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Investigating Behaviour in Russell-Silver Syndrome

Participant Information Sheet

Your child is invited to take part in a research study. Before you decide whether or not you would like your child to take part, it is important for you to understand why the research is being done and what will be involved. Please read the following information carefully and discuss it with others if you wish. You may ask for clarification of anything that is unclear or if you would like more information. Please take time to decide whether or not you wish for your child to take part.

What is the purpose of the study?

The aim of this research is to investigate behaviour in Russell-Silver syndrome (RSS). This will be assessed in a semi-structured play session in order to assess behaviours such as communication skills and social skills. A further aim of the research is to explore how individuals with RSS learn and to establish whether certain strengths and difficulties are common for these individuals. Cognitive abilities will be measured using a number of different tasks that involve skills such as remembering information, understanding a conversation and making patterns.

Do I have to take part?

It is up to you to decide whether or not you would like your child to take part. If you do decide to take part, you and your child will be asked to sign a consent form. Following this, you and your child have the right to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you decide you would like your child to take part, you will be asked to provide details of your child's school or an alternative location (e.g. your home) in which you would like the study to take place. Your child will sit in a room with the experimenter and will be asked to take part in some play activities. The estimated time to complete the play session is 40 – 60 minutes. Following this, your child will be asked to complete a series of tasks to measure skills such as memory, language and problem-solving. The estimated time to complete these



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tasks is 30 – 40 minutes. Your child will be given the opportunity to have regular breaks. You can decide whether it would be appropriate to complete the play session and cognitive tasks in one day or whether you and your child would prefer to schedule two separate visits. In addition, you (as parent/caregiver) will be asked to complete a short questionnaire about your child's behaviour, which will take 15-20 minutes. This does not have to be completed at the same time that your child is doing the tasks but can be completed before, or after, this part of the study.

What are the possible disadvantages and risks of taking part?

The only disadvantage is the fact that the study will take approximately 1 hour and 30 minutes. This may interfere with your child's school day.

What are the benefits of taking part?

If you decide you would like your child to take part in the study, you will be given individualised feedback based on your child's results in the play session and in relation to the cognitive tasks. This information will not be diagnostic but will provide an overview of your child's behavioural skills and their cognitive strengths and difficulties. In addition, a summary of the findings from the study will be made available to everyone who takes part in the research. This will not contain any identifying information.

What if I wish to complain about the way in which this study was conducted?

If you have any complaints or concerns, please contact Dr. Megan Freeth:

m.freeth@sheffield.ac.uk

Will my taking part in the study be kept confidential?

All information collected about your child during the research will be kept strictly confidential. Any information about your child that leaves the University will have your child's name removed so that they cannot be recognised from it. The results of the study will be analysed and prepared for publication in relevant scientific journals, following academic assessment. No information about any individuals will be available in publications or conference presentations. Once published, you will be able to obtain a copy of the results and



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a summary of the findings from Megan Freeth. These will also be made available to all members of the Child Growth Foundation (CGF).

This study has been reviewed by the Department of Psychology Ethics sub-committee at the University of Sheffield and conforms to the British Psychological Society “code of human research ethics”.

Thank you for taking the time to read this information sheet. If you would like to participate in the study or would like any further information, please contact:

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