**Participant Information Statement for Decision Supporters**

Appendix C

**Effective Decision-Making Support for People with Cognitive Disability**

**Researchers and contacts**

|  |  |
| --- | --- |
| Professor Christine Bigby  Living with Disability Research Centre  Email: [c.bigby@latrobe.edu.au](mailto:c.bigby@latrobe.edu.au)  Phone: (03) 9479 3041 | Dr Elizabeth (Lizzie) Smith  Living with Disability Research Centre  Email: [e.smith3@latrobe.edu.au](mailto:e.smith3@latrobe.edu.au)  Phone: (03) 9479 1954 |

You have received this information because you are somebody who has been nominated as a decision-making supporter by a person with a cognitive disability (either with an acquired brain injury or an intellectual disability).

As you would be aware, people with cognitive disabilities often require support to make important decisions in their life, for example ‘where should I live?’ and ‘what will I do when I finish school’?

This research aims to understand the best way to support people to make these and other decisions. The study is being conducted by La Trobe University, Sydney University, the University of New South Wales, and Queensland University of Technology. It is funded by an Australian Government ARC Linkage Grant and the following industry partners:

|  |  |  |
| --- | --- | --- |
| * Endeavour | * Victorian Office of the Public Advocate | * Queensland Office of the Public Advocate |
| * Melbourne City Mission | * NSW Department of Family and Community Services (FaCS) | * Queensland Mental Health Commission |
| * Inclusion Melbourne | * NSW Office of the Public Guardian | * Queensland Public Trustee |
| * Summer Foundation | * NSW Trustee and Guardian | * Queensland Office of the Public Guardian |

We are seeking people who do, or plan to, provide support for decision-making to a person with a cognitive disability.

If this describes you, and you live in Victoria, New South Wales, or Queensland and are over the age of 18, then you are eligible to participate.

**What does participation involve?**

**Interviews and questionnaires**

If you, and the person you support to make decisions, choose to participate in this research you will be asked to attend 5 interviews with one of the researchers over the course of one year. At these interviews, the researcher will go through a questionnaire with you (this will take 10 to 20 minutes). Then they will conduct an interview with you. In total, both the questionnaire and the interview will take around one hour each time.

Interviews will occur at these intervals:

* 1st interview at the beginning of the project
* 2nd interview around two weeks to a month later
* 3rd interview three months later
* 4th interview three months later
* 5th interview six months later

The interview will be audio-recorded and a transcriber who has signed a confidentiality agreement with La Trobe University will transcribe the interviews. This information will be kept on a password protected computer at La Trobe University for the duration of the research project. After this time the information will be kept for 5 years after the last publication. Once five years has passed this information will be securely destroyed.

We are interested in hearing your stories about how you have helped someone with a cognitive disability to make decisions. What you have learnt along the way, and what you would like to change.

**Effective support for decision-making education training**

If you choose to participate in this research you will be assigned to either the Education Group or the Waitlist Group. This decision will be made via random selection with the use of a computer program. You will have a 50% chance of being in either the Education Group or the Waitlist Group.

**The Education Group**

Decision supporters who are assigned to the Education Group will be asked to attend two training sessions. These sessions will last for 4.5 hours each and will be conducted in small groups of around 10 people. The training sessions have been piloted and aim to provide a forum to think through principles and strategies of providing effective support for decision-making as well as managing some key dilemmas supporters confront. After the two training sessions you will be given the opportunity to access telephone mentoring (6 sessions lasting up to 30 minutes). This will be available to you for the three months following the training sessions.

If you choose to use any of the 6 telephone mentoring sessions, we will ask you for your verbal consent for the session to be audio-recorded and used as data for the research. This will be transcribed by a person who has signed a confidentiality agreement with La Trobe University. The transcripts will be confidential, de-identified, and confidential. They will help us to understand the effectiveness of the education program and what may improve it. If you do not want these sessions to be audio recorded and used as part of the research you can still use the telephone mentoring sessions and there will be no adverse consequences for you.

All the training and mentoring is provided at no cost. The sessions will be held at a location as easily accessible to you as possible and support with travel expenses will be available should you require it.

**The Waitlist Group**

Decision supporters who are assigned to the Waitlist Group will not be receiving the training sessions at this time. Rather, you will be invited to participate in the training sessions if the findings from this research tell us that attendance in the training sessions has a positive impact on the effectiveness of support for decision-making and amendments have been made to the training modules. You will still participate in the interviews and questionnaires mentioned above.

**What is the benefit of participating?**

The personal benefit of participating includes access to education and training around proving support for decision-making to a person with a cognitive disability. However, this will come at different times depending on whether you are assigned to the Education Group or the Waitlist Group (see above). Both groups of participants will have the opportunity to reflect on the process of providing this support through the interviews which may be of benefit to some people.

The wider benefit of this research is that it will provide a good evidence base for the process and support necessary for effective support for decision-decision making for people with cognitive disability. This is especially important given the roll-out of the National Disability Insurance Scheme over the next few years and the new environment of decision-making that this will bring with it. The Education program has been developed by leading researchers in the fields of intellectual disability and acquired brain injury. This research will assess the effectiveness of this project while also increasing knowledge about the ways that support for decision-making is practiced.

**What we will do with the information we collect?**

The findings of the study will be written into a report and may be published in a journal or presented at a conference. You will not be identified in any of the reports, papers, or presentations. We are happy to provide you with a copy of your personal data, as well as copies of published and unpublished reports, resulting from this study.

**Do I have to agree to be involved?**

Participation in the study is completely voluntary and you are free to withdraw from the study at any time. If you would also like to withdraw the information and data collected through the interviews and questionnaires, you will need to let a researcher know within four weeks after an interview. You can contact the researcher by email or phone who will help you fill in a form called “Withdrawal of Consent Form”. In the event of withdrawal, all data arising from your participation will be destroyed.

**What if I want more information?**

If you have questions regarding this project, you should contact Elizabeth (Lizzie) Smith at the Living with Disability Research Centre, La Trobe University. Her phone number is (03) 9479 1954 and her email is e.smith@latrobe.edu.au

If you have any complaints about the conduct of the study you may contact the Secretary, Human Ethics Committee, Research and Graduate Studies Office, La Trobe University, Victoria, 3086. Their phone number is (03) 9479 1443 (e-mail: humanethics@latrobe.edu.au).

**If you would like to take part in this project you should contact Professor Christine Bigby or Elizabeth (Lizzie) Smith at the Living with Disability Research Centre La Trobe University. Their phone numbers are (03) 9479 3041 or (03) 9479 1954. We will then arrange to meet with you to talk to you about the project and answer any questions you may have.**

**Contact details of all researchers**

|  |  |
| --- | --- |
| Professor Christine Bigby  Living with Disability Research Centre  Email: [c.bigby@latrobe.edu.au](mailto:c.bigby@latrobe.edu.au)  Phone: (03) 9479 3041 | Professor Jacinta Douglas  Living with Disability Research Centre  Email: j.douglas@latrobe.edu.au  Phone: (03) 9479 1797 |
| Emeritus Professor Terry Carney  University of Sydney  Email: [terry.carney@sydney.edu.au](mailto:terry.carney@sydney.edu.au) | Dr Shih-Nhing Then  Queensland University of Technology  Faculty of Law  Email: shih-ning.then@qut.edu.au |
| Dr Ilan Wiesel  University of New South Wales  Email: [i.vizel@unsw.edu.au](mailto:i.vizel@unsw.edu.au) | Dr Elizabeth (Lizzie) Smith  Living with Disability Research Centre  Email: [e.smith3@latrobe.edu.au](mailto:e.smith3@latrobe.edu.au)  Phone: (03) 9479 1954 |
| Ms Lucy Knox  Living with Disability Research Centre  La Trobe University  Email: [L.Knox@latrobe.edu.au](mailto:L.Knox@latrobe.edu.au)  Phone: 03 9479 3684 |  |