

EDAC NEWSLETTER

Spring Issue

March 29th 2024

EDAC Events:

We have finalised our co-production guidelines from workstream 1. See our handouts inside!

EDAC Research:

Includes 3 EDAC recruitment calls!

Knowledge Exchange:

Hear about The 2024 PEACE Conference, Eating Disorder Awareness Week and public engagement summaries!

Community News:

Learn about new research findings including: ARFID Review, Narrative Review of Autism in women and girls and how a furry little “Purrble” is being used to guide emotion regulation in young people.

Coming Soon...

The EDAC podcast and the Impact accelerator collaboration with SUPPORTED and Autism Initiatives.

OUR WEBSITE IS NOW LIVE:



An interview with our Peer Researcher



Ellen Maloney

“

Co-Production with the Autistic Community is the **ONLY** way to do

Meaningful research ”

ABOUT US

YEAR 1

It has been a busy and productive first year of work for the EDAC team, and we are keen to share our current workstream activities, research findings and future objectives with interested readers. As such, EDAC is delighted to share the first issue of our newsletter with you, led by Emy Nimbley, Michelle Sader and Kyle Buchan.

We aim to send out new issues on a quarterly basis, and use current (and future) newsletter editions as an information hub to update you on all things EDAC!

If any readers have any feedback or suggestions for content associated with the EDAC newsletter, please feel free to reach out on Twitter/X (@EDACautism_ED), or email us at (EDAC@ed.ac.uk).



EDAC EVENTS

OUR WEBSITE

EDAC is delighted to announce that our website is officially live and accessible to all! Visitors to our

website can expect to get to know the EDAC team as well as our research collaborators, learn more about our workstreams, find information on EDs and Autistic experiences, access resources such as our Best Practice Guidelines, and stay up to date with upcoming events, workshops and webinars hosted by EDAC and other organizations. Dive into a wealth of resources, insights and community-driven initiatives at: EDACResearch.co.uk!

EDACResearch.co.uk



BEST PRACTICE GUIDELINES

From our workstream 1 workshops, EDAC has constructed the Best Practice Guidelines, which aim to guide academic teams through the research process and generate impactful work developed in partnership with the community. EDAC hopes to support researchers in the field in acknowledging the benefits of co-production and allowing for reflective discussions about how to best conduct autism-informed research for Autistic individuals.

Our Best Practice Guidelines can be found on our website (EDACResearch.co.uk) or by clicking this [link](#). The Guidelines cover discussion points on Designing Research, Conducting Research and Sharing Research. A massive thanks and congratulations to everyone involved for a fabulous job EDAC's first workstream!



EDAC RESEARCH

RECRUITMENT CALLS



Family Based Treatment for anorexia nervosa or bulimia nervosa with Autistic young people

EDAC is interested in exploring the experience of delivering and receiving Family Based Treatment for eating disorders with Autistic young people. FBT is the first line treatment for young people with Anorexia Nervosa and Bulimia Nervosa. There is a large proportion of young people with an eating disorder who are also Autistic. Though there has been more research into understanding the relationship between autism and eating disorders, there continues to be a need to improve and/or adapt treatment. To facilitate developments to treatment, it is important to understand the current experiences of FBT with Autistic young people and their families. This project is led by Fiona Duffy (Lead EDAC Co-PI). Keen to participate? Learn more [here](#).

Experiences of ED Service Transition

Have you had experiences regarding transitioning between child/adolescent and adult health services for an eating disorder (ED)? EDAC researchers at the University of Edinburgh are recruiting individuals familiar with ED service transitions. By sharing your experiences and insights with us, you will help us to better understand and cater for the specifics of those with eating disorders - Autistic and non-Autistic - during the transition period! This work is led by Dr Fiona Duffy and Dr Emy Nimbley (Post-doctorate EDAC researcher). Keen to participate? Learn more [here](#) or scan the QR code.



Workstream 2: Exploring Research Priorities for Autistic People who have Eating Disorders: A Photovoice Study.

EDAC is now recruiting for workstream 2! The aim of this workstream is to use arts-based methodologies to understand experiences of eating disorders (EDs) and to identify research priorities for people with lived experience (PWLE) of EDs in Autistic populations.

We will be using Photovoice-based workshops both in-person and online. At a later date, we will also be recruiting Autistic populations with co-occurring Intellectual Disability so stay tuned! This work is being led by Karri Gillespie-Smith (Lead EDAC Co-PI) and Sarah Kettley (EDAC PI). Keen to participate? Learn more [here](#).



KNOWLEDGE EXCHANGE



PEACE CONFERENCE 2024

Led by our colleague, Dr Kate Tchanturia at King's College London, EDAC were invited to attend the annual PEACE Pathway Conference on the 27th February. This was a fantastic event, bringing together those with lived/living experience, research, clinicians and more working in the field of autism and eating disorders. Dr Fiona Duffy and Dr Karri Gillespie-Smith presented our work at EDAC and launched our Best Practice Guidelines to an excited audience! We learnt so much from the presentations and discussions at the conference – thank you Kate, and thank you to all the attendees and presenters!

EATING DISORDER AWARENESS WEEK 2024

EDAW 2024 occurred from Monday, the 27th of February to Friday, the 1st of March. EDAC researchers Emy Nimbley and Michelle Sader partnered up with Dr Samuel Chawner from Cardiff University to provide an evidence-based review of avoidant restrictive food intake disorder (ARFID) for the UK's leading eating disorder charity, BEAT. Our review of ARFID literature is available [here](#) on the EDAC website. A large thanks to Mr Jonathan Kelly at BEAT for approaching us with an invaluable opportunity to shed light on ARFID, and to Sam for his collaboration on this work.

Also during EDAW 2024, Dr Emy Nimbley ran a knowledge exchange event in collaboration with colleagues at SupportedED and Autism Initiatives. The event aimed to share research into the identification or awareness of eating disorders in Autistic people, and to engage autism and eating disorder community support organisations in discussions on their confidence, awareness and experience. Huge thanks to SupportedED, Autism Initiatives and funders of the wider Impact Acceleration Grant at the ESRC.

PUBLIC ENGAGEMENT SUMMARIES

The most important audience for EDAC is the Autistic and eating disorder community and so we need to make sure that any research we are doing is accessed and understood by this community. Led by our Autistic peer researcher Ellen, we will be uploading videos of Ellen interviewing researchers about their studies and findings on our website. Please click [here](#) to have a look at the interviews we have already done!



COMING SOON

“TABLE TALK” PODCAST

EDAC will soon be launching our “table talk” podcast. Here we aim to produce an accessible, informal avenue of information that sheds light on neurodivergence and eating. We will be talking to a range of guests from varying backgrounds, including researchers, Autistic people with lived experience of eating disorders, Clinicians and charities to name a few! Join our mailing list to stay up to date with the progress of the podcast. If you have ideas for content for the podcast then please get in touch with Kyle Buchan at EDAC.ed.ac.uk.



IMPACT ACCELERATION GRANT

As part of the ESRC Impact Acceleration Grant, Dr Emy Nimbley and colleagues at SupportED and Autism Initiatives will be meeting again on Autism Acceptance Day, Tuesday 2nd April! The focus will be on improving support for Autistic people with an eating disorder, and we will be sharing our research and community experiences. Stay tuned for updates in the next newsletter!

COMMUNITY NEWS

PURRBLE:

Purrble is a new toy-based technology developed to guide emotion regulation in young people. Find out more [here](#).

AUTISM AND ARFID IN PRESCHOOLERS

This research has shown significant association among autistic traits, ARFID behaviours, and sensory processing patterns. Find out more about the relationship [here](#).

AUTISM IN WOMEN & GIRLS

Interested in the diagnosis of autism in female populations? This narrative review provides a compelling exploration of the gendered diagnostic bias in autism. Find out more [here](#).



ARFID & AUTISM: A REVIEW

In this review compiled for BEAT, you will find an extensive account of avoidant restrictive food intake disorder (ARFID). Read the full review [here](#).

EDAC SPOTLIGHT

ELLEN MALONEY

For our first issue of our newsletter, EDAC is thrilled to shine a spotlight on our phenomenal peer researcher, Ellen Maloney. Ellen has been a fundamental and integral part of EDAC, and consistently works to give a voice to the neurodiverse and Autistic community as we conduct our work at EDAC. She has taken time out of her busy schedule to answer some of our questions.



WHAT IS YOUR ROLE AT EDAC?

Peer Researcher!

WHAT HAS BEEN YOUR PATHWAY TO JOINING EDAC?

Two answers to this but I think they are both important: the short answer is that I have lived / living experience of an eating disorder and I am Autistic, rather than a conventional academic background.

The longer answer is that I started doing various campaigning / advocacy work using my lived experience of having an eating disorder about 7 years ago which is where I met Dr Fiona Duffy! We worked together on various different long-term projects including sitting on the committee that wrote the SIGN Guidelines for treatment of people with eating disorders in Scotland, as well as some policy work within Scottish Government following the review of eating disorder services in Scotland. Dr Duffy invited me to join the Eating Disorder and Behaviour Research Group at the University of Edinburgh because I am so interested in how research, policy, and practice work together. Through this, I had the opportunity to work with Dr Nimbley on her PhD on eating disorders and autism and then when the opportunity came to apply for funding for EDAC, Dr Duffy asked me if I'd like a formal role as a peer researcher!



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

I'm excited that this is being taken seriously and that different disciplines are coming together to try and come up with meaningful ways to support Autistic people with eating disorders better. Also, a lot of this work is being co-produced with the Autistic community which I think is the only way to do meaningful research.

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

Oh, so much! I'm interested in obsessive thoughts versus Autistic rumination and what is happening the brain during this, and whether it's possible to untangle autism from an eating disorder and what that could or would look like. I'm interested in peer support in digital spaces and community-led self-help, and recovery from iatrogenic harm in Autistic people with EDs and the resulting trauma from that. There's so much to explore and understand but very much with the aim of translating research into practical ways to help people because the amount of suffering is immense.

I have so many questions and things I want to understand but the more people I meet, the more I feel like each experience is very individual and needs a different type of understanding.

WHAT IS YOUR FAVOURITE BOOK OR FILM?

I don't know how to answer this but I love to read and I love musicals!

WHAT IS SOMETHING THAT BRINGS YOU COMFORT?

Sunshine, coffee, and my favorite way to spend time, pole 'dance' (I use the term 'dance' lightly because I don't do much dance, but I love being upside down).



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



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<https://edacresearch.co.uk>



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