

TO: The Participant

Date: 4th March 2009

Plain Language Statement

Full Project Title: **Influential factors in the self efficacy and wellbeing of parents of children with Autism Spectrum Disorder**

Principal Researcher: **Dr Jane McGillivray** Student Researcher: **Natasha O'Neill**

The Plain Language Statement is 4 pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project so you can make a fully informed decision whether you are going to participate.

Please read this Plain Language Statement carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to complete an anonymous questionnaire. By completing the questionnaire and returning it via the reply paid envelope you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Plain Language Statement to keep as a record.

2. Purpose and Background

Self efficacy is basically how strong or weak an individual believes their abilities or capabilities are to deal with particular situations. Previous experience has shown that higher levels of self efficacy are associated with greater skill in dealing with life's stressors. Self- efficacy is determined by previous experience, personality, support systems and knowledge.

The aim of this project is to examine the wellbeing and the factors that influence levels of self efficacy in parents of children with Autism. The specific factors that will be examined include the stress levels of the parent, knowledge about the disability and the available services, the amount of information received at the time of diagnosis, the support mechanisms in place, as well as the characteristics and birth order of the child with autism.

You are invited to participate in this research project because you are the primary caregiver of a child with an Autism Spectrum disorder. A total of 50 people will participate in this project. The results of this research will be included in a thesis submitted by Natasha O'Neill toward a Bachelor of Arts (Psychology) (Honours) degree.

3. Funding

This research is totally funded by Deakin University

4. Procedures

Participation in this project will involve completion of 4 separate questionnaires including the Parenting Stress Index/ Short Form which consists of 36 items taking approximately 10 minutes to complete. Answers to this questionnaire consist of indicating whether the participant Strongly Agrees, Agrees, Not Sure, Disagrees or Strongly Disagrees. Examples of the questionnaire include: Since having a child, I feel that I am almost never able to do things that I like to do & I feel that my child is very moody and easily upset. The General Self- Efficacy Scale (GSE) which consists of 10 items taking approximately 4 minutes to complete. These questions consist of answering Not at all true; Hardly true; Moderately True or Exactly true. An example includes I am confident that I could deal efficiently with unexpected events. The Maternal Autism Knowledge Questionnaire consists of 41 true/ false questions and takes approximately 10 minutes to complete. Examples include; Autism is a brain disorder; The biggest problem with diagnosing autism is that symptoms do not appear until age five or older & People with autism have trouble understanding facial expressions. The final questionnaire consists of 16 questions that were devised by the researcher which will take approximately 5 minutes to complete. Examples include: Does your child participate in organised group activities? & Does your child suffer from health problems? If so what?

The questionnaires will be handed or posted to participants with a reply paid envelope for the return of the completed papers.

5. Possible Benefits

Participants may not experience direct benefit from completion of the questionnaire, although the findings may assist you and other parents of children with autism in the future through enhanced understanding of the variables that impact on wellbeing and enhanced service delivery. Links provided to information and the new government autism package may also assist you with further support.

6. Possible Risks

Although it is not anticipated that the questions asked of participants in this study will contribute to levels of stress, it is possible that some participants may experience discomfort from thinking about their wellbeing and the level of support services available. Participation in this project is completely voluntary and participants may withdrawal from the project at any time. Should you feel the need for additional support the following telephone services are available:

Lifeline 13 11 14

Parent line 13 22 89

The following websites may also be of assistance:

www.health.gov.au/autism

Autism Victoria www.autismvictoria.org.au

State-wide Autistic services www.sasi.org.au

Irabina www.irabina.com

7. Privacy, Confidentiality and Disclosure of Information

The data obtained for this research project is anonymous (consisting of completed questionnaires with no personally identifiable material) and will be stored at Deakin in a locked filing cabinet for a minimum of 6 years after final publication; after this time the data will be destroyed.

Group findings only will be presented at an honours conference, in the thesis and an article in a professional journal.

8. Results of Project

Should you wish to obtain a copy of the general group findings please contact the researcher at the end of the year and provide an email or postal address to enable a copy to be forwarded.

9. Participation is Voluntary

Participation in any research project is voluntary. **If you do not wish to take part you are not obliged to.**

Your decision whether to take part or not to take part, will not affect your relationship with Deakin University or with any services organizations.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Complete the questionnaire only after you have had a chance to ask your questions and have received satisfactory answers.

10. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethics aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University.

11. Complaints

If you have any complaints about any aspect of the research, the way it is being conducted or any questions about your rights as a participant, then you may contact:

Secretary HEAG-H, Dean's Office, Faculty of Health, Medicine, Nursing and Behavioural Sciences, 221 Burwood Hwy, Burwood, VIC 3125, Telephone: (03) 9251 7174, Email hmnbs-research@deakin.edu.au

Please quote project number HEAG-H 37_09 in any correspondence

12. Reimbursement for your costs

You will not be paid for your participation in this project.

13. Further information, Queries or Any Problems

If you require further information or if you have any problems concerning this project, you can contact the principal researcher.

The researchers responsible for this project are:

Principal Researcher:

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