

Participant Information Sheet

Study Title

The Development and Evaluation of a Cognitive Behavioural Social Competence Therapeutic Intervention for Adults with Autism Spectrum Disorder without an Intellectual Disability (SCTI-A)

Invitation paragraph

We would like to invite you to participate in this study, which forms part of my PhD project. Before you decide whether you want to take part, please take time to read the following information carefully as it is important for you to understand why the research is being done and what your participation will involve. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to investigate the feasibility and effectiveness of a cognitive behavioural intervention which was developed as part of my PhD project.

Why have I been invited?

We are looking for volunteers that have a diagnosis of autism spectrum disorder without an intellectual disability and your parent/caretaker to take part our study. This may include a past diagnosis of: high functioning autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS). Parents or caretakers will have minimal involvement and will mainly play a supporting role. The involvement of a parent or caretaker is required to participate in this study.

Do I have to take part?

Participation in this study is voluntary. You should read this information sheet and if you have any questions or need clarification you should contact the researcher using the details at the end of this document. You should not agree to take part in this research until you have had all your questions answered to your satisfaction. If you decided to take part in the study, you are free to withdraw at any time without giving a reason and all data up to the point that you withdraw will be stored for a minimum of five years.

What will happen to me if I take part?

Initially you will receive a brief phone call from a researcher to make sure the intervention is appropriate for you. If you are interested in participating in the study, you will be invited to the Allerton Building on the University of Salford campus to meet with a researcher where you can ask any questions and further discuss the details of the study. Once all your questions have been answered to your satisfaction, we will then ask you to take an IQ test and answer a questionnaire. The Autism Spectrum Quotient (AQ-50; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) is a popular questionnaire which will take you about 20-30 minutes to complete. The questionnaire will assess your autism symptoms and provide support for your autism diagnosis. The Wide Range Intelligence Test will be used to establish your IQ score and it also takes about 20-30 minutes to complete (WRIT; Glutting, Adams, & Sheslow, 2000). An IQ score of 80 or above is needed to participate in this study (typically people have an IQ of 90-110). Altogether, this meeting is expected to last no more than two hours. If it is determined that you are suitable to participate in the study and you wish to take part, a signed consent form will need to be returned to the researcher following a 24 hour consideration time period.

As part of your participation in this study you will need to complete two brief social interaction tasks (see below for Task A & B) before the start of the intervention and once again at the end of the intervention. Both tasks will be completed on the same day and will take place in the observation suite and a small meeting room on the 8th floor of the Allerton Building on the University of Salford campus.

Task A

One of the tasks will aim to replicate a natural conversation between you and another person. During this conversation task you will be required to wear the 52 channel functional near infrared spectroscopy (fNIRS) device for about six minutes. The fNIRS is a small non-invasive device that will be simply placed on your head similar to a swimmers cap as seen in the picture below. There are only three rules for this conversation task:

- 1) The topic is chosen by you and the other person prior to the start of the conversation
- 2) Speak in turns during the conversation.
- 3) Stay on topic

At the end of the conversation you will be asked to give a brief 60 second summary of the conversation describing the other person's viewpoint on the topic you both discussed.



Figure 1. Image of a participant using the fNIRS device.

Task B

You will also be asked to complete a second tasks which involve you playing a game. You will not be required to wear the fNIRS cap for this task. For this task you will play a classic game, Tumble Tower. Tumble Tower consists of 54 precision-crafted, hard wood blocks. Players take turns removing one block at a time from the tower and placing that block on the top of the tower. Before you begin the game, you will be provided with instructions on how to set up and play the game. You will have five minutes to play the game and talk with the person you are playing against. If the game ends (the tower falls) before the five minutes is over, you will simply reset the blocks and play again. The interaction will be video record with four video cameras and video recordings will only be viewed by researchers involved in the study.



Figure 2. Tumble tower game

On the final day of the intervention, you will also be given a short questionnaire to complete and you may be randomly selected to participate in a very brief interview. The questionnaire will be completed at the University of Salford in a meeting room in the Allerton building and the interview will take place in the observation suite which is also located in the Allerton building. The Client Satisfaction Questionnaire (Larsen et al., 1979) requires you to answer only eight questions and only takes about five minutes to complete. The Short interview is scripted with six questions that are focused on your personal experience of the intervention. The interview will roughly take between 5-10 minutes. An example of one interview question is “*What did you like about the intervention?*”

Parent/Caretaker participation

Parents/Caretakers play a very important role in the study. Along with providing social support during the intervention, the parents/caretakers will complete The Multidimensional Social Competence Scale online questionnaire (MSCS: Yager & Larocci, 2013) which will help determine if there were any improvements in your social competencies as a result of the intervention. A researcher will set up a university laptop in a meeting room in the Allerton Building on the University of Salford campus. Questionnaires will need to be completed before the intervention begins and again when the intervention ends. In the event that a parent/caretaker would prefer not to answer the questionnaire online, a paper version can be provided. Should a parent/caretaker decided to withdraw from their role and not answer their questionnaire, it will not affect you from continuing on with the study.

Expenses and payments?

There is no financial incentive to participate in this research.

What will I have to do?

If you and your parent/caretaker are happy to participate in the research you will be told the full purpose of the study and you will need to sign the consent form and return it to the researcher. For participation in this study you will need to provide a commitment twice a week to therapy. All sessions will be attended in the Allerton Building on the University of Salford campus over six weeks. The intervention involves six weekly individual sessions and six weekly group sessions (two therapy session a week). The total time you will need to commit to therapy over the six week intervention is 15 hours (2.5 hours a week).

The individual sessions (just you and one other therapist) are at the beginning of the week and will last about 30 minutes. These session will follow the five areas cognitive behavioural therapy (CBT) model. In the final 10 minutes of the individual CBT sessions your parent/caretaker will be invited to join the session as we recap on any mutually agreed goals and/or homework tasks. Parents/caretakers will play a supportive role in helping you to complete your homework tasks and achieve your goals. Individual CBT will total three hours of therapy over six sessions and will run alongside the group sessions.

Group sessions are held at the end of the week and will last approximately two hours. The group size is small and will not exceed more than ten participants. The group sessions are aimed at improving general social communication skills. Activities in the group often involve socialising with others, which makes participation very important. Group therapy sessions will involve learning new skills, watching the therapists modelling behaviours, roleplay and rehearsal of social skills and social problem solving. There are six group sessions requiring a commitment from you of 12 hours of group therapy.

What are the possible disadvantages and risks of taking part?

We do not anticipate that you will experience risk or disadvantages, however you may experience a slight discomfort or pressure whilst wearing the fNIRS device. This device can be easily adjusted or removed in the event that discomfort becomes distressing. This will not affect your participation in the intervention.

What are the possible benefits of taking part?

The data gathered will be used to further develop social skills interventions for individuals with ASD. This study will help to increase the understanding of the brains response to a specialised therapeutic intervention.

What if there is a problem?

If you have a concern about any aspect of this study you can contact the lead researcher David Tate (D.Tate@edu.salford.ac.uk) or Dr Clare Allely (c.s.allely@salford.ac.uk).

If you would like to make a complain, you can contact

Dr Sue McAndrew

Room Mary Seacole 1.91

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E: s.mcandrew@salford.ac.uk

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Salford,

M5 4WT

Will my taking part in the study be kept confidential?

All information / data will be kept confidential. Video data will be recorded by the researcher using cameras within the observation suite and will not be share publicly. Conversation tasks and selective interviews will be video recorded for the purpose of assessment. Video data will be uploaded to a secure password encrypted computer and video files will be encrypted with a digital password.

The data gathered will be entered into a secure database in accordance with ISO/IEC27002 (Information Technology – Code of Practice for Information Security Management, 2013).

All hard copies will be stored in a locked filling cabinet located in an auto lock office secured with a 5 digit key code within a secure building. All data collection, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection. You will be provided with the unique identification number in order to ensure anonymity and your data will be kept for a minimum of five years.

What will happen if I do not carry on with the study?

You are free to withdraw from the study at any time and without giving reasons for withdrawing. All of the data collected up to the point of withdrawal will be stored for a minimum of five years.

What will happen to the results of the research study?

Details and results of this study will be published in scientific publications, such as journals, and/or presented at conferences and seminars, and/or research website depositories.

They will be used in the researcher's PhD dissertation. Any and all information will be anonymised.

Who is organising or sponsoring the research?

University of Salford

Long-term support

This study is unlikely to cause any persistent distress or discomfort but if you do feel continued distress or discomfort and cannot continue, the researcher will telephone security who are now the central point of contact for both physical and psychological first aid. The number for security is 01612954773 and for student wellbeing 01612950023. We can also offer a referral to Salford Autism or the Together Trust North West. Salford Autism provide social support for individuals with ASD in Salford and provide an open contact line (0771 390 3224) 24 hours, 7 days a week, including all holidays. The Together Trust is a charity that offers care, long-term support and special education to children, adults and families. Their services cover the North West of England and they accept referrals from all over the UK. Together Trust Contact details are: 0161 283 4848, 8.30am – 5.00pm or 0800 013 0014 for out of hours support. In the case of needing immediate support contact your GP or NHS helpline for advice by calling the free number 111.

For further information or to ask questions contact:

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