Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

The lived experiences of parents parenting a child with autism spectrum disorder and eating issues – an interpretative phenomenological approach**.**

Site	**Trinity College**
Principal Investigator(s) and Co-Investigator(s) *(insert names, titles and contact details. Where relevant, give the name of academic supervisor)*	**Principal Researcher**: Anne Marie Clancy, Senior Speech and Language Therapist, B.Sc (CSLS), M. Phil (Linguistics), PgDip (FEDS). Email: clancya5@tcd.ie. **Principal Supervisor**: Dr. Irene P. Walsh, Director of Research, Associate Professor, Department of Clinical Speech and Language Studies, School of Linguistics, Speech and Communication Sciences, 7-9 South Leinster Street, Trinity College, Ireland. Email: ipwalsh@tcd.ie **Co-supervisor:** Dr Julie Regan, Assistant Professor, Department of Clinical Speech and Language Studies, School of Linguistics, Speech and Communication Sciences, 7-9 South Leinster Street, Trinity College, Ireland. Email: juregan@tcd.ie
Data Controllers	**Trinity College Dublin (for research data)**
Data Protection Officer	**Data Protection Officer** **Secretary's Office** **Trinity College Dublin** **Dublin 2** **dataprotection@tcd.ie**

You are being invited to take part in a research study that is being done by Anne Marie Clancy at the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin

Before you decide whether or not you wish to take part, please read this information sheet carefully. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

This leaflet has five main parts:

- Part 1 – Information about the Study
- Part 2 – Information on how your data will be used and stored
- Part 3 – Information about Costs, Funding and Approval
- Part 4 – Future Research
- Part 5 – Further Information

Part 1 – The Study

Why is this study being done?

A large percentage of children on the autism spectrum experience complex eating needs that can impact negatively on social, nutritional, medical, and developmental aspects of their lives. These eating needs can be challenging for parents and families to manage and can impact negatively on the quality of the child and the family, especially around the social event of daily mealtimes. I am doing this research to gain a better understanding of parental experiences of parenting a child who has eating needs. Through exploring these experiences, I wish to inform clinical practice and to improve therapeutic interventions. This project is being carried out as part of a doctorate in Speech and Language Therapy.

Why have I been invited to take part?

You have been invited to take part if you are a parent of a child who has a primary diagnosis of autism spectrum disorder and is aged between 3-8 years of age. We are keen to understand your insight and perspective into your child's eating needs. We aim to include 8 parents (mothers/fathers/both) in this study.

Do I have to take part? Can I withdraw?

You don't have to take part in this study*. It is up to you to decide whether or not to take part.* If you decide not to take part, it won't affect your current or future intervention with your current service provider. You can change your mind about taking part in the study and opt out at any time even if the study has started. If you decide to opt out, it won't affect your current or future intervention with your current service provider or affect inclusion in future research projects.

You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Anne Marie Clancy, principal researcher who will be able to organize this for you (email: clancya5@tcd.ie).

What happens if I change my mind?

You can change your mind at any time by contacting Anne Marie Clancy, principal researcher (clancya5@tcd.ie). If you choose not to continue to take part, this will not affect your current or future intervention with your current service provider in any way or affect inclusion in future research projects.

If you wish, you can ask for your data to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in research studies prior to this time. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Anne Marie Clancy, principal researcher who will be able to organize this for you (email: clancya5@tcd.ie).

What will happen to me if I decide to take part? What will I need to do?

If you agree to participate, you will be invited to attend 1 interview with the researcher. The interview will be held in a location of your convenience or through online platforms (e.g., Microsoft Teams) in accordance with COVID 19 guidelines. The researcher will notify participants of location closer to the time of the interview in line with COVID 19 public health guidelines.
The interview will last approximately $1^{1/2}$ hours. It is hoped to conduct these interviews between June 2023 and April 2025. A copy of the probe questions to be asked will be provided in advance of the interview. During the interview, you can opt to respond only to questions that you feel comfortable with and to provide as much information as you feel comfortable in providing. The interview will be recorded using audio-recording devices (or video-recording devices in the case of online platforms being used).

You will also be invited to complete a short questionnaire on your child's eating preferences (the Brief Assessment of Mealtime Inventory) which should take no longer than 10 minutes.

Are there any benefits to taking part in this research?

Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand the eating patterns of children on the autism spectrum, and the impact of these issues on the child, his/her parents, and family. This may result in improved therapeutic and clinical services to meet these needs for children with autism spectrum disorder and their families.

This is a long-term research project, so the benefits of the research may not be seen for several years.

Are there any risks to me or others if I take part? What will happen if something goes wrong?

Discussing details of your child's diagnosis and associated eating preferences may give rise to feelings of upset, stress, or anxiety for you. You will be provided with an outline of the type of questions that will be asked during the interview. All questions will be general, and you will be invited to provide as much detail as you feel comfortable with. All responses will be accepted and acknowledged on the researcher’s behalf without judgement. A list of possible support networks will be provided to you should you require any further emotional support following the interviews.

Will I be told the results of any assessments performed as part of this study that relate to me?

No, however, the researcher will provide you with a written copy of the interview and you will have the opportunity to ask the researcher to delete/remove/destroy any wording/information that you may believe identifies you.

Part 2 – Data Protection

How will my data be used?

Data from this research project may be published in future in scientific / medical / linguistic / educational journals. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The original recording and all copies will be available only to the principal researcher and researcher supervisors.

Pseudonymised copies of the data may be available to postgraduate, professors and researchers in national and international institutions engaged in similar research purposes. The fully anonymised transcriptions (only) or excerpts of same may be presented at conferences as part of a paper presentation, or for teaching purposes.

If you agree to your data being used in future research, or in teaching your consent form will be held until the data is no longer in use.

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Limited personal data is required to be collected as part of this research study. Your name, email address, phone number, child’s name, gender and date of birth is the only personal data that will be required from you. This data is necessary to ensure to allow for correspondence once you have agreed to participate and for accurate collection and transcription of interviews. You will be invited to complete a brief questionnaire (Brief Assessment of Mealtime Inventory) which is a short 18 question rating scale. This data is necessary for collection of additional information about your child’s eating presentation.

Each participant will be allocated a code number to protect identities. This number will then be used in all subsequent stored data records. Only the researcher and the supervisors will have access to the key which links the code numbers of individual identities. Any records that identify participants (e.g., coding key) will be retained only for as long as may be needed for cross-reference during the study. Your clinical records will not be accessed as part of this research study.

Who will have access my personal data? What will happen to my personal data?

- All the personal data that we collect about you during the research will be kept strictly confidential and will only be accessible to members of the research team – the principal researcher and the researcher supervisors. All your personal data will be stored in the Department of Clinical Speech and Language Studies, Trinity College, Dublin. Personal data will only be disclosed to the researcher supervisors in the early stages of coding/collating personal data to a code number.
- If you agree to us sharing the information you provide with other researchers (e.g., by making it available in a data archive) then your personal details will not be included unless you explicitly request this. This may include national and international research institutions for purposes of research exploring autism spectrum disorder and eating issues.
- Data that identify you will be kept for a minimum of seven years from the date of completion of the researcher's degree and publication of the research. Anonymised data will be held for a minimum of 5 years. This includes recordings, transcriptions, consent forms and questionnaires. After this time period, your personal data will be destroyed by the primary research supervisor, Dr. Irene P. Walsh or co-supervisor, Dr Julie Regan.
- Pseudonymised copes may be available to postgraduate, professors and researchers in national and international institutions engaged in similar research purposes. The fully anonymised transcriptions (only) or excerpts of same may be presented at conferences as part of a paper presentation, or for teaching purposes.
- If you agree to your data being used in the future, or in teaching, your consent form will be held until the data is no longer in use. If you do not consent to your personal information being used for possible, your consent form will not be held beyond seven years from the date of completion of the researcher's degree and publication of the research.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

- Any information or data which is obtained during this research which identifies you will be treated confidentially. All audio-recording/video-recording data collected will be stored on an encrypted external hard drive and password protected laptop/computer in the Trinity College Dublin computer network. The data will then be deleted from audio/video recording devices. The data will then be anonymised to hide your identity. This will be done by allocating a pseudonym to all participants.
- All original files will be transferred to an encrypted hard drive that will be stored in a locked press at the research supervisor's office and in an encrypted file in a folder on the research supervisor's computer on the Trinity College Dublin network. Pseudonymous data will be stored on the researcher's password protected computer. Only the researcher and the supervisor will have access to the key which links code numbers to individual identities.

- Following this, the researcher will give you a written copy of your interview and you will have the opportunity to ask the researcher to delete/remove/destroy any wording/information which you may feel identifies you.
- Paper copies of any forms/questionnaires (e.g., consent form with your written signature) will be kept securely in the Department of Clinical Speech and Language Studies, Trinity College, Dublin.
- All individual researchers (principal researchers and researcher supervisors) involved in this project have been trained in data protection law and are bound by professional code to maintain confidentiality.
    - A data protection impact assessment has been carried out and approval obtained.

What is the lawful basis to use my personal data?

According to data protection legislation[1], we are required to inform you of the legal basis for using your personal data. The tasks we are performing are considered to be in the public interest[2].
Some data that is defined as more sensitive (name, email address, contact number, child's name, date of birth) is being used for scientific purposes[3]

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to have your data transferred to another organisation or 'data controller'
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Anne Marie Clancy (clancya5@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy or the Data Protection Officer, Consumer Affairs, HSE, Third Floor Scott Building, Midland Regional Hospital Campus, Arden Road, Tullamore, Co. Offaly Health Service Executive Email: dpo@hse.ie. Website: Data protection - HSE staff - healthservice.ie

Part 3 – Costs, Funding and Approval

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[1] The European General Data Protection Regulation (GDPR)

[1] *Article 6(1)(e)*

[3] *Article 9(2) (j))*

Has this study been approved by a research ethics committee?

Yes, this study was be submitted to the Research Ethics Committee of the School of Linguistic, Speech and Communication Sciences in May 2022 and approval was obtained.

Who is organising and funding this study?

This research study is being currently self-funded by the principal researcher.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying participants to take part in the study. Interviews will be conducted at a location that is convenient for each participant. Participants will be informed closer to the time as to the means of facilitating discussions (face to face/online platforms) in accordance with COVID 19 health guidelines.

Part 4 – Future Research

Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering future research questions about the eating issues associated with autism spectrum disorder and the therapeutic implications for the insight gained into the experiences of parents parenting a child with autism spectrum disorder and associated eating issues. We will ask for your explicit consent for your data to be used in this way. You do not have to agree to have your data available for future research. Future research will only take place if it has research ethics approval.

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- Principal researcher: Anne Marie Clancy. Email: clancya5@tcd.ie
- Principal supervisor: Dr Irene Walsh. Email: ipwalsh@tcd.ie
- Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.
- Data Protection Officer, Consumer Affairs, HSE, Third Floor Scott Building, Midland Regional Hospital Campus, Arden Road, Tullamore, Co. Offaly Health Service Executive Email: dpo@hse.ie. Website: Data protection - HSE staff - healthservice.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep. If you consent, we will contact you to arrange a time to conduct the interview.

Please note, interviews may be conducted through online platforms in line with prevailing COVID19 health guidelines. In the case of online platforms being used, an online consent form will be sent to your email address for you to provide consent. Other than the arrangements for the study as described above, we will only contact you if you have agreed to be contacted regarding future research participation.

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Consent Form

The lived experiences of parents parenting a child with autism spectrum disorder and eating issues – an interpretative phenomenological approach.

Participant code for study: ________________

There are 3 sections in this form. Each section has a statement and asks you to tick if you agree. **Please tick the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.** **Please ask any questions you may have when reading each of the statements.** **Thank you for participating.**	
Section 1: General	**Tick box**
1. I confirm I have read and understood the Participation Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
2. I understand that this study is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that deciding not to take part will not affect my current/future clinical intervention with my current service provider or affect inclusion in future research projects.	
3. I understand that all information will be kept private and confidential and that my name will not be disclosed.	
4. I understand that I will not be paid for taking part in this study.	
5. I know how to contact the research team if I need to.	

6. I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.	
7. I agree to being contacted by researchers by email/phone as part of this research study.	

Section 2: Data processing	**Tick box**
8. I agree to allow personal information about me to be shared with third parties including; national and international hospitals, and academic research institutions for the purpose of research on autism spectrum disorder and related eating needs, as described in the Information leaflet.	
9. I understand that personal information about me, including the transfer of this personal information about me outside of the EU, will be protected in accordance with the General Data Protection Regulation.	
10. I understand that there are no direct benefits to me from participating in this study.	
11. I understand that **I** can stop taking part in this study at any time without giving a reason and this will not affect my current/future clinical intervention with my current service provider or affect my inclusion in future research projects.	

Section 3: Future use of information (please tick relevant options)	**Y**	**N**
OPTION 1: I give permission for my personal information to be stored for *possible future research related* to the current study exploring autism spectrum disorder and related eating needs *only if consent is obtained from me* at the time of the future research and the research is approved by a Research Ethics Committee.		
OPTION 2: I give permission for my personal information to be stored for *possible future research related* to the current study exploring autism spectrum disorder and related eating needs		

without further consent being required but only if the research is approved by a Research Ethics Committee.		
OPTION 3: I agree that future research projects into exploring autism spectrum disorder and related eating needs may be carried out by researchers working for commercial companies.		
OPTION 4: I understand I will not be paid for any future use of my samples/personal information or products derived from it.		

Signatures

Participant Name (Block Capitals)   Participant Signature   Date

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Witness Name (Block Capitals)   Witness Signature   Date

To be completed by the Principal Researcher or nominee.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team.

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Anne Marie Clancy,

Ph.D. Student, Department of Clinical Speech & Language Studies, Trinity College, Dublin.

Senior Speech & Language Therapist (CORU No: SL018980)
Signature

Date

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2 copies to be made: 1 for participant, 1 for PI.