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AUSTRALIAN RESEARCH COUNCIL LINKAGE GRANT (LP190101011)
"NDIS: RHETORIC VERSUS REALITY?"

PARTICIPANT INFORMATION STATEMENT – EASY ENGLISH

Hello. Our names are



- Associate Professor Mary-Ann O'Donovan
- Professor Emerita Patricia OBrien
- Clinical Professor Vivienne Riches
- Emeritus Professor Trevor Parmenter
- Dr. Eric Badu
- Mr Gordon Duff
- Ms Emily Gosden-Kaye

We are doing a research study to find out more about the realities of living with intellectual disability in Australia, and the impact of individualised funding arising from the introduction of the NDIS.

We are asking you to be in our study because you are a recipient of an NDIS package.

You can decide if you want to take part in the study or not. You don't have to - it's up to you.

This sheet tells you what we will ask you to do if you decide to take part in the study. Please read it carefully so that you can make up your mind about whether you want to take part.

If you decide you want to be in the study and then you change your mind later, that's ok. All you need to do is tell us that you don't want to be in the study anymore.

If you have any questions, you can ask us or your family or someone else who looks after you. If you want to, you can call us any time on 02 9036 3600.

What will happen if I say that I want to be in the study?

You will be asked to participate in a focus group discussion. You will be asked to provide a suitable date and time for the interview. We will be considerate of any work or other obligations you might have.

You will be asked to respond to consent statement before participating in the focus group interview. During the interview, we will record the information, including your background information. All information you provide is treated anonymously and confidentially.

When we ask you questions about your experiences living with intellectual disability, specifically on the perceptions you hold about your life since the introduction of individualised funding, you can choose to answer.

If you don't want to talk about something, that's ok. You can stop talking to us at any time if you don't want to talk to us anymore.

If you say it's ok, we will record what you say with a tape recorder.

If you say it's ok, we will take some photos of you.

When you talk with us and other people in a group, we won't be able to take out the things you say after you have said them. This is because you will be talking in a group and our notes will have all the things that everyone else said as well.

Will anyone else know what I say in the study?



We won't tell anyone else what you say to us, except if you talk about someone hurting you or about you hurting yourself or someone else. Then we might need to tell someone to keep you and other people safe.

All of the information that we have about you from the study will be stored in a safe place and we will look after it very carefully. We will write a report about the study and show it to other people but we won't say your name in the report and no one will know that you were in the study, unless you tell us that it's ok for us to say your name.

How long will the study take?



The research study runs for three years; your involvement in the first phase of the focus group discussion is expected to last for an approximate time of 60 – 90 minutes. This will be repeated in the second stage of the focus group discussion after 18 months.

Are there any good things about being in the study?

“NDIS: Rhetoric versus Reality”



You won't get anything for being in the study, but you will be helping us do our research. However, given we are interested in hearing your insights about your NDIS package, your reflections may change future disability policy.

Are there any bad things about being in the study?

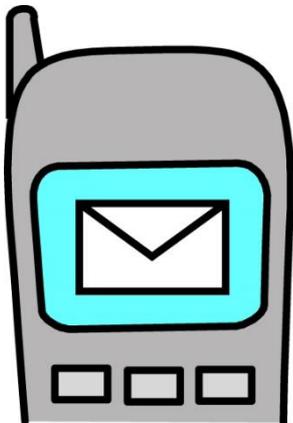


Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study. If you become upset, you will be introduced to a counsellor.

Will you tell me what you learnt in the study at the end?

Yes, we will if you want us to. There is a question on the next page that asks you if you want us to tell you what we learnt in the study. If you circle Yes, when we finish the study we will tell you what we learnt.

What if I am not happy with the study or the people doing the study?



If you are not happy with how we are doing the study or how we treat you, then you or the person who looks after you can:

- **Call** the university on +61 2 8627 8176 or
- Write an **email** to human.ethics@sydney.edu.au

This sheet is for you to keep.

The pictures we used in this sheet are from Microsoft Clip Art and from the people at Inspired Services Publishing (www.inspiredservices.org.uk). They said it's ok for us to use them.