Participant Information Sheet

Title of Project:

Exploring Research Priorities for Autistic People who have Intellectual Disabilities and Experiences with Disordered Eating: A Photovoice Study.

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.

What is the research?

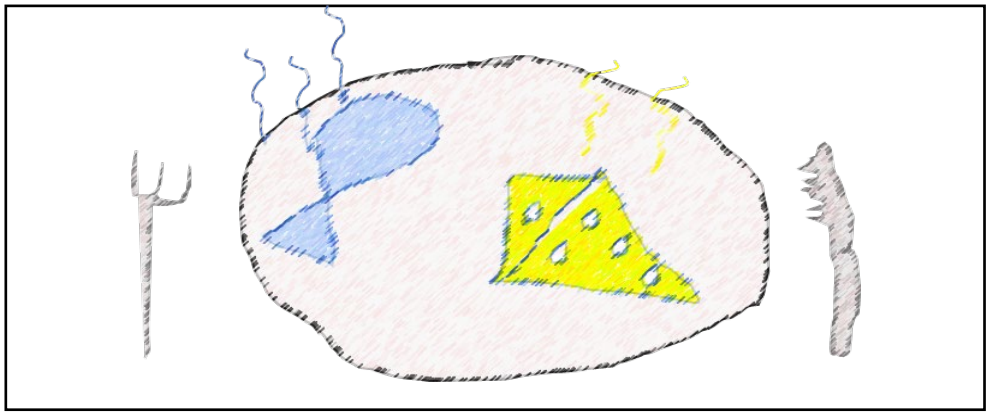
In this study you will join workshops (these can be online or in person) with researchers and other participants. In the workshops you will take photos or draw pictures of things that are important to your eating. Then we want you to tell us why you chose those pictures. These things could be anything you like.

They could be things that help you to eat, like this photo:



"I like baking with my sister and eating the cake mix. We have so much fun".

Or they could be things that make eating hard for you, like this drawing:



"I don't like eating foods with strong smells like fish and cheese."

We will do 5-8 workshops. In the workshops, we will…

- Do trust building and talk about the research
- Take photos/drawings of what is important to you and your eating
- Talk about your photos or drawings.
- Talk about textures, smells and sensory things that make eating easier or harder for you
- Talk about how we can make the research better

You can choose to take part in these workshops online or in person (the in-person workshops will take place either at the University of Edinburgh or we will come to you).

Before the workshops, you will be asked some questions about yourself, like your age and gender, and about your eating habits and behaviours. This will take about 15-20 minutes but you can have someone help you with this if you want.

Why is this research being done?

We are doing this research to learn more about disordered eating in Autistic people with Intellectual Disabilities. We want to hear about what is important to you and how we can make our research better in the future.

Why am I reading this?

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

Do I **have to join?**

No. You do not have to join the research if you don't want to.

Could joining be **good** for me?

Yes. If you join this research, you will get **£20 voucher** for every workshop you go to. Joining will also give you a chance to tell your story and help us learn more about how we can help you and others like you.

Could joining be **bad** for me?

Maybe. Joining the research could make you sad at times because we will talk about difficult things but we will do our best to support you. You can also bring a parent/carer if you would like someone to be with you in the workshops.

Can I leave if I am **not happy?**

Yes. If joining the research does make you sad or unhappy, you can leave at any time you want. You can leave to take a break or you can leave the research completely.

What data will be **collected** and **where** will we **keep it?**

Before the workshops begin, we will collect some information about you like your age, gender, ethnicity and your diagnoses, your contact information as well as your eating habits and behaviours. We will also record the workshops so that we can write down what you say in the workshops and we will collect the images that you send to

us. All of this will be kept in a safe place on the University of Edinburgh's OneDrive (which is like an online bank for information). If it is okay with you, we might also keep your data in another online place which will only be seen by other researchers at the University of Edinburgh for their research. They won't know it's your data. If you don't want us to do this you can say no and you can still take part in the workshops.

You will also be asked if you are happy for your pictures to be part of an exhibition that will take place online and in person (in Edinburgh). The images will be checked to make sure that you can't be identified, and if you are happy for us to use these pictures, they will be included in the in person and online photo exhibitions. We will also put these pictures on our 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 will take care of your information and use it properly to protect you and your privacy. This means we will use fake names or numbers to hide your identity. The University of Edinburgh will keep identifiable information about you for 5 years after the study has finished. If you want to know more, please click the link below:

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

What will happen with the results of this study?

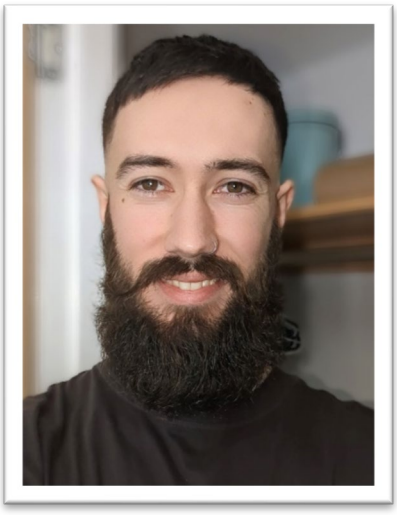
The results of the study will help us know what are important topics for research to focus on and help us develop guidelines on how to do good research when working with Autistic people with Intellectual Disabilities who have disordered eating.

The findings will be written into a research paper and may also be posted on online blogs and/or presented at conferences.

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 [CLPS046].

If you have any questions, you can contact the researcher by email:



Kyle Buchan

kbuchan@ed.ac.uk

If you would like some advice from an eating disorder researcher who isn't in the current project, you can contact 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 email, please say the study title and tell them what your complaint is.

If you feel sad in any way by any of the information provided here, you can find more information or support through the following websites. Please remember that you can always go to your GP/Doctor if you feel you need more 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/