



THE **AUTISM** RESEARCH GROUP

PARTICIPANT INFORMATION SHEET

Ethical approval reference number: ETH1920-0682: Version 7, approved November 2020

Project Title: “PAREint: Testing a Novel Parenting Intervention for Autistic Children”

Principal investigator: Gemma Ryan, MSc.

We would like to invite you and your child to take part in our research study. If you decide to participate in this study your identity will be kept completely anonymous. Before you decide whether to take part, it is important that you understand everything about the research including what is being done and what your role would be. Please read the following information carefully and feel free to discuss this with others if you want to. If there is anything that isn't clear, or you would like any further information, please contact Gemma Ryan using the details below. She will be happy to answer your questions. You will receive a copy of this information sheet to keep.

What is the purpose of the study?

This study will compare two 'structured communication techniques' that have been suggested to improve communication skills in children with autism. Our main purpose is to assess how well parents and children are able to use these techniques at home. For example, do they fit in with the usual daily routine, do children enjoy them, are the strategies easy to use, and is the time commitment acceptable. This is because, at this stage, the numbers of families involved will be too small to draw any firm conclusions about the effectiveness of either method but the study should be able to identify whether these types of approaches are associated with changes to a range of child skills, such as memory and communication.

Each method involves using a minimum of 5 minutes of activity per day over approximately 5 months. If the results are promising then this will allow us to plan for a future study, involving many more families, which will be able to provide information on whether either method helps to improve memory and social-communication abilities in children with autism. If you agree to participate in this study, you will be randomly allocated to receive training in one of the structured communication techniques. Following this, you will also be invited to take part in an optional interview to discuss your experience of using the intervention.

Why is this study important?

There are currently few evidence-based interventions for school-aged children with ASD who have no other language or intellectual disabilities and who may also be educated in mainstream schools. Instead, most interventions either target very young children or older children with additional disabilities and attempt to teach missing skills or modify behavior instead of tackling a range of

underlying psychological processes. We think these processes might be important underpinnings for your child's later development. In addition, they have been shown to reliably improve in non-autistic children when parents are taught to use structured communication techniques.

To date, no research has investigated the potential of using structured conversations for children with ASD. We aim to assess the differences in practicality and effectiveness of two types of structured communication techniques to determine whether these could be beneficial for children with ASD and their families.

Why have I been invited to take part?

We are aiming to recruit 50 parents and their children to take part in this study. We have approached schools, organisations and networks who are interested in our work and asked them to pass details of this study to all parents and children who fit the following criteria:

Parents and Children:

1. Primarily speak in English
2. Have access to the internet and a digital device able to receive video calls (e.g. smart phone, tablet or computer)
3. Not currently taking part in another autism research study
4. Not currently receiving care or treatment for a mental or psychiatric condition

Children:

1. Aged 7-11 years old
2. Diagnosed with autism spectrum disorder (ASD)
3. Have minimal or no language or intellectual disabilities additional to their autism.

As a parent with a child who fits the above criteria, we are inviting you to take part in our research.

Do I have to take part?

Participation in the project is completely voluntary, and you can certainly choose not to participate in part or all of the project. It is up to you to decide whether or not you would like to take part.

If you do decide to take part, you will be asked to sign a consent form. Even after signing this form, you can still withdraw at any stage of the project without you or your child being penalised or disadvantaged in any way and without giving a reason. If you do decide to withdraw, any data collected about you will be destroyed and no longer used in the study. However, once the results have been anonymized and analysed you will no longer be able to withdraw your data (e.g. 2 weeks after follow-up assessments have been completed). **All published data will be completely anonymous** and will relate to groups of participants, not individual parents or children. No-one will be able to identify you or your child from published reports of the work.

What will happen if I take part?

What do I have to do if I take part?

Over a course of 20 weeks you will be involved in testing a communication intervention. Firstly, you will receive a training session on how to use a structured communication technique with your child. Following this, you and your child will complete some virtual initial psychological tests (e.g. using video software on your computer) and will then be asked to use the communication technique with

your child daily for 20 weeks. Once completed, you and your child will be asked to take a final round of tests. Finally, you will be invited to take part in an optional interview with a researcher to discuss your experiences of using the structured conversations and of the research process.

Information on each of these stages is summarised below, provided timings are approximate estimates.

| <i>Phase</i> | <i>How long will it take?</i> | <i>Where will it take place?</i> | <i>Description</i> |
|---------------------------|---|---|---|
| Baseline Testing | Up to 3 hours (spread across multiple sessions) | Your home | A researcher will call you at home using video software such as Skype or Zoom and will remotely assist you and your child to complete a battery of psychological tests. This is to help us to understand your child better and to obtain pre-intervention test scores and testing may be conducted across multiple sessions or days to suit you and your child. |
| Training | Approx. 1 hour | Your home | Parents will receive a remote training session on the intervention using video calling software. |
| Intervention period | Minimum of 5 minutes per day for 20 weeks. | Anywhere | Parents will be asked to use the structured conversation training to hold conversations every day with their child for a minimum of 5 minutes per day for the next 20 weeks. This can take place at any time and any location. Parents will be asked to keep a record of these conversations using a quick online logbook, and to note any issues or problems that occur. |
| Post-intervention testing | Up to 2 hours (spread across multiple sessions) | Your home | A researcher will call you at home using video software such as Skype or Zoom and will remotely assist you and your child to complete a further battery of psychological tests. This is to obtain the post-intervention test scores and testing may be conducted across multiple sessions or days to suit you and your child. |
| Interview | Approx. 1 hour | City, University of London, your home or your child's school. | You will be invited to take part in a semi-structured interview with a researcher. This will either take place face-to-face or using video calling software, either at your home or at City University of London, or possibly in your child's school, if they have facilities. This will be to discuss your experiences of using the intervention and the training process, all of which will help us to determine its feasibility and acceptability. |

What are the possible disadvantages and risks of taking part?

This study poses no foreseeable risks of harm to you or your child, however you may experience some of the following:

As one of the main aims of this study is to see whether parents find the intervention feasible, there is a chance you may find it difficult to engage your child in the exercise which could prove to be stressful or upsetting for you. We will provide you with the option of some online face-to-face advice and lots of materials that aim to keep the activity rewarding and fun for your child to minimise this possibility.

You may struggle to find time to complete the activity everyday which could also be stressful. We have again tried to minimise this issue by asking for a minimum of 5 minutes conversation per day, which can take place anywhere and at any time of day. We have also kept the log materials as brief as possible so you can record your conversations with ease.

What are the possible benefits of taking part?

You will be provided with a brief report that summarizes your child's results from our battery of psychological tests. In addition, you will receive free training in a communication strategy that has recognized short and long-term benefits for improving known difficulties in children without ASD that are crucial for forming social relationships and learning from past mistakes.

Improvement in these skills supports literacy, academic attainment and social development later in life, all of which will improve overall quality of life for autistic individuals and their families. If found to be feasible and effective, then structured conversations would be a cheap and straight forward intervention that could be rolled out across families and significantly improve lives of children with ASD. Furthermore, results from this study will provide strong evidence towards better understanding of children with ASD.

Expenses and Payments

As a token of our appreciation, we will give you a £10 retail voucher for taking part in this study. You will receive the voucher at the end of your involvement with the project. We will also reimburse any reasonable travel expenses for both you and your child should they be necessary.

How is the project being funded?

This research is being funded by the School of Health Sciences at City, University of London as part of a 3-year PhD study.

What should I do if I want to take part?

If you are interested in learning more about this research or would like to take part, then please click the link below to check your eligibility and add your contact details to a brief online form. Gemma will get in touch to further discuss the project with you.

Register your interest here:

https://cityunilondon.eu.qualtrics.com/jfe/form/SV_ahmJM6UHkCsaJxi

Data privacy statement

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City's public task.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible (for further information

please see <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/>).

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only people at City who will have access to your identifiable information will be Gemma Ryan and one supervisor. City will keep identifiable information about you from this study for 1 year after the study has finished.

You can find out more about how City handles data by visiting <https://www.city.ac.uk/about/governance/legal>. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) <https://ico.org.uk/>

Though this study aims to keep your data completely confidential, if you or your child happen to disclose information that incurs suspicion of harm to a vulnerable person then we are required to discuss this with the appropriate persons and arrange assistance for the vulnerable person.

What will happen to the results?

The results will be written up as part of an original PhD thesis where complete anonymity will be maintained for all involved. Following this, results may be published as papers, reports or articles in academic journals or magazines. Results may also be presented at relevant research conferences.

If you would like to receive a copy of the results summary then researchers will ask for consent to keep their contact details on file for this purpose and results will be sent once completed.

What will happen when the research study stops?

Once the intervention is completed, all participant data will be anonymised and securely stored at City, University of London. The anonymised data will be retained for a minimum of 10 years after completion of the study. Hard copy data will be stored in a locked filing cabinet and electronic data will be stored in an encrypted folder on the University computer network.

Personal data records will be deleted 3 months after successful completion and award of the PhD. Hard copy data will be shredded with a City University cross cut shredder and will then be disposed of via the University's confidential waste management contract, the standard for which is specified by the Health and Social Care Information Centre. All electronic personal data (including but not limited to data on a PC, hard disk, flash drive or CDs and DVDs) will be securely destroyed in line with City University's contract, which includes detailed audit trails and validation of destruction notices.

Who has reviewed the study?

This study has been approved by City, University of London School of Psychology Research Ethics Committee.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is "**Testing a Novel Parenting Intervention for Children with Autism**".

You can also write to the Secretary at:

Anna Ramberg
Research Integrity Manager
City, University of London, Northampton Square
London, EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

Insurance

City University London holds insurance policies which apply to this study, subject to the terms and conditions of the policy. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Further information and contact details

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Thank you for taking the time to read this information sheet.