**Participant Information Sheet**

**Project title: Australia's Disability Strategy Survey – Nested study with people with intellectual disability**

**What is the project about?**

Australia’s Disability Strategy Survey (the Survey) is a new national survey to understand attitudes towards people with disability and how attitudes are changing. The Survey data will be used to track progress on community attitudes towards people with disability under the *Australia’s Disability Strategy 2021-2031*. As part of this Survey, four nested studies are being undertaken with specific people who may not be able to complete the questionnaire. This information sheet relates to the first nested study with people with intellectual disability, which aims to explore how attitudes held by others can affect their wellbeing and experiences in different spheres of life.

This nested study will comprise five focus groups with people with intellectual disability. Focus groups 1-4 will focus on the experience of people with intellectual disability with workers from one sector: health, education, personal and community support and justice. Focus group 5 will focus on how other people’s attitudes and behaviours have affected the chances of people with intellectual disability getting and maintaining meaningful employment.

**Who is involved in the project?**

The project is being undertaken by researchers from the Australian National University (ANU) and JFA Purple Orange (PO). The research has been commissioned by the Australian Government Department of Social Services (DSS). PO is conducting the focus groups for the nested studies.

**Who will be part of the nested study?**

Approximately 6-10 people with intellectual disability will be present in each face-to-face focus group/s and 4-5 participants in the online focus group/s. The health and education focus group will be face-to face, while the others will be online.

**What does participation in the focus group mean for you?**

You have been invited to attend one of the five focus groups. Your participation is completely voluntary. The groups will last for about 1.5 hours to 2 hours. The focus groups will be held online and/or in person in Adelaide. The questions asked during the session will focus on your experience of positive and negative attitudes towards people with disability. During initial recruitment and at the end of each focus group, you will be asked if you are willing to take part in a follow‑up nested study in 2024.

Sensitive or upsetting issues may arise from these questions. You are welcome to bring a support person to the focus group.

With your consent, focus groups will be audio-recorded and written notes will be taken. Which method is used will depend on the preference of the individuals in each group. For example, if one person would prefer not to be recorded and is happy to have their information written down, then this method will be used.

The focus groups are **voluntary** and you can leave at any time and not answer some questions without explaining why. If you withdraw from the focus group, information you provided will be destroyed and not used. However, it may not be possible to delete every single contribution you make to a group discussion.You can ask for any information you have provided to be removed from the data until the report is submitted to DSS by contacting PO on (08) 8373 8388 or admin@purpleorange.com.

**What are the benefits of taking part?**

By participating in this nested study, you are helping to share the real views and experiences of people with disability in Australia. Once we understand people’s attitudes, measures can be put in place to try to change those attitudes (and associated behaviours) in ways that will improve the lives of people with disability. Understanding attitudes and their impact will also assist employers and workers in a range of occupational groups, as well as people generally in the broader community, to gain confidence and interact more appropriately with people living with disability.

You will be given a $60 gift card after the focus group to thank you for taking the time and effort to be part of this research. Purple Orange will ask you if you need any assistance to attend the groups. In practice, this means that, if you do need help, they will book taxis to and from the venue and provide you with taxi vouchers. They will also cover the costs of any other support you need. For example, if you need a support worker as an accessibility requirement, the support worker can invoice Purple Orange directly.

**Are there any risks from taking part?**

You may become distressed talking about your negative experiences or hearing others talk about their negative experiences. You may also become distressed telling your story in front of other participants. You only need to answer questions if you feel comfortable and safe to do so. You can leave the focus group at any time. If at any stage in the research you feel distressed or in need of assistance, please let the research team know or contact the following support services.

Beyondblue - [www.beyondblue.org.au](http://www.beyondblue.org.au) or call 1300 22 4636

Lifeline - [www.lifeline.org.au](http://www.lifeline.org.au) or call 13 11 14

Approximately 2-5 days after focus groups, PO will check in with all participants, or their parent/carer/guardian or support person, to see if they are okay.

Please respect other participants’ stories and privacy by not repeating what you have heard in the group.

**How will the research be used?**

The data will be aggregated and analysed and results published in reports that influence key decision makers and policy in Australia. Along with the published report, findings may feature in national media and used for further research.

Feedback will be provided to participants, either through a summary of input at the end of the focus group or in an Easy English write up of the notes from the meeting, depending on the preferences of those participating in the group.

**How will my information be kept confidential?**

We will protect the confidentiality of your responses to the extent permitted by law. Your personal information will not be disclosed to any other person or body unless you consent, or it is required by law. Individuals who take part in the focus groups will not be identified in any report or publication.

In collecting your personal information within this research, the ANU and PO must comply with the *Privacy Act 1988*. The ANU Privacy Policy is available at <https://policies.anu.edu.au/ppl/document/ANUP_010007> and it contains information about how a person can:

* Access or seek correction to their personal information;
* Complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.

**Where will the data be stored?**

Your information will be stored on secure computers at the PO office in South Australia. Highly sensitive data, such as focus group audio recordings, will have additional restrictions, such as computer file encryption. Your information will be restricted to the PO team and only de-identified data will be provided to ANU. That means any identifying information will be removed. Data collected will be destroyed securely after five years from the publication of project outcomes. If you agree to taking part in a follow‑up focus group, your contact details will be stored securely, separate from the data from the group.

**Who to contact for more information?**

For more information about the nested studies, please contact PO on (08) 8373 8388 or admin@purpleorange.org.au. Alternatively, contact Dr Marian Esler (ANU) at marian.esler@anu.edu.au.

**Who to contact for concerns or complaints?**

If you have concerns about the nested studies or privacy issues, you can contact PO on (08) 8373 8388 or admin@purpleorange.org.au.

**Ethics Committee Clearance:**

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol 2022/467). If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager

The ANU Human Research Ethics Committee

The Australian National University

Telephone: +61 2 6125 3427

Email: Human.Ethics.Officer@anu.edu.au

**Our research team:**

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