

**ASSOCIATE PROFESSOR MARY-ANN O'DONOVAN**

*Chief Investigator*

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"NDIS: RHETORIC VERSUS REALITY?"*

**PARTICIPANT INFORMATION STATEMENT**

**(1) What is this study about?**

You are invited to take part in a research study about the realities of living with intellectual disability in Australia, and the impact of individualised funding arising from the introduction of the NDIS. The study will examine, within this era of disability reform, how people with intellectual disability are having their needs met, and the extent to which they are involved in decision-making about their lives. The study will be conducted over three years using a mixed method design. It will specifically examine the relationship between self-directed individualised funding and its effect on personal well-being, self-esteem and voice, choice and control. People with intellectual disability will act as co-researchers within the study.

You have been invited to participate in this study because you are a recipient of an NDIS package. 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?**

The study is being carried out by the following researchers:

Associate Prof Mary-Ann O'Donovan	Chief Investigator	The University of Sydney
Prof Patricia OBrien	Chief Investigator	The University of Sydney

Prof Vivienne Riches	Chief Investigator	The University of Sydney
Em/Prof Trevor Parmenter	Chief Investigator	The University of Sydney
Prof Dr Roy McConkey	Partner Investigator	University of Ulster, UK
Dr Tom McClean	Partner Investigator	Uniting (NSW/ACT)
Mr Richard Gregg	Partner Investigator	New Horizons Enterprises Limited
Ms Nicola Hayhoe	Partner Investigator	The Housing Connection Limited
Ms Joanne Hewitt	Partner Investigator	Achieve Australia Limited
Rev Dr Andrew (Andy) Calder	Partner Investigator	Synod of Victoria and Tasmania - Uniting Church in Australia
Eric Badu	Post-doctoral researcher	The University of Sydney
Mr Gordon Duff	Researcher / PhD Candidate	The University of Sydney
Ms Emily Gosden-Kaye	Researcher / PhD Candidate	The University of Sydney

This study is being funded by the Australian Research Council.

### **(3) What will the study involve for me?**

You will be asked to participate in a quantitative survey. If you express interest in this research, and after reading the participant information statement, you will be asked to respond to the consent statement. You will then be provided with survey items which has been program into Qualtrics software for collecting data. The survey will take approximately 30-45 minutes to complete.

All information you provide is treated anonymously and confidentially. Your details will not be shared with anyone other than researchers from the Centre for Disability Studies, an affiliate of the University of Sydney.

The survey will ask questions about your personal well-being voice, choice, and control.

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

The research study runs for three years; you are expected to take approximately your 30 -45 minutes to complete the survey. You are required to complete the survey again after 18 months period.

### **(5) Who can take part in the study?**

The person with a mild or moderate disability:

- Is registered with the NDIA;
- Has a plan to hold an annual review at least within six months of the start date of the project ;
- Has a support person/s available at the time of the data collection who is aware of their goals (family and/or service support);
- Reflects a sample of the adult age range, and gender and ethnic/indigenous diversity (CALD backgrounds and Aboriginal and Torres Strait Islander people); as well as a range of support indicated by the size of the financial package; a range of accommodation types; and varying contact hours with family members.

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

Being in this study 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.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by writing to the Research Coordinator via email.

You are free to stop the survey at any time. Unless you say that you want us to keep them, any information will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

Submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your responses if you change your mind about having them included in the study, up to the point that we have analysed and published the results.

If you decide to withdraw from the study, we will not collect any more information from you. Please let us know at the time when you withdraw what you would like us to do with the information we have collected about you up to that point. If you wish your information will be removed from our study records and will not be included in the study results, up to the point that we have analysed and published the results.

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

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study. Although not expected, if you do become personally affected by your participation in this research project, the researchers will connect you with a professional counselling organisation.

**(8) 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. However, given we are interested in hearing your insights about your NDIS package, your reflections may change future disability policy.

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

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise. Information will be

stored securely and your identity/information will be kept strictly confidential, except as required by law.

**(10) Can I tell other people about the study?**

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

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

When you have read this information, Eric Badu will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Eric Badu via email [eric.badu@sydney.edu.au](mailto:eric.badu@sydney.edu.au) or call mobile number: 0452414632

**(12) 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 on the consent form. This feedback will be in the form of a one page lay summary. You will receive this feedback after the study is finished.

**(13) 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 [**INSERT protocol number once approval is obtained**]. 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](mailto:human.ethics@sydney.edu.au)
- **Fax:** +61 2 8627 8177 (Facsimile)

*This information sheet is for you to keep*