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Use and helpfulness of parent strategies to support young people who experience mental health conditions

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study about the strategies that parents use to support a young person who is experiencing a mental health condition. This study will provide information for parents about what strategies other parents have found helpful, and in what circumstances. You have been invited to participate in this study because you are a parent who is supporting, or has in the past supported a young adult (15-24 years old) who is experiencing a mental health condition. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

Andrea Mizzi is conducting this study as the basis for the degree of Bachelor of Applied Science (Occupational Therapy) Honours at The University of Sydney. This will take place under the supervision of Dr Anne Honey, Dr Justin Scanlan and Dr Nicola Hancock.

(3) What will the study involve for me?

You are invited to participate in an online parent survey. The survey contains:

- a) Questions about you and the young person (for example ages, diagnoses, and family structure);
- b) A list of strategies that parents have reported using to try to support a young person with their mental illness. You will be asked to rate how often you use/used each strategy and how helpful you found it to be.

(4) How much of my time will the study take?

The survey should take around 30 to 45 minutes to complete, depending on how much time you take thinking about each question.

(5) Do I have to be in the study? Can I withdraw from the study once I've started?

Completing the survey is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney. Doing the questionnaire is an indication of your consent to participate in the study. You can stop doing the survey at any time and can change your answers. Once you have answered the questions, your data cannot be withdrawn because they are anonymous and therefore we will not be able to tell which is yours.

(6) Are there any risks or costs associated with being in the study?

There is a small risk that filling in the survey may make you may feel uncomfortable or distressed because it may remind you about the difficulties involved in supporting a young person who experiences mental illness. If this occurs, you are welcome to stop completing the survey. At that time or afterward, you are encouraged to call one of the phone numbers provided at the end of this information sheet.

(7) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study.

Findings from the survey will be used to identify strategies that parents have found most useful and helpful in different circumstances. The findings will enable parents of other young people living with mental illness to benefit from your experiences.

As a token of our appreciation, you can elect to go into a draw to win a \$100 gift voucher of your choice. We will give 1 gift card per 25 respondents. The email address you can provide for this draw is not linked to your survey answers.

(8) What will happen to information about me that is collected during the study?

The information will be used, along with responses from other parents, to determine strategies most likely to be helpful under different circumstances. Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published in an honours thesis, conference presentation and journal article, but you will not be individually identifiable in these publications.

(9) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(10) What if I would like further information about the study?

If you would like to know more at any stage during the study, please feel free to contact Anne Honey on anne.honey@sydney.edu.au or 93519370.

(11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box and providing your contact details at the end of the survey. You will receive a lay summary of the survey findings.

(12) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [*Protocol #2017/741*]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

If you feel distressed or concerned by issues brought up in the survey, please contact one of the following: Anne Honey (Chief investigator) - 93519370; Carer Line - 1800 242 636 (9.00am to 4.30pm, Monday to Friday); Lifeline - 13 11 14 (24hrs, 7 days).

This information sheet is for you to keep