



Parent/carer perspectives on specialist speech and language therapy assessment for children and young people with Down Syndrome.

Thank you for your interest in taking part in this research project, which involves completing an online questionnaire. Please find below information on why this research is being done and exactly what it will involve. If you would like any further information, or would like to ask questions about this, then please feel free to contact Louise Miller (lcmiller1@sheffield.ac.uk). Please take time to read the following information and decide if taking part in this research project is right for you.

What is the purpose of the study and why have I been invited to take part?

I am conducting this research as the dissertation for my Master's in Language and Communication Impairment in Children with the University of Sheffield. The research aims to explore parent/carer experiences of specialist Down Syndrome speech and language assessment for children/young people and their views on the impact of this specialist assessment. This research is therefore aimed at parents/carers of a child/young person with Down Syndrome who has had a specialist speech and language therapy assessment.

Do I have to take part?

Taking part in this research study is entirely voluntary and entirely your decision. If you decide you would like to take part, you will be asked to provide consent on the next page. You are not obliged to answer all the questions within the questionnaire, and if at any point you wish to discontinue, you can withdraw without giving a reason by closing your browser. Once you have completed the online questionnaire, the data will be included within a large dataset and cannot be withdrawn from the study beyond that point.

Please note that that by choosing to participate in this research, this will not create a legally binding agreement, nor is it intended to create an employment relationship between you and the University of Sheffield.

If you wish to be sent a copy of the information sheet at any point, please feel free to request one by contacting Louise Miller, (lcmiller1@sheffield.ac.uk).

What will happen to me if I do take part?

This research project involves filling in a questionnaire online that should take approximately 15-20 minutes to complete. The answers from these questionnaires will then be analysed

and written up in project form by the end of the 2022-2023 academic year (so by August/September 2023).

The answers from these questionnaires will be anonymised, and if any identifying data such as names are given in the answers, these will be anonymised before any analysis takes place.

The questionnaire starts with three brief demographic information questions. These are non-identifying and are the age of the child now and when they had the specialist assessment and which local authority they lived in when the specialist assessment took place. The main questions themselves revolve around your experiences of obtaining a specialist assessment, the outcomes that stemmed from it and the impact you feel that it has had.

Are there any disadvantages/risks to taking part?

The research team have not identified any significant risks to those taking part in this project

Are there any benefits to taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will increase our understanding of the process of obtaining and implementing a Down Syndrome specialist speech and language therapy assessment, and the impact of this on provision of speech and language therapy in relation to local NHS services and /or educational settings.

Will the information I give stay confidential?

The answers you provide for this research project in the questionnaire will be kept confidential and accessible only to the research team.

If the answers you give in the questionnaire have any names or other identifiable data this will be removed and replaced with anonymised and unrelated labels such as 'AB'. Similarly, any geographical place names or school names in the answers will also be replaced to further anonymise the data.

What will happen to the data collected, and the results of the research projects?

Anonymised data taken from the surveys will be used by the researcher in their dissertation project and could also additionally be disseminated at conferences or published in peer-reviewed publications. Data will be stored securely in the University of Sheffield's Google suite, which is password protected. Any personal data will be destroyed upon submission of the thesis, and anonymised data after 5 years.

Who is the data controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the Human Communication Sciences department.

What if something goes wrong and I wish to complain about the research?

In the event of having any complaints regarding this research project, please contact Dr Chloë Bate (c.bate@sheffield.ac.uk), In the event that you feel that the complaint has not been appropriately addressed then you can contact the Head of the Human Communication Sciences Division, Professor Judy Clegg (j.clegg@sheffield.ac.uk) who will then escalate the complaint through the appropriate channels. If the complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

Contact for further information or for clarification about this research:

Researcher: Louise Miller (MSc Student in Language and Communication Impairment in Children) lcmiller1@sheffield.ac.uk

Research Supervisor: Chloë Bate c.bate@sheffield.ac.uk

Thank you for taking the time to participate in this research study