

Study Information Sheet (for parents of children aged 4-7 years)

We would like to invite you and your child to take part in our study. Before deciding, we would like you to understand why we are doing this research and what it would involve. It would be very helpful if you could take a few minutes to read this information and consider it.

If you have any questions about the study, please make contact with the researchers. Their contact details are at the end of this Information Sheet and they will be happy to discuss the study with you. If you decide to take part, then a member of the research team will go through this sheet with you again before the study begins and answer any further questions.

Part 1: What does the study involve?

What is the purpose of this study?

The Neurodevelopment Assessment Unit (NDAU) is part of the School of Psychology at Cardiff University, and funded by the Waterloo Foundation. The NDAU is run by a group of scientists interested in understanding the social, emotional, cognitive and behavioural problems experienced by young children and where possible, overcoming these difficulties. To do this, we work with the child to measure different skills important for learning and behaviour – such as short-term memory, attention, verbal ability and understanding emotions. The information that we collect about your child will be fed back to the professional that provided you with this information sheet, who will discuss it with you.

One aim of this study is to provide information that can be used by professionals to help shape the support that children might receive. A second aim is to build a picture from the research findings of the different abilities and difficulties that children have, which will help identify new methods for improving behaviour and learning.

Why have we been invited to take part?

The additional learning needs coordinator (ALNCO) at your child's school has agreed to identify children and pass on information about the NDAU to parents if they think the child may benefit from the study. We call these professionals your child's 'referrer'. Our assessments might be useful in shaping the support that your child receives from this referrer. This is why you have been invited to take part.

Do we have to take part?

No, it is up to you to decide to join the study. We will describe the study and go through this Information Sheet again in person. If you agree to take part, we will then ask you to sign forms that provide consent for you and your child to participate. Even if you provide this consent, you are free to withdraw at any time without giving a reason. This will not affect the standard of care or support that your child receives.

What will happen if we decide to take part?

You and your child will be invited to visit the NDAU at a time convenient to you both. When you are at the NDAU, a researcher who is a psychologist, will work one to one with your child to complete a number of tasks that assess areas such as memory, language skills, attention and emotion recognition. These are all designed for use with children, and where possible we have designed these like games, and they tend to take around 5 to 10 minutes each.

There will be plenty of breaks and in total it will take one morning and one afternoon (around 2-3 hours each). Whilst we assess your child, a second researcher will interview you in a separate room to identify your child's main needs and challenges. Only one parent/care-giver is required to complete this interview and therefore we recommend that only this individual accompanies your child to each appointment. We also have some questionnaires for you to complete. These tell us about your impressions of your child's strengths and needs, as well as about your family history. The information collected from yourself will be used for research and not fed-back to the school (except for your ratings about your child on the 'Strengths and Difficulties Questionnaire', which will be fed-back in the report, with your consent). Your child will receive a small present for their participation in the assessments.

A video recording will be made of your child's assessment sessions for research, safety and training purposes. In particular, the video may be used to demonstrate important aspects of children's development to new researchers. This video recording will be identifiable only using a research identification number and so your child's name will not be linked to the video. This video will be under the supervision of Professor van Goozen's research team and will not be passed onto unauthorised individuals.

Is there anything else that I will be asked to do?

In the consent form you will be asked if you would like to be contacted about any possible future studies. You are under no obligation to agree to this, and even if you did then you are under no obligation to respond to any future contact.

During the session, we will also ask to measure your child's heart rate for about 15 minutes using a small monitor device. The monitor will be worn on the wrist as a watch and does not cause any risk to your child. The device enables us to receive important information about your child's heart rate to show us how relaxed or excited your child is when completing some tasks. If your child finds the device uncomfortable it can be removed immediately, and the task can continue without the device.

What are the possible advantages and disadvantages of taking part?

The risks involved in this study are very low: the procedures that are used have all been tried and tested with many hundreds of children with no ill effect. The advantage of taking part is that we can provide the referrer with a detailed assessment of your child's strengths and needs. This may be useful in helping your child in the school environment. Furthermore, your participation in our study will help us understand why these difficulties occur and how they can be overcome.

What if there is a problem?

Any complaint about the way you or your child have been treated during the study or any harm you or your child might suffer will be addressed. Our complaints procedure is explained in Part 2.

Will our information be kept confidential?

Yes. We will follow ethical and legal practice and all information about you and your child will be handled in confidence. More detailed information about this is provided in Part 2. If having read this information you are now considering taking part in the study, please read the additional information in Part 2 before making any decisions.

Part 2: What other factors should I consider?

What will happen if we don't want to carry on with the study?

You and your child are free to withdraw from the study at any time, without giving any reason. This would not affect the standard of support that your child receives. If you would like, we can delete all data collected up to your withdrawal.

What if there is a problem?

If you have a concern about any aspect of this study, you should first ask to speak to the Director of the NDAU, Professor Stephanie van Goozen (contact details below). In the very unlikely event of anything untoward happening during your visit, Cardiff University covers all volunteers against negligent harm.

Will my taking part in this study be kept confidential?

All personal information collected in the course of the study will be handled confidentially. All information is stored securely and in an anonymised form that prevents non-authorized users (people from outside of the research team) from linking it with any information that identifies your child or family. Cardiff University complies with the requirements of the General Data Protection Regulation and Data Protection Act 2018 with regard to the collection, storage, processing and disclosure of personal information and is committed to upholding the Act's core Data Protection principles.

What will happen to the results of this study?

A technical account of the results of our assessments with your child will be sent back to the referrer in the form of a report, which they can use to guide their support for your child. We will let you know when we have sent this report (via a letter) and you can schedule a meeting with the referrer to discuss the report. The scientific results of the

study will be analysed and studied by the research team; only members of the research team will have access to the data. These will be reported in scientific papers and published in journals and may be presented at conferences. You and your child will not be personally identifiable in the description of our findings.

Will I receive a copy of my child's assessment report?

No, you will not receive a copy of the assessment report. The study's ethical approval only permits us to send a report to your child's school as the acting referrer. This technical account of the results may be useful in helping your child in the school environment. We recommend that the referrer meets with you as parent/caregiver to discuss the results of this report.

Who is organising this research and how is it funded?

The research is funded by The Waterloo Foundation. All research that recruits children is looked at by an independent group of people called a Research Ethics Committee. This study has been considered carefully and approved by the School of Psychology Research Ethics Committee at Cardiff University.

I am interested in taking part, what should I do next?

Please complete the Expression of Interest form and Consent form with your school's ALNCO and they will return these to the NDAU.

Please visit our website (<https://www.cardiff.ac.uk/research/explore/research-units/neurodevelopment-assessment-unit>) for more information and to watch a video showing what happens during a visit to the NDAU.

Contact details of the research team:

Dr Steve Eaton (Postdoctoral Research Associate) – NDAU@cardiff.ac.uk.

Professor Stephanie van Goozen (Director of the NDAU) – vangoozens@cardiff.ac.uk.

If you would like to speak over the telephone with any of the researchers, then please telephone reception (02920 870354) and ask for the team member that you would like to speak to.

**Neurodevelopment Assessment Unit,
Cardiff University Centre for Human Developmental Science,
Park Place,
Cardiff, CF10 3AT
Tel. 02920 870354
Email: NDAU@cardiff.ac.uk**

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. James Merrifield is the University Data Protection Officer and can be contacted at merrifieldj1@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: <https://www.cardiff.ac.uk/publicinformation/policies-and-procedures/data-protection>

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form, and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only members of the NDAU research team will have access to this information. After 7 years the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.