Parent/Carer Information sheet

Project title:	Exploring Research Priorities for Autistic people with Intellectual Disability and Disordered Eating: A Photovoice
Principal investigator (PI):	Dr Karri Gillespie-Smith
PI contact details:	Karri.gillespie-smith@ed.ac.uk

What will the research involve?

This research consists of a series of workshops which will involve discussions of eating disorder experiences with Autistic people with Intellectual Disability. Part of this process will be using a Photovoice methodology, which involves taking photos or drawing pictures of things which resonate with the individuals experience of the research questions, these questions being ""*What are the experiences of Autistic people with Intellectual Disabilities and current/prior disordered eating*?"
And "*What are the research priorities of Autistic people with Intellectual Disabilities and current/prior disordered eating?"*

What Is **Disordered Eating**?

Disordered eating means any type of eating behaviour that has negative impact on the person's immediate or long-term health. This may include:

- **Pica**- when you eat non-food items such as dirt or cotton.
- **Selective eating**- such as only eating a beige coloured food
- **Binge eating**- eating very large amounts of food in a short space of time
- **Anorexia Nervosa**- eating very small amounts of food to lose weight or to change your appearance.

Workshop Content:

Workshop 1: Trust building and Introduction.	Discuss research purposes and Photovoice. Discussion of Photovoice process. Send away to do 1st assignment – 'What is your experience of disordered eating?'

Workshop 2: Discuss photos/drawings (RQ1)	Give feedback to participants. Send away to add to do 1st assignment.
Workshop 3: Discuss photos/drawings (RQ1, send away for RQ2).	Discuss images. Send away to answer research question 2: 'What are your research priorities?'
Workshop 4: Discuss photos/drawings (RQ2)	Feedback images for research question 2. Send away to add to 2nd assignment.
Workshop 5: Themes RQ1	Provide general themes for the RQ question 1: What is your experience of disordered eating?'
Workshop 6: Themes RQ2	Provide general themes for the RQ question 2: 'What are your research priorities?'
Workshop 7: Reflecting	Reflecting on the research process, asking was it accessible? What worked? What didn't work? How can we improve?
Workshop 8: Reflecting and Conclusion	Continue reflections if needed, answer questions, well-being checks. Say goodbye and wrap up research.

These workshops will run over a period of around 2 months (5-8 weeks) with a workshop occurring on a weekly basis. Your child can choose to take part in these workshops online or in person (please note in person workshops will take place in a room at the University of Edinburgh, attendance at the location of the participants request must be agreed upon and arranged prior to completing this survey). Prior to the workshops, your child will be required to complete a survey which provides demographic information as well as answer questions on their eating habits and behaviours and some screening questions about their diagnoses. This is estimated to take around 15-20 minutes.

Why is this research being conducted?

This research is being conducted to understand the research priorities of the Autistic, Intellectual Disability community and to reflect on best practice for future research.

Why am I reading this?

You are reading this because you are the parent/carer of an Autistic person with an Intellectual Disability who has lived/living experience of an eating disorder over the age of 14 years old.

Are there benefits to participating?

Yes. There are numerous benefits to taking part, such as monetary compensation of £20 voucher per workshop your child attends, the opportunity to meaningfully contribute to research priority setting within the field of autism and EDs, and taking the lead on the direction of research.

Are there risks to participating?

There is a chance that participation may cause some distress for some participants. This is because the workshops will involve revisiting potentially upsetting memories through the collection of images and subsequent discussion of eating disorders. We will offer comprehensive support throughout the process and will monitor and respond to signs of distress carefully. Please remember that you have the right to pause or withdraw at any point of the workshop. If you are distressed following the interview, please contact a member of the research team, your GP or any of the support networks that will provided at the bottom of this Participant information sheet and on the debrief sheet. You will be reminded of these options before and after each session.

Can you withdraw from the research after you've consented to join?

Yes. You have the right to withdraw your child from the study at any time. If you/ they would like to withdraw during the sessions, they can stop the in-person session by leaving the room or the online session by closing the computer window. If after consenting to take part you would like to withdraw your child from participation from the rest of the study, then you can do by this by contacting the Kyle Buchan, whose contact details are provided at the end of the sheet. If you would like to withdraw your child's data after the study has finished, you have up to 3 days to do this, after which your child's data will have begun to be analysed and anonymised.

What data will be collected and how will it be stored?

The information and data generated from this study will be collected and processed in line with Data Protection Laws and the University of

Edinburgh's Data Protection policies. All data will be kept strictly confidential and pseudonyms or numerical codes will be assigned to protect your identity.

We will collect demographic information in a survey prior to the workshops such as gender, age, ethnicity and diagnosis(es) to inform our data analysis. Here we will also collect information on participant eating habits and behaviours as well as contact information so that we can contact participants before the upcoming workshops. Material from the Photovoice sessions will be stored in a secure, encrypted and password-protected platform at the University of Edinburgh (OneDrive). Photovoice sessions will be recorded and transcribed. Once the sessions have been transcribed, the recordings will be deleted (no later than two weeks following the last session). Anonymised transcripts will be stored for a minimum of 5 years in an online data repository where other researchers may access it to use as part of future research, subject to ethical approval. All information and data will be kept on the University of Edinburgh servers which are encrypted.
You will be additionally asked if you are happy for your images to be part of an exhibition that will take place online and in person (in Edinburgh). The images will be checked for any identifying information and if they do not have any identifying information and you have provided permission they will be included in the in person and online photo exhibition. The images will then be hosted on the EDAC website (https://edacresearch.co.uk/).

As this study is being conducted at the University of Edinburgh, we will act as data controller for this study. This means we are responsible for taking care of your information, provided in order for you to participate in the study, and using it properly with regard to protection and privacy. The University of Edinburgh will keep identifiable information about you for 5 years after the study has finished. For further information please visit:

https://www.ed.ac.uk/records-management/privacy-notice-research

What will happen with the results of this study?

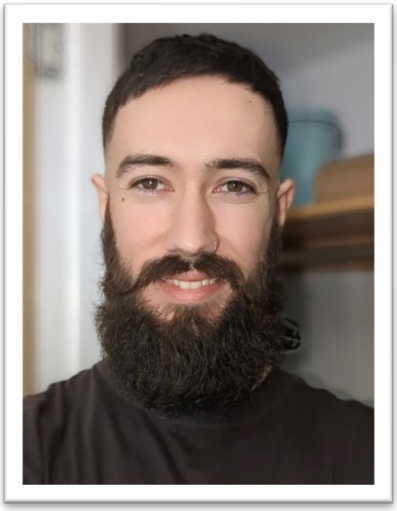
The results of the study will contribute towards practice guidelines for ethically co-producing research with Autistic individuals with EDs. Results focusing on specific aspects of the discussions, such as barriers

and facilitators to co-production or the use of language, will be analysed and submitted for peer-review in a relevant academic journal. The findings may also be summarised in the form of online blogs and/or presented at conferences. As mentioned above the images (optional interview recordings) will be included in a photo exhibition that will take place in Edinburgh and also be hosted online within the EDAC website.

Who has reviewed the study?

The study has been reviewed and received ethical approval from the School of Health in Social Science at the University of Edinburgh, School of Health in Social Science [CLPS046].

Research Assistant Contact Details:



Kyle Buchan

kbuchan@ed.ac.uk

If you would like some objective advice from a researcher in this area who is external to the current project: Dr Emily Newman, Department of Clinical and Health Psychology, Email: emily.newman@ed.ac.uk

If you have any complaints, please do contact the Head of School of Health in Social Sciences:

Prof Matthias Schwannauer

Department of Clinical and Health Psychology

School of Health in Social Sciences

Tel: +44 (0)131 651 3954
Email: headofschool.health@ed.ac.uk
In your communication, please provide the study title and detail the nature of your complaint.

For general information about how we use your data go to:

https://www.ed.ac.uk/records-management/privacy-notice-research

If you or your child feel affected in any way by any of the information provided here, you can find more information and/or support through the following websites. Also please remember that you can always go to your GP if you feel you need further support:

SUPPORT:
If any aspect of participating in this study causes you to feel uncomfortable please let the researchers know. The study will be stopped immediately and you may wish to contact your GP or one of the following:

- Samaritans provides confidential non-judgmental emotional support for anyone who is struggling to cope: call 116 123, or email jo@samaritans.org
- Breathing Space is a free, confidential phoneline service for any individual who is experiencing low mood and depression, or who is unusually worried and in need of someone to talk to: call 0800 83 85 87

- Counselling Directory provides information to help people find a qualified counsellor or psychotherapist in their local area: https://www.counselling-directory.org.uk/
- NHS 24 provides urgent health advice out of hours, when your GP practice is closed: call 111.
- The Autism Helpline of the National Autistic Society offers information and advice for individuals on the spectrum and their families: please call 0808 800 4104 or go to www.autism.org.uk/enquiry.
- BEAT Eating Disorders also offers information and advice for people struggling with eating disorders. Please go to https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/online-support-groups/

Please remember to download a version of this for your records.