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Project title: Experience of mealtimes and eating for children with disabilities who are restricted eaters.

PARENT INFORMATION STATEMENT - CHILDREN PARTICIPANTS

(1) What is this study about?

Your child/young person is invited to take part in a research study that aims to understand the experience and perception of mealtimes and eating. This will enable children and young people's experiences to be prioritised and inform practice in this area. The findings will inform development of resources to support high quality interventions for this group of people.

Your child/young person has been invited to participate in this study because they have been identified as a restricted eater and have a disability. This Participant Information Statement tells you about the research study. There is a separate information sheet that has been developed to support your child/young person to understand the study. Knowing what is involved will help you and your child/young person decide if they want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent for your child/young person to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Discussed with your child/young person what the research involves.
- ✓ Your child/young person is agreeable to participating.
- ✓ You agree for you and your child/young person to take part in the research study as outlined below.
- ✓ Agree to the use of your child/young person's personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers:

- Rene Fraser, Higher Degree Research Student, The University of Sydney

- Dr Kim Bulkeley, Senior Lecturer, The University of Sydney
- Dr Rebecca Barton, Senior Lecturer, The University of Sydney

Rene Fraser is conducting this study as the basis for a higher degree by research at The University of Sydney. This will take place under the supervision of Dr Kim Bulkeley and Dr Rebecca Barton.

(3) What will the study involve for me?

You and your child/young person must be able to give fully informed consent to participate in this study. At the beginning of and throughout each interaction your child/young person's continuing assent to engage will be monitored. We will ask you to provide demographic information regarding your child/young person's age, diagnosis and description of their eating skills. The study involves a number of steps

- An online meeting using Zoom with you and your child/young person. The researcher will speak to you alone for about 30 minutes and then you and your child/young person for about 15 minutes. The aim of this meeting is to gain consent, answer questions, learn about your child/young person's interests, learn how the researcher can best support your child/young person's communication and build rapport with your child/young person.
- One week of your child/young person taking photos or short videos (at least one a day) related to mealtimes or eating. Children/young person will use their parents or a family device to take photos with.
- An online meeting using Zoom (15-30 minutes) with you and your child/young person to answer questions and provide support with taking photos and short videos.
- One week of your child/young person taking photos and short videos (at least one a day) of their mealtimes
- An email from researchers to parents providing a link to upload photos and videos taken by the child/young person enabling them to be shared with the researcher.
- An online semi structured interview (45 minutes - 1 hour) with your child/young person using the photos and videos to generate conversation about their experiences of mealtimes and eating. Your child/young person will be asked about the content of their photos and videos, why they took them and to explain what they do or not like about the photos. There are no right, or wrong answers and the purpose of the study is to learn about the children and young person's experiences so their voice can be represented.

With your permission the interviews will be recorded enabling the researchers to accurately recall what was discussed. You can decide if your child/young person's photos and videos are only to be used by the researcher during the interview and data analysis phase or if they can be edited using Adobe Photoshop technology to have a cartoonish effect, protecting your child's privacy and dignity, and included in published articles and conference presentations.

All information (photos, videos and interviews) obtained throughout the study will be stored securely in accordance with The University of Sydney procedures and deidentified for publication purposes.

(4) How much of my time will the study take?

- Initial interview will last around 45 minutes.
- Time to take daily photos (Up to 10 minutes) for two weeks
- Mid-point check in will be about 15-30minutes
- Semi structured interview with your child/young person will last from 45 minutes to 1 hour.

(5) Who can take part in the study?

Children and young people aged between five and sixteen years of age; who have a lifelong permanent disability; and are restricted eaters. Restricted eaters are people who eat less than 30 foods, exclude whole food groups or their participation in family mealtimes is affected.

Your child/young person is able to participate in this study communicating verbally or with alternative and augmentative communication (AAC).

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your or your child/young person's current or future relationship with the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by emailing Rene Fraser rfra6188@uni.sydney.edu.au and there will be no consequences of withdrawing from this study.

You or your child/young person are free to stop the interview at any time. If you choose to withdraw any recordings will be erased and the information you have provided will not be included in the study results, unless you say that you want us to keep them. You or your child/young person may also refuse to answer any questions that you do not wish to answer during the interview.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

In the unlikely event that you or your child becomes upset or distressed you can seek support from your local healthcare provider, Kids helpline (Ph. 1800 55 1800) or Lifeline (Ph. 13 11 14)

(8) Are there any benefits associated with being in the study?

It is not anticipated that this research study will directly benefit you. The results arising from this research will contribute to the knowledge base around children and young people with disabilities who are restricted eaters to develop resources to support high quality practice.

(9) What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you and your child/young person for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise. Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications. All research materials including photographs, videos, and interview transcripts will be permanently deleted five years after study completion.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(11) What if I would like further information about the study?

When you have read this information, Rene Fraser will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Rene Fraser, HDR Student, The University of Sydney,

rfra6188@uni.sydney.edu.au or Dr Kim Bulkeley, Senior Lecturer, The University of Sydney, kim.bulkeley@sydney.edu.au.

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. This feedback will be in the form of a one page plain English summary. You will receive this feedback after the study is finished.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney 2024/HEOO1270. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep