

RESEARCH INFORMATION SHEET

SUPPORTING YOUNG PEOPLE WITH AUTISM BY USING THE STORIES ONLINE FOR AUTISM (SOFA) APP.

Dear Parents / Guardians,

I am Dr Louis Camilleri (D.Ed.Ch.Psy), a warranted Educational & Child Psychologist who is currently reading for a PhD with the University of Bath's Centre for Applied Autism Research (CAAR).

I am presently conducting a study that aims to investigate how digitally-mediated social stories can help children with autism. For this study, I am working under the supervision of Prof Mark Brosnan and Dr Katie Maras (University of Bath).

The aims of this study are the following:

1. To learn if stories, which are developed and delivered through a digital application, can be useful for autistic children.
2. To learn if a story or narrative can help parents/guardians to support their children's understanding of social situations.
3. To learn if digital applications, such as SOFA, can help parents/guardians with developing and delivering stories accurately and independently.

I would like to invite you to participate in this study. I hope that by reading this information letter, you will be in the position to make an **informed decision on whether to consent to participate in this study, consent for your child to participate in this study**, and allow for the pseudonymised data gathered to be included in a write-up and subsequent academic publications and presentations to continue to support the autism community.

The study will consist of the following procedures:

- Step 1. Parents/guardians will complete a consent form.
 - *N.B. Parents/guardians are also invited to obtain their child's assent (i.e., check with the child if they would like to participate in the study).*
- Step 2. Parents/guardians will complete an online questionnaire.
- Step 3. Parents/guardians will follow training on how to use a mobile application (SOFA) which will be used for developing and delivering the stories and on how to identify an adequate goal.
- Step 4. Parents/guardians will identify a goal for the child and develop a story using SOFA.
 - *N.B. If necessary, at this point parents/guardians will be further supported by Dr Louis Camilleri*
- Step 5. Parents will deliver the stories daily to the children for 2 weeks using the SOFA application.
 - *N.B. Frequency of delivery is up to the parents/guardians.*
- Step 6. Parents/guardians will complete a weekly progress checklist.

- Step 7. Parents/guardians will be invited to participate in a one-to-one interview, together with myself, at the end of the 2 weeks where outcomes of the intervention will be discussed.
- Children are also invited to participate in an interview, online or face-to-face, in the presence of their parents/guardians. However, this interview is not compulsory.
- *N.B. If parents/guardians are not comfortable to participate in an interview, they can instead complete an online evaluation survey.*

The following are answers to questions you may have about the study:

What are social stories/narratives? A social story is a learning instrument, that is usually created by a parent/guardian or a professional, that aims to promote the safe and meaningful exchange of information between them and people with autism of all ages. The parents/guardians or professionals who develop the social stories are referred to as “Authors”. These authors work on behalf of a child, adolescent, or adult with autism, who in turn is referred to as the “Audience”. Social stories are individualized short stories (descriptions) written by authors to specifically describe a situation, teach a new skill, introduce a person, define a concept, or prepare the audience (usually the individual with autism) for a social event. Social stories are also used as a means to teach communal skills through the use of precise and sequential information about everyday events.

What are “digitally-mediated social stories?” Digitally-mediated social stories are social stories/narratives that are developed, accessed and delivered by using a digital application.

How will digitally-mediated social stories be delivered in this study? For this study, digitally-mediated social stories will be developed and delivered using the SOFA app (SOFA).

What is SOFA app? SOFA is an application, for smart devices, through which social stories can be accessed and/or created. It is an App that can be used on a smartphone or tablet. The application can be downloaded for free from the Play Store or App Store.

Who is SOFA for? SOFA is aimed at helping adults (parents/guardians and/or professionals) create and use social stories with their children. These social stories are then presented/read to children and/or adolescents who are on the autism spectrum (ASD). The goal is to facilitate the understanding of what is socially acceptable behaviour and what is not.

What is the purpose of the study? The study aims to examine the use and suitability of social stories when being delivered through a digital application by parents/guardians.

Will I be given support on how to develop and deliver stories by using SOFA? Yes. The one of the objectives of this study is to “upskill” the autism community. Thus, video tutorials are being made available for the study’ participants. Further individual support, that goes beyond the video tutorials, will also be available to participants. However, the objective of this study is to investigate if the digital application can support participants in developing and delivering stories autonomously.

How will the information that I share in this study be treated? Any information that will be gathered from this study will be treated with the utmost discretion. I.e., your personal information, or that of your child, will be stored in a private and secure location that will be accessed only by Dr Louis Camilleri. Furthermore, as a participant, you have the right under the General Data Protection Regulation (GDPR) and national legislation to access, rectify and where applicable ask for the data concerning you or your child to be erased. All data collected will be stored in anonymised form.

Is my child’s, and my own, participation voluntary? Yes. Participation in this study is entirely voluntary; in other words, you, as well as your child, are free to accept or refuse to participate, without needing to give a reason. You are also free to withdraw from the study at any time, without needing to provide any explanation and without any negative repercussions for you.

How will I obtain my child's assent? Assent is the technical word used for participants in studies who are below the age of 18. It is important that you take the time to explain the study's procedure, and goals, to whilst also checking that the child is comfortable participating. You will be "coached" on how to obtain a child's assent through instruction videos.

What will happen to the results? The results of this study will be gathered into a write-up/report. The report will be included in academic writeups and presentations, published in various academic journals, and used to inform future studies. At no stage in the publication of the results will your identity be disclosed.

Will my participation in the study be kept confidential? Yes. I will ensure that no clues of your identity appear in the study.

Will my child and myself be rewarded for our time? Yes. As a token of appreciation for the time you would have dedicated to this study, at the end of your study you will be receiving an honorarium of €100.

Are there any possible disadvantages and risks to parents/guardians or to children who would be participating in this study? I do not envisage any negative consequences. Social stories are safe and have been researched extensively.

Who has reviewed the project? This project has been vetted and approved by the University of Bath's Psychology Research Ethics Committee (PREC).

If you would like to participate in this study, or have any questions, please get in touch on WhatsApp at (+356) 99450534 or by email at lc2295@bath.ac.uk

Best Regards



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