



EDAC NEWSLETTER



Autumn Issue

October 28th 2024

EDAC Events

Happy One Year at EDAC, First ep. of Table Talk! Kyle Started his PhD! Mental Health Awareness Day.

EDAC Research

Recruitment calls! – FBT (parents, young people) – transition experiences. Learning Disability Stream WS2. Underlying ED mechanisms. New Publications. Collaboration with Phaedra Longhurst.

Knowledge Exchange

Eating Disorder Research Society 2024 in Sitges. New Blog section on our website!

Community News

Meet our newest collaborators!

Coming Soon...

Workstream 3 pilot projects. Photovoice Exhibitions

EDAC SPOTLIGHT



Dr Karri Gillespie-Smith



EDAC EVENTS



Happy One Year at EDAC



We are just over the halfway mark here at EDAC! In our first year, we worked together to co-produce best practice guidelines for the ethical co-production of research with Autistic people with an ED. Using this knowledge, we then designed and ran a number of Photovoice studies, which used images or drawings to explore research priorities of the Autistic and ED community. The results of these workshops are currently being written up and we hope to share our results with you on our website soon!

[<https://edacresearch.co.uk/publications>]

“From research priorities we co-developed with our Autistic collaborators during Photovoice studies, we provided a funding call to support autism-affirming research addressing these priorities. We received many applications with exciting and novel ideas that were reviewed by a lived experience panel of Autistic people with lived experience of an eating disorder. Currently, we are in the process of getting research studies from successful applicants off the ground!

Table Talk Episode 1 is now Live!

We are delighted to announce that EDAC’s podcast, Table Talk, is now formally live! Join us for a discussion on the role of technology in autism and eating disorder research, with special guests Kate Tchanturia and Ellen Maloney [<https://edacresearch.co.uk/podcast-and-blog/1/the-table-talk-podcast-episode-1>]

Kyle Has Started his PhD!

Congratulations to Kyle, who has formally started his PhD, which focuses on the role of monotropism in the development of eating disorders in Autistic people. The EDAC team is lucky enough to still have Kyle on board as a research assistant. Thanks, Kyle, and keep up the great work!



Mental Health Awareness Day

This year's World Mental Health Day took place on Thursday, the 10th of October. Here at EDAC we are keenly aware of the higher rates of mental health difficulties reported in Autistic people, and hope that our research will work towards improving mental health, wellbeing and quality of life in the autism and ED community!

EDAC RESEARCH

Recruitment Call: FBT Study

Are you an Autistic young person who has experience of Family Based Treatment for anorexia nervosa (FBT)? Researchers at the University of Edinburgh would love to hear from you. We are looking for participants aged 14-21 living in the UK to take part in an interview about their experiences of treatment. This can help clinicians understand how to make treatments more effective. If you're interested, you can find out more here: https://edinburgh.eu.qualtrics.com/jfe/form/SV_3K6mlVQREsmRwKa or contact vanessa.haugaard@nhslothian.scot.nhs.uk with any questions.

Recruitment: Learning Disability Photovoice Study

Having just finished a truly insightful course of Photovoice workshops with Autistic people with lived experience of eating disorders, we are now seeking to extend our data collection to include Autistic people with co-occurring learning disability. We are conducting this research to develop understanding of the experiences in this underrepresented group and to begin to develop an understanding of some of the potential clinical implications of such findings. Workshops have just gotten started, but we are eager to hear from more community members! Click this link:

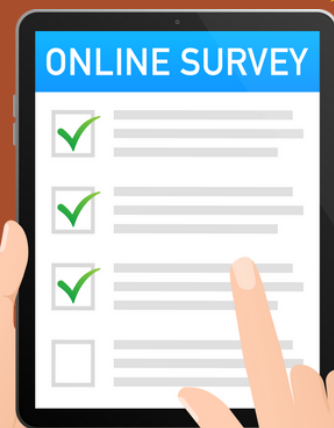
(https://edinburgh.eu.qualtrics.com/jfe/form/SV_1Y9kQ6OdVAmlBVc?Q_CHL=qr) if interested or email us at EDAC@ed.ac.uk

Underlying ED Mechanisms Survey

Using data collected from our photovoice sessions, Karri and Kyle, along with some students at the University of Edinburgh, are exploring underlying ED mechanisms in Neurodivergent people. This study is for people aged 16 and above, who live in the UK, and who are Autistic and/or ADHD. You don't need any clinical diagnoses to take part.

You will be asked to complete a survey, which will probably take 45-50 minutes. It will ask you about your experiences as an Autistic person and/or a person who has ADHD and about your eating behaviours. You can then enter a prize draw (two £50 and one £100 voucher up for grabs)!

Interested? Find the online survey [here](#):



WorkStream 3 Recruitment Opportunities

Research studies for work stream 3 are now getting started; keep an eye out for recruitment opportunities on our website!

(<https://edacresearch.co.uk/get-involved>)

Publications! Mixed-method systematic review of ED treatment outcomes (Emy)

This review looked at ED treatment outcomes such as ED service use, ED symptoms and psychosocial outcomes. We found Autistic people are at higher risk of being admitted to inpatient wards more often and for longer. Autistic people reported higher rates of mental health difficulties than non-autistic people both before and after treatment.

Finally, interventions that support emotional difficulties were more positively received compared to cognitive or group-based support. More research is needed in underserved ED presentations, such as binge eating disorder and ARFID, as well as studies that do not rely on Autistic traits as an indicator of autism.

Brain imaging opinion piece (Michelle)

Michelle Sader, Ellen Maloney and other EDAC researchers wrote a perspective piece based off feedback we received from Autistic research collaborators in our first workstream. This perspective piece aims to outline concerns from the Autistic community in relation to both magnetic resonance imaging (MRI) and the functionality of the open-access scientific framework, utilising these approaches as examples to outline research-wide concerns and barriers to ethical research. From available quotes and feedback, this work also addresses a bias in research regarding who can reasonably tolerate an MRI scan as an Autistic person, and whether certain Autistic characteristics are being disproportionately highlighted or suppressed through these research practices. Lastly, this perspective piece focuses on methods with which MRI, open-science philosophy and general research disciplines can improve practice to conduct ethical autism research.

ED Measurements in Autistic People (Phaedra)

Phaedra Longhurst, a PhD student looking at body image in Autistic people at Angela Ruskin University, recently published a paper looking at how eating disorders are measured in Autistic people. The paper explored how autism-specific behaviours or mechanisms have previously been excluded from eating disorder measures, and the implications this has on research, clinical practice and the Autistic individual, before making suggestions for future research to improve this. Fiona, Karri and Emy were collaborators on this paper, as well as were the amazing Dr Keren Maclennan at the University of Bath and Dr Elizabeth Evans at the University of Durham. Huge congratulations to Phaedra and the rest of the lovely author team!

All publications will be uploaded to our website soon!



KNOWLEDGE EXCHANGE



This September, Fiona Helen and Emy attended the Eating Disorder Research Society 2024 in Sitges, Spain. It was also hugely exciting that the opening keynote speech this year focused on mental health and eating disorders in Autistic people (during which Fiona and EDAC got a shout out from Francesca Happé!) It was an amazing opportunity to meet leading eating disorder researchers and to spread the word about EDAC's exciting research with an international audience.



New BLOG Post Section

We have recently added a blog post section to our website, in order to highlight perspectives, experiences and stories shared by our research and lived experience community.

Check out our blog section here!

<https://edacresearch.co.uk/podcast-and-blog>



Remember: You can access our plain speaking summaries [here](#)



COMMUNITY NEWS

Meet Our Newest Collaborators!

Pictured below are our newest EDAC collaborators, who have hopped on board after helping EDAC establish research priorities and studies to support for our third work stream. Each of our EDAC collaborators brings their unique set of knowledge, skills and understanding which have been developed through their own personal and professional lived experience journeys. Whether it's designing study materials, screening research proposals, working on our podcast, or simply giving us feedback on what we could be doing to better serve the community, our collaborators will ensure EDAC is always being the best it can be.



Heidi



Emma



Kate

Luka has had their newest paper published!

Earlier this month, Luka had their paper titled "*Minority Stress, Camouflaging, and Mental Health Outcomes in Transgender and/or Non-Binary Autistic Adults*" published. They found that many participants experienced both transphobia and anti-Autistic discrimination. Generally, gender minority stress, Autistic minority stress and camouflaging were related to an increase in depression, anxiety and post-traumatic stress. However, Autistic pride was related to reduced depression! Read the full paper here: [here](#). Amazing work Luka!!

COMING SOON

Workstream 3 pilot projects

As part of workstream 3, we created a research panel consisting of Autistic people with lived experience of eating disorders and researchers to screen research proposals. We have just finished our screening process, and are delighted to support the following studies:

Phaedra Longhurst - Autistic People's Experiences, Understanding, and Perceptions of Intuitive Eating: A Qualitative Photovoice Study.

Nicola Llowarch - Supporting Autistic Adults with Anorexia Nervosa: A Scoping Study Highlighting Perspectives Towards Development of Autistic Peer Support.

Hannah Lewis - Adapting 'The Body Project' Intervention for Neurodiverse Pupils: What Reasonable Adjustments are Needed to Support Implementation in Schools?



A giant thanks to our lived experience panel members for their hard work in helping EDAC decide which research to prioritise.

Photovoice Exhibitions

As part of our latest photovoice study, we will be hosting both an online and in-person exhibition to promote the impactful collection of images provided by our participants. As with the study, these images have been separated into two distinct, yet equally important galleries: The Autistic Experience of Eating Disorders and The Research Priorities of Autistic People with Lived Experience of Eating Disorders. Stay tuned for updates and event details (coming soon!).

EDAC SPOTLIGHT

Dr Karri Gillespie-Smith



WHAT IS YOUR ROLE AT EDAC?

I co-lead EDAC with Dr Fiona Duffy. I am a non-autistic autism researcher which compliments Fiona's background in Eating Disorders and Clinical work.

WHAT HAS BEEN YOUR PATHWAY TO JOINING EDAC?

When I joined Edinburgh I happened to be next door to Fiona Duffy and Helen Sharpe (who do research in Eating Disorders). I began talking to them about Eating and Autism and we became really interested in exploring this overlap further. So we started working together and it's been fantastic.

WHAT IS EXCITING ABOUT THE FIELD OF AUTISM AND EATING DISORDERS?

It is exciting because both fields can learn so much from each other. In Autism research so much more is done around co-production and accessible research and in the Eating Disorder research there is a real emphasis on research translation to clinical practice.



WHAT DO YOU THINK WE NEED TO UNDERSTAND MORE ABOUT IN THE FIELD OF EATING DISORDERS?

We need to better understand what are the autism specific mechanisms and factors that drive Eating Disorders in Autistic groups. By understanding autism-specific mechanisms, interventions can be better adapted or co-produced to suit autistic needs.

WHAT IS YOUR FAVOURUTE BOOK OR FILM?

Favourite Film - The Fifth Element.

Favourite Book - A Discovery of Witches.



WHAT IS SOMETHING THAT BRINGS YOU COMFORT?

Hugging my daughter Blair - could squish her all day long.

A massive thanks to Karri for all the amazing work she does at EDAC!



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