

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
Gender Inequity and the National Disability Insurance Scheme
Chief Investigators: *Natasha Cortis, Gemma Carey and Georgia van Toorn*
Student Investigator: *Molly Saunders*

1. What is the research study about?

You are invited to take part in this research study. The research aims to understand how the National Disability Insurance Scheme (NDIS) is affecting the lives of women with disability.

2. Who is conducting this research?

The study is being carried out by the following researchers: Molly Saunders (PhD Candidate, Social Policy Research Centre, UNSW) supervised by Associate Professor Natasha Cortis, Professor Gemma Carey, and Dr Georgia van Toorn.

Research Funder: This research is conducted as part of Molly's PhD, which is funded by the Australian Government Research Training Program Scholarship.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- Women with disability, including mental ill health;
- Who are over the age of 18 years old; and
- Who have applied, or have considered applying, for the NDIS.

4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

5. What does participation in this research require, and are there any risks involved?

If you agree to participate you will be asked to complete the following research procedures.

Interview: An interview, in which you will be asked questions about your experiences with the NDIS. You can choose whether the interview occurs face-to-face, via telephone, or via online video. If you wish, you may bring a support person to assist with communication or emotional support. The interview will be scheduled at a time convenient to you and will take approximately 60-90 minutes. However, you can choose to take breaks, which may lengthen the interview time to 120 minutes. With your permission, the research team would like to audio record the interview. If you do not wish to be recorded but you would like to participate, advise the research team and written notes will be taken.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project. However, you will receive \$50 Mastercard Gift Card as a thank you for your time.

Psychological Distress: Depending on your experiences with the NDIS, you may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Alternatively, a number of free contactable support services are included at

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section 9. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

6. What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about you for the research study. The research team will store the data collected from you for this research project for a minimum of 5 years after the publication of the research results.

The information about you will be stored in a non-identifiable format where any identifiers, such as your name or location, will be replaced with a unique code. The information collected from you, including audio recordings, will be stored in an electronic format, on a UNSW password protected OneDrive, only accessible to the approved research investigators. Any paper-based information, such as handwritten notes taken during the interview, will be stored in a locked drawer. They will be destroyed after they are uploaded to the OneDrive.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

7. How and when will I find out what the results of the research study are?

The research team intend to publish the results of the research. All Information will be published in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

8. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document, or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or the NDIS. If you decide to leave the research study, the researchers will not collect additional information from you.

9. What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC211026

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10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact Details

Name	Molly Saunders
Position	Student Investigator, PhD Candidate
Telephone	0421 285 591
Email	Molly.saunders1@unsw.edu.au

Chief Investigator

Name	Natasha Cortis
Position	Associate Professor
Telephone	+61 2 9385 7833
Email	n.cortis@unsw.edu.au

Support Services Contact Details

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

Name/Organisation	Lifeline
Telephone	13 11 14

Name/Organisation	People with Disabilities Australia
Telephone	1800 422 016

Name/Organisation	Blue Knot National Counselling & Referral Service
Telephone	1800 421 468

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Consent Form – Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- Recordings: I understand that the research team will audio record the interviews groups; I agree to be recorded for this purpose.
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I will be given a signed copy of this document to keep.
- Optional: If the interview does not occur face-to-face, I would like to receive a copy of the gift card via email or post. I have provided my details below and consent to my details being used to send me the gift card. Please select your preference:
 - Via Email
 - Via Post
- Optional: I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: _____

Address: _____

Email Address: _____

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Declaration by Researcher*

- I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	
Signature of Researcher	
Date	

***An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

Note: All parties signing the consent section must date their own signature.

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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales or any other participating organisations.

- I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

Name	Molly Saunders
Position	Student Investigator, PhD Candidate
Telephone	0421 285 591
Email	Molly.saunders1@unsw.edu.au