

## Participant Information Statement

### *Research study: Developing an Evidence Base for Improved Outcomes for People with a Psychosocial Disability*

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### **This letter explains the research project so you can decide if you would like to take part in the project.**

You can read this letter with someone else if you like. This information is for NDIS participants and their supporters.

#### **1. Who is doing this research project?**

This project is being conducted by these researchers from the University of Sydney:

- Professor Jennifer Smith-Merry, Director of the Centre for Disability Research and Policy, the University of Sydney
- Dr Joel Hollier, Postdoctoral Research Fellow, The University of Sydney

#### **2. What is this project about?**

We are conducting a research study about the experiences of people with psychosocial disabilities on the NDIS. This is part of a larger program of work about how to make the NDIS better for people with psychosocial disability. We are working closely alongside the NDIA to give them information to help them improve the NDIS.

Taking part in this study is voluntary. Please read this sheet carefully and ask questions about anything you don't understand or want to know more about.

#### **3. Who can take part in this research project?**

We are seeking people over the age of 18 who currently receive NDIS supports, with a primary psychosocial disability type.

You may wish to discuss your involvement in the project with a family member or support person. If you are someone who supports a NDIS participant, you may want to have a conversation with them before they agree to participate so they understand the research. You should respect their wishes about whether they participate.

You have been invited to take part in this study because you have indicated to the NDIA that you are willing to take part in this type of research, you have read about this research in a newsletter, or someone has told you about the research in another way.

#### **4. What would I do in the research project?**

If you decide to take part in this study, you will be asked to take part in an interview. An interview is a conversation between you and an interviewer who will ask you questions. We expect the interview to go for about an hour.

We will ask you about:

- Your experiences of being on the NDIS,
- What sorts of supports you currently receive, and if you have difficulty accessing any supports,
- Your expectations of the scheme, and if they are being met,
- Your thoughts on how the NDIS could be improved
- Your needs for support and any needs you currently have that are not being met
- Your current mental health experiences and needs (including thoughts of harm)

Interviews will take place at a time that is convenient for you.

The audio of the conversation will be recorded to ensure we capture your thought accurately. This audio will only be available to the research team and the secure transcription service who will transcribe what you say. That transcription service is called Pacific Transcription and complies with all Australian Privacy guidelines.

As this is part of a larger research program, you will also be invited to take part in future research if you would like to (and you can always change your mind later). If you decide to take part in future research we will ask you whether we are able to match your responses in this interview with your later responses.

#### **5. Where will I do the interview?**

You can choose whether you want to participate on the phone or online via an app such as zoom. If you require an in-person interview for accessibility, we will try our best to arrange this.

- You are welcome to have a support person with you throughout the interview
- An interpreter can be arranged.

#### **6. Will the researchers have access to information about me and my NDIS plan?**

No. The researchers are separate from the NDIA and will only have access to information

that you provide them. The NDIA will not know if you have participated in the interview

### **7. Do I have to join this research project?**

No. You do not have to participate in this project if you don't want to.

Your NDIS funding and plan will not be affected if you do not want to be a part of the research project. Your decision will also not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

### **8. Can I edit what I said in the interview?**

Yes. If you did an interview, you can ask for a copy of your interview transcript. You will have 2 weeks to make edits to what you said in the interview after we email you the transcript.

### **9. Can I withdraw after I have joined the project?**

Yes. You can stop being in the project at any time, you just have to let us know this is what you want. You can ask that what you say is removed from our records for up to two weeks after the interview. If you choose to you can review the transcripts that we make from the audio recordings. If you choose to do so you will have 2 weeks from when they are sent to you to make any changes that you want.

You can withdraw by emailing Dr Joel Hollier ([joel.hollier@sydney.edu.au](mailto:joel.hollier@sydney.edu.au)).

If you take part in an interview, you may refuse to answer any questions that you do not wish to answer.

### **10. Are there any risks to me if I join this project?**

Yes. There is a small risk that you will feel upset or uncomfortable during the interview. You can take a break whenever you want to or finish the interview on another day if you want to. You just need to tell us what you want to do.

If you feel uncomfortable or distressed at any point during or after the interview, we encourage you to reach out to your current supports. Or you can call Beyond Blue's 24/7 helpline (1300 22 4636).

### **11. Are there any benefits to me if I join this project?**

Participants in this research will be given a \$50 gift card for participation. Aside from this, we do not anticipate any direct benefits to participants. We are hopeful however that participants' stories will help inform the shape of the NDIS in the future

### **12. What will you do with the information I give you?**

The audio from the interview will be recorded. A transcription company that has signed a confidentiality agreement will write up what you say in the interview.

The transcript will have your details removed and your name changed so that people don't know that it is you.

The transcript will be kept on the university's secure, password protected storage facility. Once we receive the transcript from the secure transcription service only the people named on this research project will have access to your transcript. We will store this information and dispose of it securely following the University's Record keeping Policy. For more details about how your information will be handled please see the University's [privacy webpage](#).

Sharing research data is important for advancing knowledge and innovation. A de-identified set of the data collected in this study may be made available for use in future research.

Any identifiable information you provide us will be stored securely and will only be disclosed with your permission unless we are required by law to release information. If during the interview you express thoughts that you may be at risk of harm to yourself or someone else, the researchers may assist you to receive appropriate support, including contacting people to help you. If there is any risk of harm to children or young people, the researchers will report this information to appropriate authorities.

### **13. Will I get a copy of the results?**

You have the right to receive feedback about the overall results of this study. At the end of the interview, we will ask if you would like to receive feedback. This feedback will be in the form of summary of findings.

### **14. Who pays for this research?**

This research is funded through the University of Sydney, who received an Australian Research Council grant.

### **15. Will the NDIS, my planner, delegate, or Local Area Coordinator know that I am in this research?**

No. The NDIS will not know that you took part in the research. The research team do not make decisions or choices about your NDIS plans or funding. The research team do not have access to your plan or budget.

### **16. Can I speak to someone about this project?**

When you have read this information, Dr Joel Hollier will be available to discuss it with

you further and answer any questions you may have: [joel.hollier@sydney.edu.au](mailto:joel.hollier@sydney.edu.au)

### 17. Can I complain to someone about this project?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [ethics reference: 2024/HE001102] according to the National Statement on Ethical Conduct in Human Research.

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:

Human Ethics Manager [human.ethics@sydney.edu.au](mailto:human.ethics@sydney.edu.au)

+61 2 8627 8176

### 18. How do I join this research project?

If you would like to take part in this research, you can:

- call Joel on 02 9351 9934
- send an email to [joel.hollier@sydney.edu.au](mailto:joel.hollier@sydney.edu.au)

Or you can ask someone you trust to contact us for you.

***This information sheet is for you to keep***