TANDA STUDY (Therapeutic Assessment and Neurodevelopmental Assessment)

We would like to invite you to take part in a research study. You have been invited because the clinician who saw your young person from crisis services wondered if they might be neurodivergent and if they would benefit from an assessment for this.

Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Our contact details are given below. Take time to decide whether or not you wish to take part.

Who are we?

We are a team of clinicians and researchers based at the University of Glasgow and NHS Ayrshire and Arran. Our team includes doctors, Speech and Language Therapists, and researchers with expertise in working with children and young people, especially those who may be neurodivergent or experiencing mental health challenges.

This study is led by a researcher from the University of Glasgow and an NHS Consultant Psychiatrist.

Our research is supported by colleagues from NHS services, academic researchers, and partners who have developed new ways to identify and understand neurodivergence.

Our goal is to understand and evaluate the way young people in crisis are supported, by combining therapeutic approaches with early, holistic assessments of possible neurodivergence. We are particularly interested in making services more responsive, affirming, and accessible for young people and their families.

What is the purpose of the study?

We want to find out whether a new, quicker way of assessing a young person's neurodevelopmental profile is acceptable to families, and whether it supports professionals in understanding and responding to young people's needs.

At the moment, families often face long waits to receive an assessment—and even longer before support can begin. This study will explore whether this approach can be delivered more efficiently and accessibly within existing services.

As part of this study, we are testing two things:

1. **An online questionnaire** for parents and carers to complete about their child's development. Normally, parents are asked to fill in several different forms during an assessment. This new online tool brings all the questions together in one secure place, making it easier and quicker to complete at home.
2. **A new type of clinic appointment called NEURO-Obs.** This is a one-off session where you and your child will meet two clinicians. Together, you'll do some simple, activity-based tasks in a calm and supportive environment. NEURO-Obs is the first tool designed to look at all types of neurodivergence in one go— rather than involving multiple appointments with different professionals, this approach brings information together within a single assessment session.

If we find that this new approach is both quicker and acceptable to families, we'll run a larger study in other areas to test it more widely. If the findings support feasibility and acceptability, the results may be used to inform decisions about future service development.

What do I have to do?

If you think your young person might be neurodivergent (for example, if you think they might be autistic or have ADHD - attention deficit hyperactivity disorder) and you would like them to be assessed, you can volunteer to take part in this study.

Taking part is completely voluntary. You and your young person can withdraw from the study at any time, without giving a reason. Choosing not to take part—or deciding to withdraw later—will not affect the care or support you receive now or in the future.

If you decide you would like to take part, we will give you this information sheet to keep. You will also be asked to complete a written consent form. Even after you have consented, you remain free to change your mind at any time.

What will happen if I take part?

If you decide to take part, you and your young person will be offered an appointment with Dr Helen Smith, a Consultant Child and Adolescent Psychiatrist. At this appointment, you will have the opportunity to talk about how your young person has been feeling, behaving, and developing. Together, you will decide whether you would like to go ahead with a neurodevelopmental assessment. If you do wish to go ahead, then the process will be explained to you.

If you choose to proceed, you will be sent a secure electronic link to complete a new online questionnaire about your young person's development. If your young person is attending school, we may also ask a teacher who knows them well—such as their guidance teacher.

You will then be invited to a second appointment for the NEURO-Obs assessment. During this appointment, two clinicians will spend time with you and your young person, completing some simple, activity-based tasks. After the assessment, we will share our understanding of your young person's neurodevelopmental profile (sometimes called their "neurotype"). This may include a formal diagnosis if appropriate, or a broader understanding of your child's developmental strengths and needs.

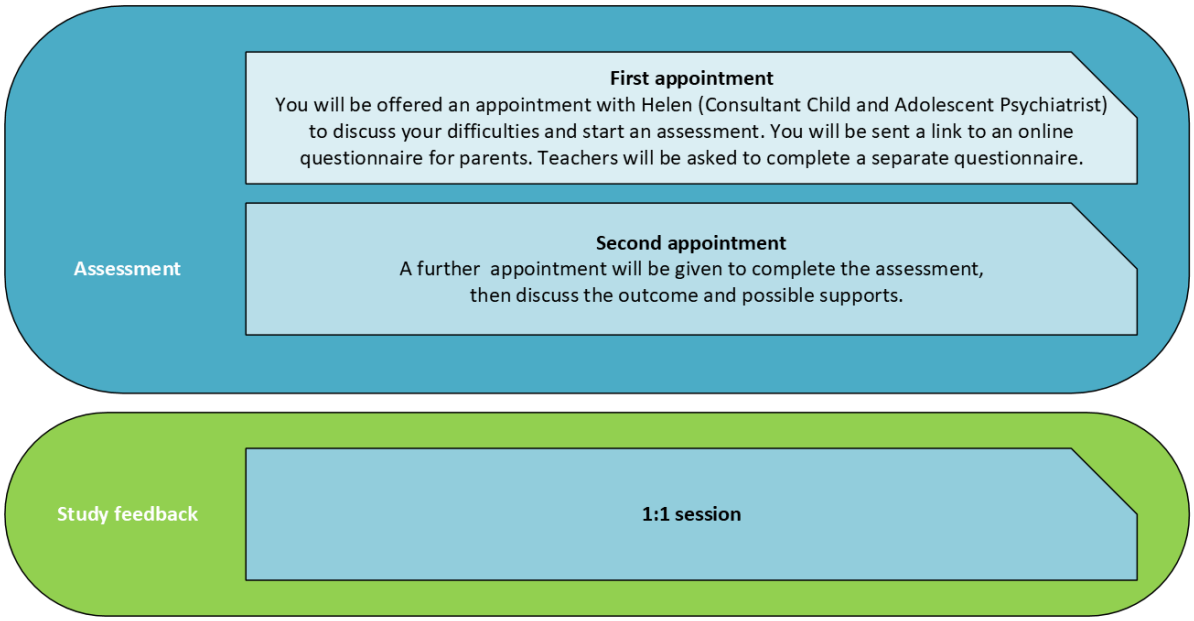
Following the assessment, you will receive a written report summarising the findings. With your permission, this report will also be shared with your GP and any other professionals you agree to, such as teachers.

After the assessment, our research assistant will invite you to take part in a feedback interview. This will be a one-off meeting, lasting no longer than one hour. You can choose whether to meet in person or by video call (e.g., Microsoft Teams or Zoom). The interview will explore your views on the new assessment process—what worked well, what could be improved, and any suggestions you may have. Your young person can also choose to attend this if they wish, or they can also have their own interview. Alternatively, they can also choose not to do an interview.

The interview will be audio-recorded to make sure we accurately capture what is said. A written transcript will be created, and your name and any identifying details will be removed. Only the research team and the transcriber will have access to the transcript, which will be stored securely at the University of Glasgow.

Taking part (or choosing not to take part, even after giving consent) will not affect any NHS services you or your child receive.

As a thank you for your time, you will receive a £25 Amazon voucher after completing the feedback interview.



Are there any risks or benefits?

Are there any risks?

Taking part in the study is very low risk. However, talking about your child's experiences or your experiences with services might sometimes bring up difficult feelings. If this happens, you will be offered time and support. You can pause or stop at any time. We can also offer to involve a support worker if you would find that helpful.

There is also a small risk that, if you disclose any concerns relating to the safety or wellbeing of a child, the research team would be required to follow child protection procedures in line with NHS policies.

Are there any benefits?

You and your young person may receive a neurodevelopmental assessment through a different pathway than the usual NHS process. You will receive a written summary of the assessment, and, where appropriate, a formal diagnosis or a detailed understanding of your child's neurodevelopmental needs. This may help guide future support and intervention planning.

However, because this is a feasibility study, we do not yet know how the new assessment process compares to the usual longer pathway. Your participation will help us understand whether this approach could be a good way to deliver services in the future.

Although you may not experience a direct benefit, the information you provide will help shape the way services are delivered for other young people and families in the

future. The findings will be shared through research publications, but no information that could identify you or your young person will ever be shared.

Will my taking part in this study be kept confidential?

Yes. All information collected about you and your young person during the study will be kept strictly confidential. You will be assigned a unique study ID number. Any information we collect will be stored securely, and anything that could identify you (such as your name or contact details) will be removed. This means that you cannot be personally recognised in any reports or publications.

Completing the electronic questionnaire will involve the information which you enter being sent to the company who run the questionnaire. However, they will not be able to access your personal data.

All research data will be stored securely on NHS secure servers, and only data which could not be used to identify you will be stored on University of Glasgow secure servers. This is in line with UK Data Archive and GDPR guidelines. Any clinical data will be stored securely by the NHS in the young person's medical record in the usual way.

Anonymised research data from this study will be securely archived in the University of Glasgow's research repository, Enlighten, for use in future ethically approved research. This data will not contain information that could identify you or your young person. Any future use of the data will be subject to appropriate ethical approval and data access controls

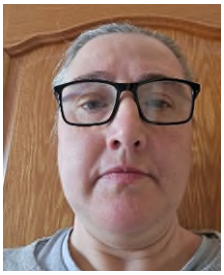
Please note that confidentiality will be maintained unless there is evidence of serious risk of harm to yourself, your child, or someone else. In that situation, we may be required to share relevant information with appropriate services to ensure safety. Wherever possible, we will discuss this with you first.

What's Next?

You can let us know if you want to take part by emailing Helen or Annemarie, at the addresses below. Or you can phone and ask for Helen or Annemarie at…….

If you have any further questions about the study, please also contact Helen or Annemarie in the first instance at the contacts below.

If you still have questions, or wish to contact the study lead, email Jason at the address below. If you want to speak to someone who is not involved in the study, then contact Professor Helen Minnis by emailing Helen.Minnis@glasgow.ac.uk.



Dr Helen Smith

Project Lead in NHS A&A

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INSERT PICTURE

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INSERT PICTURE

Research Assistant Name

Research Assistant

Email: .....

Thank you for reading this information sheet.