

# PARENT AND GUARDIAN INFORMATION & CONSENT

This research is about how young people with cognitive disabilities aged 15-24 get support to make decisions when they are socially isolated or don't have many people in their lives. Below is some information for you to read before supporting a young person to participate and/or provide consent to support their participation.

## **What is supported decision-making?**

Supported decision-making is when a person makes their own decisions with help from someone else. Decisions can be big or small and are about making choices. Some people might get help to make some decisions in their life. Other decisions they make on their own. The people who give the support might be family, or support workers or friends.

## **Who is conducting the research?**

Danielle Notara is a PhD student at the Centre for Children and Young People at Southern Cross University in Lismore. Danielle is on a scholarship funded by the Australian Research Council. She is experienced in research with children and young people with disability. The Research is supervised by Professor Anne Graham, Dr Sally Robinson and Professor Karen Fisher.

## **Why is the research important?**

Supported decision-making is being trialled in Australia. Young people with intellectual or cognitive disability have not been asked very much about this yet. So this research aims to promote young people's experiences of being supported to make decisions.

## **How will the young person participate in the research?**

Young people will be asked if they would like a support person present in the interviews. They can participate in the interview by sitting and talking or drawing or taking photos. Young people will be asked to talk about their experiences of using supported decision-making. Young people will receive an \$80 gift voucher at the conclusion of the research in recognition of the time and expertise contributed to the project.

## **When and where will the research take place?**

Danielle will visit up to four times between June and December. The interviews will be arranged with the service provider and young people will nominate an available space where they would prefer the interview to take place.

## **What happens with the information from the research?**

The information will be used to write a PhD Thesis and the report will be published. All details of the young people will remain anonymous and all names and identifying information, such as their service, support people, location, will be changed. Only the researcher will listen back to recordings and review the material from the interviews. These will then be stored securely at the University.

**What else do I need to know?**

The ethical aspects and evaluation of this study have been approved by the Southern Cross University Human Research Ethics Committee (approval number: ECN-17-077).

Any complaints about the ethical conduct of this research should be addressed in writing to the Ethics Complaints Officer, Human Research Ethics Committee, Southern Cross University, PO Box 157 Lismore, NSW, 2480 Email: [ethics.lismore@scu.edu.au](mailto:ethics.lismore@scu.edu.au).

All complaints are investigated fully and according to due process under the National Statement on Ethical Conduct in Human Research and this University. Any complaint you make will be treated in confidence and you will be informed of the outcome.

**What should I do now?**

Young people will be required to sign accessible forms or to give a recorded verbal consent to indicate they understand the research and wish to take part.

We do this to prioritise the young person’s consent and to ensure they have the final say on their participation.

We understand in some cases, if the young person is under the age of 18 or can not provide formal consent, parents and guardians will first need to provide consent. In this case, please sign the consent form below and return to [danielle.notara@scu.edu.au](mailto:danielle.notara@scu.edu.au)

**CONSENT FORM**

I, ..... have read and understood the attached information and any questions I have asked have been answered to my satisfaction.

As parent or legal guardian, I give permission to the research team to approach the young person in my care and ask if he/she wishes to participate in the project.

I understand:

- The research will involve at least one, and possibly up to four interviews. I understand the young person will have the choice to have a support person in their interview.
- In all written work associated with this research the privacy and confidentiality of the young person in my care is ensured. I give permission to the researcher to listen to and transcribe the digital recordings.
- The aim of the research project is to understand better how socially isolated young people with cognitive disability experience supported decision-making.
- The project is funded under the Australian Research Council Linkage Grant
- We can withdraw from the study at any time.
- I can contact the researcher Danielle Notara on 02 66203802 or research supervisor Sally Robinson, on 02 6620 3134 during work hours with any queries that I have.

Signed:.....

Date:.....