

EDAC NEWSLETTER



Summer Issue

June 28th 2024

EDAC Events | PRIDE! Birmingham Event, Kyle's PhD

EDAC Research | Recruitment call for Photovoice with people with Learning Disabilities and our latest publications!

Knowledge Exchange | Autism and ED's Collaborative Exchange Event with SupportED, Autism Initiatives and NAIT. Michelle presents at SINAPSE!

Coming Soon... | Episode 1 of the Table Talk Podcast, Workstream 3 research priorities panel and Photovoice exhibition!

Community News | Thank you to our collaborators!

An interview with our Co-PI:

Dr Fiona Duffy



EDAC EVENTS

Happy Pride Month



Happy Pride from all of the EDAC Team! As part of our pride segment, we wanted to give a huge EDAC welcome to Luka! They will be joining the University of Edinburgh to start their PhD in September and will also be working closely with EDAC. They will be exploring body-related gender euphoria and eating disorders in trans and/or nonbinary (TNB) Autistic adults. They will investigate 1) What is the experience of disordered eating like for TNB autistic adults? 2) What is a valid and acceptable self-assessment tool for gender dysphoria/euphoria in Autistic and non-autistic TNB adults? 3) Does gender dysphoria/euphoria have a role in predicting eating disorder-related outcomes in TNB Autistic adults? Luka wants more representation of TNB Autistic people in research and as a TNB themselves, they will strive to make the most of this opportunity and to use the knowledge and skills learned to give back to their communities.

EDAC Birmingham Event

On the 26th - 27th of June we (EDAC) travelled to Birmingham to meet with the other eating disorder-based lab groups that received the same UKRI funding pot as ourselves! We met to discuss each others research and to network with one another, creating collaborations across the U.K! Information on the other lab groups can be found in [here](#).

Kyle's PhD Starts Soon!



Kyle, our EDAC Research Assistant, will soon be starting his PhD at the University of Edinburgh! Kyle is passionate about co-production and is keen to adopt methodologies such as photovoice, to centralise Autistic voices in the academic narrative. He hopes to continue to collaborate with EDAC to ensure his research reflects the priorities of the Autistic, eating disorder community. Good luck Kyle!



EDAC RESEARCH

RECRUITMENT CALLS



Eating disorder Experiences of Autistic people with Learning Disability: A 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 under represented group and to begin to develop an understanding of some of the potential clinical implications of such findings. Workshops begin August 11th! Scan the QR code if interested or email us at EDAC@ed.ac.uk!

EDAC PUBLICATIONS



EDAC Overview Paper:

This paper gives a detailed account of EDAC's 4 workstreams, how they operate within a neurodiverse-affirming framework and what each of these aims to achieve. Workstream 1: coming together and improving co-production. Workstream 2: setting research priorities. Workstream 3: conducting research in prioritised areas. Workstream 4: informing clinical change.

ARFID: Looking Beyond the Eating Disorder Lens

This opinion piece, led by Dr fiona Duffy, highlights key considerations for the Avoidant Restrictive Food Intake Disorder literature. The paper acknowledges the dangers of only viewing ARFID through an eating disorder lens and missing out on the important skills offered by our colleagues in Occupational, and Speech and Language therapy.



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

KNOWLEDGE EXCHANGE

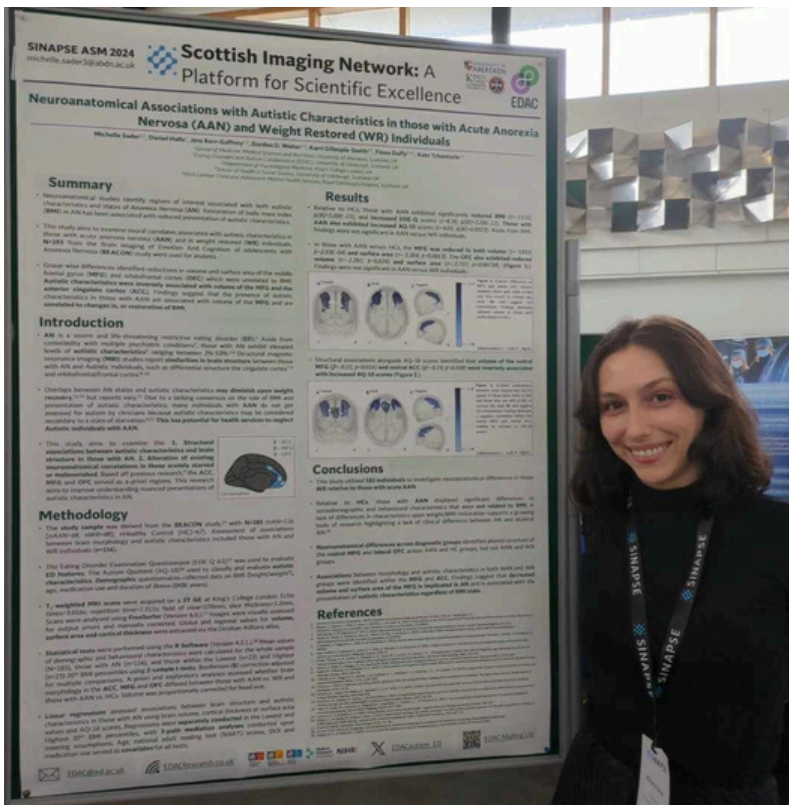


Autism and ED's: Collaborative Exchange Event

On Thursday 13th June, Emy Nimbley & Fiona Duffy hosted a knowledge exchange event in collaboration with SupportED and Autism Initiatives. The event focused on collaborative change, bringing together Autistic people with lived/living experience of an ED, researchers, clinicians, parents, carers, charities, and organisations. At this in-person event in Edinburgh, attendees shared their experiences and discussed how to better support Autistic people with ED's. Guest speakers from the National Autism Implementation Team (NAIT) lead this discussion, sharing their insights into how to develop autism-affirming practice. We will share these exciting discussions from this event with you later in the year!



Michelle Wins "Best Talk" at SINAPSE Conference!



Michelle won the "Best Talk" prize for her presentation of EDAC's work with the Brain imaging Of Emotion And Cognition Of adolescents with anorexia Nervosa (BEACON) dataset at the 2024 SINAPSE Conference! EDAC is using this data to expand prior findings and investigate: 1) associations between brain structure and Autistic traits in those with Anorexia Nervosa (AN) 2) assess the impact of starvation on these associations between and 3) assess whether Autistic characteristics can inform predictions of future social and emotional behaviours. Well done Michelle!

COMING SOON

“TABLE TALK” PODCAST: Episode 1



TABLE TALK

Special Guests: Prof Kate Tchanturia & Ellen Maloney

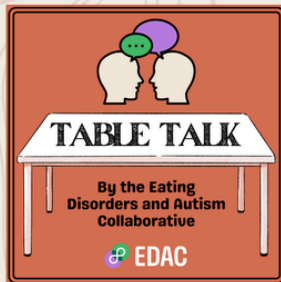
PROFESSOR TCHANTURIA IS THE LEADING FIGURE IN AUTISM AND EATING DISORDER RESEARCH. SHE IS ALSO THE FOUNDER OF THE ACCLAIMED PEACE PATHWAY AND A INTEGRAL MEMBER OF THE EDAC TEAM. WE WILL ALSO BE JOINED BY OUR PEER RESEARCHER ELLEN



MALONEY, WHO'S EXPERTISE, LIVED EXPERIENCE, HUMOR AND ALL ROUND PERSONALITY MAKES HER NOT ONLY AN IRREPLACEABLE COLLEAGUE, BUT A PERFECT GUEST FOR THE PODCAST!

TOPIC: Technology

EP. 01



EP. 01



Join us for our discussion on the use of technology in autism and eating disorder research, potential therapeutic uses, and the dangers of technology. We also ask “If you could design any piece of technology for Autistic people with ED’s, what would it be and why?”

Workstream 3: Research Priority Pannel

As part of workstream 3, we will create a research panel, consisting of Autistic people with lived experience of eating disorders, researchers, and clinicians to screen research proposals. Proposals will only be accepted if they are deemed to reflect the priorities of the community as highlighted by those agreed upon in workstream 2. Details on how to apply to be a member of the panel are coming soon!





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!) ✨ ✨ ✨

DATE: Est. Dec 2024/ Jan 2025!

FREE ENTRY



COMMUNITY NEWS



Meet our collaborators!



Isla



Casper



Rebecca



Lin



Tasha



Julie-Anne



Ollie



Kayleigh



Jess



Callum



Emily



Bryanna

Thank you

Pictured above is our growing team of EDAC collaborators! Each individual brings to EDAC a 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. We feel grateful to have the opportunity to work alongside our collaborators, utilising each individuals strengths and goals to help fully realise EDAC's potential to go beyond being just a research group, but a community of like-minded people who want to change the academic and clinical landscape of eating disorders for the better.

EDAC SPOTLIGHT

Dr Fiona Duffy



WHAT IS YOUR ROLE AT EDAC?

I am one of the Primary Investigators on EDAC (alongside Karri Gillespie-Smith) meaning we lead and manage the grant activity and associated research.

WHAT HAS BEEN YOUR PATHWAY TO JOINING EDAC?

I am a Consultant Clinical Psychologist having worked for over 20 years in NHS child and adolescent mental health services (CAMHS), primarily with young people with eating disorders and their families and I currently co-lead our CAMHS eating disorder team in NHS Lothian. About 10 years ago I found myself entering back into academia part time, partly because I believe engaging with research makes you a better clinician (and the other way round, being a clinician gives you different insights to research!) but also because I was frustrated about the lack of research guiding clinical activity in eating disorders and wanted to do something about it. For EDAC I come from a clinical eating disorders background meaning this was the dream opportunity to team up with Karri who comes primarily from an autism research background. Together we represent what EDAC is about - the collaboration between the autism and eating disorder fields.

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



I would say both exciting in terms of opportunities (but also frustrating and slightly overwhelming!) is the infancy of research in this area. There are so many areas that need further exploration, and it is so refreshing to work alongside Autistic individuals with lived experience of eating disorders at EDAC who co-produce and guide the development of meaningful research from the outset.

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

There is so much. As a clinician I feel frustrated that a lot of our treatments are not as effective as I would hope, many of our clinical manuals are now 20 years old, and that there has been a chronic historical underfunding of eating disorder research. When we developed the SIGN guidelines for eating disorders, there was literally whole clinical groups that we couldn't make treatment recommendations for because there was a complete lack of robust research (including Autistic individuals with eating disorders and ARFID). This leaves clinicians without guidance on the most appropriate and effective approaches, and most importantly is a barrier to supporting individuals to recover from an eating disorder. This would not be acceptable in physical health (and even some other mental health conditions) and I feel frustrated that this is the case for eating disorders.

WHAT IS YOUR FAVOURITE BOOK OR FILM?

Indiana Jones and the Temple of Doom (childhood nostalgia)



WHAT IS SOMETHING THAT BRINGS YOU COMFORT?

My dog Josie who is currently napping on my foot.

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

https://twitter.com/EDACautism_ED

[@edac.uk](https://www.instagram.com/edac.uk)

<https://edacresearch.co.uk>

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