

PARTICIPANT INFORMATION STATEMENT (NDIS participants and family):

Planning for a better life under the NDIS - A disability workforce in rural and remote regions of Central Western NSW and Central Australia

This is for you to keep.

Purpose of the study



Hello, my name is Penny Watson from the Centre for Remote Health, Flinders University. I am working on a research study involving a number of universities. We want to understand the experience of Aboriginal and non-Aboriginal people with disability living in rural, regional, remote and very remote areas who have developed an NDIS plan. With this information, we plan to design resources and training for people working as NDIS planners, Local Area Coordinators (LAC), formal advocates, Community Connectors (CC) and Early Childhood Intervention Agencies (ECIA) to enable them to better respond to the needs of NDIS participants who live outside of the major cities. We are asking you to be in our study because your thoughts and experiences about the NDIS are important.

This information sheet tells you what we will ask you to do to if you want to be in this study.

What we are asking you to do

We would like to have a conversation with you about your experience of developing an NDIS plan. We will begin by asking you some questions about yourself, like your age, what town or community you live in, and the ways in which your disability impacts your life. Then we will ask you about whether you got the support you wanted to develop your plan, what the experience of developing the plan was like, and whether you were satisfied with the outcome. We will also ask you what worker skills, knowledge, attitudes and values are helpful for NDIS participants.

You do not have to answer all the questions. You only need answer the questions you feel comfortable to answer.

We will ask you if we can record the conversation. If you don't want us to do this, we will ask you if we can take notes. It is important that we can remember everything you told us.

If you decide that you want to be in our study, you can either;

- Let us audio record your consent, or
- Sign the consent form

Will you be asking me cultural or sensitive information? No, we will not be asking about this. If you think something you have told us is cultural or sensitive information and not for sharing please let us know. We will not use this information.

How long will it take?

We think it will take about one hour. If this is too long for you we can stop before that.

Do I have to be involved?

No, you do not have to be involved if you don't want to. It is your choice. If you decide to be involved and then change your mind that is okay. You can stop the conversation at any time. You just need to let us know. You do not have to have a reason. There are no consequences for deciding not to get involved, or for changing your mind.

At some point during the research we will not be able to identify the specific information you told us. When we begin to make sense of what everyone has told us we remove any way of linking what someone said to their name. After this point we cannot withdraw your information.

Can I have someone with me?

We want you to feel comfortable so yes, you can have someone to support you.

Will I get paid?

No, you won't get paid.

What are the benefits of being involved?

There is no direct or immediate benefit to you. However, we hope that, in the future, what we learn from you about your experience with the NDIS planning process we will improve this process for you and for others.

Are there any risks?

If you have had a bad experience and you need to tell us about this so we understand your experience, you may become upset. We will talk about what you would like us to do if you become distressed and we can assist you contact someone to assist you.

Will anyone else know that I am part of the study?

We will not tell anyone that you have been involved in this study. You can tell anyone you want to. We will make sure your information is stored in a secure place, protected by a password, and only the researchers will be able to access it. If you talk with us in a group we cannot guarantee that others attending will not speak about their involvement although we will ask that they keep what is said private.

Where will this happen?

We will ask you where you feel most comfortable and we will have the conversation there. However, we will ask you to think about a place that is quiet with not too many interruptions.

How will the information be used?

We will write research papers and report about the study and show it to other people, and we will speak about it at public events. We will use what we have learned from talking to many people, not just you. We will use the information to try and improve the planning process for NDIS participants. If you would like we can also tell you when we have written any reports or articles and where to find them.

What if I have a complaint about this research?

This project has been approved by the Central Australian Human Research Ethics Committee in Alice Springs. If you are concerned about this research, or have a complaint you can email cahrec@flinders.edu.au.

Who can I contact to learn more, or to get involved?

If you, your family, or someone else has any questions, you can call the researchers you are working with:

You can call Penny Watson on 08-89514700 or email her at penny.watson@flinders.edu.au

You can call Heather Jensen on 08-89514700 or email her at heather.jensen@flinders.edu.au.

You can call John Gilroy on 0427 238 776 or email him at john.gilroy@sydney.edu.au

