



University of East Anglia
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INFORMATION SHEET

You are invited to take part in a study carried out by Ian Mallandain, trainee clinical psychologist at the University of East Anglia. Within my role as a trainee clinical psychologist, the aim is to reduce psychological distress, as well as enhance psychological well-being. The focus of this research is regarding the relationship you have with your son or daughter with autistic spectrum disorder. Increased understanding of the father-child relationship can be used to help inform the type of interventions and support which could be of benefit to families experiencing psychological distress.

Please read the following information carefully because it is important that you understand why the research is being carried out and what it will involve.

The purpose of the study

The purpose of this study is to investigate what impacts on the relationship that fathers have with their son or daughter with autistic spectrum disorder. In order to do this, I will be distributing questionnaires to interested fathers.

Why have I been chosen?

Fathers of children with autistic spectrum disorders living in the United Kingdom are being asked to participate in this study.

This study is interested in fathers who are either living with their son/daughter with autistic spectrum disorder or are in regular face-to-face contact with them (i.e., several times per month as a minimum). Your son/daughter should be between the ages of 3-16.

If you would like to take part in this study, you will be asked to sign a consent form which indicates that you understand the purpose of this study and what it will involve. If

you agree to take part, you will be free to withdraw from the study at any time, and do not need to provide a reason for this.

What will taking part involve?

This study will take place over the duration of a year. During this time, you will be interviewed once and asked to complete a set of questionnaires. The information obtained through this study also meets part of the requirements for the doctorate in clinical psychology at the University of East Anglia.

I will arrange a mutually convenient time in which to carry out the interview and send you the questionnaires. Interviews can be arranged either face to face where practical or over the telephone.

I will ask you to take part in a five minute interview to talk about your son/daughter. In addition, you will be asked to complete four brief questionnaires. The four questionnaires will assess demographic information, child factors including autistic spectrum disorder symptoms and behavioural problems, and parental factors such as psychological well being. Completing these measures will take up to half an hour.

Are there any risks involved in taking part in this study?

Taking part in this study has few risks. However, if any of the relationships in your family are difficult, it may upset you to talk about them or complete some of the questionnaires. If this occurs, you may have some time to discuss these issues further with Dr. Peter Langdon, who is supervising this study. Dr. Langdon's contact details are included at the end of this information sheet.

What are the benefits of taking part?

Taking part in this study will not directly benefit you or your family. However, your participation will help increase understanding of the relationship between fathers of children with autistic spectrum disorders and associated factors. In turn, increased understanding of the father-child relationship can be used to help inform future interventions and support.

What will happen with the results of this study?

Following the study, a research report will be prepared for examination by the University of East Anglia. No personally identifiable information about you will be used throughout this process. All the information you tell us is kept confidential. Information about you and your child will be stored in such a way as to ensure that you and your child's identity

are kept secret. This means that no one will be able to tell if you took part in this study by looking at the data that I have collected. However, if you tell me something that suggests that you, or someone in your family, or someone else you know is at risk of serious harm, I may have to tell someone else.

The study findings will be submitted to a scientific journal that will review the results and may decide to publish them. No personally identifiable information about research participants will be used through-out this process. A summary of the findings will be forwarded to you and charities facilitating the research following completion of the study.

Will my information be kept confidential?

The information collected for the purpose of this study will be kept strictly confidential, in line with the Data Protection Act (1998). All measures used in this study will be made anonymous by allocating a code. Throughout the study, your information will be kept in a locked cabinet that can only be accessed by the researchers. Following the completion of the study, your information will be stored in the archive room at the University of East Anglia for a period of five years. Your name or the names of people in your family will not be written on the questionnaires, or stored with the data we collect.

Who has given permission for this study to go ahead?

This study has been reviewed by the University of East Anglia (UEA) Faculty of Health Ethics Committee, and they have agreed for the study to go ahead.

Who can I contact for further information about this study?

You can contact Dr Langdon, who is supervising this study:

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