Patient/Participant Information Leaflet

Study title: Speech and language therapy interventions for children with complex needs as a result of a disability

Principal investigator's name:	**Dr Noreen O'Leary**
Principal investigator's title:	**Lecturer School of Population Health**
Co-investigator's name:	**Dr Ciara O'Toole**
Co-investigator's title:	**Senior Lecturer, Speech & Language Therapy, UCC**
Data Controller's Identity:	**RCSI**
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Data Protection Officer's Identity:	**Donall King**
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You are being invited to take part in research study exploring speech and language therapy intervention provision for children attending Children's Disability Network Teams (CDNT), led by Dr Noreen O'Leary at RCSI and co-researcher Dr Ciara O'Toole at UCC

Before you decide whether or not you wish to take part, you should read the information provided below carefully. Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You don't have to take part in this study. If you do decide to take part you can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don't have to give us a reason.

Why is this study being done?

The aim of this study is to gather the views and experiences of SLTs in relation to current intervention provision for children attending Children's Disability Network Teams (CDNT)

Who is organising and funding this study?

This study is being organised by Dr Noreen O'Leary as part of her work at RCSI School of Population Health

Why am I being asked to take part?

You are invited to participate in this study if you:

- A speech and language therapist currently working with a CDNT

OR

- A speech and language therapist who has worked with a CDNT within the last 12 months

How will the study be carried out?

There are two parts to this study, and you may choose to participate in both parts, only the first part or neither part

Part 1: an online survey

- If you choose to participate, you will be asked to complete an anonymous online survey.
- The survey will take approximately 10-15 minutes to complete.
- The questions will ask about your experiences and opinions regarding current speech and language therapy intervention provision with CDNT.
- Data will be collected using a secure platform (Survey Monkey) and stored on university approved servers such as OneDrive and computers.

Part 2: an online interview or focus group

- If you choose to participate you will be invited to an individual interview or focus group to talk about your experiences of providing SLT interventions within a CDNT
- The interview or focus group will be hosted online via Microsoft Teams and may last up to one hour.
- Data will be collected using a secure platform such as Microsoft Teams and stored on university approved servers such as OneDrive and computers.

What will happen to me if I agree to take part?

- If you agree to take part in the survey you will complete the survey online, using a computer, tablet or mobile device.
- If you agree to take part in an interview or focus group you will be contacted by a researcher to arrange a suitable time for the focus group or interview

Video/and or Audio recordings?

- No video or audio recordings will be made as part of the survey
- If you take part in an interview or focus group an audio recording will be made and converted into written transcript

What are the benefits?

- Benefits include contributing to a better understanding of SLT intervention provision in CDNTs and providing your input into any ideas on how these could be changed or developed.

What are the risks?

- There are minimal risks associated with participating in this study, such as potential upset from answering questions. You can discontinue the survey at any stage by exiting the survey webpage. You can discontinue the interview or focus group at any stage by telling the interviewer or facilitator you would like to discontinue and do not need to provide any reason

Is the study confidential?

- Your participation in the survey is anonymous, meaning that your responses cannot be traced back to you. No personally identifiable data such as IP address or email addresses will be gathered as part of the survey.
- Your participation in an interview or focus group will be anonymised as soon as possible by converting the audio file to an anonymised written transcript. The transcript will be reviewed for accuracy at which point the audio file will be deleted and data will not be traceable to any individual.
- All data will be stored securely in accordance with RCSI Data Protection policies.

Data Protection

1. We will be using your data in our research to help us better understand the experiences of those providing SLT interventions with CDNT

2. Data is being processed under Article 9(2)(j) of the General Data Protection Regulation 2016- Scientific Research purposes

3. The PI and co-researcher will have access to the data

4. The data will be stored for up to ten years as there may be future uses not currently anticipated and avoid duplicate data-collection and may also inform future comparative research. You can choose to only allow your data to be used for the current research by ticking 'No' when you are asked for consent for your data to be used for future research. If you choose this option your data will be deleted within 12 months of data collection (See section on 'Consent for future use' for further details)

5. If a data breach were to occur survey data would not be traceable to you as it will be anonymous from the point of collection. Interview and focus group data will be anonymised within 48 hours of data collection and not traceable to you from that point. If a data breach were to occur within the 24-hour period the Data Protection Officer at RCSI will be notified and relevant procedures followed.

6. You can withdraw from the study at any point by exiting out of the survey or telling the interviewer/facilitator you wish to leave the interview/focus group

a. As a participant/ data subjects you have a right to lodge a complaint with the Data Protection Commissioner.

b. As data will be anonymised it will not be possible to provide a copy of individual data

7. Data processing is necessary to carry out this research. If you do not wish your data to be processed you should not participate in the research

8. Data cannot be corrected or amended after collection and processing as it will be anonymous and not traceable

9. Data cannot be deleted after collection and processing as it will be anonymous and not traceable

10. Data profiling is not part of this research.

11. Automated processing is not part of this research

12. Data will only be used for the purposes you have provided consent for.

13. Data will not be transferred to country outside of the EU or an international organisation

Consent to Future Uses

- You have the option to provide permission for the researchers to use your data for future research related to the current study. For example, research about children's disability services and/or speech and language therapy interventions.
- This research may be carried out by the current researchers who would seek ethical approval for future research using your data
- Other researchers may also request access to your data. Other researchers would be granted access if:
  - they are affiliated with a recognised academic or research institution
  - provide proof that the proposed research has obtained ethical approval from a recognised research ethics committee
- Only anonymised data would be used for future research
- Data will be stored for a maximum of ten years after which time it will be destroyed in line with RCSI Data Retention policies.
- Data will not be shared with commercial entities.

Where can I get further information?

If you have any further questions about the study please contact:

Name: Dr Noreen O'Leary
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