

Information Sheet for Parents/Guardians of Individuals with Down syndrome and Learning Disabilities

Title of the study: **Language abilities in adolescents and adults with Down syndrome: Searching for language markers of age-related changes in individuals with learning disability: A pilot study**

Department: UCL Division of Psychology and Language Sciences

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UCL Research Ethics Committee Approval ID Number: **2693/014**

Introduction

You and your child are being invited to participate in a research project. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve.

Please take time to read the following information carefully. If anything is not clear, feel free to ask any questions.

What is the purpose of the study?

Research suggests that adults with Down syndrome and learning disability experience changes to their cognitive abilities and behaviour as they age (e.g. memory, executive functions such as attention and planning might become worse and daily activities more difficult as the person gets older). Many also develop Alzheimer's disease at quite an early age. However, there is limited understanding of how language and communication skills change during adulthood, and the ways in which ageing and Alzheimer's disease can affect communication skills.

We are carrying out a study to look at the relationship between language abilities and cognitive skills such as memory, attention, planning and daily living skills. In our study we will assess different areas of language to identify patterns associated with changes in

cognition and behaviour. In particular we will focus on areas of cognition and behaviour which are usually impaired by Alzheimer's disease. We will look at different areas of language, such as grammar, vocabulary and the use of language in social contexts (pragmatics).

By doing this, we hope to identify patterns of language performance that can help clinicians detect cognitive decline and improve their ability to diagnose dementia in people with Down syndrome and learning disability. We hope that this research will encourage and inform the development of targeted interventions to help adults with Down syndrome and learning disability.

Why have I been invited?

You have been invited because you are the parent or guardian of a person with Down syndrome or learning disability who is aged 15 years or older. We would like to invite your child to complete some activities and ask you some questions about your child.

Do I have to take part?

No, it is up to you and your child whether you would like to take part and there will be no penalty for choosing not to take part. If you and your child decide to participate, you will be required to sign a consent form. You and your child can withdraw your consent at any time without having to give a reason.

What will happen to me and my child if we take part?

If you agree to take part, you will be invited to speak to the researcher over phone or video call to answer some questions about your child. This will not be recorded. The questions will take no longer than 90 minutes in total to answer, and can be completed over separate sittings if necessary.

Additionally, you will be asked to attend 2 or 3 sessions with your child and the researcher. During the sessions the researcher will complete a series of assessments with your child. Given that the assessments will be administered by the researcher remotely, we may ask you to assist in the administration by sitting with your child and helping when required. The sessions will take between 30 and 60 minutes each and will be conducted over videocall. During these sessions we will complete a series of tasks that will involve listening to and repeating words/sentences, looking and pointing at pictures, playing memory games, and telling a story.

If you agree to this on the separate consent form, we will videotape or audio record the sessions with your child. However, you can still take part in the study without consenting to your child being recorded. These recordings are useful for our research purposes;

however, they will never be used for non-academic purposes. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

The sessions will be conducted by a member of the research team. All the researchers involved have undergone training, are experienced in working with vulnerable participants, and have full DBS clearance.

We may contact you after the completion of the study to ask if you and your child may be interested in participating in future projects. You can indicate whether you agree to being contacted about future projects on the consent form provided.

What are the possible disadvantages and risks of taking part?

We do not anticipate that there will be any risks to taking part in the study. If for any reason, you or your child are upset by the content of the discussions, we can pause the session and resume when you are ready, or stop the sessions altogether.

What are the potential advantages of taking part?

There are no direct advantages of taking part in the study. However, we hope that the information you provide will help understand how to better support the communication needs of individuals with learning disability throughout adulthood.

Will there be any payment or reimbursement of expenses?

As a thank you for your time taking part in the sessions, we will offer you and your child £10 gift voucher each.

Will my participation be kept confidential?

Yes. All information about you and your child will be kept strictly confidential. A code number, instead of your and your child's name will be used to identify data about you. Information that links the codes to your identity will be stored securely and kept separately from the data.

How will we use information about you?

We will need to use information from you and your child for this research project.

The data of the study will be used for scientific publications. It will not be possible to identify you or your child from these publications.

Video and audio recordings will be stored securely and will only be used for the purposes of our research. The recordings will be retained for up to 5 years after the completion of this research project and then deleted securely in line with UCL's policy.

All data will be collected and stored in accordance with the General Data Protection regulation (GDPR) and the Data Protection Act (DPA) 2018. Data will be stored securely by UCL for up to 5 years after completion of the project.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the research team
- by sending an email to elisa.mattiauda.18@ucl.ac.uk or a.perovic@ucl.ac.uk
- by ringing us on 020 3987 2421 (Elisa)
- by contacting the Data Protection Officer at data-protection@ucl.ac.uk

Local Data Protection Privacy notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

- For participants in health and care research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

What will happen if I don't want to carry on with this study?

You and your child are free to withdraw from the study at any time without giving a reason and will not be penalized in any way. If you have taken part in any of the sessions we will delete the data we have collected unless you agree otherwise.

You will be able to withdraw your and your child's data for up to 4 weeks after taking part in the study.

Who is organising and funding this research?

The study is being organised by Dr Alexandra Perovic, and Professor Angela Hassiotis, from University College London, who are the Principal Researchers responsible for overseeing the research and for the secure storage of data.

The study is being funded by The Baily Thomas Charitable Fund. They will have no involvement in the conduct of the study. The study is being sponsored by UCL.

Has the research been reviewed by an appropriate research ethics committee?

We have had this study reviewed by UCL Research Ethics Committee (REC ID: **2693/014**) who have given us advice about the study documents and conduct of the study.

What will happen to the results of the research?

This study is part of a larger research project on language in adults with learning disabilities who may be at risk for cognitive changes and Alzheimer's disease. Study findings will be presented at scientific conferences and research publications. We also plan to hold a public engagement event where we present and discuss the results with stakeholders (e.g. clinicians and health professionals, researchers, individuals with learning disabilities and their carers). We will provide a summary of the results that we can send to you if you wish.

What happens if there is a problem?

If you have a complaint about this study or are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, then please contact the Principal Investigator.

If, for any reason, you are not satisfied with the response that you receive or the action taken following your complaint, then you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk.

What happens if you would like more information about the study?

If you would like more information about the study, please contact the researchers:

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Thank you for reading this information sheet