis on [attachment following preterm birth](#) was submitted last month and will be examined later this year – good luck Lorena! Heather Love is continuing her project on the genetic developmental disorder '[eEF1A2 syndrome](#)' and is currently focused on attempts to classify sub-types of the syndrome based on shared molecular mechanisms, while planning a world-first online event for families of children with the syndrome. Mark Somerville's first paper from his Masters has now been published in *Autism In Adulthood* and reveals the links between [camouflaging and mental health](#) for non-autistic people with high self-reported "trait" scores, suggesting that camouflaging is also expected and has a negative impact for people without an autism diagnosis. Kabie Brook's groundbreaking work on [play between autistic parents and their children](#) was submitted earlier this year and Kabie will be both graduating and submitting their dissertation as a journal article in the next few months.

Outreach and Impact Highlights

There is no doubt that the centrepiece of our impact this year was the [ITAKOM](#) (It Takes All Kinds Of Minds) conference, which took place in March 2023. This world-leading event attracted more than 1,000 delegates to explore the impact of neurodiversity in research, services, and communities. The conference was an overwhelming success with a huge amount of positive feedback – a selection is shown below – and some constructive recommendations “for next time”. The team are now working to make all the content permanently available and building on that foundation for future events.



The [Embracing Complexity in Neurodevelopment](#) project, in partnership with Professor Duncan Astle and colleagues at the MRC Cognition and Brain Sciences Unit in Cambridge, uses cutting edge statistical modelling techniques and transdiagnostic data to challenge the concept of “core deficits”. The project contributed to ITAKOM through the generation of short films sharing the experiences of neurodivergent young people and their parents. These powerful narratives were shown as part of the *Neurodivergent Stories* stream at the conference and are now available via the Patient Voices website: <http://www.patientvoices.org.uk/calm.htm>

Meanwhile the [LEANS project](#) continues to go from strength to strength. Since its release in June 2022, the pack has been downloaded more than 5400 times, in over 70 countries! Dr Alyssa



Alcorn, who leads the project, has been working tirelessly on systems to allow for sustainable dissemination of LEANS even once she has moved on to a new professional role. This has included creation of the [LEANS Champions network](#) of trained expert educators who are informed about LEANS and can promote the programme, and support teachers with delivery queries. Alyssa also worked closely with the Salvesen Mindroom Centre to create [resources to enable parents to find out about LEANS](#) and recommend it to their child's school. Finally, she and Professor Sue Fletcher-Watson, supported by Edinburgh Innovations, have formalised materials and processes to enable authorised adaptations of LEANS for non-UK cultural contexts and languages other than English.



In a second example of the application of the principles of the neurodiversity paradigm in schools, this year we completed a programme of research to develop and evaluate what is now known as **NEST: NEurodivergent peer Support Toolkit**. This free, downloadable package will enable schools to set up peer support groups for neurodivergent pupils: a chance to be together, forge connections, share advice, and drive change. A report on the participatory design process which formed the basis of the toolkit has recently been accepted for publication in the new journal *Neurodiversity* and will be followed by a report on the recent evaluation. Preliminary findings from focus groups with pupils who took part in the trial include evidence of wellbeing benefits: *"you get to be yourself and not hide your true personality"* and new friendships: *"I have found people similar to me and I don't feel alone again"*. We anticipate releasing the toolkit, following a final design and production phase, in 2024.

Dr Bérengère Digard and Dr Rachael Davis have continued their impactful work about bilingualism and autism. They added [a new co-produced animated video for parents](#), voiced by Nariese Whyte, a Scottish Edinburgh-based autistic advocate. This video, funded by a CAHSS Knowledge Exchange and Impact Grant, is the English version of their existing [open-access information platform for parents and families](#) already available in 16 languages, with new translations being added regularly. This expands their library of open-access resources, that already includes a [co-produced open-access information resource for education practitioners](#) and another for [clinicians](#).

In February 2023, the **fourth annual Salvesen lecture** was delivered, at a date rather later than intended, but to the usual audience of hundreds, by Professor Edmund Sonuga-Barke, Dr Sylvan Baker and Dr Susie Chandler. Together they spoke eloquently about the RE-STAR project which is examining determinants of poor mental health in autistic young people and those with ADHD. The project adopts a co-production methodology and we were extremely lucky at our post-lecture panel discussion to hear from two of the members of the RE-STAR Youth Researchers and Advisory Panel as well as Dr Georgia Pavlopoulou who leads the qualitative elements of the work.



The Neurodiversity Concept
foundation for a new science of neurodevelopment?

Professor Edmund Sonuga-Barke, Dr Sylvan Baker & Dr Susie Chandler
Tuesday 7th February 2023, 6pm, broadcast live online
Register at 2022-salvesen-lecture.eventbrite.co.uk

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.

In addition to the major external conference presentations listed below, in the last year Centre Pls have presented at a number of University events. At home, our work was shared at the *Child Life and Health* research symposium on early childhood, the *Edinburgh Student Psychiatry Society* conference, *Division of Psychiatry* journal club and the same department's special lecture series. Sue also belatedly delivered her inaugural lecture – marking her promotion to Professor. Further afield, members of the SMRC have presented at *Autism Europe*, the *Autistica Research Festival*, *Psychonomics*, the MQ and DATAMIND scientific Meeting, five separate regional SEND Fora in England, the *Scottish Autism Research Group*, the *Centre for Autism Research* science meeting (UPenn, Philadelphia), the *West Lothian Additional Support Needs* conference and the University College Dublin *Neurodiversity Masterclass* seminar series. Members of the Centre are now also regular presenters at SERA and BERA (the Scottish and British Educational Research Associations respectively) with Dr Alyssa Alcorn jointly winning the **Best Paper award** at BERA 2022.



Members of the Diversity in Social Intelligence research project in Stockholm, May 2023

At the **International Conference for Autism Research** this year in Stockholm, SMRC members contributed five posters, three talks and a panel as well as chairing a discussion group session. Topics included autistic people's experiences of social interactions, the *Learning About Neurodiversity At School* project, community input in early intervention, and reporting standards in clinical autism research. The Centre's strong presence at this important scientific meeting is a marker of the quality of the work we do.

Dr Alyssa Alcorn joined forces with Aileen Shrimpton from the Salvesen Mindroom Centre to deliver **neurodiversity training for NHS Fife**. Audience feedback was glowing, including: "Well that was AMAZING! I think that will have done loads to change and challenge people's understanding and attitudes towards neurodiversity", "the speakers were excellent, and the expert panel was just fantastic. I was quite emotional during their descriptions. It really makes me reflect on our work in CAMHS" and "I just wanted to congratulate all of you on what was a fantastic CPD event. It was extremely engaging, thought provoking and relevant to all of our work."

In addition, Sue took part in a brand new "In Conversation..." **plenary session at the British Neuroscience Association** meeting in Brighton in April 2023, interviewing autistic doctor, researcher and activist Mary Doherty live on stage. Feedback from this experimental session in the BNA programme was exceptional, including this review in *Technology Networks*:

One of the day's – and perhaps the conference's – most impactful events came at the close of Monday's evening program ... In exchanges delivered with frank honesty and weary humor, Doherty explained how the field's medicalized terminology, which often positioned autism as a problem to be solved or even a disease to be cured, had grown increasingly

removed from the real objectives that autistic people wanted to see achieved through research. Too often, we've seen researchers who have built and maintained paradigms within the field that no longer help autistic people dismiss calls for change as censorship or obstruction of progress. Instead, Doherty showed how researchers can continue to help marginalized communities by championing research that addresses the everyday issues that autistic people face. The decision by the BNA to give a plenary slot to this kind of discussion, which is often conspicuous by its absence at academic conferences, must be applauded...

Last but certainly not least, this past year saw the publication of the final article with our departed friend and colleague, **Professor Anne O'Hare**, as a co-author. The paper is listed below (Delahunty et al., 2022) and includes the following dedication:

This paper is dedicated to Professor Anne O'Hare, a kind and generous mentor, colleague and paediatrician, who dedicated her life to improving diagnosis and support for children with neurodevelopmental disorders and their families.

Major Presentations and Symposia

Alcorn, A. *A mixed-methods evaluation of Learning About Neurodiversity at School (LEANS)*. British Educational Research Association, Inclusive Education SIG, **September 2022**.

Fletcher-Watson, S. *Neurodiversity and Participatory Research*. Keynote, EUNETHYDIS, Cardiff, **October 2022**.

Fletcher-Watson, S. *Neurodiversity and Speech & Language Therapy Practice*. National Speech and Language Therapy Study Day, online, **October 2022**.

Brook, K. *How do autistic parents describe playing with their children and why should we be listening?* Autism Europe, Krakow and online, **October 2022**

Digard, B. *The influence of bilingualism on cognitive and affective perspective-taking abilities in autistic and neurotypical adults*. Autism Europe, Krakow and online, **October 2022**

Fletcher-Watson, S. *Neurodiversity Acceptance and Affirmation in the Classroom*. LEARNUS annual lecture, online, **November 2022**.

Fletcher-Watson, S. *Neuro-Affirmation in the Classroom*. Keynote, American Speech-Language-Hearing Association Convention, New Orleans and online, **November 2022**.

Fletcher-Watson, S. *Neuro-Affirmation in the Classroom*. Keynote, Reframing Autism, Melbourne Australia and online, **February 2023**.

Fletcher-Watson, S. *Autism and Neurodiversity: A New Paradigm*. Keynote, British NeuroPsychiatry Association, London, **March 2023**.

Alcorn, A. *Learning About Neurodiversity at School—and Beyond*. Invited Talk, NAS professionals conference, **March 2023**

Fletcher-Watson, S. *Participatory Methods for Autism Intervention Science*. Invited Panel, International Society for Autism Research, Stockholm, Sweden, **May 2023**.

Alcorn, A. *Teaching and Learning About Neurodiversity at Primary School*. Invited Talk, Middletown Autism conference, Belfast and online, **May 2023**.

Fletcher-Watson, S. *Neurodiversity-Affirmative Practice in Education and Healthcare*. Keynote, Middletown Autism conference, Belfast and online, **May 2023**.

Fletcher-Watson, S. *Supporting Neurodivergent Children and their Families*. Keynote, Middletown Autism conference, Belfast and online, **May 2023**.

Fletcher-Watson, S. *Principles and Practices in Neurodivergence-Informed Education*. Keynote, Neurodiversity and Mental Health conference, online, **May 2023**.

Fletcher-Watson, S. *Autistic Communication and the Neurodiversity Paradigm*. Keynote, International Pragmatics Association conference, Brussels, **July 2023**.

Alcorn, A., *Learning About Neurodiversity at School (LEANS)*. European Conference on Educational Research (ECER), **August 2023**

Cebula, K., Fotheringham, F., Foley, S., Fletcher-Watson, S., & Crompton C.J. *Neurodivergent Peer Support Toolkit: Co-Design of Peer Support for Neurodivergent Young People in Mainstream Secondary Schools*. BPS Developmental Section, **September 2023**

Commentaries, Book Chapters and Editorials

Alcorn, A., & Fletcher-Watson, S. (2022). Choosing and using technologies to support autistic children and young people. In J. Gainsborough (Ed.) *Educational Psychology Perspectives on Supporting Young Autistic People: insights from Experience, Practice and Research*. Jessica Kingsley Publishers, UK

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Davis, R., Hampton, S. C., & **Fletcher-Watson, S.** (2022). Why study bilingualism in autistic people?. *Autism*, 26(7), 1601-1605.

Fotheringham, F., Axbey, H, & **Crompton, C.J.,** (2023) Neurodiversity informed peer support in mainstream education: Development and Evaluation of the Neurodivergent Peer Support Toolkit (NEST). In Herbert, R. (Ed) *Beyond Autistic Stereotypes*, Oxford University Press

Hobson, H., Poole, D., Pearson, A., & **Fletcher-Watson, S.** (2022). Opening up autism research: Bringing open research methods to our field. *Autism*, 26(5), 1011-1013

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Pearson, A., Surtees, A., **Crompton, C. J.,** Goodall, C., Pillai, D., Sedgewick, F., & Au-Yeung, S. K. (2022). Addressing community priorities in autism research. *Frontiers in Psychology*, 6189.

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Journal Articles and Preprints

Preprints

Alcorn, A. M., McGeown, S., Mandy, W., & **Fletcher-Watson, S.** (2023). Learning About Neurodiversity at School (LEANS): Evaluation of the LEANS resource pack in mainstream primary schools. <https://doi.org/10.31219/osf.io/fhc2k>

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Bradley, S., Moore, F., Clarke, L., Duffy, F., Knightsmith, P. & **Gillespie-Smith K.** (2023). Camouflaging, social identity not sensory processing predicts eating disorder behaviour in Autistic adults. <https://osf.io/b9jv5>

Cage, E., **Crompton, C.J.**, Dantas, S., Strachan, K., Birch, R., Robinson M., Morgan, S.A., MacKenzie-Nash, C., Gallagher, A & Botha, M. What are the autism research priorities of autistic adults in Scotland? <https://psyarxiv.com/nbq8h/>

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Digard, B.G., Johnson, E., Kašćelan, D., & Davis, R. (2023) Raising bilingual autistic children in the UK: At the intersection between neurological and language diversity. *Front. Psychiatry*, 14, 1250199

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Morris, V., Hendry, G., Wilson, C., **Gillespie-Smith, K.**, & Ballantyne, C. (2023). A comparison of attitudes and knowledge towards autism based on adult sibling experiences. *Journal of Adult Development*, 1-13

Nimbley, E., **Gillespie-Smith, K.**, Duffy, F., Maloney, E., Ballantyne, C., & Sharpe, H. (2023). "It's not about wanting to be thin or look small, it's about the way it feels": an IPA analysis of social and sensory differences in autistic and non-autistic individuals with anorexia and their parents. *Journal of Eating Disorders*, 11(1), 89.

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