

Participant Information Statement



Research Study: National Disability Services Annual Market Survey

Associate Professor Jennifer Smith-Merry

Centre for Disability Research and Policy, Faculty of Medicine and Health

Phone: +61 2 9351 9060 | Email: jennifer.smith-merry@sydney.edu.au

1. What is this study about?

We are conducting a research study about the opinions of CEOs and senior executives of disability service organisations in regard to the impact of NDIS, changes in their operating environment and their organisation's responses to market changes. Taking part in this study is voluntary.

Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

The study is being carried out by the following researchers:

- Associate Professor Jen Smith-Merry, Centre for Disability Research and Policy, the University of Sydney
- Lesley Reid, Data Manager, National Disability Services (NDS)
- Associate Professor Mary-Ann O'Donovan, Centre for Disability Studies, the University of Sydney
- Gordon Duff, Centre for Disability Studies, the University of Sydney
- Associate Professor Justin Scanlan, Centre for Disability Research and Policy, the University of Sydney
- Dr Roxanna Pebdani, Centre for Disability Research and Policy, the University of Sydney
- Dr Damian Mellifont, Centre for Disability Research and Policy, the University of Sydney
- Dr Margaret McGrath, Centre for Disability Research and Policy, the University of Sydney

This study is being funded by National Disability Services.

3. Who can take part in the study?

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

- The CEO or senior executive of their organisation, or are the business owner if operating as a sole provider; and
- Represents a service that offers disability services to its clients.

You have been invited as the CEO or senior executive of a disability service organisation, or you are the business owner/ sole provider. Your contact details were obtained through the NDS network and/or from publicly available lists of NDIS registered providers.

You may also have received a link to the survey via an advertisement on social media and have self-identified as being part of the target group for the research.

4. What will the study involve for me?

Participation in any research study is voluntary. If you do not want to take part, you do not have to. 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);
- Complete the online survey.

The survey will ask you questions about your organisation and your organisation's:

- views on the changes to the disability service environment, from the NDIS and other systemic changes
- sustainability and growth in light of market changes
- views on disability policy and systemic changes
- use of research and data
- participation in collaboration and partnership activities

The questionnaire should take approximately 30 minutes to complete. You are free to leave the survey and come back to it at a later time if you need to.

Your responses will remain identifiable, meaning that we will know who gave the responses. However, you will not be asked any questions about your clients, nor any other confidential business information. You are free to skip any questions you would prefer not to answer.

Quantitative results will only be reported in aggregate. Quotations from text responses may be used in reporting but no organisation or person will be identifiable in that reporting, nor will any information collected from this survey be distributed to any third party, including the NDIA.

5. Can I withdraw once I've started?

Being in this study is completely voluntary and you do not have to take part.

Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

Your decision will not affect your relationship with National Disability Services.

The two NDS investigators listed on the project will know which organisations have participated in the survey but the data that you share in the survey will not in any way impact on your ongoing relationship with those investigators, the NDS or the University of Sydney.

If you do consent to participate, you may withdraw up until you submit the survey. After that time data will be aggregated and it will not be possible to remove your individual responses. If you decide to leave the research study prior to survey submission, the researchers will destroy any information that has already been collected and no additional information will be collected from you.

Your decision not to participate or to withdraw from the study, will not affect your relationship with NDS or the University of Sydney.

6. Are there any risks or costs?

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.

7. Are there any benefits?

You will not receive any direct benefits from being in the study.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you for the purposes of this study.

Any information you provide us will be stored securely on University of Sydney servers, which are fully compliant with Australian privacy and data protection requirements and we will only disclose it with your permission, unless we are required by law to release information.

We are planning for the study findings to be published. You and your organisation will not be individually identifiable in these publications.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998. You have the right of access to personal information held about you by the University of Sydney and NDS, the right to request correction and amendment of it, and the right to make a complaint about a breach of the 13 Australian Privacy Principles as contained in the Privacy Act. Information will be held for 5 years according to statutory requirements regarding this type of data.

Information on how NDS collects and uses personal data can be found in [NDS's Privacy Policy Statement on the website](#).

9. Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. Data will be published in the annual State of the Sector Report and you will be sent a link to this report when it is released in November.

10. What if I would like further information?

When you have read this information, the following researchers will be available to discuss it with you further and answer any questions you may have: Jennifer Smith-Merry, The University of Sydney, 02 9351 9060, jennifer.smith-merry@sydney.edu.au; or, Lesley Reid, NDS, 0448 325 356 lesley.reid@nds.org.au,

11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [Approval number 2021/596] according to the *National Statement on Ethical Conduct in Human Research (2007)*.

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
+61 2 8627 8176

This information sheet is for you to keep