

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	<i>HRE2018-0267</i>
Project Title:	<i>The use of medication for the management of challenging behaviour among people with intellectual disability: Family member perspectives.</i>
Principal Investigator:	<i>Dr Emily Castell, School of Psychology</i>
Student researcher:	<i>Drianca Naidoo</i>
Version Number:	<i>Version 1</i>
Version Date:	<i>30/04/2018</i>

What is the Project About?

Family members of those with intellectual disability can play an important part in providing support for their loved one. Few studies have investigated how family members make treatment decisions concerning their loved one, particularly in regard to challenging behaviour and anti-psychotic or neuroleptic medication. We hope to speak with 12 to 16 family members who are legally appointed guardians to individuals with intellectual disability (whom are 18 years of age or older) in one-to-one semi-structured interviews about their experiences with decision making on these issues.

Who is doing the Research?

The project is being conducted by Drianca Naidoo under the supervision of Dr Emily Castell. The results of this research project will be used by Drianca Naidoo in partial fulfilment of a Bachelor of Psychology (Honours) degree at Curtin University.

Why am I being asked to take part and what will I have to do?

We are looking for people who are the legally appointed guardian to a family member with an intellectual disability. We are interested in your experiences of being a guardian and making decisions, particularly around the prescription of neuroleptic and or anti-psychotic medication. If you choose to participate, we will ask that you either meet the researcher at a mutually convenient time and location, for example, a local library or cafe, or in the case of long distance, we can conduct the interview through Skype or over the phone. The interview will take between 45 and 60 minutes of your time and will contain questions that ask about your role and decision making in this role. We will make a digital audio recording, so we can concentrate on what you have to say and not distract ourselves with taking notes. After the interview we will make a full written copy of the recording. After the interview you will be asked to complete a short, demographic survey, which will be stored separately to your interview data. Towards the end of the research project, in October 2018, I will email you a summary of the preliminary findings and invite you to provide your feedback. Providing feedback is entirely optional. Any feedback you provide will be considered and included in the findings of the final research paper. There will be no cost to you for taking part in this research and you will not be paid for taking part.

Family member perspectives

Are there any benefits' to being in the research project?

There may be no direct benefit to you from participating in this research. Although, sometimes people appreciate the opportunity to share their experiences. We hope the results of this research will respond to a gap in the literature and give us a better understanding of the experiences of decision-making for legally-appointed guardians who are family members of individuals with intellectual disability.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

Apart from giving up your time, we do not expect that there will be any risks or inconveniences associated with taking part in this study. We have been careful to make sure that the questions in the survey or interview do not cause you any distress. But, if you feel anxious about any of the questions you do not need to answer them. If the questions cause any concerns or upset you, we can provide you with details of a counselling service.

Who will have access to my information?

The information collected in this research will be re-identifiable (coded). This means that the stored transcripts will be re-identifiable which means we will remove identifying information on the transcript and replace it with a code. Only the research team have access to the code to match your name if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project unless otherwise specified. The following people will have access to the information we collect in this research: the research team and the Curtin University Ethics Committee. The transcripts of the interview will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed. You have the right to access, and request correction of, your information in accordance with relevant privacy laws.

The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?

Towards the end of the research project (October 2018), I will email you a summary of the research findings and invite you to respond on whether you feel like the summary captures your thoughts and feelings. The summary will not be individual but based on all the information we collected in the project. Responding to this email is optional, however if you do, we will then integrate your comments into the findings. In the email I will also ask you if you would like to receive a full copy of the research report when it is available in December 2018.

Do I have to take part in the research project?

Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just tell us at any stage that you want to stop. There are no consequences for withdrawing.

What happens next and who can I contact about the research?

If you decide to take part in this research, we will ask you to sign the consent form. By signing you are telling us that you understand what you have read and what has been discussed. Signing consent indicates that you agree to be in the research project. Please take your time and ask any

Family member perspectives

questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

If you have any questions about the research, please do not hesitate to contact my supervisor or myself.

Miss Drianca Naidoo

Drianca.Naidoo@student.curtin.edu.au

Dr Emily Castell

Emily.Castell@curtin.edu.au

Curtin University Human Research Ethics Committee (HREC) has approved this study (HRE number 2018-0267). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.